Submission to the Productivity Commission's Inquiry into Disability Care and Support

Young People In Nursing Homes National Alliance
September 2010

The Young People In Nursing Homes National Alliance welcomes the opportunity to contribute to the Productivity Commission's public inquiry into Disability Care and Support.

The Alliance is a national peak organisation that promotes the rights of young disabled Australians with high and complex clinical and other support needs living in residential aged care facilities or at risk of placement there (YPINH™); and supports these young people to have choice about where they live and how they are supported.

The Alliance's membership is drawn from all stakeholder groups including YPINH, family members and friends, service providers, disability, health and aged care representatives, members of various national and state based peak bodies, government representatives, and advocacy groups.

We encourage a partnership approach to resolution of the YPINH issue by State and Commonwealth governments; develop policy initiatives at state and federal levels that promote the dignity, well being and independence of YPINH and their active participation in their communities; and ensure that young people living in nursing homes and their families have

- a voice about where they want to live and how they want to be supported
- the capacity to participate in efforts to achieve this, and
- 'a place of the table', so they can be actively involved in the service responses needed to have "lives worth living" in the community.

As the pre-eminent national voice on this issue, the National Alliance's primary objectives are to

- Raise awareness of the plight of YPINH™
- Address the systemic reforms required to resolve the YPINH™ issue and address the urgent need for community based accommodation and support options for young people with high and complex needs
- Work with government and non-government agencies to develop sustainable funding and organisational alternatives that deliver 'lives worth living' to young people with high and complex clinical and other support needs
- Provide on-going support to YPINH, their friends and family members.

THE YOUNG PEOPLE IN NURSING HOMES COHORT

Approximately 6800 young Australians with disability presently occupy a not insignificant 5% of residential aged care beds nationally because our existing disability service system cannot provide the supports and services they need.

Many more young Australians are at risk of placement in aged care if this situation continues and the disability system remains unable to respond to their complexity of need; and integrate the clinical and other supports these young people require.

It is for this reason that, since 2002, the Alliance has consistently argued for a life time care and support (LTCS) approach to service development and delivery for these young people; and for an insurance based approach to funding to support this methodology.

Because of their complexity of need and requirement for clinical input, the Alliance believes that a life time care approach directly involving health and disability services as partners in the delivery of care for these young people is essential.

The Alliance also believes that until a comprehensive LTCS service system is operational, the aged care services system will need to partner with health and disability services in the delivery of care for this group from time to time.

Key features

Characterised by disabilities acquired as a result of catastrophic injury or through progressive neurological diseases, these young people require service responses from not one arm of the service system but several, including health, disability and sometimes aged care amongst others.

They arrive at the door of the disability system without warning and require immediate and often intense responses that the service system, in its current form, cannot deliver in a timely or effective manner. Data received from aged care providers indicate that the majority of younger residents in aged care are categorised as high dependency.[1]

Recent studies have also concluded that

> [YPINH] have high levels of complex health conditions which require daily care and a range of specialist expertise and equipment…accommodation services

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[1] Of a total 6,505 residents under 65 in June 2006, the majority or 4,911,.were categorised as high dependency (RCS 1-4); the remainder or 1,594 were considered low dependency (RCS 5-8). *Source*: AIHW analysis of DoHA Aged and Community Care Management Information System (ACCMIS) database. Australian Institute of Health and Welfare, *Older Australia at a Glance*, 4th Edition, Canberra, 2007: 135.

need to develop strategies and supports to integrate management of these complex health requirements.[2]

Previous studies indicate that the population breakdown of young people in nursing homes group with acquired disabilities is

Acquired Brain Injury (ABI)	*30%*
Physical Disability	*27%*
Neurological	*23%*
Intellectual/psychiatric	*20%* [3]

These figures also include a large number of people with high needs without speech who are particularly at risk.

ABI was the primary disability group of close to half (46%) of all Younger People In Residential Aged Care (YPIRAC)[4] service users in 2007–08. This compares with 4% of Commonwealth State Territory Agreement (CSTDA) service users with ABI as a primary disability group. Two in five YPIRAC service users (40%) had neurological disability with or without another type of disability. This compares with 13% of CSTDA service users with neurological disability.[5]

The poor representation of this group within disability services shows the service gap that exists and underscores the need for a better articulated, whole of government, life time care approach to service responses. Delivering such a response will not only benefit the YPINH group; it will benefit all Australians with disability who are increasingly expecting to access these same 'joined up' service responses.

Having an able bodied life before injury or illness delivered significant, lifelong impairment means the YPINH group has different expectations around service responses to those living with a congenital disability. These young people expect to access the rehabilitation needed to restore health and independence; and to live in the community as other able bodied young people do.

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[2] Winkler, D., Sloan, S. and Calloway, L. *Younger People In Residential Aged Care. Support needs, preferences and future directions*, Summer Foundation for the Victorian Department of Human Services, Melbourne, 2007: 26.

[3] See *The ABI Strategic Plan*, Victorian Department of Human Services, Melbourne, 2001.

[4] The Younger People In Residential Aged Care (YPIRAC) initiative is a 5 year , joint Federal/State program that was intended to be a first step to resolution of this longstanding and entrenched problem. The first tranche concludes in July 2011.

[5] AIHW, Australia's Welfare 2009. 9th Biennial Welfare Report of the AIHW, AIHW, Canberra, 2009: 169-172.

USING A LIFE TIME CARE AND SUPPORT APPROACH TO INFORM DISABILITY SERVICE DEVELOPMENT AND DELIVERY

Position statements

- In its current form, the existing disability service system is unable to deliver timely and effective responses for the severe and profound group, including those with high and complex clinical and other support needs.

- There is urgent need for a better integrated, 'joined up' service response involving the various arms of the service sector, including disability, health, aged care and housing, partnering to deliver the supports required. A Life Time Care and Support scheme (LTCS) should take a lead role in the development of such an articulated system and in its ongoing development and review.

- An integrated Lifetime Care and Support scheme should support those individuals with severe and profound need unable to receive the responses they require through the existing disability system.

- A new lifetime care scheme can neither be a total replacement of, nor a life buoy for the existing suite of disability, health, education transport or housing services.

- To prevent a new lifetime care **scheme** being a resort of first and only choice, or the default funder for all disability requirements; to prevent funding gouging and reliance on the scheme as the only option, the other service system arms must be compelled to deliver what they are established and required to provide, approaching the scheme for assistance only after their legislative requirements to deliver services have been exhausted.

- An integrated lifetime care **system** needs to be developed that incorporates the other arms of the service system including disability, health, aged care, housing, education, transport et al. Such a system should include a range of schemes and funding programs, of which a new, no-fault insurance scheme for people with severe and profound disability should be a key part. This new no fault insurance funding scheme must see itself as a leader, providing strong leadership, vision and innovation to set the benchmark for other parts of the lifetime care system.

- The relevant COAG instruments in health, education, transport, aged care and disability et al, need to take account of this new scheme through the National Disability Strategy and encourage an integrated approach across jurisdictions.

- An LTCS scheme must not reside in disability services but be located in a separately

constituted, legislatively derived authority (a National Lifetime Support Commission).

- If an LTCS scheme is developed, funding to the extant disability system must be maintained and grown to service individuals with disability with less severe and profound impairment who are outside the purview of the new LTCS scheme.
- If an insurance levy is introduced to fund an LTCS scheme, funding to the existing disability system must be maintained and grown separately to ensure increased capacity.
- Funding derived from an insurance levy, whether directed to support an LTCS scheme or to disability more generally, must be maintained in a separate, legislatively bound authority and not be part of disability services.
- Every year, over 700 Australians are catastrophically injured to such a degree that they need care and support for the rest of their lives. Motor vehicle accidents account for approximately half of these injuries. Over 70% of those injured are under 30 years of age. [6]

  The Alliance believes that, in the short term at least, a new disability insurance scheme cannot include other CTP schemes for the reasons following. The Alliance does believe, however, that a new no fault authority must be established to bring existing fault based schemes to no fault status; establish benchmarks for no fault services that reflect those established by the Victorian Transport Accident Corporation (TAC) *or better*; and harmonise existing no fault schemes, again ensuring that in this harmonisation, *standards and services reflect those of the TAC or better*.

  As a funding base for an LTCS system, a newly developed **disability insurance scheme** should not include existing CTP schemes for WorkCover and motor vehicle accidents. Existing CTP schemes must remain separate. They have very different rules, benefits and schedules. Most importantly, they are a mix of fault based and no fault entities.

  Extant fault based motor vehicle schemes, such as those in WA, SA and QLD, must be brought to no fault status. Benchmarks for these schemes should be no less, but potentially better than, those employed by the Victorian TAC. Similarly, time limited WorkCover schemes, such as Queensland WorkCover's 5 year limit to coverage, must move to deliver support for the life course as other schemes around the country presently do.

  Until harmonisation of existing no fault and fault based schemes is achieved, people who are ineligible for their state fault based scheme should be funded by the LTCS. However, the LTCS scheme should recover this cost from the relevant state government.

- An LTCS scheme should be a stand alone scheme dealing only with the severe and profound

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[6] Walsh, J., Dayton, A., Cuff, C. and Martin P. *Long Term Care. Actuarial Analysis on Long-Term Care for the Catastrophically Injured*, PwC, Sydney, 2005: 2.

population; providing for the latter's needs exclusively; and underwritten and fully funded by a precisely targetted disability insurance levy. As the scheme grows and matures, it may, however, consider partnering with state based disability services to provide top up funding in specified areas that other services arms are unable to deliver, but that are required to maintain the health and wellbeing of the individuals in question. If this is to be done, each case should be considered on its merits. To ensure equity, recovery rights need to be established for the LTCS for cases where it ends up funding a person who is eligible but rejected by other government programs.

- The new LTCS scheme's funding should be kept separate and *not* be held as part of general revenue. A separate legislative entity must hold and invest the LTCS scheme's funds and provide oversight.

- The new LTCS scheme must have protocols in place to work with other arms of the service system and coordinate responses with health, disability, aged care, housing et al; ensuring these service arms maintain effort as part of a continuum of care.

- The new LTCS scheme needs to integrate a system of community based lifetime care management that can assist the scheme to manage lifetime care programs, determine partial and full eligibility, and assist eligible individuals with community support inside and outside the scope of the scheme. The successful operation of the new scheme depends of this function being available, capable and connected to community infrastructure. This is an important design feature in that it can be articulated with existing case management methodologies to soften the border between the LTSC and the mainstream disability system. It is the lack of guaranteed lifetime planning and access to services that makes the current system deficient, so making lifetime care planning an entitlement across both systems will create a significant systemic improvement.

- A new life time care and support scheme should have a declared view of itself as
  - An innovator in LTCS thinking, research and practice.
  - Holding a leadership position relevant to the service system.
  - A developer of innovative service responses *in partnership* with service providers, not-for-profit organisations and others.
  - A developer of best practice benchmarks, quality controls et al.
  - A researcher with declared interest in innovation in service practices and trialling of alternatives.
  - An entity whose purpose is to enhance and support learning, understanding and collaboration in all areas of the service system.
  - An organisation that facilitates and requires evidenced based approaches for funding.

- In summary, a newly developed life time care and support scheme should

- Take lifetime responsibility for individuals with severe and profound need only.
- Start small, supporting those unable to obtain timely and effective responses from existing resources; and potentially grow to incorporate existing service system features over time from disability, aged care and health; and as the latter move towards delivery of a coordinated long term approach for their consumers. (We note Dr Anna Howe's submission to the Inquiry (Submission 59) and recognise the increased capacity of 20% that she estimates can be created in existing disability services through applying a new revenue stream to a targeted group of individuals with catastrophic injury. In our view, however, this initial group should be larger than the one suggested in that submission and include people with neurological conditions and children with significant disabilities. Maintenance of funding to the National Disability Agreement sector must be maintained to enable this to occur).[7]
- Be party to COAG agreements that require existing service programs to deliver their agreed responsibilities and have recovery rights from these programs if this does not occur.
- Embody flexibility in planning and service design to deliver individually targetted responses that can adapt to consumers' changing needs and life circumstances. Individual budgets.
- Incorporate a range of purchasing structures including individual budgets, financial intermediaries and/or direct provider funding. These are merely point of purchase decisions but will deliver flexibility and choice for consumers.

SERVICE SOLUTIONS FOR THE LTCS COHORT

Because of their complex interacting clinical and other support needs; their expectations and aspirations; their need for immediate access to resources from different arms of the service system, the YPINH group have been beyond the capacity of the existing system. Where people with similar disabilities are compensated, the problems of service access are not as acute. Service development and pathways have, however, remained sluggish, largely market driven and without systemic planning.

Delivering better service responses for this group will, however, have clear flow on benefits for *all* Australians with disability as they raise the bar in terms of service response, effectiveness and possibility, thus delivering an improved service system better able to respond to the needs of every Australian with a disability. Providing a new revenue stream that enables the creation of alternative services (including equipment services) will increase capacity in the aged care system and provide greater allocative efficiency in the health system.

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[7] Howe, A. *Submission to Productivity Commission Inquiry into a Long Term Disability Care and Support Scheme,* June 2010: 2-3.

Our experiences with the Council Of Australian Governments (COAG) Younger People In Residential Age Care (YPIRAC) initiative have revealed not only where service gaps exist and what systemic reforms are required to resolve them; they have also enabled a clear view of those service responses required to effectively respond to the needs of disabled Australians with severe and profound needs.

The Alliance believes that an LTCS scheme that

- delivers a joined up service response involving the health, aged care, disability, education, transport and housing arms of the service system
- uses lifetime support coordination to deliver a forward looking and comprehensive approach to service development and delivery that incorporates a risk management approach (See Appendix A, *The CCP Pilot Final Report,* in this regard)
- delivers a continuum of care across all arms of the service system but especially those of health, disability and aged care and
- *operates as an adjunct to the existing service system*, rather than replacing it, can deliver the kind of lifetime care presently missing from the service system at large.

The design of the LTCS must guard against the scheme becoming a default funder of services for which other areas of the service system have a responsibility. Due to resource constraints and demand management imperatives, service programs have become expert at border protection and demand diversion in the current system and will actively cost shift to the scheme if there is the smallest opportunity. As citizens, eligible individuals should be able to access a range of services in health, education, transport, aged care, housing et al without having to have the scheme 'buy' entitlement. The scheme needs to complement these areas of community egress and interaction; and not be required to take over their existing portfolio responsibilities, as doing so would place unreasonable financial burden on the scheme and risk the commodification of scheme members or claimants.

In this sense the LTSC must be a companion piece to the National Disability Strategy in addressing the life opportunities, as well as the service gaps, for people with disabilities in Australia. Although eligible people may have severe and profound support requirements, they should not be defined just by their service needs and their place in a no-fault scheme. Their citizenship needs to be respected and honoured by the community and encouraged by the LTCS. It is vital that this be a feature of the scheme as there is the ever-present risk (demonstrated by private sector behaviour around compensation schemes) that people can become market commodities for service providers.

The Alliance believes a **National Lifetime Support Commission (NLSC)** should be created and structured as described in Figure 1. Comment on the various aspects of this new entity, follow.

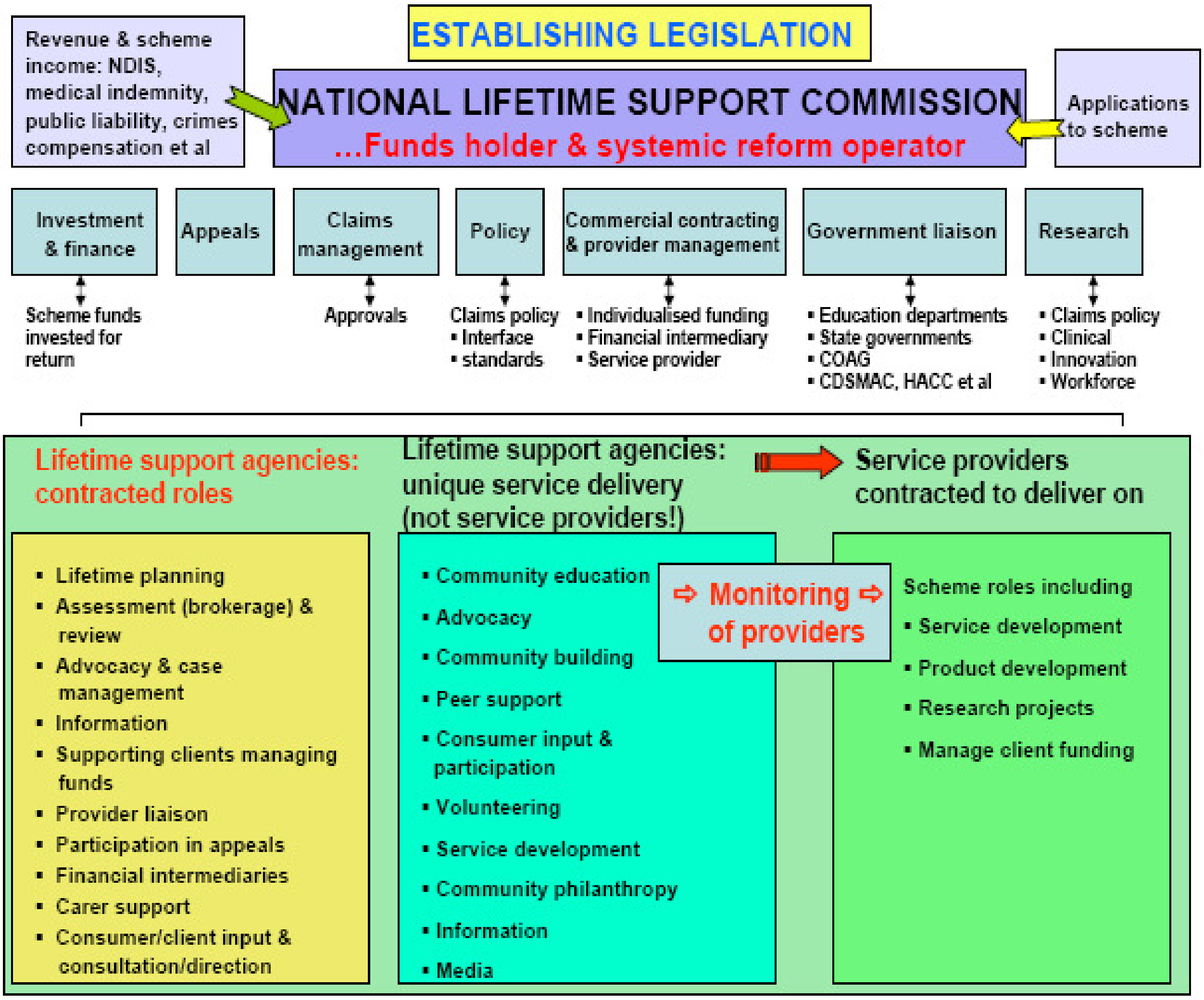

Figure 1 Organisational Chart, National Lifetime Support Commission

National Lifetime Support Commission

The cornerstone of a new LTCS should be a National Lifetime Support Commission that is empowered by legislation to run a no-fault lifetime care scheme for people with severe and profound disability; as well as perform a range of other important functions. It should be separately constituted and have its own Board that reports to the Federal Parliament. At the national level, it can be the governing body of a network of State and Territory offices that would run claims management; manage Lifetime Support Agencies and service providers; and negotiate with other local service programs. It should also have a national reform and coordination mandate.

Because of the fragmented state of disability care programs in Australia, there is a need to embark on a program of national reform of long term care. The new Commission is the body that would undertake this reform in much the same way that the Health and Hospitals Commission has done in the health care area.

Much of the discussion around an LTCS is how it may develop to absorb other disability programs. A reform platform must be developed, however, before any expansion or harmonisation occurs. The Commission needs to assume leadership in developing such a platform; and informing it through a dedicated research program. Research into long term care is extremely thin in Australia and should be made a priority through the Commission to inform reform and service development; and develop and support a vibrant long term care research community. In this respect, the Commission could even lead a lifetime care Cooperative Research Centre (CRC) program.[8]

This is an essential but longer term aim, so this function can run alongside the scheme's extant claims function.

The Commission will not only undertake this reform work in the long term care area, but also interact with similar reform programs in other community areas at State and Federal levels of Government. It will also need to be a key player in the implementation of the 10-year National Disability Strategy.

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[8] As described in the Productivity Commission's *Research Report into the Contribution of the Not-for-Profit Sector*, a Cooperative Research Centre Program is open to research in any field that has a strong end-user focus. The CRC program should provide development support for collaborations between NFPs, government agencies, business and research organisations to develop proposals for undertaking research and trials to address areas of major social concern. See Productivity Commission, *Research Report into the Contribution of the Not-for-Profit Sector*, Australian Government, Canberra, January 2010: xxxviii.

As part of its work, the Commission will need to establish Lifetime Support Agencies (LSAs) that will carry out its key work. These LSAs will, amongst other roles, be charged with

- assessing eligibility to the scheme;
- determining claimant need and developing lifetime planning to support identified needs;
- managing brokerage funds available for immediate and urgent service interventions;
- maintaining viable and effective working partnerships with service providers accredited under the scheme;
- convening Claimant Advisory Groups (CAGs) comprised of individuals with information pertinent to a claimant's health, well being and needs; and including acute care and allied health professionals, GPs, specialists, family members, service providers, advocates, disability specific member organisation representatives, as well as the claimant him or herself et al;
- managing information flow to claimants, family members, providers and CAGs;
- developing and sustaining effective networks and partnerships with all areas of the welfare and service systems;
- monitoring effectiveness of lifetime plans and coordinating plan reviews as required or requested;
- supporting development and trialling of innovative service responses with service providers, claimants, family members, CAGs and others;
- contract service providers and others, including allied health providers, to deliver specified services to claimants through the scheme.

Despite there being major disappointment with the disability system and its capacity to deliver services in a timely and effective manner, some not-for-profit organisations are delivering innovative activities to their members and communities. This activity will be of critical importance to the National Lifetime Support Commission's success and we have drawn heavily on the Productivity Commission's *Research Report on the Contribution of the Not-for-Profit Sector* to highlight the strategic value and importance of these organisations and their work for the National Lifetime Support Commission going forward.

Key components of the National Lifetime Support Commission

Policy

The National Lifetime Support Commission should

- Promote innovative policy development that investigates and promotes best practice.

- Assess and develop best practice benchmarks, quality controls and service delivery methodologies.
- Develop a specialist workforce skilled in the needs of the severe and profound cohort, including management and delivery of clinical support needs.
- Address systemic reforms not only within its own purview, but within the service system more broadly and at a national level.
- Be identified as the peak reform body for long term and lifetime disability care and support across Australia and internationally.
- Develop a long term/lifetime care and support research agenda.

Scheme income and revenue

Scheme income and revenue is derived from a range of sources including

- NDIS: a social insurance levy from general taxpayer contribution similar to the Medicare levy
- Crimes and other compensation payouts
- Medical indemnity
- Public liability
- State Government contributions (a sliding scale based on current no-fault coverage and other gaps that the LTCS is required to fill in its first iteration).

Applications to scheme

Application to the scheme should be made through a 'claim form' process that requires a range of assessments, proofs and demographic descriptors. Any person or organisation can make a claim, by application to one of the contracted Lifetime Support Agencies (LSAs).

As soon as an application is received, a Lifetime Support Coordinator (LSC) is appointed to filter the claim and request assessments, reports and other information required to assess eligibility and need. While ultimate decisions about eligibility must reside with the LTCS, the claimant's service needs and configurations can be managed by the LSAs. Capacity to defer active service responses until required should be part of the eligibility and planning processes.

Given the different disability types that may be covered by the LTCS, it is unrealistic to assume that a single assessment methodology will be feasible to determine entry to the scheme; or to determine needs during the life of a claim. Different medical specialists, health professionals as well as advocates, individuals and families will all need to be involved at various points of the

eligibility and claims management process. A claim form entry system that allows the input of whatever specialist or generalist is required to provide information is a more practical and preferred solution to determinations than a rigid assessment model.

Once eligibility is established, a planning process begins that will

- Establish immediate level of need
- Identify associated risks to the health and well being of the individual in the short, intermediate and long term
- Develop a plan that manages identified risks; and articulate those services and other interventions required to do so
- Contract service providers to deliver the suite of services required and
- Monitor and review the plan's effectiveness.

Investment and Finance

To ensure maximum return on the Commission's income, managed investment of funds via a specialist advisory board similar to the Victorian Funds Management Corporation (VFMC), should be established. The VMFC provides centralised funds management for Victorian TAC, Work Cover and State Trustees funds.[9]

A similar entity is required to invest and manage the Commission's income from which claims will be funded.

Appeals

A National Lifetime Support Commission (NLSC) must be flexible and 'porous' enough to address the myriad of ways in which its members will require a considered response; and manage changing needs in response to altered health, well being and life circumstances.

If 'whatever is reasonable' is its considered response[10], the appeal process should address how the scheme might potentially fail to support the health and well being of claimants if an appeal is not upheld.

The scheme also needs to be mindful of the variations in need that will occur in the severe and profound group. In other words, what is essential for one person may be a non essential item for another.

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[9] For further information see the VFMC website at http://www.vfmc.vic.gov.au/

[10] "A rigorous reasonableness test" is part of the determination of response used by the Victorian TAC.

As one example, air conditioners are essential to deliver the dry cold air in summer that many people with disease related impaired breathing require, especially those on ventilated support. For those without these conditions, however, an air conditioner has relevance to overall comfort in summer and may not be considered an item essential to maintenance of health and well being.

Claims Management

The overall process of claims management for the scheme should entail the following steps:

- Application is made to the National Lifetime Support Commission by claimant; family member; service provider; member organisation; advocate; health, disability, aged care representative via the Lifetime Care Agencies.
- A Lifetime Support Coordinator is assigned to determine eligibility for each application and manage the planning aspects for the applicant once eligibility is approved. One key advantage of utilising existing specialist disease and disability organisations is that they are already active in the existing service system; and can provide support to the applicant whether their application to the LTCS is successful or not. In the case of unsuccessful applications to the scheme, the LSCs can refer to other agencies or areas outside the scheme for assistance.
- Once eligibility is established, lifetime planning commences using a proactive, risk management and lifetime support methodology.[11] A limited brokerage fund is available to claimants on acceptance into the scheme. This fund is to provide immediate responses where urgent need is identified.

  Planning and assessment should involve all relevant persons with information pertinent to the individual including GPs, allied health personnel, specialists, acute care personnel and providers, service providers family members, employers et al.

  All information obtained must be maintained and available to all participants (including the claimant and family members) so that a body of knowledge about the claimant is maintained. This ensures that as members of this “claimant advisory group” or CAG change, the information gathered is maintained, kept up to date and available to new members coming on board. The Lifetime Support Coordinator is responsible for maintaining and managing this body of information.
- Lifetime Care Agencies have access to an urgent need brokerage account to provide a fast (but limited) response to urgent unmet need identified by the Lifetime Support Coordinator during the application process; or while other decisions are being made in the life of a claim.

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[11] Where a lifetime support methodology does not presently exist, one will obviously have to be developed. This is something that the scheme itself should research and progress.

The Lifetime Support Coordinator submits a considered plan to claims management for final approval and/or negotiation or review. The Lifetime Support Coordinator should be mandated to include elements in the planning process that are community based and do not require scheme funding, but for which support services can enable participation. This can include family and volunteer roles, participation in education or other activities, healthcare, or employment.

It is important that plans are multi-dimensional and include steps to interface with other parts of the community and service systems. In almost all cases, there will be a requirement to manage complementarity with other program areas (such as education, health, aged care, employment etc) so the Lifetime Support Coordinator will need to be an active negotiator with and for the claimant and the scheme around these interfaces to ensure maintenance of effort and delivery of outcomes.

- On approval, the Lifetime Support Coordinator recruits service provision from the accredited provider group and/or other accredited personnel for service response and training. Providers must be subject to a separate approval and accreditation process established by the scheme.
- As the claimant's support plan is activated, the Lifetime Support Coordinator monitors the support plan's effectiveness; and reviews progress with the claimant advisory group (CAG) to ensure the claimant's support plan is properly targeted to identified need and/or apparent risks. The Lifetime Support Coordinator maintains a clear information flow to all members of the CAG and is available to them for updates as required. The Lifetime Support Coordinator can also call on the expertise of this group to refine the claimant's support plan as needed.
- The Lifetime Support Coordinator monitors and adjusts the support plan as required. The LSC also manages the review process as required or requested by individuals, families, guardians, service providers and clinicians.
- Where a claimant's decision making is impaired, the Lifetime Support Coordinator will consult with guardians, friends and families, clinicians et al and where the individuals' preferences can be expressed, take these into account.
- The role of the Lifetime Support Coordinator is dynamic. Once the support plan is fully operational and running smoothly, the Lifetime Support Coordinator steps back, becomes less actively involved and less 'visible'. When changed needs are identified or further discussion is required or warranted, the Lifetime Support Coordinator becomes fully operational again and remains actively involved until the support plan is running smoothly and responding to the claimant's identified needs once more.
- A key role of the Lifetime Support Coordinator is to exert the authority of the National Lifetime Support Scheme to ensure that outcomes are delivered to the claimant and the

scheme; and to ensure that other programs are aware and participating in the overall lifetime support plan. As well as being an advocate and case manager, the Lifetime Support Coordinator will also need access to a fully functioning, independent disability advocacy sector to assist where other programs are resistant or failing.

This independent advocacy will also be a safeguard to hold the Lifetime Support Coordinators and the scheme more generally to account. While the resuscitation and capacity building of the disability advocacy sector remains the job of the National Disability Agreement signatories, it is an important adjunct to the establishment of the National Lifetime Support Commission and its work.

This is an ongoing, iterative process that should not have predetermined review dates, but be flexible enough to incorporate constant adjustment as needed.

Commercial contracting and provider management

In undertaking commercial contracting and provider management through its Lifetime Support Agencies, the National Lifetime Support Commission should

- Develop a provider management function that includes
    - provider accreditation and approval
    - provider audits
    - contracting of service development and delivery to accredited providers
    - encourages research and trialling of innovative service development and delivery with accredited providers
    - requires adherence to world's best practice standards
    - prevents commodification of disability and individuals with disability by the for-profit sector
    - ensures providers meet identified needs
    - incorporate essential workforce and other training by utilising its Lifetime Support Agencies to contract and monitor service delivery
    - deliver training modules for skilled workforce development.

Although it should require standards compliance from providers that it funds, the National Lifetime Support Commission should not be a standards monitor.

Government liaison

As an agency with a clear mandate to develop a national lifetime care strategy and innovative service responses, the National Lifetime Support Commission needs to lead the development of

a lifetime service *system* for the nation; and collaborate with state and federal government departments including health, disability, aged care, housing, transport, education et al.

We already have entitlement based systems for health (Medicare), pharmaceuticals (Pharmaceuticals Benefit Scheme), employment (Job Services Australia), aged care and school education and compensation/insurance schemes. The National Lifetime Support Commission needs to find a place beside these and the existing disability services system, and

- Must be an integral part of state and federal government planning for disability, health and aged care, housing, education, transport, justice et al
- Have input into relevant ministerial councils where its reform brief is relevant including the following councils and fora
    - Council of Australian Governments (COAG)
    - Health, Ageing, Community and Disability Services Ministerial Council (HCDSMC) including
        - Australian Health Ministers' Conference (AHMC) and its subsidiary Australian Health Ministers' Advisory Council (AHMAC)
        - Community and Disability Services Ministers' Conference, (CDSMC) and its subsidiary Community & Disability Services Ministers' Advisory Council (CDSMAC)
        - Ministerial Conference on Ageing
    - Ministerial Council for Federal Financial Relations
    - Housing Ministers Conference
    - Local Government and Planning Ministers Council
    - Ministerial Council for Tertiary Education and Employment
    - Australian Transport Council
    - Workplace Relations Ministers Council.
- Have State/Territory branches to
    - liaise with State and Territory jurisdictions around differing needs and requirements
    - promote and improve quality in service response through leadership and partnership with the States and Territories.
- Play a lead role in bringing fault based motor vehicle insurance schemes to no fault status and harmonisation (if desired) with other schemes.

- Play a lead role in delivering harmonisation of all WorkCover schemes to world's best practice standards including lifetime support.
- Gather and provide data to government (both federal and state jurisdictions) to compliment future planning of services in health, aged care, disability, housing et al.
- Coordinate with the States and Territories on the development of rehabilitation and habilitation services for the severe and profound group including development of a national framework for rehabilitation services. The Commission should take a lead role in partnering and coordinating efforts with health, disability and aged care peaks in delivering this work.
- Participate directly in the Commonwealth's Health and Hospitals Reform Program.
- Participate directly in aged care reform programs.
- Have membership of Local Government Authorities (LGA) and work with these authorities on articulation of Home and Community Care (HACC) services where required; and until Victoria signs up to the national HACC Agreement.
- Work with trade unions, employers and others on skilled workforce development for the severe and profound cohort, including
  - delivery of clinical and complex support needs and other systemic reforms
  - retention of skilled workers
  - development of career pathways for skilled workers to aid in retention
  - development of accredited training modules for skilled workforce development.

Research

As an identified leader in lifetime care and support, the National Lifetime Support Commission must develop and deliver a comprehensive research agenda.

Research, as an integral part of targetted and innovative service development and delivery, is something that has been sadly lacking in disability services. The need to deliver a better articulated and integrated services system that can support the high and complex clinical and other support needs characterising the severe and profound group, is a critical component of the National Lifetime Support Commission's work. The Commission must establish a comprehensive research agenda that

- Promotes evidenced based research.
- Collaborates with other organisations in Australia and overseas on research and development of innovative service responses and trialling of same.

- Collaborates with not-for-profit organisations, service providers, industry representatives and consumer groups to trial innovative, alternative approaches.
- Seeks international as well as national research collaboration in key areas.
- Collaborates with health, aged care, housing, education, disability services et al to deliver comprehensive data sets that indicate trends in need and effectiveness of articulated service responses.
- Develops best practice in service design and delivery; and innovation in service response.
- Collaborates with its Lifetime Support Agencies to develop training modules for skilled workforce development and retention.
- Invites and includes consumer input in its research portfolio.

To fulfil this function it may be appropriate to create a Lifetime Care Co-operative Research Centre to govern research in this area and ensure its translation into service provision and the wider community.[12]

Lifetime Support Agencies (LSA: contracted roles)

In proposing that not-for-profit (NFP) member organisations become Lifetime Support Agencies, the Alliance believes these organisations can make a unique contribution that is not similarly available in other commercial or for-profit enterprises. This is a view that is confirmed and reiterated in the Productivity Commission's Research Report into the *Contributions of the Not-For-Profit Sector*.[13]

The Commissioners' comments are instructive in this regard. In their report, they indicate that not-for-profits utilise processes that are *"…participatory, inclusive, quality focused and accessible…"*[14] The Report goes on to say that these processes are "central" because they

- *engender trust and confidence in the organisation, enhancing the reach and quality of the activities undertaken*
- *facilitate access to resources from multiple stakeholders including volunteer workers, as well as access to funding and in-kind resources, as NFPs can provide value to those making these contributions*

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[12] See Productivity Commission, *Contributions of the Not-For-Profit Sector,* Research Report, Australian Government, Canberra, January 2010: XXXVIII, XLIX, 224, 380 et al.

[13] Productivity Commission, *Contributions of the Not-For-Profit Sector,* Research Report, Australian Government, Canberra, January 2010.

[14] Op.cit: 16.

> - *build the capacity and capabilities of staff, volunteers, members and clients for effective engagement over time, including their knowledge and ability to influence the design of future activities.*
>
> *These 'quality' processes contribute to achieving the outcomes of the NFP, including what might be incidental outcomes such as improved community connections. In some areas of activity, process, in particular for maintaining trust, can be critical to achieving outcomes.*[15]

The report goes on to quote from submissions made to the Inquiry including the following:

> ***Trust and continuity*** *of relationships is essential. It is the establishment of trust through the continuity of staff and service provision that builds the basis from which change can happen. … [The] degree of trust rises with extent of trustworthiness of information about the trustee. It is this element of trust where the NFP sector has an advantage over the for-profit sector and why the capacity to deliver such programs is as strong as it is. (SDN Children's Services, sub. 160, pp. 10-11)*[16]

In this section, the Commissioners conclude by quoting Billis and Gennerster (1998) who argue that "…NFPs have a comparative advantage in delivering services where the motivation to address disadvantage, and knowledge of and sensitivity to client needs, are in scarce supply. In NFPs there is often a blurring of stakeholder roles, reducing the gap between clients and those delivering services, and between workers and management."[17]

When value for money is discussed, not-for-profits are again the declared winners in the Commissioners' view. They say

> *The choice by government to involve NFPs as providers involves consideration by government of value for money. Discussed in detail in chapter 12, value for money considerations should include:*
>
> - *cost-effectiveness of service delivery — and the extent that this depends on the development of relationships with clients*
> - *complementarity or joint-production with other services — which can enhance client wellbeing beyond that arising from the particular service being funded*
> - *spillovers (positive and negative) associated with the service delivery — these arise as a by-product that affects others in the community, such as the utilisation of a community centre as a base for services for other groups, and*

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[15] Ibid.
[16] Ibid.
[17] Ibid.

> *the benefits that flow on from improvements in the lives of individuals as a result of their engagement with NFPs*
>
> - *sustainability of the service delivery and/or client relationship, where the longterm effectiveness depends on the continued presence of the provider.*[18]

The Alliance concurs with the Productivity Commission when it says in its Report that not-for-profits contribute by

- *service delivery* to members or clients
- *exerting influence* and initiating change in economic, social, cultural and environmental issues
- *connecting community* and expanding people's social networks
- *enhancing community endowment* by investing in skills, knowledge and physical, social, cultural and environmental assets for current and future generations
- *and that while NFPs may pursue one, some or all of these purposes*, their outcomes can interact with others in shaping the eventual impact.[19]

In declaring NFPs as drivers of social innovation, the Commission says "The purpose-driven nature of NFP activities can give freedom to explore new approaches to achieving that purpose, allowing them to take risks where failure is accepted as part of learning. In addition, scope to try new things can be a highly valued part of what the NFP offers to its stakeholders. Indeed, some see NFPs as leaders in social innovation."[20]

Furthermore, because social innovation often requires multi-part and collaborative approaches, the Commission's Report identifies NFPs having a unique role to play because they can embrace and take note of responses from different stakeholders. The Report declares that

> *Not only multidisciplinary views are required, but views from different stakeholders.*
>
> *The client, their family, the local community, the school, the youth centre, and the welfare agency for example, all have valid and valuable input required to understand the problem. Second, a solution must be designed that will adequately balance all aspects of the problem, recognising that they interact in complex ways. Success in an experiment or trial may be the only way to be confident that a proposed solution will be effective.*
>
> *Third, implementation must allow for adjustments to suit the different situations that arise with location, clients and other variations from the model. This will often require action on a number of fronts, requiring collaboration between a range of organisations.*[21]

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[18] Op.cit: 32.

[19] Op.cit: 29.

[20] Op.cit: 238

[21] Ibid.

In proposing that not-for-profit member organisations are ideally suited to form the National Lifetime Support Commission's ***Lifetime Support Agencies***, the Alliance wholeheartedly supports the Productivity Commission's statement that community organisations have a comparative advantage in this area.

> *As an organisational type, NFPs have a number of characteristics (in terms of what motivates their decision making, their structure, sources of finance and workforce) that distinguish them from other forms of agency (chapter 2).*
>
> *Billis and Glennerster (1998) argue that the distinctive characteristics of community organisations give them a comparative advantage in delivering human services where the motivation to address disadvantage and knowledge of, and sensitively to, client needs are in scarce supply. The authors suggest that this is most likely to be the case in relation to personal and societal disadvantage and particularly in those cases where personal and societal needs are combined.*
> *What appears particularly important to the comparative advantage of NFPs in delivering these types of services is their reach into the community and community participation in decision making processes.*

The Alliance believes that not-for-profit member organisations with expertise in supporting individuals with high and complex clinical and other support needs are ideally suited to deliver the assessment, planning and monitoring processes that consumers with severe and profound need will require to successfully engage with the Lifetime Support Commission and its services. These organisations include such entities as Multiple Sclerosis Australia, Huntingtons Australia, Parkinsons Australia, Spinal Cord Injuries Australia, Australian Quadriplegics Association, Muscular Dystrophy Australia, Motor Neurone Disease Australia amongst many others.

As the Productive Commission's Report into the not-for-profit sector indicates, these organisations have the capacity to deliver key services as Lifetime Support Agencies that for-profit organisations are not well placed to deliver, including, amongst many

- Volunteers to maintain community involvement and commitment
- Provision of information to scheme members and the general community
- Community awareness raising
- Philanthropic input and in kind support
- Development and delivery of training modules in the clinical and other support needs of the severe and profound group. These organisations already have significant expertise in the support needs, expectations and aspirations of their members; and are best placed to develop this into training modules that can become part of the Commission's best practice approach to training and service delivery

- Collaboration with other agencies and service providers on improvements in best practice in service development and delivery
- Compilation and maintenance of comprehensive information on each claimant they 'manage' through the lifetime support process
- Host and support specialist Lifetime Support Coordinators.

Locking in the existing specialist disease and disability NFP organisations would provide the link between the scheme and the rest of the service system at the community level; and would safeguard against the commercial imperatives that could so easily undermine the social goals of the disability movement and the Scheme itself.

By creating a lifetime support model that goes beyond the strict borders of the scheme, it means that eligibility for the scheme is less of a holy grail for people, and capacity remains to be supported elsewhere in the system (utilising the additional capacity created by the scheme's additional revenue). It also harnesses the community capital of these organisations in implementing the scheme's programs into an already complicated community service environment; and enables continued roles for philanthropy and volunteering which remain essential parts of our society.

While becoming a Lifetime Support Agency may not be for every NFP organisation, those who do wish to undertake this work will have to comply with a range of criteria to become accredited agencies with the Commission. Some of these criteria include

- 10-15 years active experience as a specialist disease disability agency
- Maintenance of a volunteer program
- Demonstrated expertise in and delivery of community education
- Provision of peer support through active peer support programs
- Demonstrable skills in lifetime care management including assessment and planning
- Active and articulated networks in the clinical, community and government sectors
- Active relationship and collaboration with the philanthropic sector
- Demonstrated expertise in media communication
- Has state wide coverage and capacity.

Service Providers

The Alliance believes a clear difference must exist between Lifetime Support Agencies who deliver assessment and planning services for the National Lifetime Support Commission's clients or claimants and monitor the delivery of services by providers; and service providers

responsible for the timely, effective and efficient delivery of services to the Commission's clients.

The Alliance also believes that member organisations who have an existing service provision arm, should not be able to become accredited Lifetime Support Agencies until they have divested themselves of their service provision responsibilities. In other words Lifetime Support Agencies cannot be service providers and vice versa. Those agencies that are currently engaging in service provision as well as other peak body roles, may need to transfer their service provision roles to separate corporate entities, including social enterprises.

Service providers must comply with a clearly articulated accreditation process and commit to maintaining compliance with the National Disability Standards.

In short, service providers

- Are contracted by the National Lifetime Support Commission's Lifetime Support Agencies to deliver designated services.
- Cannot be Lifetime Support Agencies. Member organisations with service provision capacity cannot become Lifetime Support Agencies until their service provision capacity has been divested. In other words, a service provider cannot be a Lifetime Support Agency and vice versa.
- Have their service development and delivery monitored by Lifetime Support Agencies.
- Must comply with designated training of support workers in the delivery of support and according to defined criteria and accreditation protocols.
- Must be willing to work with families and claimants to refine service delivery and outcomes.
- At a minimum, must be conversant and compliant with the National Disability Standards.
- Must be accredited and approved as service providers by the National Lifetime Support Commission.

Eligibility for individuals with severe and profound impairment

Once a claim is accepted by the National Lifetime Support Commission and the need for response is established, the individual becomes a claimant of the scheme, including those

- Recovering from catastrophic injuries that involve acquired brain injuries and spinal cord injuries.

- Diagnosed with progressive diseases. An individual may make application to the scheme on diagnosis of a progressive disease but choose to defer the scheme's active involvement until need arises through the disease process. However, for many with progressive disease, early interventions may prevent disease exacerbation and/or slow disease progress. These subtle iterations of need will need to be established and examined by a Lifetime Support Coordinator skilled in the particular disease process.
- Experiencing episodes of disease exacerbation.

Eligibility is established through

- Application to Lifetime Support Agencies who must establish severe and profound impairment (or capacity to develop such impairment in the case of progressive diseases) according to clear eligibility criteria.
- If eligibility criteria are not met, the individual exits the application process at that point. An appeals process is available to individuals refused access to the scheme.
- Once eligibility is established, a Lifetime Support Coordinator is appointed and a transparent and broad ranging planning and assessment process is activated.

Risk management as an integral component of lifetime support

Together with the MS Society and Calvary Healthcare Bethlehem in Melbourne, the Alliance recently participated in a Continuous Care Pilot (CCP) that examined potential benefits for individuals with progressive diseases when a risk management methodology was used to manage health and well being.[22] Undertaken through the Younger People In Residential Aged Care (YPIRAC) initiative, a copy of the Victorian CCP's Final Report is included in this submission in Appendix A. This pilot was also successfully undertaken in NSW and its Final Report is forthcoming.

The success of this methodology is described in the Victorian CCP Pilot's Final Report and forms the basis of the Alliance's belief that adopting a risk management approach to identify short, medium and long term risks to an individual's health and well being will result in

- improved outcomes for individuals with severe and profound need
- integral roles for individuals and families in planning and service delivery
- cost savings for the Commission (and the service system more generally) through amelioration of risk and associated cost blowouts
- improved efficiencies and effectiveness as the service system delivers proactively by identifying and delivering on identified risks

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[22] Calvary Healthcare Bethlehem and MS Australia, *The Continuous Care Pilot Final Report,* Melbourne, December 2009.

- improved collaboration, partnership and understanding between the disparate arms of the service system
- more efficient and effective use of the existing service system with accompanying cost savings
- reduction in the impact of disease progression and anticipated appropriate increments to services that might accompany such progression
- support for individuals with progressive diseases and their families to become better informed about disease pathways and better able to address future planning issues as a result.

Workforce: development of a Lifetime Support Coordinator workforce

Life time Support Coordinators (LSC) are part of a new, highly skilled and specialised workforce that is required to develop and delivery lifetime support. As well as their key involvement in the assessment of eligibility, need and management of the planning process, LSCs will have

- Authority to engage with all arms of the service system and develop partnered responses.
- A brief to develop and maintain effective networks in all arms of the service system.
- A broad ranging brief to ‘think outside the square’ in delivering effective, timely and financially efficient service responses.
- Capacity to collaborate with all those with information pertinent to the health and well being of claimants including acute care personnel, GP’s, specialists, allied health professionals, service providers, advocates, member organisations, claimant’s family members and the claimant his or herself.
- Have capacity to recognise the need for innovative responses; collaborate in the design and delivery of innovative responses; and provide in depth reports on the net results of innovations to the scheme and others as required.

Lifetime Support Coordinators will

- Assess claimants’ eligibility for membership of the scheme.
- Manage a small brokerage fund for each claimant to deliver immediate responses if urgent need is identified.
- Develop and manage agreed service responses with claimant and family, service providers and others with necessary input into desired outcomes.
- Maintain a ‘watching brief’ on service responses and be ready to activate more intensive involvement if required or requested.

- Provide information if an appeal is mounted regarding denial of scheme eligibility or involvement.
- Maintain and manage all information and data pertinent to the claimant and to those services developed and delivered by the scheme for benefit of the claimant.
- Have capacity to recognise the need for innovative responses; collaborate in the design and delivery of innovative responses; and provide in depth reports on the net results of innovations to the scheme and others as required.
- Receive pay and conditions commensurate with the skill set required to carry out this role.

Workforce development: support workers skilled in delivery of care to individuals with high and complex clinical and other needs

The existing disability support workforce is poorly trained to deliver support to individuals with disability but particularly lacks the skills and capacity to support those with high and complex clinical and other support needs.

The National Lifetime Support Commission must

- Recruit workers with capacity to learn subsets of clinical care as well as other support need requirements
- Provide a defined career path for skilled workers where skills gained through accredited training can form part of nursing or other higher level qualifications
- Deliver improved pay and conditions to attract and retain highly skilled workers
- Develop accredited training in the needs of the severe and profound group including training in delivery of clinical support needs.

Social insurance funding base for disability service delivery

The Alliance has worked on development of a social insurance base for disability funding since 2002 and has included calls for such a levy in submissions to

- the Productivity Commission's *Review of Pricing Arrangements in Residential Aged Care* (2002/03);
- 2004's *Senate Inquiry into Aged Care*;
- the 2005 *Senate Inquiry into the Funding and Operation of the Commonwealth/State/Territory Disability Agreement*;
- 2006's *Senate Inquiry into the Provisions of the Medibank Private Sale Bill*; and
- the 2008 *House of Representatives Inquiry into Better Support for Carers*, amongst others.

The Alliance also convened a meeting of national peak organisations and the state Executive Directors of Disability on the need for such a scheme in 2007.

We have also worked with the Victorian Government to develop a no fault catastrophic injury insurance scheme as an expansion of the existing Victorian Transport Accident Commission (TAC).

The operation of the YPIRAC initiative has only reinforced the fact that if money is simply 'washed' through the existing system, nothing will change. If a social insurance levy is to be introduced, resources, expertise and pathways need to be developed and in place on day one. Governments – both state and federal – have a clear responsibility to begin developing this infrastructure now so that when funding from a social insurance levy comes online, the services it needs to buy will exist and be available in the not-for-profit as well as the for-profit sectors.

The Alliance believes that a social insurance funding scheme should

- Operate as an adjunct or companion scheme to the existing disability service system. The disability system should be left to do what it already does. Removing the severe and profound group should release significant capacity back to the existing disability system. In other words, the scheme should have a home in the fabric of what already exists.
- Be limited to those with severe and profound needs.
- Should not absorb existing CTP schemes into a social insurance base for funding. Existing schemes, including Victoria's TAC, NSW's LTCA, Tasmania's MAIB, as well as state based WorkCover authorities, all have different structures, benefits and risk based premiums that should be maintained separately and continue to deliver services for their client bases.

Infrastructure development

While it is widely acknowledged that the existing disability service system is badly in need of reform, we cannot afford to wait for a social insurance base for disability funding to be delivered to subsidise these reforms; or for reform to begin only once alternative funding arrangements are in place.

There is an urgent need to begin addressing service gaps now and delivering the service pathways we know are needed for Australians with severe and profound impairment.

It is also clear that the advent of innovative new service responses, or the address of systemic reform areas, will not succeed in and of themselves without government commitment to fix existing infrastructure deficits in education, transport, health, social housing et al. In other words, we cannot introduce a new scheme over the top of the existing service system mess we currently have.

Developing a better integrated, better targetted and more responsive service system requires major heavy lifting be done in raising awareness and developing understanding in all arms of the service system, but particularly disability in its relation to health and aged care. None of the service arms know or particularly understand the others because they have never had to and while this may have been acceptable in the 19th century, it is no longer viable – or acceptable – to do so in the 21st.

State and Federal Governments have a responsibility to develop the capital and service infrastructure needed for the scheme to buy its services from. Indeed, governments need to anticipate that a social insurance scheme will look to purchase services from them and start developing these now.

The Productivity Commission needs to make this point in the interim or draft report of this Inquiry. Failure to prepare for the implementation of a lifetime care scheme by building capacity now, risks extensive delays and potential cost shifts later.

Whether Governments adopt a lifetime care scheme or not, the status quo is unsustainable and change of some kind will result because of increased demand for disability services.

This is an area where Governments and the community cannot stand still, and the dangers of seeing the lifetime care scheme as a silver bullet that will solve all problems for all people all of the time; of waiting for it to begin; and of not beginning reform in the interim, are real and potentially damaging.

Service and infrastructure development must, however, acknowledge and exist within the framework of the Commonwealth's National Disability Strategy that will be announced later this year.

These service 'pathways' will also require extensive mapping to establish service gaps and negotiation with the health, housing, aged care and disability sectors et al to deliver comprehensive suites of service options for individuals with severe and profound impairment.

As one example, there is clear and urgent need to develop a range of step up/down services for individuals with Acquired Brain Injury (ABI) on discharge from acute care and to continue their recovery. Failure to do so will make room for service development and delivery to be market or demand driven, rather than developed according to evidence based and best practice approaches.

This is already starting to occur. As one example, there has been a reduction in provision of rehabilitation services available for purchase by one state's predominant CTP scheme over the

past 12 months. A not-for-profit provider with no experience of brain injury rehabilitation or management, has identified this service gap and moved to fill it by importing an overseas model of rehabilitation and care that is inferior to two already well established, evidence based and successful Australian rehabilitation service responses. This new service is only available to compensable individuals.

Age as a definition of access to services

The Alliance questions the wisdom, viability and responsibility of limiting any scheme to those with disability acquired before the age of 65.

The YPIRAC initiative has already demonstrated the negative impact of such age related limitations and the drastic intensification of need and consequent blow out in costs that results when individuals are denied proactive responses because they have aged beyond a particular point.

While the Alliance understands the concern that the huge increase in costs associated with age related disabilities may bring, it does not support the reinvigoration of our extant ‘apartheid’ system of support that exists through the current Australian disability/aged care interface of 65 years of age.

When 65 years was chosen as the definition of aged to introduce Australia’s first Aged Care Pension by the Queensland Government in 1907, life expectancy was approximately 55.2 years for men and 55.8 years for women.[23] Few were expected to reach 65 years and draw a pension.

Now, however, life expectancy sits at around 82-85 years[24] and some 3,400 Australians are aged 100 years or older, a number expected to swell to 78,000 by 2055.[25] As a result, Australia is experiencing a demographic phenomenon in which its citizens enjoy the fourth longest life expectancy in the world; and a major shift is occurring in the number of people living to be more than 100 years of age.[26]

Given these facts, using 65 years as a demarcation for access to services via a Lifetime Support Scheme and/or a social insurance levy, seems questionable, especially as the aged care sector is moving to embrace its own social insurance levy for aged care service provision post the age of 65 years.

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[23] *Australian Bureau of Statistics*, ABS Cat. No. 3302.0; ABS Cat. No. 3105.0.65.001.

[24] Ibid.

[25] Australian Bureau of Statistics, ABS Cat 3201.0 - *Population by Age and Sex, Australian States and Territories*, June 2009.

[26] Ibid.

Fundamentally, this is all about need related to disability and community capacity, of which age should not be a factor. Designing the National Lifetime Support Commission as a complementary scheme rather than a comprehensive scheme, means that the aged care system still has an important role to play and can continue to fulfil its role where appropriate.

Where an older person acquires a catastrophic disability unrelated to natural ageing, then the scheme should meet those needs. Where a joined up response is required, a way of negotiating joint funding of planning and required services is not only a desirable outcome, but a highly intelligent and responsible one too.

Whether the general public will agree to pay for two additional social insurance levies remains to be seen. But there would seem to be a case for one decent 'whole of life' levy to be considered if this came to pass.

Further information:
This submission was prepared with the assistance of Alliance members MS Australia and Brainlink Services.

If further information or clarification is required, please contact
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Appendix A

Calvary Healthcare Bethlehem and MS Australia, *The Continuous Care Pilot Final Report,* Melbourne, December 2009.

Appendix B

Disability Studies and Research Centre *NSW Continuous Care Pilot Evaluation, Final Report*, University of NSW, November 2010.

The Continuous Care Pilot – Final Report

MS Australia (ACT, NSW, Vic) and Calvary Healthcare Bethlehem

This report on the Continuous Care Pilot is in three parts:

1. **The Project Report**
2. **Detailed case studies**
3. **The draft independent Evaluation Report**

The Pilot was independently evaluated by Plexus Consulting, and the draft evaluation report is included in this final report. The evaluation used Concept mapping and Program Logic methods along with a documentation review, interviews with clients and service providers, observation of the Clinical Advisory Group (CAG), in operation, and workshops in order to conduct the evaluation. The evaluation focuses on the outcomes of the pilot for participants and family, and considers aspects of the program design and implementation.

The Evaluation project worked closely with the project and contributed to its development, however the evaluator was not able to finish the final report, so the draft has been included as an independent piece of work. Key data and findings from the evaluation have been taken up and detailed in the Project Report. The case studies within the Evaluation document constitute preliminary work; and a more detailed exploration of case studies is included within the presented in part three of the report.

The Project Report was written by staff involved in the pilot from MS Australia and Calvary Health Care – Bethlehem. This report details the development of the model used in the pilot including governance arrangements, recruitment of participants, the Clinical Advisory Group role, identification and management of risks for project participants, and how to address the workforce education needs.

The detailed Case Studies provide a snapshot of the issues and needs of a sample of the clients within the pilot. The case studies highlight some of the areas the CCP was able to provide assistance with, and demonstrates the ‘red flags’ indicating risk and the Risk behaviours exhibited by individuals and their families and carers.

The case studies then show the interactions and their outcomes of the CCP, and conclude by showing the risks at the end of the pilot. The summary information below each table gives some information from the follow up contact done twelve months after the conclusion of the pilot.

The three parts of this report read together will give an illustration of the project as a proof of concept Pilot evaluation of the model; the learning and development from a staff perspective; and then demonstrate the individual stories of the people who require the assistance of a Continuous Care Program.

The Pilot shows particular learning in a number of areas including:

- The imperative to identify and manage the disease related risk factors for people with degenerative neurological conditions living in the community.

- The practice of a continuous care approach in that it manages, monitors and reviews the changing needs of people as they emerge.

- The effectiveness of a collaborative model using a clinical support team and social supports from multiple programs. The CCP has similarities to highly successful coordination models used in Motor Neurone Disease, Palliative Care and Aged Care.

- The development and formalisation of an articulated partnership between health and community organisations.

- The value of the inclusion of the provision of symptom and disability management advice for clients and families, including the education of community case managers allied health professionals and direct care staff on the nature of progressive neurological diseases.

Continuous Care Project
Final Report

December 2009

Report prepared by:
MS Australia: ACT/NSW/Vic
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The Continuous Care Pilot was achieved through a collaborative partnership between Calvary Health Care Bethlehem and MS Australia.

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Executive Summary:

Introduction

Over the next two decades, Australia faces an explosion in demand for disability services that will see a doubling of service delivery costs by 2020.[1] Its reliance on a demand management approach to service delivery makes the existing service system poorly placed to meet this growth in demand and the complexity of need that accompanies it.

For a long time the misalignment of the health and disability systems have resulted in young people with complex progressive conditions being institutionalised in hospital and aged care facilities. The announcement of the COAG Young People in Residential Aged Care program was a recognition that this problem needed specific attention.

One way of addressing this blow out in demand for services and funding is to make the existing service system more efficient and effective in its approach to service design and delivery.

Employing a 'Continuum of Care' approach, the Continuous Care Pilot obliges the service system to work collaboratively and in partnership across service areas in health, disability, aged care and community services; and utilises a proactive, preventative approach to service interventions that ensures existing resources are used in a timely and more effective manner than may be possible otherwise.

Providing a viable and cost effective way of addressing the needs of individuals with disability generally, a continuum of care is an essential methodology for individuals with progressive neurological disorders (PND) who experience growth in need over the disease course.

The Pilot

The Continuous Care Pilot (CCP) program was designed to re-route the pathway into aged care for young people with progressive conditions through the implementation of a comprehensive set of interventions. It was funded through the 'My Future My Choice' Initiative and undertaken by MS Australia (ACT/ NSW/Vic) in partnership with Calvary Health Care Bethlehem.

The overall objective of the CCP is to work with people with progressive neurological disability and the service delivery network to manage the risk of premature entry into residential aged care by creating an articulated service pathway to provide a managed stream of support to meet their increasing support needs over time in the community.

It utilised an intensive disease management approach based on pathways and a risk management focus.

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[1] 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.

CCP Components

The pilot model included a number of components:

- A thorough assessment process based on consideration of all life domains, the clients ' history of service usage and future expectations
- A *Specialist Tertiary Case Manager* with considerable expertise in understanding the needs of people with progressive neurological conditions
- An expert advisory group called the *Clinical Advisory Group* that undertook detailed, future-oriented planning based on their understanding of risk issues affecting the client
- Development of *Service Continuity Protocols* with agencies that provide services to the client group. These were to be agreements to provide continuing services even if a client started receiving additional, supplementary services
- Training for service provider agencies to increase their ability to understand and address the needs of people with progressive neurological conditions
- An independent evaluation
- A limited brokerage fund

CCP Results

The risk management, future oriented planning approach employed in the CCP enables timely and effective interventions that are imperative to the maintenance of health and well being for this group and offers capacity to reduce downstream costs in health, disability, aged care and community services consequently.

As a multi disciplinary, multi systemic approach to service design and delivery, the CCP's successes have included

- Development of a risk identification – intervention – service provision model of service design and delivery
- Improvement in the health and well being of pilot participants
- Diversion of participants at risk of inappropriate placement in residential aged care with consequent reduction in downstream costs to health and aged care
- Diversion of participants at risk of inappropriate, long term placement in acute care with consequent reduction in downstream costs to health, disability and aged care
- Maintenance of auxiliary informal care arrangements at risk of breakdown so that families have been supported to stay intact with consequent reduction in costs to health, disability and community services
- Improved collaboration, partnership and understanding between the disparate arms of the service system
- Promotion of a case coordination approach to service delivery that has seen a more efficient and effective use of the existing service system with accompanying cost savings
- Investment in a proactive, preventative approach that has reduced the impact of disease progression and anticipated appropriate increments to services that might accompany such progression
- Support for individuals with progressive diseases and their families to become better informed about disease pathways and better able to address future planning issues as a result.

The CCP exemplifies the value of a life time care approach to service provision and the need for a whole of government commitment to service delivery. In this and its other features, it aligns well with the federal government's forthcoming National Disability Strategy and the latter's focus on a whole of life approach to service development and delivery.

Independent Evaluation

MS Australia engaged Plexus Consulting to undertake an independent evaluation of the Pilot. A detailed report is in preparation that includes an examination of the intervention model, the context, case studies and stakeholder experience. The evaluation report details conclusions and recommendations about the model and future action required to address the needs of this complex progressive neurological group.

This report summarises the work undertaken and basic findings and should be read as a companion to the evaluation report.

Next Steps

While the Evaluation Report details recommendations, MS Australia has identified that a Chronic Neurological Continuous Care program is needed for those people at risk of clinical and/or social breakdown. This program needs to

- Address the needs of individuals with complex progressive neurological diseases (PND) and their families at risk of preventable institutionalisation
- Integrate health services and community support by improving planning, communication and case coordination across programs and jurisdictions
- Improve access to interdisciplinary care and specialist care
- Be person centred and flexible, with delivery points as close as possible to the home.

Moving to designing and implementing this service response, the CCP has identified 3 main pieces of work that need to be undertaken early in 2010.

1. **A research project with a specialist working party of senior clinicians, service providers and consumers to**

   - Develop a complex PND risk identification matrix to be used to identify emerging and immediate risks requiring intensive continuous care intervention
   - Define 'threshold' criteria which are appropriate to diagnosis and social context of individuals at risk
   - Estimate numbers of potential clients requiring this intensive support in Victoria.

2. **Identification of a service delivery framework**

   - Identification of regional and metropolitan interdisciplinary health care teams with the capacity to respond to this group
   - Identification of specialist clinical and community service providers
   - Implementation of Tertiary Case Managers linked to these service areas

- Identify areas of involvement of disease specific support organisations

3. **Development of a support framework for consumers and providers within the CCP**
    - Information and education about the program
    - Identify a targeted brokerage pool for non-recurrent services.
    - Create secondary consultation pathways for community providers in addition to peer support and access to interdisciplinary neurological teams
    - Design of risk management planning process involving all relevant services and supports and ensuring consumer participation

The CCP Steering Committee

The Steering Committee held quarterly meetings to agree on project milestones and provide governance level support for the achievement of these milestones. Members provided insights and advice to the Project from their various perspectives, and informed the development of the project's products and provided necessary linkages to promote the operation of the project.

The committee consisted of:

- MSA Client Services Manager - chair person
- Senior Project Officer, MFMC
- DHS Southern Disability Representative
- DHS Representative
- National Director YPINH Allicance
- CHCB representative
- CCP Project Manager

The project was independently evaluated by a consultant from Plexus Consulting

CHRONIC PROGRESSIVE NEUROLOGICAL DISEASES: What are they?

Progressive neurological diseases 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 palliating symptoms, improving quality of life and can be life prolonging.

The age of onset and timeframe of progression in these diseases can be quite variable. Some follow a relatively predictable path, others relapse and remit unpredictably. Most are uncommon, and therefore poorly understood in the wider community, including among health professionals and community service providers, working outside the neurological field.

Because the nervous system controls our movements, sensations, our thoughts, memory and emotional responses, the impact of many of these diseases can leave the individual both physically and cognitively disabled. Mood, behavior, 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, demoralization and depression commonly impair the person's ability to face the future and address even the practical consideration of future needs. 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.

Methodology

The pilot used an intensive disease management approach based on risk identification, intervention, service planning, monitoring and review. The clients, their informal and formal care providers and health professionals were involved throughout the project. The establishment of a Clinical Advisory Group (CAG) and the appointment of a Continuous Care Coordinator were pivotal to these activities.

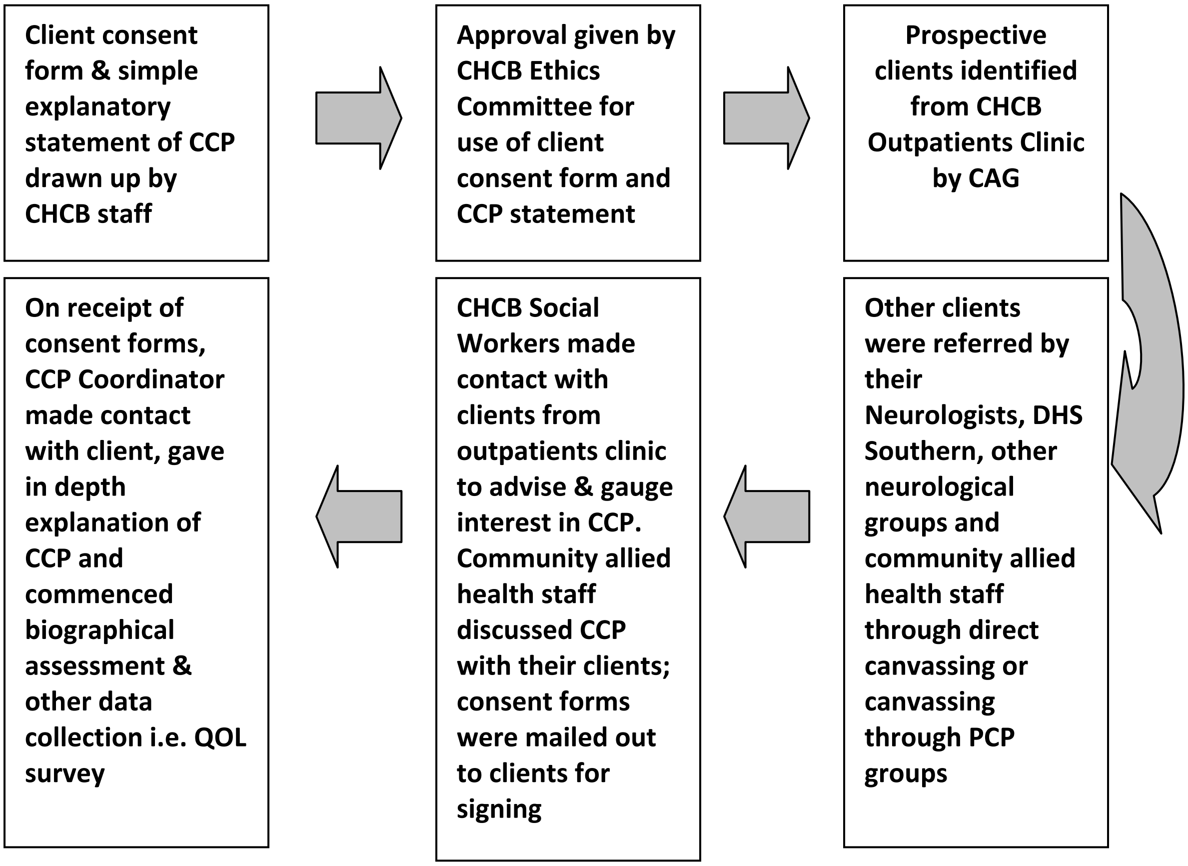
Admission criteria to pilot

- Progressive Neurological disorder living in the community
- Under 50 years of age
- Ideally registered on the Disability Services Register and currently in receipt of services
- Attend neurological outpatient clinic at Calvary Health Care – Bethlehem (CHCB)
- Has stable accommodation in the community and Is deemed to be at reasonable future risk of placement in aged care if additional supports are unavailable.

Recruitment of participants/intake

Prospective participants for the CCP were identified from CHCB outpatients clinic, clients who had visited the clinic within the last twelve months. Other participants were referred to the CCP by their Neurologists, by other Neurological groups or community allied health staff that had become aware of the CCP via direct canvassing or canvassing through the various Primary Care Partnership groups. They were considered appropriate because of the progressive nature of their conditions and deemed to be at significant risk of losing their homes and supports.

Diagram 1: This depicts the process taken to engage clients into the CCP



Client consent form & simple explanatory statement of CCP drawn up by CHCB staff

Approval given by CHCB Ethics Committee for use of client consent form and CCP statement

Prospective clients identified from CHCB Outpatients Clinic by CAG

Other clients were referred by their Neurologists, DHS Southern, other neurological groups and community allied health staff through direct canvassing or canvassing through PCP groups

CHCB Social Workers made contact with clients from outpatients clinic to advise & gauge interest in CCP. Community allied health staff discussed CCP with their clients; consent forms were mailed out to clients for signing

On receipt of consent forms, CCP Coordinator made contact with client, gave in depth explanation of CCP and commenced biographical assessment & other data collection i.e. QOL survey

The Clients

Twenty one clients were recruited to the Continuous Care Pilot. Two clients died during the course of the project. Of the 19 participants 10 were female and 9 were male. All participants had a diagnosis of a progressive neurological condition (PND). All data is based on these 19 living participants.

The range of diagnoses represented in the pilot included
- Spino-Cerebellar Ataxia
- Cerebral Palsy/ Cervical Dystonia
- Multiple System Atrophy
- Myotonic Dystrophy / Muscular Dystrophy
- Parkinson's Disease
- Mitochondrial Disease
- Multiple Sclerosis

The initial aim was to recruit clients already known to CHCB services. This was widened to include people who had had some contact with CHCB services, but were not necessarily still under regular review and also some clients, previously unknown to Bethlehem, but referred as potentially suitable for this project by their case manager, social worker, GP or neurologist. This resulted in a group of clients with a range of diagnoses, demographic backgrounds and metropolitan or regional locations. This served to reduce the influence of the "Bethlehem" model of care on the outcomes for this project, and made any recommendations more able to be generalised.

The clients lived across a number of Local government areas. These were City of Monash, Dandenong, Knox, Baw Baw, East Gippsland, Glen Eira, Port Phillip, Casey, Cardinia, Mornington Peninsula, Boroondara, Bayside, Kingston, Stonnington/Whitehorse* (1 client moved area during the course of the pilot).

The Service Providers

At the beginning of the Pilot, a number of providers were delivering services to the 19 pilot participants. They included services from HACC, health, disability and aged care sectors
- HAAC service – local council
- Community disability case management service – managing Linkage packages
- A wide range of attendant care agencies
- Commonwealth and State funded services
  - Private medical specialists
  - Acute, subacute,and aged care sector
  - Community health centres
  - Community rehabilitation centres
- Chronic Condition program
- Respite services

Continuous Care Pilot Coordinator (CCP Coordinator)

The key staff appointment in the Pilot was the CCP Coordinator. The Coordinator position was the key liaison between the CAG, participants and their families, providers and the evaluator. The role of the CCP Coordinator was to provide secondary consultancy for case managers and service providers and worked to ensure the implementation of the CAG recommendations. The role of the CCP Coordinator was to also allow for improved information flow, referral to services, the identification of gaps, and the practical application of resources to ensure continuity of care and lifestyle. The Coordinator was central to conducting the biographical / journey interviews enabling the Clinical Advisor group (CAG) to perform its functions.

Biographical Approach

Essential to the identification and amelioration of risks was the use of a biographical interview / assessment approach that works with the individual in the context of their family situation and clinical requirements.

The Biographical approach provided information pertaining to each individual's particular journey which also encompassed and told the story of the contributions and capacity of family and significant others. Without getting to know the individual, services do not successfully match to the diversity of the client's capacities such as attitudes, interests and other attributes. The stories told the project team of each individual's childhood, adolescence, their experiences and events in life, responses to events and the impact of events.

Some of the key areas of information gathered in the journey captured the impacts of various milestones including; time of diagnosis, first significant relapse, giving up paid employment/study etc. The impacts were measured in the domains of: Social Isolation, Relationships, Financial issues, Employment, Motivation, Loss / grief /anger, Pain, Fatigue, Anxiety and Communication.

The biographical interviews were conducted by the CCP Coordinator. This information was shared with the CAG with consent of the client. While the interviews were a time consuming activity, and sometimes fatiguing for the individual, it helped to establish rapport and trust, paving the way when sensitive and difficult issues needed to be raised. It also gave insights into their emotional and psychological responses to change.

Among many benefits of biographical /journey interviews is the feeling of being heard, understood and appreciated as an individual and valued as a person. Importantly it provided knowledge upon which to assist with decision making, influencing direction and tailoring applications and referrals that were appropriate to meeting the needs of the individual and the family.

Clinical Advisory Group (CAG)

The CAG was conceived as a forum within which specialist clinical input could be provided to the project team, and in particular the CCP Coordinator. The CAG clinicians had access to clinical information on all of the clients enrolled in the project, but did not necessarily have a direct professional relationship with the client. The CAG clinicians liaised with the client's treating health professionals as required. In this way the CAG clinicians provided secondary consultation advice. Decisions concerning a client's care and management were made between the client and the treating health professionals / case manager / service providers, supported by the project officer, who was in turn supported by the CAG.

The CAG team was also careful to use local service providers whenever possible for clinical assessments (eg. physio, OT), as this was seen as more realistic and optimized the use of current services on the ground.

CAG membership consisted of clinical staff from CHCB and staff from MSL. Case managers, allied health staff and other experts were invited to attend the meeting as relevant to provide input. The CAG team met on a twice monthly basis. The CCP Coordinator provided coordination for the meetings, set the agenda and took minutes of the meeting using a standard template.

CAG Functions

- Risk Identification
- Risk Management: developing realistic strategies for risk amelioration
- Developing the Continuous Care Model

Risk Identification

The CAG Meetings provided a forum to explore potential risks and possible options for risk amelioration. Risk identification was based on review of the detailed information gathered by the CCP Coordinator in discussion with the client / family/ carer and service providers and the clinical information reviewed by the clinical staff. Whenever possible and with the client's consent the individual case managers were involved in these discussions. These meetings therefore brought together:

- first-hand, up-to-date information about the client, their concerns and the context of their current care
- people experienced in community-based care and the service sector
- clinical expertise in chronic progressive neurological disease

Risk Management

Through case conference, the CAG generated realistic management options. These were discussed with the client, usually by the CCP Coordinator, the case manager or relevant clinician and decisions were reached. The CCP Coordinator tracked and facilitated where necessary the implementation of plans and reported regularly to the CAG.

Careful consideration was paid to systemic risks and barriers by the CAG team in recommending interventions and service provision options. Using the experience and knowledge of the CAG members, they identified pathways and strategies to improve the outcomes for the participants and the sector as a whole.

The CAG was proactive in responding to the identified risks; first addressing immediate risks through more effective use of existing resources, or when necessary, brokered services or equipment to stabilise the environment. Medium and longer term risks were discussed, and future planning recommendations made.

Developing the Continuous Care Model

The CAG meetings were also used to explore ideas which could inform the Continuous Care Model

- modeling of direct 'information sharing' and 'the transfer of knowledge' between health and community service providers who, in the real world, often work in isolation
- Understanding the clinical milestones which underlie risk and triggers for intervention
- streamlining the application process to the Disability Support Register
- identification of 'Red Flags' for clients at risk
- identification of patterns of 'behaviour' (in clients, carers, clinicians and service providers) which contribute to poor decision-making and increase the risk of crisis
- Education and training needs of providers

The CAG also developed and ran 2 Workshops and a Neurological Forum to engage other service providers and health professionals in Victoria, to provide

- a broader understanding of the service sector's experiences and issues delivering care to clients with progressive neurological diseases
- an exploration of the training and educational needs in the service sector
- stakeholder input to the development of a model for Continuous Care

<u>Brokerage Funds</u>

The pilot had a finite pool of brokerage funds which provided the capacity to directly purchase no recurrent services or resources. This was only used when no other response was available to meet an urgent, identified risk such as

- Home visits
- Physiotherapy: assessment – intervention/ prescription & education /training
- Neuro psychological input
- Equipment assessments, prescriptions. (Payment of the gap from AE&P, full payment and hire of equipment until equipment could be supplied.) Examples include:
    - Wheelchairs
    - Shower / commode chair
    - Hi /lo bed & pressure mattress
    - Thermal vest
- Respite (client contribution and contribution to family respite)
- Family counseling and child counseling
- Medical intervention
- Home/bathroom modification (GAP in funding)
- Travel: support for participants to get to healthcare appointments which is a necessity in supporting their health care management

Continuous Care Pilot Reconciliation 08/09 & 09/10 financial years

Consultation costs – Calvary Health Care Bethlehem	**Hours / dollars**
Clinical advisory group (CAG) meetings /preparation time.	**Approx: 196hrs 2-3 meetings per month**
Specific follow-up activities by Social Work and Neurologist – (referrals, family meetings, liaison with medical professionals etc	**Approximately 32hrs**
Services to Participants – Brokerage funds $100K	
Home visits, physiotherapy, Neuro- psychology input	**$ 6,124.54**
Equipment: purchases/ hire & A&EP gap	**$ 56,548.83**
Equipment assessment	**$ 1563.75**
Services: Respite / counselling	**$ 7024.80**
Medical intervention	**$ 650.00**
Travel	**$1243.08**

During the course of the pilot the brokerage funds were not exhausted. This was in large part due to the efficiencies which were achieved by the CAG's ability to navigate within the existing service system and to avoid unwarranted expenditure by focusing on achievable outcomes.

Discharge Process

The discharge process has involved summarizing the social and environmental situation for each participant of the pilot including activities and events of intervention received through the term of the pilot. Most important is the completed table for each participant. The table documented their ongoing identified needs and supports (risks), the recommendations to address these risks, the suggested or required intervention and contact person responsible to make this happen. This table is the most relevant to the individual and their family, providing them with current and future planning with an articulated pathway that can respond to the need.

The complete discharge document is provided to the GP or primary clinical practitioner and service provider/s such as Case management. The social and environmental component together with the table of current and future recommendations is a method of transferring information and knowledge that the CAG has established including further recommendations during the term of the pilot.

The final role of the Coordinator has been to support the individual participants, their significant other and case manager (if there is one) to understand the plans and ensure they have the relevant information to continue to work together along the continuum.

Results

Client Characteristics and Life Domains

The participants of the pilot are young people ranging from 33 to 49 years of age, (average 45 years).

In general, the individuals in the pilot group have a degree of physical disability which makes them partly or completely dependent on others for activities of daily living. Many have disturbances of cognition, behaviour or mood, and there were many other significant symptoms requiring regular management and review.

The broad areas of support required in the individual participants included:

- Physical limitations / disability,
  - partly or completely reliant on others to attend to mobility and transfer, toileting, personal hygiene, grooming and support to eat and drink.
- Impairment of cognition, behaviour,
  - requiring support with memory, planning, decision making/ judgement, compliance with agreed arrangements
- Symptom management
  - relating to mood disturbance, pain, spasticity, incontinence, communication, range of movement, breathing and swallowing difficulties, etc.
- Social and emotional support
  - both informal and formal
  - Including; financial, legal, relationship advice and counselling

Two clients were in paid, part-time employment. All of the others had been out of the workforce for an average of 9.7 years (1 – 20 years). This had had a major impact on their financial security. Only 7 households had an independent income; all of the others relied on a pension and / or savings, including 5 families with dependent children. Extended family or informal carers were significantly involved in the care of their family member. In 8 cases, care was provided by elderly parent(s).

The risks associated with the future health and social well-being of this cohort of people are therefore very significant, and many risks are predictable, based on the precarious social and financial capabilities of their environment and the progressive nature of their disabilities. It is not surprising then, that the well-being of a person and family living with a long-term and progressive illness may come under threat from medical complications and financial or social breakdown.

Emotional & Spiritual Domains

The biographical interviews with participants and their families highlighted the attributes, concerns and anxieties which had contributed to their experiences of living with illness and the ways in which they felt their lives had changed as result of a diagnosis of a family member with a progressive neurological disease. The common personal, social and emotional attributes gathered during the initial interviews are summarised in the diagram 2, below.

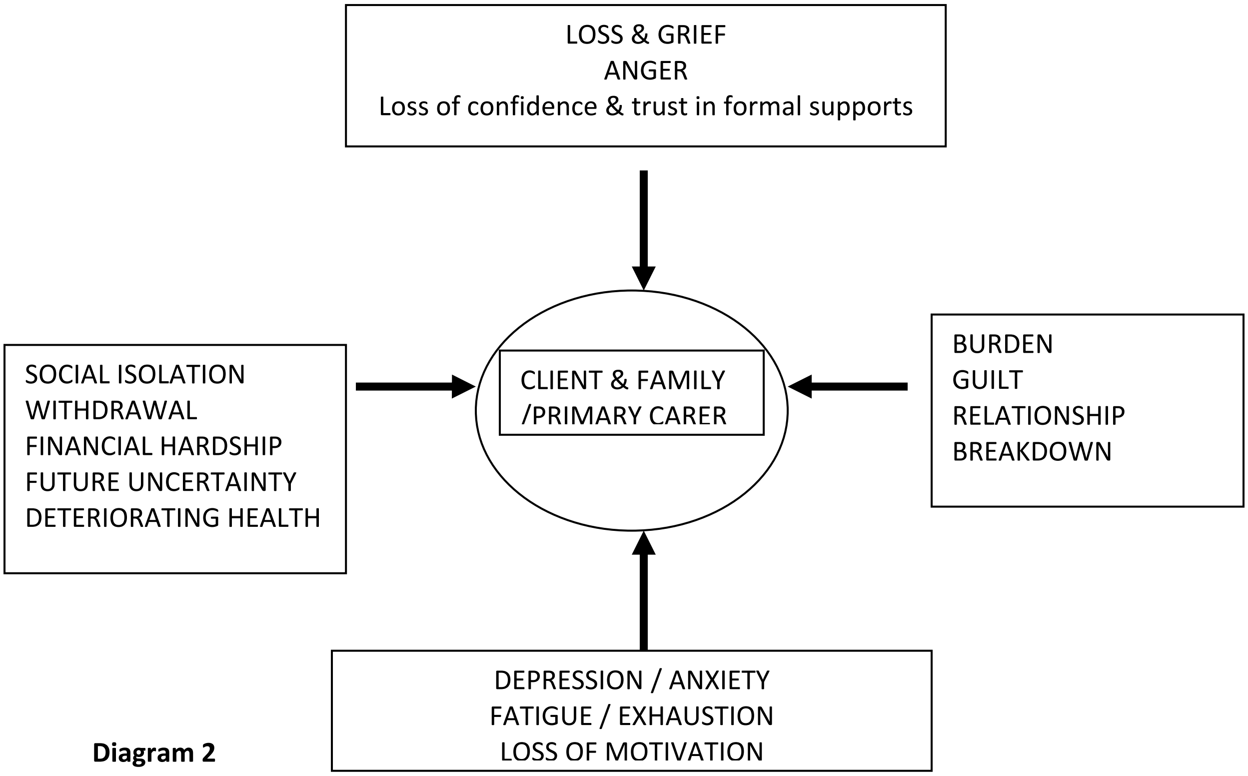


Diagram 2

Identifying Risks

Red Flags

A number of themes were apparent through the narrative of the life journeys and domains. The following 'Red Flags' highlight characteristics which place individuals or families at risk of breakdown in their health or social well-being.

Red Flags

- Living alone / social isolation
- Single parent / dependent children
- Ageing parents / reduced family support
- Cognitive impairment
- Mood / behaviour disturbance
- Carer strain
- Sleep disturbance
- Unsustainable housing: structural/financial
- Financial strain

Risks and Unmet Needs

The initial assessment of the clients by the Continuous Care Coordinator and the CAG revealed a significant number of risks and unmet needs. The majority were found in the following areas –

1. Disability support packages
2. Community services / case management
3. Health care
4. Client's social context
5. Workforce issues
6. At-risk behaviours
    - Client
    - Family /carers
    - Workforce
    - Systems

Risk Amelioration: responding to identified need

One of the aims of the CAG was to show how the bringing together of information from the client, the community service providers and the health care sector would identify unmet needs and the areas where no forward planning had occurred. The responses of the CAG to these factors are summarized below:

1. **Identified Risk / Need: Disability support packages**
    - No applications lodged
    - Inadequate level of current support and poor forward planning for future needs
    - Packages and providers change rather than increment as needs increase

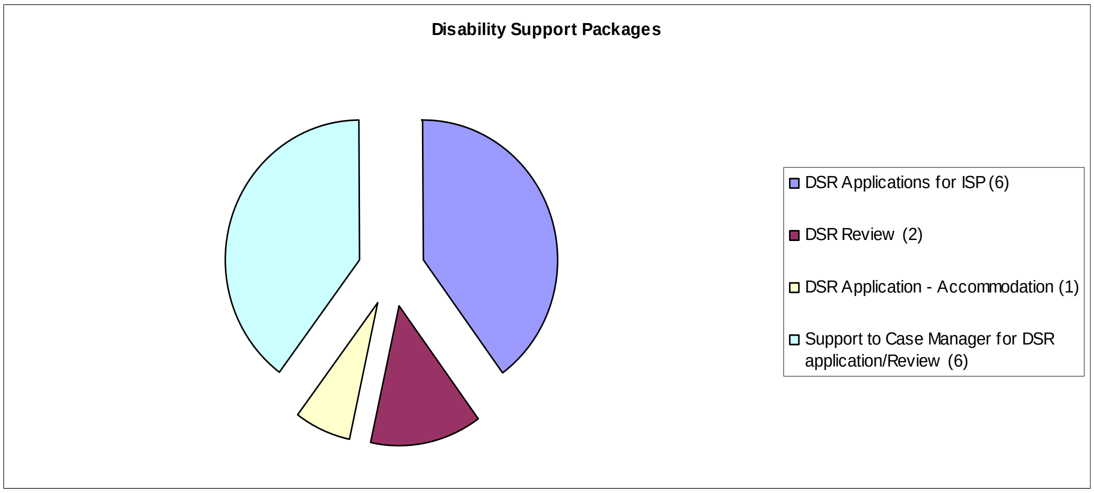
Risk Amelioration

In all, the CCP Coordinator and CAG members directed or assisted in 15 DSR applications or DSR application reviews (Diagram 3). Case managers were often uncertain about the information required when writing these applications for clients with progressive neurological diseases, and without a good understanding of the disease trajectory were failing to anticipate need.

Educational and peer support requirements of case managers were explored further in the Workshops (see below).

It proved difficult to develop agreed protocols to maintain HACC funding support when clients were allocated individual support packages, i.e. to allow incremental funding of service delivery. However, one on one negotiation by the CCP Coordinator often reached a workable compromise that ensured continuity of services for individual clients.

Diagram 3: Risk Amelioration strategies

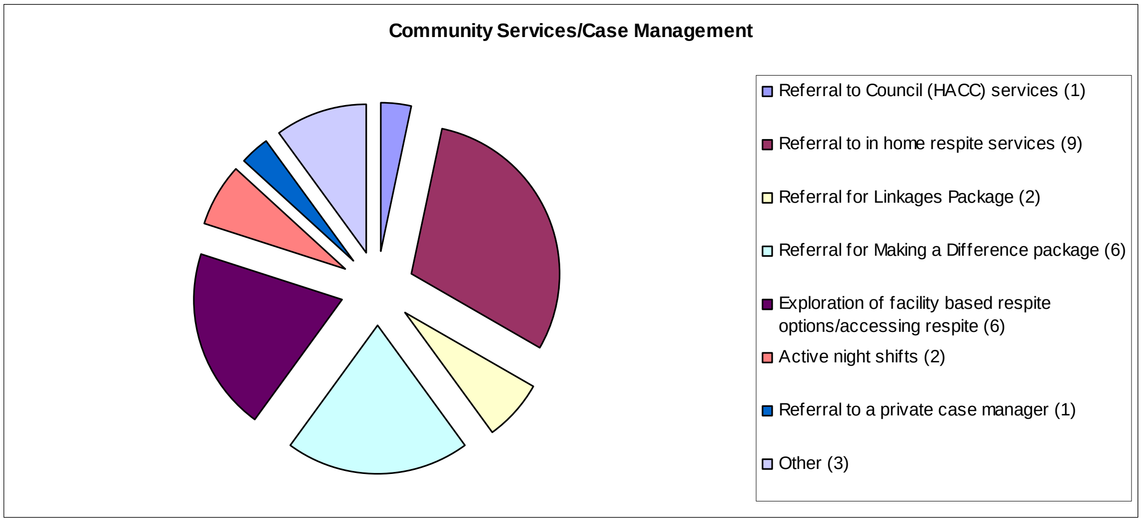


2. **Identified Risk /Need: Community services / case management**
    - Urgent need for more services
    - No case management in place
    - Case manager / attendant carers lack necessary skills

Risk Amelioration

A number of clients needed more supports. Following recommendations from the CAG meetings, referrals were made for increased services. The education and training needs of care providers and health professionals in this field are discussed further under ‘Workforce’ and were also identified during the Workshops and the Neurological Forum.

Diagram 4: Risk Amelioration strategies



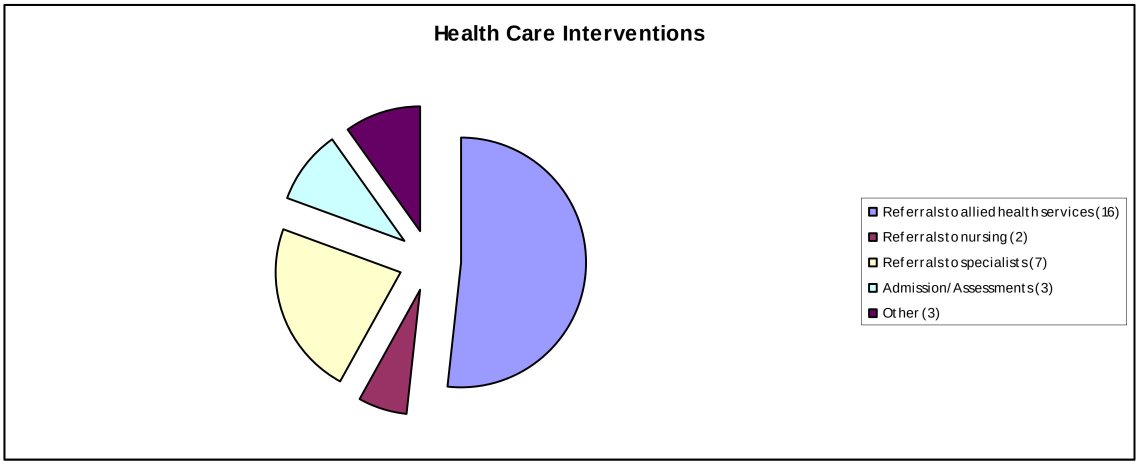
3. Identified Risk / Need: Health care

- Poorly controlled symptoms
- Lack of monitoring
- Poorly coordinated health care
- Not integrated with community services

Risk Amelioration

Most clients had a number of identified symptoms which were either poorly controlled or prone to relapse after periods of stability (pain and depression, for example). It was not uncommon to find that the client had sought advice and treatment for their symptoms from various health professionals in the past, but had either failed to follow through with the treatment plan or had not returned for review by the same specialist when symptoms recurred. Thus poor continuity of care and incomplete compliance with treatment often underpinned the poor outcome and the client's perceived dissatisfaction with care. This also highlighted the need for health professionals to find ways to more effectively reinforce their treatment recommendations titrate therapy and monitor compliance.

Diagram 5: Risk Amelioration strategies



4. Identified Risk / Need: Client's social context

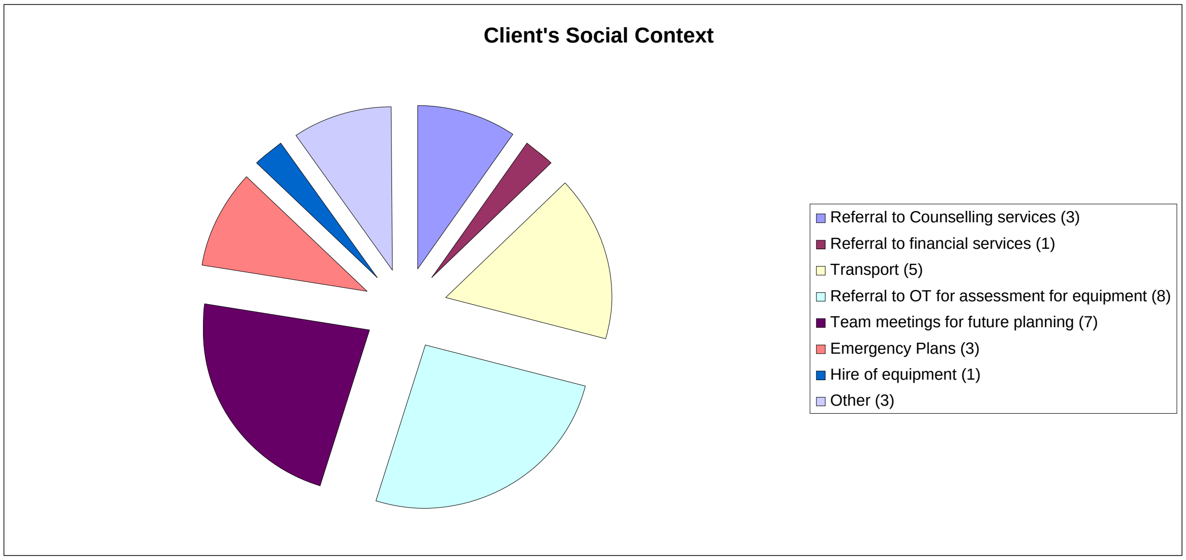
- Social isolation
- Dependent children
- Carer stress or illness
- Inadequate respite
- Financial strain
- Accommodation issues
- Environmental and equipment needs

Risk Amelioration

Many clients had limited informal supports or financial reserves to call on in times of increased need. Changes in their health or the well-being of their family or regular carer(s), therefore placed immediate strain on their ability to manage at home. This also emphasized the importance of access to appropriate emergency and regular planned respite services to both meet these contingencies and also prevent carer burn-out.

Primary carers and families were also living with these chronic diseases. Even in well adjusted families, roles and relationships had been forced to change as a result of the client's illness and care needs. Without adequate support or respite, many carers were juggling demands rather than feeling in control and able to see their way ahead. In these circumstances, some carers did not pursue respite options. For some, planning respite was more burdensome than pressing on, and their views were often coloured by previous negative experiences or resistance from the client or client's extended family. The welfare of children, their futures inextricably linked to the welfare of their family unit, is also an area of concern, particularly in sole-parent families.

Diagram 6: Risk Amelioration strategies



5. Identified Risk / Need: Workforce Issues

This is the feedback from interviews with participants by CCP Coordinator of the risks and unmet need by the workforce.

- Difficulty recruiting and retaining paid carers
- Inconsistent quality and reliability of paid care
- Skill-base of carers, case-managers and health-professionals to manage this client group
- Waiting lists for community based assessment

Risk Amelioration

Transfer of knowledge, sharing of information, planning and facilitation took place many times across the workforce sector to respond to risks and gaps as expressed above. Examples include:

- Manual handling / transfer training, training of a prescribed exercise program to paid carers and family members
- Mentoring and coaching by the CCP Coordinator of community providers in the preparation of funding applications, navigating the service systems in relation to respite, meeting equipment needs etc. Also considerable time was provided in facilitating client and service provider meetings to support understanding around issues of equipment/ OH&S/ coordination and planning / coordinating care arrangements.
- Support was provided by CHCB social workers and CCP Coordinator to Case Managers in conducting family meetings in order to discuss future planning.
- Case managers of participants, other service providers including DHS staff attended CAG meetings, specific to known clients to share in the discussion, to hear clinical information, reasoning and planning.
- Workshops with case managers and services providers that promoted the health and community care needs necessary to best meet the progressive neurological groups continuous care needs.

<u>At-Risk Behaviours</u>

The CAG often identified at-risk behaviours, which formed the basis of why problems had occurred in the past, or were likely to lead to problems in the future.

Certain behavioural traits could be seen to confound constructive planning and lead to frustration. Human behaviour is naturally diverse. Some of these unhelpful behaviours are part of the human spectrum and occur in people from all walks of life. They were seen therefore in service providers as well as clients. Others are pathological, that is disease-related, and could disrupt the client’s ability to cope with the situation at hand, weigh up options, deal with distractions and plan ahead.

At-risk behaviours often related to –

- the client’s underlying disease process affecting higher executive cognitive functions
    - Impulsive decision-making / poor judgement / rigidity
    - Lack of insight into problems
    - Poor planning

  - Failure to persist with agreed arrangements
  - Brittle emotional responses
  - Egocentricity / loss of empathy
  - Avoidance / denial
  - Impaired communication

- The carer's or provider's poor understanding of neurological disease and its effect on cognition and behaviour resulting in failure to
  - Make allowances
  - Modify decision and planning processes
  - Provide additional support and counseling
  - Apply behaviour management skills

- Behaviour of carers/families
  - Poor life / caring balance
  - Effects on children's behaviour
  - Depression/anxiety
  - Poor uptake of support / respite options

Addressing the Workforce Challenges: Workshops and the Neurological Forum

The clients and their families voiced a number of concerns about the workforce's ability to meet their needs. Service delivery often fell short of the consistent, reliable and skilled care that was required. During interviews, service providers and health professionals commonly acknowledged similar deficiencies, and those attending the workshops and forum unanimously called for systemic reform in the delivery of chronic care and improved training and support for service providers and health professionals in this field.

Health professionals working with people with progressive neurological conditions often felt they had a poor understanding of how the disability services sector worked. Community providers and case managers had little experience of these diseases and inadequate direct contact with the clinicians. Some clients had infrequent or no planned clinical review. Services and providers were generally not joined-up to benefit the client.

A lack of care coordination and poor communication between the different stakeholders were common problems. In particular, the different providers often knew little about the involvement of other services, especially across the boundary between Disability and Health sectors. Not only did this lead to poor sharing of information between the client's service providers, but also a lack of knowledge could deny clients access to potential benefits and resources.

- Inadequate knowledge / skills base to manage this client group
- Poor communication
- Poor case coordination
- Poor continuity of care
- Breakdown of relationships: client / service providers
- Workforce shortages
- Withdrawal of services

Workshops

A total of 2 Workshops were held as follows

> Two workshops attended by Senior team leaders, managers and case managers and health professionals involved in service delivery to clients with progressive neurological conditions.
>
> The aim of the workshops was for participants to develop skills in the early identification and analysis of risk for clients with complex neurological conditions and to explore pathways and planning requirements to address prioritization of these needs (immediate, medium and long term).

The workshops also identified the need for ongoing education looking at factors that enhance the identification of risks by:

Understanding Person → **Understanding change** → **Consultation with specialist to understand prognosis & progression** → **Supports changing needs in a planned & controlled way**

There were 23 workshop participants who offered the following comments listed below.

"I learned the importance of forward thinking with families and the value of informal gatherings of interested people as good strategies to try"

"All of this was fairly new to me in a formal way. I find I do most of these things eg Identifying risks with my clients but was not sure where to get these services from and to whom. It is much clearer now."

"I believe that further study based on evidence practice and reflection will improve my skills to 'high' (rated medium) as best as I can with clients with PND"

"I really enjoyed this workshop. I learned a lot and would like to participate in other workshops to extend my skills and knowledge"

"Thank you- need more opportunities to network across fields and sectors and learn to manage gaps, negotiate and navigate. Best wishes for CCP to continue and expand."

"The workshop would be highly beneficial to those new to writing DSR's – however I sit on the DSR team and feel I am competent in writing these applications."

"Very thorough, informative and useful"
"Greatly improved my understanding about multidisciplinary involvement"

"Has helped me to identify needs of new referrals and what information I need to obtain"

Has helped me to identify risks within clients in my caseload"

'Key to successful/meaningful case management when working with people with PNDs in building up trust with the clients and their family"

Gaps and Barriers

There were many barriers and gaps to providing a continuous care model within the current community services workforce. The following barriers were identified by the CAG and CCP Coordinator through liaison and working along side providers. Service providers also contributed to the list in one of the workshops.

Barriers and Gaps:

- limited understanding of the disease trajectory, complexity of need, changing need
- lack of knowledge of specialist networks and importantly at what point do you refer – where to start, (what, how and where services can be accessed)
- no clear pathway to integrated, multidisciplinary health and disability services. The fragmentation of service provision and inability to draw down from the range of services and cross jurisdictions for integrated care delivery.
- Client and family lack confidence in current formal service provision
- Response time – long wait for packages and at time inadequacy of the funding and range of services
- Poor communication between individual/family/health providers/community care providers etc impacting on capacity for good coordination
- Lack of understanding of the need to work from 'recognising the risks' through to 'planning service provision', if crises are to be avoided.

Many service providers felt they were working outside of their scope, but they were eager for information and different ways to approach their work.In particular, they found the CCP Coordinator a great support and mentor. The CCP Coordinator provided Services with the capacity to take a more proactive approach to identifying need, understanding root cause, understanding the services required and to increase communication to establish a collaborative and continuous partnership with the client, their family and other service providers.

The Neurological Forum:

19 senior clinicians: neurologists, rehabilitation specialists, palliative care clinicians and nurse specialists, and a representative from Disability Services attended the Forum.

The forum began with a discussion of the policy context for chronic care delivery, in Victoria, Australia and overseas. This included

- **The National Service Framework for Long-term Conditions.**
  Department of Health. London: DH, 2005.
- **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
- **Care in your community; DHS 2007**
- **The Victorian Health Independence Program Guidelines DHS(2008)**
- **Victorian State Disability Plan: Implementation Plan 2006-2008**
- **Strengthening Palliative Care Policy 2004-2009. A policy for health and community care providers**

The aims of the Continuous Care Pilot and the Neurology Forum were outlined

Clinicians were invited to present issues concerning their particular patient diagnostic groups, and open discussion occurred. Concerns which were raised included –

- **Significant burden of chronic neurological diseases for patients/families, health care services and community services.**
- **Equity of Access**
    - Patients disadvantaged by -
        - Distance from metropolitan specialist services. Lack of specialist regional or outreach services.
        - Lack of clarity about what, how and where services could be accessed (by patients/families and health professionals). No clear pathway or program for continuous care delivery for people who meet the criteria for this model of care.
        - General understanding, but no documented and agreed criteria / clinical profiles of patients requiring such a program.
            - When would individual patients benefit from referral to a continuous care pathway?
            - Which diagnostic groups?
            - Disability criteria?
            - Social criteria?
        - No clear provision for managing cognitive and behavioural changes in patients with neuro-psychiatric conditions (eg Huntington's Disease, Fronto-temporal dementias, and neuropsychiatric complications of many other neurodegenerative conditions) - buck passing between medical and psychiatric services
        - Complexity of care needs. Generic service providers (community nurses, rehab services, GPs) often have a poor understanding of the disease process and prognosis / lack confidence / and are reluctant to get involved
    - Patients with rapidly progressive diseases (MND, brain tumours) are particularly disadvantaged by -
        - Lack of fast-tracking of service delivery and funding means many patients miss out completely and die before service is offered
        - patient may not be able to stay in residence of choice
        - poor access to age-appropriate residential and respite care

- **Community Care Packages**
    - Poor knowledge of what is available and how to apply, amongst many health professionals, and even case managers
    - Inadequate supply of funding packages to meet patient/family needs
    - Long waiting times for most packages / funding
    - Needs become more critical as delays lengthen
    - Expensive health professional time is wasted following-up applications and emphasising urgency with DHS, or managing consequences of failure to provide support services to patient.
    - Opaque internal DHS processes in deciding priority of package allocation
        - ? level of professional clinical input into decision-making process for allocation of funding packages

        - ? DHS internal contacts, to whom clinicians could escalate their concerns in urgent cases
    - Confusing array of support packages and eligibility criteria
        - Need for streamlined, flexible system, preferably linked to patient.

- **Failure to provide continuous care, despite a strong evidence-base for this model of care for people with long-term neurological diseases**
    - Inflexible funding and service agreements for health care providers
    - No HARP: Chronic Disease Management stream for chronic neurological care.
    - Most specialist neurological services in the tertiary-level setting are not resourced to provide a multidisciplinary team-based paradigm of care to non-inpatients.
    - Specialist centres are not resourced or funded to provide secondary consultation and support to local health care providers and case managers
    - Many Community Rehabilitation Centres and hospital-based Rehabilitation Services restrict their practice to ‘episodes of care’ rather than ‘continuous care’. This is driven in part by –
        - Funding and reporting requirements
        - In this chronic setting, an inappropriate mindset, which views ‘the goals of rehabilitation’ as ‘effecting improvement’ rather than efforts to maintain and support the independence, comfort and quality of life of an individual with a progressive disability.

Discussion: The Case for Continuous Care

The project has confirmed the high rate of social and financial disadvantage in this client group. These diseases often begin in young people 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 become frail or ill themselves. Dependent children, by default, 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. 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 early 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.

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.

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.

A Model for Continuous Care

A Continuous Care Model for the progressive neurological sector will improve service outcomes and reduce the risk of unplanned entry to aged care. It will require systemic reform.The model proposes a structure inclusive of community and 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, a transfer of knowledge and effective responses from all sectors to deliver an integrated approach to disease management for the progressive neurological sector.

The project has recognised 6 steps, that 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

The components required to enable these steps are –

1. **Transition: timely referral systems**
    a. Describe ‘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’ and educate health and community providers to recognise them
    c. Inform public and consumers (including consumer groups)
2. **Specialist multidisciplinary team and specialist case management**
    - Comprehensive assessment of needs / risks
    - Specialist input to risk amelioration and care planning
    - Support to local case managers, service providers and health professionals
    - Planned review as required – step-up / step-down mechanisms for level of specialist involvement
    - Trouble-shooting mechanism for contingencies – protocols for access to brokerage funds
3. **Streamlined information-sharing and consent processes**
    - Client-centred and confidentiality protected
    - Case-conferencing
    - Uniform documentation
    - Shared electronic record
4. **Decision-making support for client / family and professionals.**
    - Information, advice and education
    - Counseling and emotional support for client and family / carers
    - Secondary consultation and peer support for health professionals and service providers
5. **Monitoring and review**
    - Support continuing client engagement with services
    - Follow-through action plans
    - Troubleshoot problems
    - Timely response to contingencies

Transition:

The Neurology Specialist forum recognized that not all people with a progressive neurological disease require this comprehensive model of continuous care, but may transition to this model of care years or decades after their initial diagnosis. However, some diagnostic groups already need this level of care planning and support soon after diagnosis, for example, people with Motor Neurone Disease or highly malignant brain tumours.

Assessment:

The client, their family and their current formal and informal care providers are involved in the review. The client is encouraged and supported to identify their current concerns and preferences for future care.

Access to a specialist multidisciplinary health care team working in conjunction with specialist case management is recommended. The aim is to manage physical and psychosocial problems within a client-centred social and cultural context. Client autonomy and choice is best preserved by early identification of risks, and by action to avoid crises.

Information-sharing:

Family meetings, case-conferencing and shared records allow information to be shared between the client /family, the health care team and the community service providers. Care-planning embraces the personal goals of the client and family, and addresses realistic options.

Decision-making support:

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 was not uncommon for clients or families to fail to persist with agreed plans, and defer decisions that had seemed important to them initially. Many project participants acknowledged that discussions and decisions were confronting.

The support and encouragement offered by the regular contact with the CCP coordinator clearly helped many clients to move forward with their plans, which would otherwise have stalled. Specialist advice and decision-making support which clients needed ranged from legal, financial, relationship and medical. However it was the ‘continuous care’ method, and not just the specialist advice, which helped people persist with planning and to accept change.

The findings suggest 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 case management, coupled to the availability of appropriate advice and counseling, went a long way to providing that framework, even in the short timeframe of the project. This was especially true for people who were socially isolated and could not draw on the informal support of significant ‘others’ in their lives.

Peer-support and secondary consultation for health professionals, case managers and primary service providers.

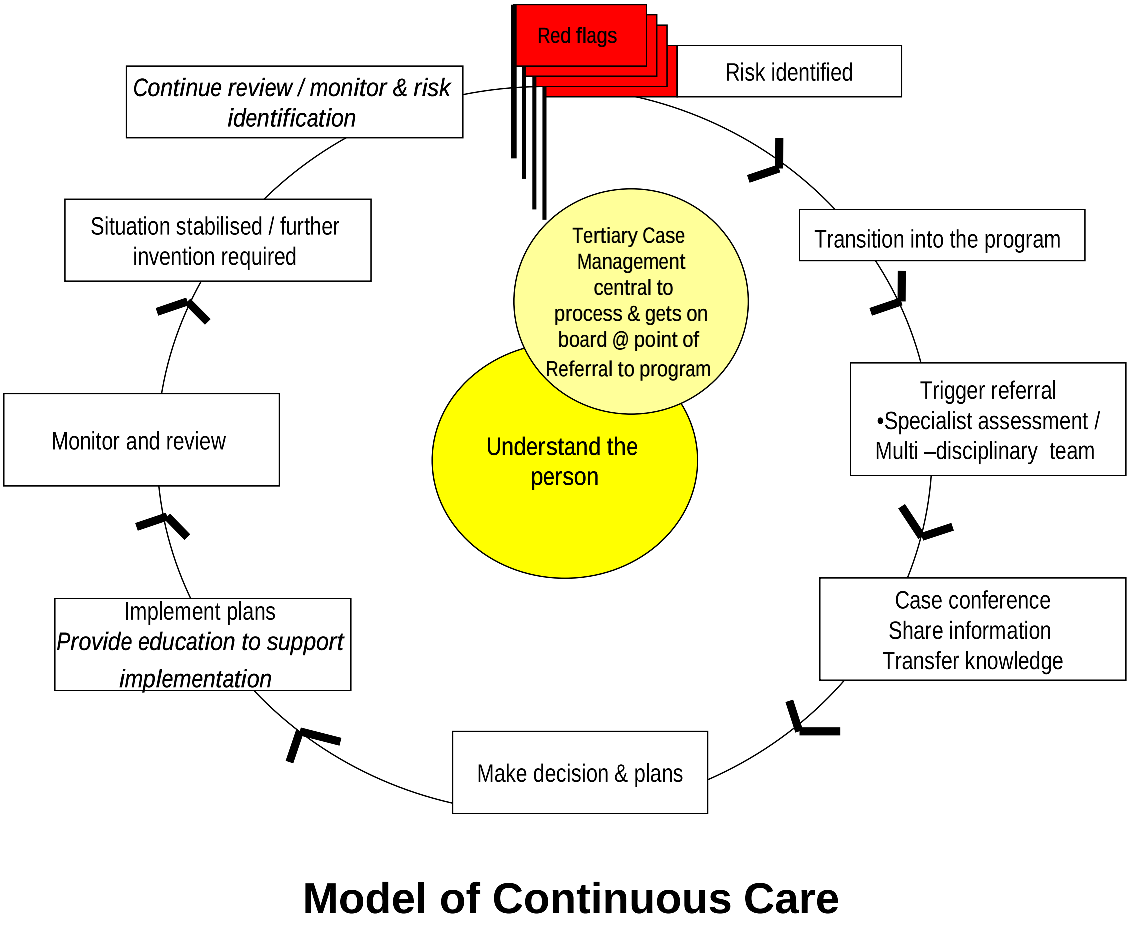
Case managers and health professionals also valued the peer support and advice from the CCP Coordinator and the CAG members.
This confirms the benefits of specialist peer support and secondary consultation advice for primary service providers in health and community care, which have been reported in the literature and through other recent DHS sponsored projects; (Palliative Care Pathway in MND, Collaborative Care in MND, Victorian Paediatric Service Model.)

Monitoring and Review - sustaining the continuous care model.

It is clear from the findings of this project that comprehensive assessment and promotion of self-management would not alone result in sustainable benefits to this client group.

Structured review at appropriate time intervals and the ability to step-up or step-down the intensity of case management and health professional input is required. Even during periods of relative stability in their lives, people with progressive neurological conditions, (and their carers, service providers and primary health care team) need a two-way communication channel with the Continuous Care Program. This ‘point of contact’ would be through a designated worker, the Program Case-Coordinator. This would allow the client or primary service provider to trigger a step-up response from specialist providers when necessary and enable the Continuous Care Program to monitor the effectiveness of risk identification and amelioration over time.

Diagram 7 Model of Continuous Care



Ethical issues in continuous care.

People with significant neurological disability, especially those with associated cognitive or behavioural change, are a vulnerable group in society. They are often unable to advocate on their own behalf and may have a dependent relationship with caregivers and service providers. The law supports an expectation of personal autonomy and undertakes to safeguard those who have lost individual capacity to determine their own decisions. The person may retain capacity for some decisions but not others. The extent to which capacity has been lost has to be recognised by well-intentioned others for the best interests of the client to be realised. In the real world, even well-intentioned formal and volunteer care providers struggle with the dilemmas surrounding ‘duty of care’, ‘paternalism’ and the rights of the individual client. They tend to err on the side of minimising risk, (often medico-legal risk to themselves or their organisation), rather than pursuing the least restrictive option for the client. Similarly, an over-protective approach to supporting individual clients encourages dependency and constrains personal freedom.

Care agencies and health professionals need a better understanding of ethics and the law in these often complex situations and need to know where to go for advice and when to act. There is an important role for the Office of the Public Advocate in providing guidance and education to professionals and the general public. Greater awareness amongst health professionals and the public should encourage early documentation of a person’s wishes or appointment of appropriate surrogate decision-makers, should they be needed in the future as the disease unfolds.

When problems are addressed late in the day, there are often pressing safety issues (for the client, their informal carers and the occupational safety of the paid workforce), which can quickly lead to conflict when care is delivered in the home. It is natural for people with developing disabilities to try to hold onto ‘normality’ for as long as possible. Coupled to this, people with additional cognitive impairment will lack insight into the risks and may be intransigent to changes which would make living at home safer and often easier. Better anticipation of the likely need for these changes to the home environment and care delivery, allows more time to the person to negotiate and adapt to these changes and reduces the risk that the service provider will withdraw services.

In the same way, the appropriateness of medical interventions and the goals of treatment need to be regularly reviewed with the client, their next of kin or other surrogate decision-makers. These diseases are usually life-limiting and result in increasing medical complications as time goes by. A Continuous Care Program would assist and encourage people to think through these issues in a timely way, to enhance end of life care and minimise the personal and societal burden of futile medical interventions.

Tracking and addressing the changes in a person’s medical and social wellbeing caused by these diseases can help them avoid the disadvantages and loss of control which occur when decisions and change only occur in response to crisis.

Summary Comment

The Continuous Care Pilot has demonstrated and continues to be committed to a collaborative partnership approach and has lived up to the Good Will Statement made on Tuesday June 3rd 2008 agreeing to:

- Foster this collaborative approach to partnerships beyond the completion of the pilot
- Sustain and promote the focus of supporting people to maintain self care at home
- Commit to removing barriers that prevent individuals remaining in the community
- Inform and educate others about the benefits of collaborating for all involved – improving the lives of individual with a progressive illness and their families.

References

1. Foulsum, M. 2007, *The Neurological Complex Care Project,* NCCP Project Management Group, Unpublished report commissioned by the Victorian Dept of Human Services.

2. Reynolds, A. 2002, Complex care needs - complex issues : the need for collaborative planning : a study of linkages clients aged 16-64 who have high cost needs care, commissioned form Research and Consultancy Unit Ecumenical Housing by the Community Care Issues Network, Traralgon, Vic.

3. Biographical Assessment in Community Care
Brian Gearing, Ph.D and Peter Coleman,Ph.D

Continuous Care Pilot Reconciliation 08/09 & 09/10 financial years

	Brokerage	DHS Independent Evaluation	Operating	Total
Income				
Brokerage	**$100,000**			**$100,000**
DHS		**$21,700**		**$21,700**
Operating			**$126,316**	**$126,316**
Total Income	**$100,000**	**$21,700**	**$126,316**	**$248,016**
Expenditure				
Brokerage	**$73,165**			**$73,165**
Evaluation		**$63,201**		**$63,201**
Consultation			**$16,042**	**$16,042**
Salary May 09 to June 30th			**$59.730**	**$59.730**
Salary July 1 to Oct 30 2009			**$ 3,739**	**$ 3,739**
Workshops /functions			**$ 4931**	**$ 4931**
Consumables			**$ 4318**	**$ 4318**
Salaries/wages – project Management			**$14,750**	**$14,750**
Total Expenditure	**$73,165**	**$63,201**	**$103,510**	**$239,876**
Total	**$26,835**	**($41,501)**	**$22,806**	**$ 8,140**

- **MSL delivered the Continuous Care Pilot within the funding allocated. The reconciliation shows a small surplus of $8,140, due to the under spend of the Brokerage funds as result of the advisory groups ability to effectively navigate and work within the existing service systems.**

Part 2

Detailed Pilot Case Studies

Key

Case Manager as a risk factor – this relates to the individual in place working with a particular client at the time CCP came onboard. The individual case managers may have been a risk for reasons such as their inexperience in the role, their lack of follow up of tasks, or their need for further education and training

Time – includes all Coordinator administration, home visit, travel, liaison with other service providers, and CAG attendance, preparation and follow up

Red Flags – relates to characteristics which place individuals or families at risk. These are indicators of potential risks and were identified during the assessment process. This concept is discussed within the Final Report.

Acronyms and definitions

CAG	Clinical Advisory Group
CCP	Continuous Care Project
CHC	Calvary Health Care – Bethlehem Hospital
CM	Case Manager
Continuum of Care	The US Department of Health and Human Services (2003) defines continuum of care as The entire spectrum of specialized health, rehabilitative, and residential services available to the frail and chronically ill. The services focus on the social, residential, rehabilitative and supportive needs of individuals as well as needs that are essentially medical in nature. The Canadian Council on Health Services Accreditation (CCHSA), defines a continuum of care as "an integrated and seamless system of settings, services, service providers, and service levels to meet the needs of clients or defined populations".
DHS	Victorian Department of Human Services
DSR/ ISP	Disability Support Register/ Individual Support Package
EPOA	Enduring Power of Attorney
HACC	Home and Community Care
ISP	Individualised Support Package
MRI	Magnetic Resonance Imaging - a non-invasive medical imaging technique used in radiology
MS	Multiple Sclerosis
MSL	Multiple Sclerosis Limited
NIV	Non-Invasive Ventilation
OT	Occupational Therapist
PEG	Percutaneous Endoscopic Gastronomy – a feeding tube directly into the stomach through the abdominal wall
PND	Progressive Neurological Disorder
RDNS	Royal District Nursing Service

Presenting information				CCP intervention			
Basic demographics	Services in place prior to CCP	'Red flags' identified at CCP Assessment	At Risk Behaviours	Interventions of CCP	Impact/ outcomes of CCP interventions	Cost of interventions - Supports provided - Time	Risks at conclusion of CCP interventions
• Male • Aged in 40s • Single • Lives with ageing parents **Health** • Myotonic Dystrophy • Painful right shoulder • Sleep apnoea and hypoventilation **Carers** • Elderly parents assist with care **Activities of Daily Living** • Weak hands make some personal care and household tasks difficult • Non-Invasive Ventilation (NIV) – finds uncomfortable on face, does not wear at night **Length of time out of workforce** = 13 years	• HACC • Inpatient respite	• Ageing parents/Carer illness • Cognitive Impairment • Carer strain • Sleep disturbance • Lack of community supports • Co-resident carer	• Failure to persist with agreed arrangements /poor planning **Carer/ Family risks** Poor uptake of support/ respite	**Respite** • Inpatient respite • Offered Residential respite set up • Offered in home respite • Holiday support organised via Yooralla • Taxi vouchers provided **Health** • Medication & NIV review • Review of client compliance with night sedation and use of NIV • Ongoing education regarding ventilation recommendation • MRI conducted for shoulder pain • Neuropsychology assessment **Disability Support Packages** • Short term case Disability Case Management package accessed **Future planning** • Contingency planning for the future	**Respite** • Regularly accesses inpatient respite • Declined in-home respite **Health** • Comfortable with NIV **Disability Support Package** • Declined further support following initial short term CM package	**CAG meeting discussion** 2 hrs & 35 mins **Coordinator time** 109.2 hrs **CCP Brokerage** $36.00 on taxi vouchers	Future planning has commenced reducing risk associated with ageing parent strain. Respite in place supporting carers Family given information and support to consider future accommodation needs and legal decision making when ready Ongoing risk associated with living arrangement sustainability, due to both client and ageing parents deteriorating health

Follow up summary:

- Short term case management package ceased, no services identified
- Last admission in respite, family meeting for discussion on future planning. Agreed to resubmit DSR for accommodation, possibly Shared Supported Accommodation as individual is very social and is at risk of being socially isolated.
- Future need for regular coordination to maintain emphasis / identified need.
- Carer strain still very evident

Presenting information				CCP intervention			
Basic demographics	Services in place prior to CCP	'Red flags' identified at CCP Assessment	At Risk Behaviours	Interventions of CCP	Impact/ outcomes of CCP interventions	Cost of interventions - Supports provided - Time	Risks at conclusion of CCP interventions
• Male • Aged in 40s • Married • Lives with wife and children **Health** • Multiple Sclerosis • Pain and sleeping pattern concerns **Carers** • Wife is primary carer **Activities of Daily Living** • Needs full assistance • Mobilises in wheelchair • Hoist transfer • Wife turns at night 2-4 times **Length of time out of workforce** = 14 years, primary carer still working	• Making a Difference Package • Respite • District Nursing • HACC • Holiday support • Counselling for family members & client	• Dependent children living with client • Carer strain • Chronic pain • Sleep disturbance Unsustainable housing physical/financial • Working carer • Don't have GP/neurologist/health review • Lack of community supports • Social isolation • Case manager • Frequent hospital admissions • Co-resident carer • Financial strain	• Egocentricity/ loss of empathy • Impulsivity **Carer/ Family risks** • poor life/ caring balance • Effects on children's behaviour	**Respite** • In home respite weekly • Residential respite **Health** • Pain review- MRI • Referral to Pain Clinic • Stretching regime • Referral to Urologist **Disability Support Packages** • DSR application completed with ongoing review to advocate for urgent need **Future Planning** • Support in looking for other accommodation options	**Respite** • Unable to access respite as self catheterises at home **Health** • Stretching regime in place and staff trained to provide assistance • Pain clinic options explored • Awaiting Urologist appointment **Disability Support Package** • Making a difference but package unable to sustain increasing needs **Future planning** • Awaiting Individual Support Package to assist with future care and future care options. • Wife unable to sustain primary care role long term • Case conference with family and support agencies to discuss behaviour management and future planning options	**CAG meeting discussion** 4 hrs & 50 mins **Coordinator time** 156 hrs **CCP Brokerage** $2006 on equipment, physio training, respite for family, and CM attendance at CAG meeting	Family given information and support to consider future accommodation needs and legal decision making when ready Insufficient formal support in home to prevent family breakdown

12-month follow up summary:

- All the intervention s of the CCP have been implemented including the provision of an ISP
- Insertion of an Supra Pubic Catheter following Urologist intervention
- While the follow up of CCP recommendations had been done, there are numerous other ongoing disease issues identified that require a continuous care approach.

Presenting information				CCP intervention			
Basic demographics	Services in place prior to CCP	'Red flags' identified at CCP Assessment	At Risk Behaviours	Interventions of CCP	Impact/ outcomes of CCP interventions	Cost of interventions - Supports provided - Time	Risks at conclusion of CCP interventions
• Male • Aged in 40s • Married • Lives with wife and 2 small children **Health** • Advanced Motor Neurone Disease • Has no speech • PEG fed • Excessive salivary production **Carers** • Wife is primary carer **Activities of Daily Living** • Needs full assistance **Length of time out of workforce** = 9 years	• Linkages Package • DHS package	• Dependent children living with client • Carer strain • Sleep disturbance • Social isolation • Case manager • Co-resident carer • Impaired communication	None	**Health** • Botox treatments to reduce saliva production • Discussion re tracheostomy • Discussion regarding advanced planning /directives **Communication** • New computer tower as this is client's mode of communication • Pastoral care support following discussion regarding advance directives	Client deceased Oct 2009 Elected to continue with NIV and not choose tracheostomy if he became very ill. Found this support helpful	**CAG meeting discussion** 55 mins **Coordinator time** 93.6 hrs **CCP Brokerage** $2025 on botox treatments and computer tower	

12-month Follow up – n/a

Presenting information				CCP intervention			
Basic demographics	Services in place prior to CCP	'Red flags' identified at CCP Assessment	At Risk Behaviours	Interventions of CCP	Impact/ outcomes of CCP interventions	Cost of interventions - Supports provided - Time	Risks at conclusion of CCP interventions
• Male • Aged in 40s • Single • Lives with family **Health** • Secondary progressive Multiple Sclerosis • Swallowing problems • Intrathecal baclofen pump for spasms **Carers** • Mother is primary carer • Young child lives with ex-partner but visits alternate weekends **Activities of Daily Living** • Wheelchair to mobilise • Hoist transfer **Strains** • Parents supplementing costs of mortgage, taxis, District Nurses etc **Length of time out of workforce** = 10 years	• Linkages Package • DHS package • Bethlehem OT & ST • District Nursing • HACC • Respite	• Ageing parents/Carer illness • Carer Strain • Sleep disturbance • Don't have GP/neurologist/health review • Lack of community supports • Social isolation • Case manager • Co-resident carer • Financial strain • Impaired communication • Constraint of access to child	**Carer/ family risks** • poor life/ caring balance • Poor uptake of respite • Loss of relationship with child due to grandmother / primary carer	**Respite** • Residential respite trial recommended • Short term respite during school holiday to support outing with child **Disability Support Package** • Follow up regarding ISP changes required **Future Planning** • Support in considering future accommodation options	**Respite** • No initial follow up of respite options, however trial has been requested	**CAG meeting discussion** 1 hrs & 55 mins **Coordinator time** 78 hrs **CCP Brokerage** $16,511 for active overnight supports, equipment, botox treatment, and services	Ongoing risk regarding accommodation if ageing parent unable to maintain care Ongoing financial strain due to child support & other family issues Agreement of family to consider future planning and respite

12 month follow up summary:

- Family meeting in March 2010 at home with case manager and social worker. Outcome is a plan to lodge DSR for Shared Supported Accommodation in the future. Issue with DHS not accepting an application at the moment as the need is a future one and DHS considered client has sufficient hours to be supported at home. Issue raised is one of systemic barriers regarding proactive future planning to defer crises and provide for people within a continuum of care.
- CM was to look at disability facility respite options to trial however this did not happen. Follow up will occur by CCP coordinator as result of this long term follow up. It was identified that there is lack of clarity between case manager and service provider as to responsibility of activities, and without proper management this creates a potential risk to the continuity of care for this individual.
- Requires acute admission with Urinary Tract Infection / bladder stones (who follows this up?)
- Now has a neurologist / GP review coming up with neurologist, OT, Speech and social work

-

Presenting information				CCP intervention			
Basic demographics	Services in place prior to CCP	'Red flags' identified at CCP Assessment	At Risk Behaviours	Interventions of CCP	Impact/ outcomes of CCP interventions	Cost of interventions - Supports provided - Time	Risks at conclusion of CCP interventions
• Male • Aged in 40s • Widower • Lives with 2 teenage children **Health** • Multiple Sclerosis • Grief over loss of wife • Sleeping difficulties • Pain, pins & needles, fatigue **Carers** • Primary carer for his children **Strains** • At risk of homelessness • Effects of house sale & imminent move impacting on children • Ongoing financial issues • Concerns about future support for children **Length of time out of workforce** = 6 years	• Linkages Package • Young Carers Program • CHC Bethlehem	• Dependent children living with client • Unsustainable housing • Financial strain • Cognitive Impairment • Mood/behaviour disturbance • Lack of community supports • Social isolation • Case manager	• Failure to persist with agreed arrangements /poor planning • Avoidance/ denial • Poor budgeting **Carer/ Family risks** • Depression/anxiety • Effects on children's behaviour • Poor uptake of support	**Health** • Neuropsychology assessment referral made • Children referred to specialist grief and loss program • Referral of children to Creative Connections Program • Development of strategies to monitor ongoing health issues **Future planning** • Appointment made with Psychiatrist to discuss future planning • Financial counsellor to draw up budget and consider Trust for children's future • Link made to MS employment officer • Exploration of social housing options • Support to contact volunteer agencies to support house move • Support to Case manager • Applications for financial assistance	**Health** • All offers for counselling rejected • Neuropsychology assessment completed • One child attending Creative Connections program **Future Planning** • Client did not keep future planning appointment • Financial Counsellor engaged • Refused meeting with employment officer • Family housed in private rental property • Not going ahead with establishment of a Trust for children	**CAG meeting discussion** 4 hrs & 17 mins **Coordinator time** 202.8 hrs **CCP Brokerage** $1300 for Neuropsychology	Ongoing financial planning issues Risk to children regarding financial planning issues in terms of potential debt affecting lifestyle in future

12-month Follow up summary:

- This person remains under financial threat – no financial planner in place, refused budget plan /trust
- CCP provided education about the need to maintain appointments with health professionals, which has been maintained by individual
- Identified need for increase in income , referral for employment advice/also broad financial issues , office of housing application
- These and other identified risks are escalating – requires ongoing and active monitoring to resume to manage these risks

Deleted:

Presenting information				CCP intervention			
Basic demographics	Services in place prior to CCP	'Red flags' identified at CCP Assessment	At Risk Behaviours	Interventions of CCP	Impact/ outcomes of CCP interventions	Cost of interventions - Supports provided - Time	Risks at conclusion of CCP interventions
• Female • Aged in 40s • Single • Single parent with a young child **Health** • Cerebral palsy and Cervical Dystonia • Surgery on neck left her almost a quadriplegic • As risk of quadriplegia or death from fall • Constant pain and numbness in arms/ fingertips **Carers** • Primary carer for young child **Supports** • Identified need for increased & ongoing support and case management services **Length of time out of workforce** = 7 years	• HACC • Case management • Taxi vouchers	• Dependent children living with client • Mood/behaviour disturbance • Sleep disturbance • Unsustainable housing physical/financial • Lack of community supports • Social isolation • Chronic pain	• Failure to persist with agreed arrangements /poor planning • Avoidance/ denial	**Disability Support Packages** • New DSR application **Community Services** • Meeting with council & OT to discuss maintaining hours of support • Letter of support written to council by Neurologist advocating services not be reduced **Future planning** • Meeting with Neurologist, Key worker, Social Worker & client to discuss future planning for child • Client supported with enquiries regarding Foster Care • Supported with enquiries regarding Adoption • Solicitor names provided regarding future care of daughter • Support with application to Office of Housing	**Community Services** • Council reduced hours of service • DHS regional funding accessed • Regular Pain Management appointments in place **Disability Support Package** • Offered an ISP of 25 hours **Future planning** • Visited Solicitor to discuss adoption issues & EPOA • Remains on Housing waiting list • Case conference with Neurologist, family, case manager and Social Worker to discuss future planning • Support to client in meeting regarding Foster Care enquiries • Support in application for housing	**CAG meeting discussion** 3 hrs & 10 mins **Coordinator time** 180 hrs **CCP Brokerage** $512 for taxi vouchers and care worker support	Ongoing health instability Awaiting appropriate housing from Dept of Housing Future planning for child's future

12-month follow up summary:

- All interventions by the CCP have been implemented
- Requires ongoing advocacy for housing
- Participants own words- "very happy with the way things are , directly to do with the CCP"

Presenting information				CCP intervention			
Basic demographics	Services in place prior to CCP	'Red flags' identified at CCP Assessment	At Risk Behaviours	Interventions of CCP	Impact/ outcomes of CCP interventions	Cost of interventions - Supports provided - Time	Risks at conclusion of CCP interventions
• Female • Aged in 40s • Married • Lives with husband and 2 teenage children **Health** • Secondary Progressive Multiple Sclerosis • Fatigue • Grief and loss over life and health • Catheter in place **Carers** • Husband is primary carer • Mother & Mother in law assist in daytime **Activities of Daily Living** • Elderly mother & mother in law assist • RDNS 3 times a week for personal care • Uses wheelchair • Hoist transfers **Length of time out of workforce** = 15 years, primary carer still working	• HACC • District Nursing • Day Program x 1 day a week	• Carer strain • Dependent children living with client • Ageing parents/Carer illness • Cognitive Impairment • Working carer • Lack of community supports • Social isolation • Co-resident carer • Financial strain	• Avoidance **Carer/ family risks** • Poor uptake of support/ respite	**Disability Support Packages** • DSR Application made • Application for Linkage package on waitlist **Health** • Offer for counselling for grief and loss • Recommendation for Physiotherapy to assist with arm strength	**Disability Support Packages** • On waiting list **Health** • Refused counselling • Arm bike /exercise machine	**CAG meeting discussion** 1 hrs & 45 mins **Coordinator time** 124.8 **CCP Brokerage** $484 on equipment	Family strain due to caring roles, particularly with ageing parents

12-month follow up summary:

- All issues addressed
- Fatigue management emerging as a risk– individual requires advice and support in this area
- Does not always have support to transfer to a recliner when at home and does not have a chair that reclines when in the community - referral being made for wheelchair review and assessment

Presenting information				CCP intervention			
Basic demographics	Services in place prior to CCP	'Red flags' identified at CCP Assessment	At Risk Behaviours	Interventions of CCP	Impact/ outcomes of CCP interventions	Cost of interventions - Supports provided - Time	Risks at conclusion of CCP interventions
• Male • Aged in 40s • Married • Lives in Public Housing house with extensive family support • Wife is a younger person living in a nursing home **Health** • Multiple Sclerosis • High level care needs **Carers** • Elderly parents **Community Services** • Living at home with full care package **Length of time out of workforce** = 9 years	• DHS package • Case Management • District Nursing • Day Program x 1 day a week	• Lives alone • Ageing parents/Carer illness • Carer strain • Cognitive Impairment • Lack of community supports • Social isolation • Case manager • Frequent hospital admissions	• Anxious about going to Residential aged care **Carer/ family risks** • Anxiety • Poor life/caring balance	**Health** • Fluid intake needs to be encouraged in care plan • OT review • Bowel regime reviewed • Physio engaged **Community Services** • New care plan completed • Case conference to discuss issues of care workers filing shifts and emergency plan **Respite** • Referral to MSL Respite Coordinator • Substantial involvement in planning by care coordinator	**Health** • Fluid regime in place • Stretching exercises updated and staff trained • Bowel regime implemented **Community Services** • Keysafe in place in case of emergency • Personal alarm in place **Respite** • Did not follow up on respite options • On Shared Accommodation waiting list	**CAG meeting discussion** 1 hrs & 50 mins **Coordinator time** 202.8 hrs **CCP Brokerage** $4051 for OT services and equipment	If DHS package is reviewed and reduced would not be able to maintain living alone Ageing mother with health issues who provides a lot of care and support Health issues / deconditioning as result of caring for disabled wife Unstable workforce and care arrangements.

12-month follow up summary:

- Has remained at home longer than initially expected.
- Facilitation and comprehensive care planning has assisted in improved health with no acute health issues and has regained weight to a healthy level.
- Has increased connectedness with wife who is in a nursing home.
- Workforce issues have improved – shifts are shared by various agencies with training and education for staff.
- Individual requires regular monitoring

Presenting information				**CCP intervention**			
Basic demographics	Services in place prior to CCP	'Red flags' identified at CCP Assessment	At Risks Behaviours	Interventions of CCP	Impact/ outcomes of CCP interventions	Cost of interventions - Supports provided - Time	Risks at conclusion of CCP interventions
• Female • Aged in 30s • Single • Lives at home with mother and siblings **Health** • Multiple Sclerosis • Continence issues • Weight gain causing issues with manual handling/ hoisting **Carers** • Mother is primary carer • Difficulty accessing care workers to fill shifts at weekends and public holidays **Strains** • At risk of long term hospitalisation as family struggle to cope with support needs • Socially isolated **Length of time out of workforce** = 10 years, primary carer still works	• My Future My Choice • Respite • Allied Health	• Ageing parents/Carer illness • Carer strain • Cognitive Impairment • Working carer • Lack of community supports • Social isolation • Case manager • Frequent hospital admissions • Co-resident carer	• Failure to persist with agreed arrangements /poor planning • Lack of insight **Carer/ family risks** • poor life/ caring balance • Depression/anxiety • Poor uptake of support	**Respite** • Residential Respite being used in preparation for eventual Shared Supported Accommodation **Disability Support Package** • Review of DSR to accommodate increase to support care needs and social support • OH&S review of home **Community Services** • Four agencies to be engaged to cover care shifts • Care plan in place for use by care workers • Case Conference to review all support options and current care plan **Health** • Urology review • Lap banding exploration • Referral to Exercise Psychologist	**Respite** • Residential respite has successfully commenced **Disability Support Package** • Review submitted for consideration **Community Services** • Care plan clarifies all OH&S issues that caused care workers to withdraw from shifts • Still some shifts that remain unfilled causing strain on mother and siblings • Substantial facilitation in the planning of care & support, communication plan and OH&S **Health** • Urology assessment conducted; client unsure of catheter option • Lap banding operation delayed due to exacerbation of MS symptoms	**CAG meeting discussion** 3 hrs & 50 mins **Coordinator time** 171.6 hrs **CCP Brokerage** $523 for equipment and care worker support	Ageing mother health has been unstable in the past Ongoing workforce issues of accessing paid care workers Own health issues : weight and emotions Both impacting on access to respite to doctors rooms etc

12-month follow up summary:

- Interventions of the CCP have assisted the individual to improve access to community and social situations and ability to be cared for at home. There is sustainability of in home support reducing stress.
- Good outcome for stomach stapling
- Regular respite arrangements
- Individual and family are happy and confident with their arrangements.

Presenting information				**CCP intervention**			
Basic demographics	Services in place prior to CCP	'Red flags' identified at CCP Assessment	At Risks Behaviours	Interventions of CCP	Impact/ outcomes of CCP interventions	Cost of interventions - Supports provided - Time	Risks at conclusion of CCP interventions
• Female • Aged in 40s • Single • Lives with partner **Health** • Multiple Sclerosis **Carers** • Partner is primary carer • Partner has own health issues that limit physical ability to provide care **Activities of Daily Living** • Unable to mobilise as current wheelchair and scooter do not provide upper body support required **Length of time out of workforce** = 7 years	• Respite • Personal Care daily • HACC • Community Access Program • Advocate	• Carer strain • Threat that Primary carer will cease in carer role • Ageing parents/Carer illness • Cognitive Impairment • Mood/behaviour disturbance • Lack of community supports • Social isolation • Co-resident carer • Financial strain • Impaired communication	• Avoidance/ denial **Carer/ family risks** • poor life/ caring balance • Depression/anxious & aggressive • Egocentricity/ loss of empathy • Dysfunctional relation	**Health** • Appointment made with Rehab specialist • Air mattress in place via RDNS OT • Speech therapy assessment • Manual handling assessment • OT shower assessment • Care plans completed • Home assessment • GP Referral **Disability Support Package** • DSR application completed • Interim case management in place **Respite** • Residential respite in place including transport to and from • Access to short term in home respite **Financial** • Financial assistance and Discretionary Funding applications discussed • Taxi Vouchers issued	**Health** • Soft diet & thickened fluids in place • Requires 2 staff for personal care and hygiene • Bathroom & equipment at home adequate for showers • Neck stretching routine in place • Client missed Rehab appointment • Care plan clarifies all OH&S issues for care workers **Respite** • Unhappy with transport organised **Future planning** • Client awaiting permanent placement as unable to be sustained at home	**CAG meeting discussion** 6 hrs **Coordinator time** 234 hours **CCP Brokerage** $2726 for taxi vouchers, care worker support, and equipment	In ward at hospital awaiting permanent residential placement

12-month follow up summary:

- Despite exploring all options, it became unsustainable for this individual to remain at home. Lack of appropriate accommodation options that have led to lengthy waiting times for accommodation. The lack of ongoing care management is identified as a critical risk for this individual.

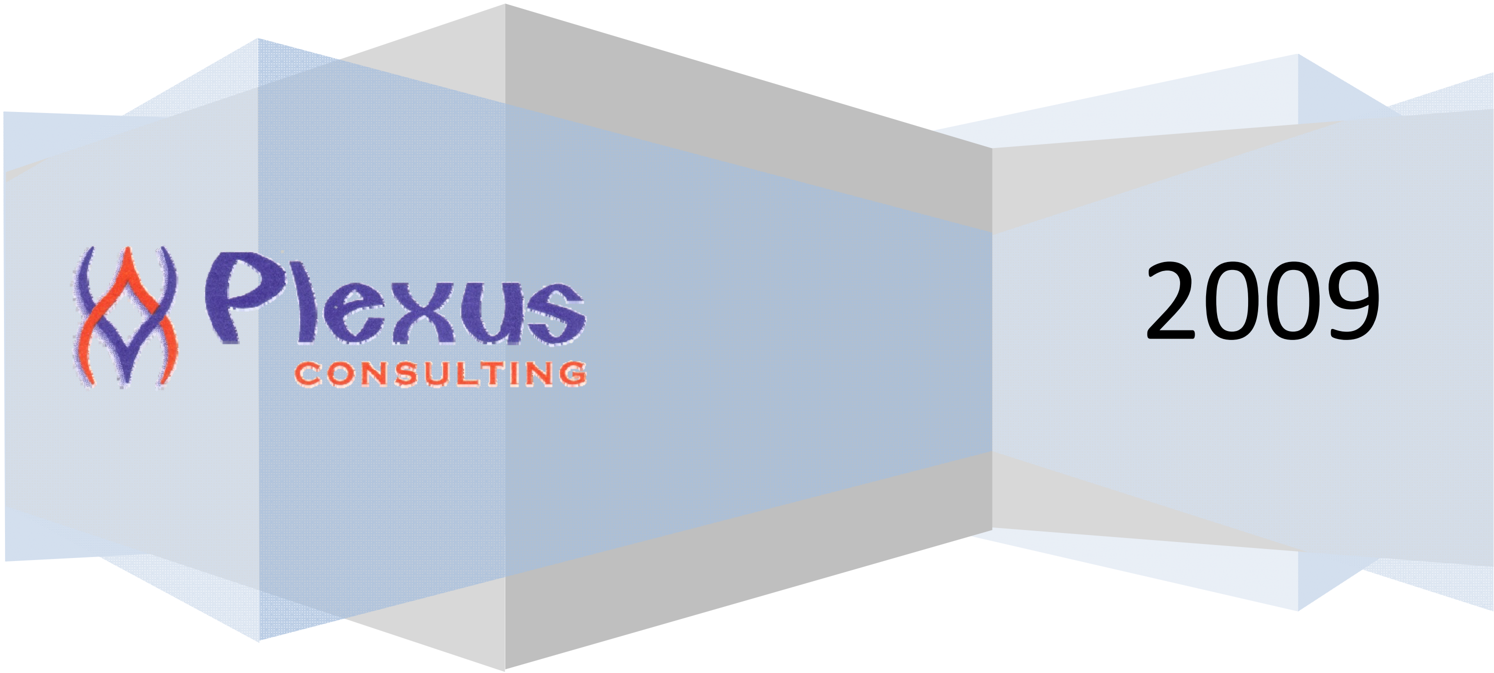
Section 3

Independent Draft Evaluation Report

Evaluation of the Continuous Care Pilot

Draft Final report

Roy Batterham
Plexus Consulting



2009

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Abbreviations

ANZAN	Australian and New Zealand Association of Neurologists
CAG	Clinical Advisory Group
CCP	Continuous Care Pilot
CHCB	Calvary Healthcare Bethlehem
DHS	Department of Human Services
DSR	Disability Support Register
GP	General practitioner
HACC	Home and Community Care
ISP	Individual Support Package
MND	Motor Neurone Disease
MNDV	Motor Neurone Disease Victoria
MS	Multiple sclerosis
NCCP	The Neurological Complex Care Project
YPINH	Young People in Nursing Homes

Executive summary

Introduction to the Continuous Care Pilot

People with degenerative conditions provide significant challenges to the service system. Maintenance of their health and well being requires support services provided in a timely manner, clinical supervision and managed access to multiple services across a range of health and community programs including the HACC and Carers Programs, State Disability Services and sub-acute services.

The purpose of the Continuous Care Pilot intervention is to assess what is required to deliver a predictable and sustainable response for people with progressive disabilities.

The aim of the Pilot is to provide managed access by people with progressive neurological conditions to comprehensive supports to meet their increasing support needs over time.

People with progressive conditions are at high risk of untimely entry into Residential Aged Care. The Pilot is expected to reduce entry to residential aged care facilities through an articulated pathway in the community combining community support with pro-active disease management, referral and brokerage within an intensive case management structure, to identify issues for individuals and for the service system in this transition phase, and to demonstrate pathways and options for improved management of this group that allow them to remain in their own homes for as long as possible.

The proposed pilot model included a number of components:

- A thorough assessment process based on consideration of all life domains, the participants history of service usage and future expectations
- A *Specialist Care Coordinator* with considerable expertise in understanding the needs of people with progressive neurological conditions
- An expert advisory group called the *Clinical Advisory Group* that undertakes detailed, future-oriented planning based on their understanding of risk issues affecting the participant
- Development *Service Continuity Protocols* with agencies that provide services to the participant group. These were to be agreements to provide continuing services even if a participant started receiving additional, supplementary services
- Training for service provider agencies to increase their ability to understand and address the needs of people with progressive neurological conditions
- A small amount of brokerage money.

Evaluation methods

The evaluation occurred in two phases to date; a phase prior to commencement of recruiting in which concept mapping and program logic activities were undertaken and a phase concurrent with the live phase of the pilot. The main evaluation activities are summarised in the following table.

Data collection processes	Actual data collection activities and reasons for changes
Review project documentation	Review of project proposals, tools, education materials, terms of reference Also conducted a detailed review of all participant notes and the outcomes of CAG meetings
Concept mapping with	2 groups conducted prior to commencement of the active phase of the

Data collection processes	Actual data collection activities and reasons for changes
participants/carers and providers	project
Program logic workshop	Workshop with project personnel, participants/carers and provider representatives held prior to commencement of the project
Initial participant assessment	Notes from the initial participant assessment were reviewed including the detailed life history and a Life Domains instrument that included quantitative and qualitative components
Client and carer interviews (evaluator)	The interviews with all participants and primary carers (where relevant). These interviews included discussion of confidence in the service system and satisfaction with the project
Interviews with CAG	Participation in three CAG meetings and ongoing discussions with three of the CAG members. Special meeting with the CAG to discuss project learnings
Meetings with project officer (and other key project personnel)	Meetings were conducted at least monthly through the life of the project and weekly towards the end of the project to allow detailed discussions of every participant
Interviews with service providers	• 8 interviews were conducted at the midpoint of the project • Interviews at the end of the project included the case-managers/key workers of each participant • Additional provider input was obtained in a provider meeting held at the end of 2008 and from the training workshops and the neurologists workshop
Participant observation	Attended three Clinical Advisory Group Meetings, one training session for service providers and participated in a Specialist Clinicians workshop
Early learnings workshop	A workshop with some initial evaluation findings was held with key stakeholders approximately half way through the project
Interpretation and recommendations workshop	A workshop with key stakeholders will be held once a preliminary analysis of the evaluation data is complete. The evaluators provisional interpretation of the data will be presented and participants will be invited to offer their interpretations. Key questions hat may lead to recommendations will be discussed.

Conclusions and recommendations

This section highlights the most important conclusions drawn previously in the report.

C1. The CCP almost certainly prevented between 2 and 5 admissions to residential aged care during its period of operation

C2. The CCP has already achieved other substantial benefits for a number of participants. These included:

a. Resolving problems with service providers
b. Accessing additional or more appropriate services
c. Accessing larger and more adequate funding packages
d. Identifying and resolving outstanding equipment issues
e. Establishing respite arrangements that were more acceptable to participants

f. Increasing confidence due to the knowledge that the MS care coordinator was available to contact

C3. A number of common risks for requiring residential care were identified. These included immediate impact risks and gradual impact risks.

a. Immediate impact risks included:
    i. Health problems requiring hospitalisation
    ii. Pressure problems
    iii. Requirements for night time care, especially more than once per night
    iv. Health problems for the primary carer
    v. Serious breakdown in relationships with care agencies

b. Gradual impact risks included:
    i. Carer stress
    ii. Funding and care provision not keeping up with needs
    iii. Failure to update equipment as requirements change
    iv. Cognitive issues leading to erratic decision making and a failure to persist with arrangements (this was considered to be a contributing factor to many of the other risks in most participants)
    v. Stress on relationships with care agencies
    vi. Weight gain
    vii. Financial difficulties
    viii. Erosion of participants quality of life and emotional well-being

C4. The assessment processes undertaken in the pilot were effective in identifying risks but the time spent in building rapport an giving participants the opportunity to discuss there concerns as well as observation of the physical environment and tasks were probably more important than the assessment tools.

C5. The CAG provided input that was used in developing applications for funding packages and was able to identify creative options for meeting participant's needs. None-the-less there were issues related to the structure and processes of the CAG that may limit its generalisability.

C6. The most important aspect in achieving these outcomes has been the role of the Specialist Care Coordinator. This role has been supported by the CAG but other additional features of the role have been:

A. The depth of assessment that has been undertaken and the open nature of the assessment
B. The secondary consult role taken by the Specialist Care Coordinator
C. Supporting the development and submission of appropriate applications for individual funding packages.

C7. Case management services provided to people with progressive neurological disorders are extremely variable and this variation does not relate to need or complexity. Means to improve access to a consistent standard of case management need to be developed. This will probably include access to a secondary consult support service.

C8. The project did not succeed in establishing *service continuity protocols* with agencies. It did, however, succeed in negotiating to maintain adequate service levels on a case-by-case basis in all but one case. Clarifications provided by DHS assisted in this.

C9. There are a number of reasons why agencies were reluctant to commit to maintenance of care and thus to *service continuity protocols*. These include:

A. A history of long-fought policy development within individual agencies that prioritises services that can be delivered to many participants over services that are provided intensively to a few
B. In some cases, the belief that continuing services with a participant who commences additional services elsewhere would constitute a breach of their funding agreement
C. In some cases, the belief that a neurological disease is not a disability
D. In most cases, service providers are more used to working with participants with relatively stable, life-long disabilities and have difficulty understanding the needs of those whose disabilities may progress rapidly.

(Clarifications by DHS in relation to point 'b' assisted in resolving this issue.)

C10. Brokerage funding has been expended judiciously and usually as a supplement to other funding sources. In many cases alternative funding sources have been found. This suggests that only a modest brokerage capacity is required as part of the model which bodes well for sustainability.

C11. A major focus has been on the development of submissions for individual packages through the Disability Services Register. This has required considerable support to both the case managers who were preparing the application and the DHS staff processing it. These applications have been informed and strengthened by input from the CAG.

C12. There were a number of problems identified with individual service packages (ISPs):

A. They take a long time to obtain by which time needs have often changed
B. The people responsible for planning the package are often unfamiliar with the needs of people with progressive neurological conditions and find the process difficult
C. The packages are inflexible. Modification of how money is expended requires a time consuming written process.
D. Packages usually don't provide support to 'lifestyle' needs
E. Packages don't support recipients' parenting role and responsibilities.

C13. Many people in the target group are parents of dependent age children and there is a lack of services, information and support options for this role.

Recommendations

Please not these recommendations are opinions of the evaluator and, while they have been discussed in workshops with key stakeholders, they have no official status as views of the MS Society and Calvary Bethlehem.

These recommendations are grouped into two categories recommendations for service delivery and recommendations for future research and development.

Recommendations for service delivery

R1. A system for providing quality case management to all people with progressive neurological conditions who meet a certain threshold of need should be established. This system will need to:

1. Define criteria for when people with progressive neurological conditions should receive case-management and establish processes to ensure hat they have access to funded case management
2. Develop a set of performance criteria for case management services to this population. These should include:
    a. Requirements for initial assessment
    b. Frequency of contact and formal review
    c. Requirement for a comprehensive, multi-agency approach
    d. Specification of role in preparing applications for funding packages and in service planning
3. Develop an additional set of guidelines, resources and tools to assist case managers meet these criteria
4. Establish a means for case managers to obtain specialised advice related to clinical issues, care planning and service options
5. Ensure that the people responsible for assessing DSR applications and planning packages either have knowledge of progressive neurological conditions or have access to advice to assist them.

R2. The recommendations arising from the development of the Motor Neurone Disease (MND) model should be implemented and broadened to include all progressive neurological diseases. Indicative roles for the two levels of hubs are:

A. Disease specific hubs providing services to the whole state:
    a. Providing a tertiary consultation service including tele-consults
    b. Developing guidelines and standards for service delivery
    c. Research
    d. Advocacy
B. Regional hubs covering all progressive neurological conditions:
    a. Responsibility for implementing training including the NPCC training package and also training, mentoring and secondary support to case managers
    b. Offering general secondary consultation support especially around service issues
    c. Holding a number of service packages that can be used in whole or in part to meet emergency needs
    d. Holding a modest pool of additional brokerage funds
    e. Participating in the development of service packages
    f. Coordinating linkages between health and community services
    g. Service planning in the region.

R3. Processes to improve the timeliness, quality and flexibility of individual support packages need to be developed, these processes should include:

a. Mechanisms for providing advice to those responsible for making decisions about and planning packages

   b. More uniform access to case management and empowering of case managers or the designated package manager to quickly redirect funds
   c. Guidelines that allow the use of funds to support recipients in their parenting roles and responsibilities where these apply

R4. Consider means to increase the potential and speed of access to aids and equipment programs and night time care programs

R5. The 50 year age limit should be abandoned for all services and programs where it applies. It serves no function for the community and merely serves to hide need and window-dress government programs.

Recommendations for future research and development

R6. A major forum should be held involving relevant medical specialties and organisations involved in advocacy and community service delivery for people with progressive neurological conditions. This forum should seek to build on and broaden the work undertaken in the development of the MND model and elaborate the role and requirements for statewide specialist hubs and regional hubs as described in recommendation R2. The forum should consider the outcomes of the NPCC, the CCP and the Motor Neurone Disease model and seek to achieve an integration as discussed on p 81 (see particularly Table 20).

R7. Out of this forum a progressive neurological consortium should be established under the auspices of the Australian and New Zealand Association of Neurologists, the Royal Australasian College of Physicians and related bodies. This consortium should have a leading role in:

1. Defining common risks and standard care requirements
2. Defining standards for care provision including case management
3. Advising governments on policy and program development
4. Seeking means to achieve closer collaboration between the health and community services sectors

R8. A major project should be funded to investigate the needs of people with neurological conditions who are parents of dependent children and the needs of these children. The terms of reference should include the development of guidelines for incorporation of the needs of parents and children in funding packages.

Section 1: Background and initial evaluation proposal

Background and Aims for the Continuous Care Pilot

Aims of the Continuous Care Pilot

People with degenerative conditions provide significant challenges to the service system. Maintenance of their health and well being requires support services provided in a timely manner, clinical supervision and managed access to multiple services across a range of health and community programs including the HACC and Carers Programs, State Disability Services and sub-acute services.

The purpose of the Continuous Care Pilot is to assess what is required to deliver a predictable and sustainable response for people with progressive disabilities.

The aim of the Pilot is to provide managed access by people with progressive neurological conditions to comprehensive supports to meet their increasing support needs over time.

People with progressive conditions are at high risk of untimely entry into Residential Aged Care. The Pilot is expected to reduce entry to residential aged care facilities through an articulated pathway in the community combining community support with pro-active disease management, referral and brokerage within an intensive case management structure, to identify issues for individuals and for the service system in this transition phase, and to demonstrate pathways and options for improved management of this group that allow them to remain in their own homes for as long as possible.

The Target Group

The Pilot target group is people with degenerative neurological conditions in the Calvary Bethlehem neurological community outreach program. These people are already in need of clinical support, and their future needs, if not properly met, will place them at some risk of aged care entry. They all live at home in the community with varying levels of support. Some receive low level HACC services, have access to carer respite services, and/or have used inpatient services.

The Pilot is primarily aimed at people whose disability/disease progression necessitates increased and additional services over and above basic HACC and primary care services. Up to twenty five people will be recruited to the project who:

- Are living in the community and have stable accommodation
- Have a progressive neurological disorder [excluding complex Huntington's Disease]
- Are under 50 years of age
- Are registered on the Disability Services Register and currently in receipt of services
- Attend neurological outpatient clinic at Calvary Bethlehem
- Are deemed to be at reasonable future risk of placement in aged care if additional supports are unavailable.

Individuals will exit the project upon:

- Death
- Inability to sustain community program due to:

  - A highly progressive condition
  - Breakdown of living situation to the point where the individual requires residential care or extended hospitalisation
  - Unsustainable program cost.

Challenges and Key Pilot Features

People in the target group have the need for and eligibility to access multiple programs in health, disability services, community aged care and residential aged care at various stages. Some programs have a policy to 'exit' people once they have secured support funding from another program or jurisdiction. This presents a major barrier to securing and maintaining comprehensive programs to meet their needs.

To enable matching of physical and community support to individuals and families and timely and managed access, the Pilot, building on work done by the Neurological Complex Care program in the Northern Metropolitan Region, will employ a comprehensive case coordination approach to identify and manage increasing disability transitions with access to timely support and clinical expertise, and limited brokerage capacity to manage the changing needs of people to specifically reduce the risk of entry into aged care. It will aim to act as an 'Early Intervention' diversion program to manage the risk of entry into aged care and to foster a systemic response for people with progressive conditions. To enable this, formal protocols are to be negotiated with funding programs to ensure continuing and complementary service delivery to participants as they move into other programs in accord with their changing needs i.e. funding programs will be required to maintain effort based on individual functioning. A neurological service network will be established and evaluated at the regional level.

The project does not aim to duplicate existing services or programs, but seeks to proactively manage participants' health and care needs. Project personnel work to locate step up services from the service system where these are required. The Pilot does, however, have one-off non recurrent brokerage funds to provide a service response when a timing or service gap cannot be resolved, or a key service such as an equipment assessment is needed urgently.

Project Objectives and Expected Outcomes

The main objectives of the Pilot are to:

- Actively prevent premature aged care placement through pro-active disease management and service partnerships
- Trial and evaluate a model of combining complementary funding programs to manage the health and community care needs of participants
- Establish program protocols for funding programs to maintain effort and work with other programs – providing a continuous care pathway for people with progressive conditions
- Locate timely/appropriate services, including direct purchasing where no other option exists
- Establish a clinical reference group to inform case planning and case decision making
- Develop service networks and responses to meet the changing needs of participants in a timely and clinically effective way

- Evaluate the intervention model and report on key risk factors for this group for aged care placement
- Develop a specific regional network of clinical and other services utilised by this group to promote referral pathways and other opportunities
- Provide data on the specific service requirements of participants for service planning
- Evaluate the cost savings and emotional impact of preventing long stays in acute/sub acute services through the pilot's intervention to locate services earlier.

The primary anticipated outcomes are to:

- Keep individuals in the community, with their families and to reduce the number of preventable admissions to RAC
- Describe a disease management model that identifies transition risks, reduces the risk of RAC admission and demonstrates a process of coordinated and effective responses from all relevant sectors
- Define and establish training required to effectively deliver services to individuals with degenerative disease by existing support programs and providers
- Generating a model regional service network for neurological health/disability management
- Establish mentoring and education about the impact of degenerative disease for staff in related services
- Develop specific protocols with community aged care, sub acute and other programs about maintenance of effort in servicing participants as they move into the disability services jurisdiction
- Provide data that supports the development of dedicated service pathways for people with complex needs associated with progressive neurological conditions.

Evaluation Requirements

Evaluation Objective and Scope

The primary purpose is to determine whether or not this Pilot (a) delivers significant benefits to participants and their families above and beyond what usual practices/services deliver, and (b) decreases usual overall costs by reducing the use of acute/sub-acute health care services and delaying residential care admissions. In relation to participant/family significant outcomes include changes in relation to met/unmet needs, quality of life, carer strain, timing of service delivery and admissions to residential care.

Evaluation Requirements, Deliverables and Timeframe

Evaluation Scope and Tasks

In addition to the overall purpose outlined above it is expected that the evaluation will examine key aspects of the pilot's design and implementation including:

- Identification of stakeholder (participant, family, service provider & bureaucratic) values and perceptions in relation measuring the success/failure of the Pilot
- Ability of the Pilot to establish protocols across funding streams, programs and service providers
- Effectiveness of these protocols in maintenance of effort/funding for participants across funding streams, programs and service providers
- Perceptions of service providers of the implementation process and effectiveness of the Pilot to deliver for participants and generate overall cost savings
- The role and impact of the Pilot's brokerage funds and of providing intensive case management in relation to both participants/families and service providers (such as the sustainability of services and programs).

The evaluation approach

The evaluation has two main focuses:

a. The assessment of outcomes in terms of benefits to participants and families and in terms of the reduction of costs associated with earlier than necessary residential care admissions

b. Aspects of the programs design and implementation.

For reasons discussed in the previous sections we see these components as interacting in that we believe that careful description and analysis of program processes and the tracking of causal mechanisms that are either explicitly or implicitly assumed in the program design will greatly strengthen our ability to make valid causal inferences about outcomes.

This synergism was only possible with careful planning before the program commenced. This planning included:

a. Making as explicit as many as possible of the assumptions about the mechanisms by which the program is expected to benefit participants and produce the anticipated outcomes
b. Development of means to measure and monitor key aspects of these both before and during the pilot period.

For this reason two evaluation activities were undertaken prior to recruitment of participants into the pilot that focused on making explicit the assumptions and presumed causal mechanisms that are important in the program.

Based on these considerations it was determined that the evaluation needed to have three main components.

1. Elaboration and refinement of the program logic with a focus on the assumed causal mechanisms at both an individual and organisational level
2. Assessment of outcomes as above
3. Assessment of program design and implementation as above.

The following sections provide a broad overview of approaches to each of these components.

Component 1: Methods for elaborating and refining the program logic and developing tools

The initial phase focused on elaborating and critically assessing program design assumptions as discussed above. This component involves three main tasks:

a. Explicitly defining and describing the programs logic including its assumptions
b. Obtaining critical feedback on this from multiple perspectives (especially program staff, participants, and other related health providers)
c. Developing tools or agreed processes for assessing critical factors.

Methods utilised in relation to these tasks were:

a. Concept mapping with a group of participants and carers and with a group of providers
b. Explicitly defining and describing the programs logic including its assumptions
    - Reviewing program documentation
    - Meeting with key personnel and the program steering committee
c. Developing diagrammatic illustration of the program logic
d. Obtaining critical feedback on this from multiple perspectives (especially program staff, participants, and other related health providers)
    - Conducting a workshop with key stakeholders to clarify and refine the program logic and to identify key elements of the program logic for assess as a) markers of successful program implementation, b) evidence of critical causal mechanisms and c) outcomes (participants and the health system)
e. Developing tools or agreed processes for assessing critical factors

- Developing a draft list of aspects of the program logic to be measured or otherwise appraised
- Developing a draft list of measures of appraisal approaches
- Subjecting these to critique and refinement by the evaluation steering committee
- Developing tools and data collection methods (using where possible, existing clinical assessment and care planning processes).

Component 2: Methods for assessing outcomes

The latter sections of this report propose a number of quantitative and qualitative approaches for the assessment of outcomes, including:

- Assessment of participant satisfaction and the perceived adequacy of the package of services provided to them
- Measures of participant and carers' ability to cope and function at home
- Rates of admission to residential care
- Measures of key intermediate outcomes related to mechanisms that are considered important (e.g. confidence in using the service system, self-monitoring skills)
- Costs associated with services delivered.

In relation to cost analysis methods were developed to try and ensure that all costs are considered in any cost comparisons, these include financial, time and opportunity costs borne by carers as well as out of pocket expenses borne by participants. Only a few participants completed the data collection and so these data are presented as illustrative.

From the outset the intended participant numbers were small (30-35). In actuality the numbers were still smaller (19 participants with 16 having really active involvement). Given the small numbers it iwas necessary to rely heavily on detailed qualitative work including one or two interviews with each participant and their primary carer.

Component 3: Methodology for assessing program design and implementation

The first stage in assessing the program design has been covered in relation to component 1 (i.e. the clarification and critical appraisal of the program logic). Client feedback on critical causal aspects of the program as described above will also be an important component of the evaluation of program implementation.

In addition there will be a number of other important measures of program implementation. These are likely to include but not be limited to:

- The ability to develop agreed protocols with other organisations
- The extent to which these are adhered to and participants are able to receive 'step-up' services without affecting existing services
- The number and type of issues raised with the Clinical Advisory Group and the resultant actions and outcomes
- Satisfaction of other service providers with the overall care coordination approach

The evaluators sought to enhance the ability of program managers and the steering committee to develop and improve the program by providing feedback and discussing implementation issues on a regular basis.

Principles guiding data collection

Minimising burned and maximising usefulness

The evaluation sought to minimise the burden on participants by integrating the evaluation data collection processes with the care provision processes wherever possible and the emphasis was on the collection of data that serves three purposes:

a. Planning for service provision
b. Assisting the participant to think about and understand their own needs
c. The needs of the evaluation.

In relation to point 'b', the evaluation will focus on methods that are readily understandable by, and meaningful to participants.

To illustrate the tool in Attachment B was developed by integrating a Life Domains interview tool that had been developed by the MS Society with a Quality of Life tool that had been developed by the evaluator for application in palliative settings. The tool was structured to provide maximum meaningfulness and transparency to the participants and to facilitate an insightful discussion about needs between the project officer and the participant.

In practice this tool was more useful as a care planning tool than as a quantitative evaluation tool. Many participants rated themselves at or close to the maximum on the quantitative scales despite identifying numerous issues of concern. This left little room for improvement.

Qualitative emphasis

Given the relatively small numbers of participants and the exploratory/developmental nature of the project there is an emphasis on qualitative data. In general interviews are structured in accordance with the program logic and will often use questions drawn from the concept mapping statements. Interviews were loosely structured with considerable scope to explore issues raised by the interviewee.

Involvement of family and carers

All consenting participants are being interviewed and approximately half the primary carers. Clients and family/carers are interviewed separately wherever possible to allow them to express themselves as freely as possible without concern for the effects that things they say might have on the other.

Section 2: Evaluation report and findings

Overview

Section 2 focuses on the on the evaluation methods as implemented and on the findings of the evaluation, it includes three main sub-sections:

1. The refinement of the program logic and development of the evaluation framework
2. Development of the evaluation methodology in response to emerging issues in the project
3. Findings.

Refinement of program concepts and logic

This section presents the results of two preliminary evaluation activities that were undertaken to:

a. Identify the key program descriptors, intermediate outcomes and ultimate outcomes that need to be assessed
b. Critically assess the program logic to identify:
    - Any missing steps or spurious assumptions
    - Likely critical success factors
    - Areas where there is lack of clarity or agreement.

The two activities were:

a. Concept mapping workshops with a group of participants and carers and with a group of providers
b. A program logic workshop with people representing participants, carers, providers and key program personnel.

Concept mapping

Two concept mapping workshops were held: one with a group of eight participants and carers and the second with a group of nine service provider representatives.

Concept mapping is an enhanced brainstorming method that seeks to:

a. Identify the broadest possible range of issues around a particular topic, and
b. Organise the ideas identified into a single conceptual framework that does justice to all the distinctions and shades of meaning that the group members see as important
c. Present this in a pictorial diagram that shows the main relationships between the categories of ideas that were developed.

The workshops used a process and software developed by William Trochim in the 1980s. This process differs from other concept mapping processes in that it uses a computer to try and integrate the thinking of **every individual member of the group** in the development of categories. Other processes for concept mapping tend to create winners and losers in terms of how the concepts end up being organised (depending on who is loudest and most forceful in the group).

The process involved three stages.

Concept mapping stage 1

In the first stage participants individually listed as many ideas as they wished in response to the following 'seeding statement':

> *Thinking as broadly as possible,*
> *What are the main issues (personal or systemic) that jeopardise the ability of a person with a deteriorating or unstable neurological condition to remain at home?*

These ideas were then shared with the group in a process based on the nominal group technique.

Concept mapping stage 2

The statements were typed into a computer and printed onto small slips of paper (cards). Each participant was given a full set of statements printed onto cards and was then asked to sort the cards into piles "according to any system that makes sense to you". Participants did this as individuals. They were also asked to give a name to each pile that indicated what the pile was about.

In addition participants were given a list of the statements and asked to rate their importance using the scoring shown in the first column of Table 1. The provider group also rated the statements according to the immediacy of the threat posed using the scoring shown in the second column.

Table 1: Ratings categories for concept mapping

Rate the statements according to the IMPORTANCE of that issue as risk to he person's ability to remain at home:	***Rate the statements according to how immediate the risk to the person's ability to stay at home is? (e.g. how long could you cope with this if extra help wasn't available?)***
1 = Unimportant (no real risk),	1 = No risk,
2 = A little importance,	2 = Long term risk (year or more)
3 = Moderately important,	3 = Medium term risk (few months to a year)
4 = Very important,	4. = Immediate risk (days or weeks)
5 = Essential (Extreme risk, probably wouldn't be able to remain at home)	

Concept mapping stage 3

The data from the participants sorting and rating tasks was entered into the computer and this produced the maps seen in Figure 1 to Figure 5[1]. The way in which the software produces he maps is imperfect and the group was given an opportunity to refine the maps. They were also asked to agree on a name for each cluster of statements.

Concept mapping – presentation of results

The following sections show the results for the consumer/carer and provider concept mapping groups. For each group a number of presentations of results are shown. These are:

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[1] The software uses two statistical processes to produce the maps. The first process is called multidimensional scaling and that produces a spread of dots on the page where each dot represents one statement and statements that were sorted together by many group members sit close together while statements that were sorted together by few or no group members sit far apart. The second process is called cluster analysis and this attempts to draw boundaries around groups of similar statements.

- a table listing the statements that ended up in each cluster together with the ratings for each statement according to the scales shown above (Table 2 and Table 5)
- a map showing the clusters and their relationship to each other (Figure 1 and **Error! Reference source not found.**)
- a map for each of the ratings (more concentric rings indicates a higher score) (Figure 2, Figure 4 and Figure 5)
- a list of the top statements for each rating
- a rank order list of the clusters according to each rating.

Consumers Concept Mapping Group

Table 2: Statements by cluster with importance ratings (participants and carers)

Num	Statement	Imp
CL 1	***Service consistency/reliability (carers and other services)***	***4.50***
1	Need to have regularity of service giver	4.7
19	Consistent response to urgent needs	4.3
Cl 2	***Physical environment - equipment, home enviro and transport***	***4.23***
3	Need for housing alterations (which can be VERY substantial)	4.5
7	Need for adequate facilities and equipment at home	4.5
9	Difficulty getting access for transportation (achieving mobility)	3.8
18	Issues with maintaining equipment and dealing with breakdowns	4.0
22	Need for communication equipment and support for communication needs	4.3
Cl 3	***Knowing about and accessing services (esp funding packages)***	***4.42***
4	Need to be able to find out about all the services from different agencies (information is too disparate)	4.3
8	Hard to know what packages for eligible for	4.5
Cl 4	***Appropriate care/services in the home***	***4.17***
12	Difficulty getting doctors who will come to the house (and other radical services)	4.0
23	Need for support, psychological for carers (someone to debrief with where you know it is confidential)	4.3
Cl 5	***Knowing about and accessing services (incl bureaucracy)***	***4.25***
15	Need to know about residential options other than aged care facilities	4.0
20	Difficulty dealing with bureaucracies to get things done	4.0
24	Lack of a central source of information to know what assistance you can get	4.5
28	Difficulty dealing with forms and paperwork makes it too hard to get services	4.5
Cl 6	***Community facilities and attitudes***	***3.56***
10	Community understanding of requirement of people with disability and their willingness to respect this (eg: disabled parking spots)	3.5
11	Appropriate design of community facilities (eg: size of parking spots)	3.3
25	Need for psychological support for the person with the condition (someone they can talk to other than their primary carer)	3.8
Cl 7	***Paid carer support – qualities, skills and resourcing***	***4.47***
2	Need to have care givers who understand the conditions	4.7
5	Dependability of carers (need them to actually do their job)	4.7
6	Carers with appropriate personality and understanding	4.2
16	Reliability of carers	5.0
17	Lack of flexibility in caring arrangement (eg: what times they're available)	4.2
21	Not enough carer workforce	4.2
Cl 8	***Needs of family carers***	***3.33***

Num	Statement	Imp
13	Lack of freedom (time off) for family	3.5
14	Aging of carers (family members and others)	3.2
Cl 9	***Service adaptability to changing needs***	***4.08***
26	Services don't adapt to rapidly changing needs	4.3
27	Almost need to be able to predict what people with need in a few months time	3.8

Figure 1: Cluster map for clients and carers

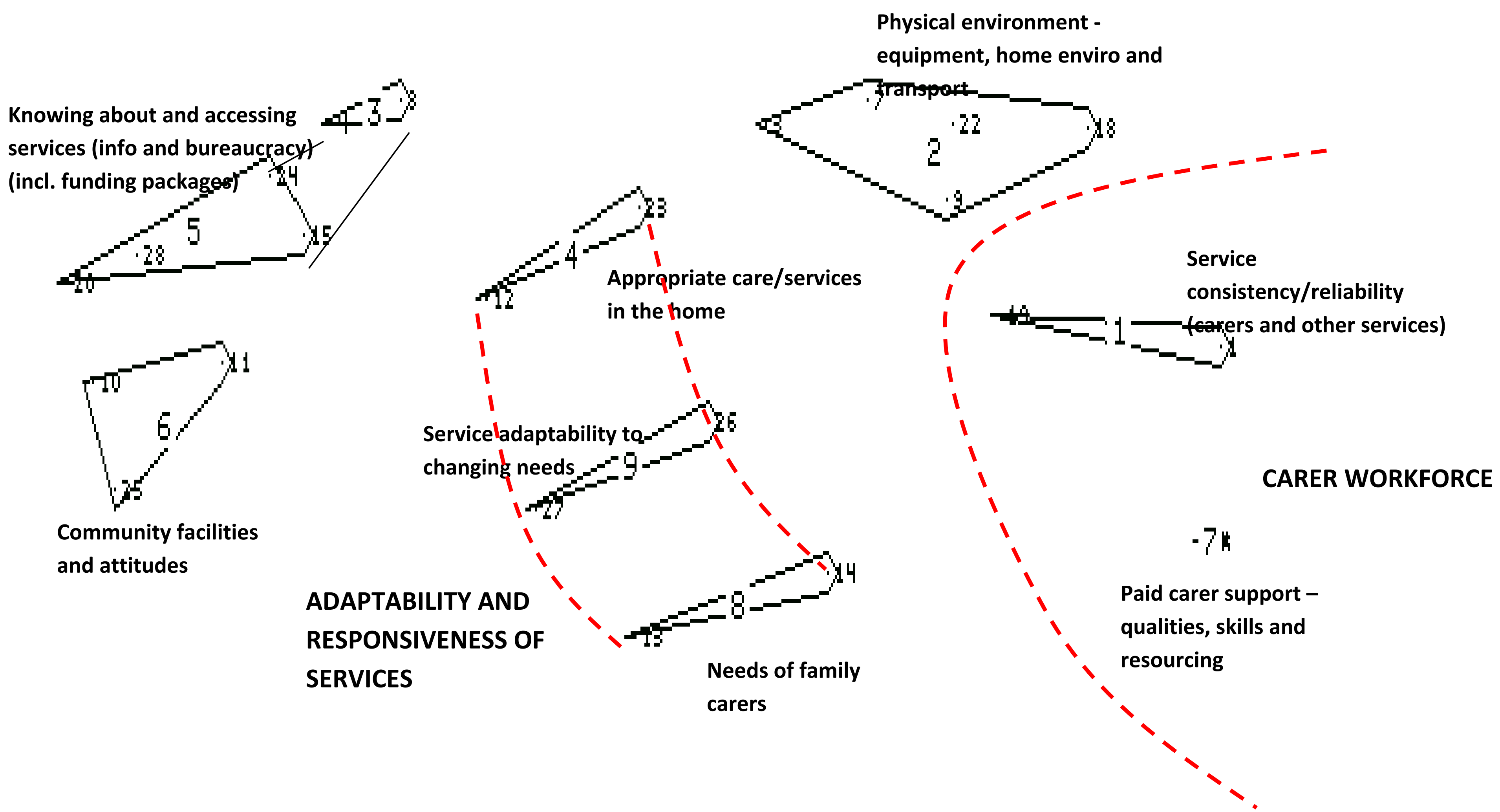


Figure 2: Importance ratings map for clients and carers

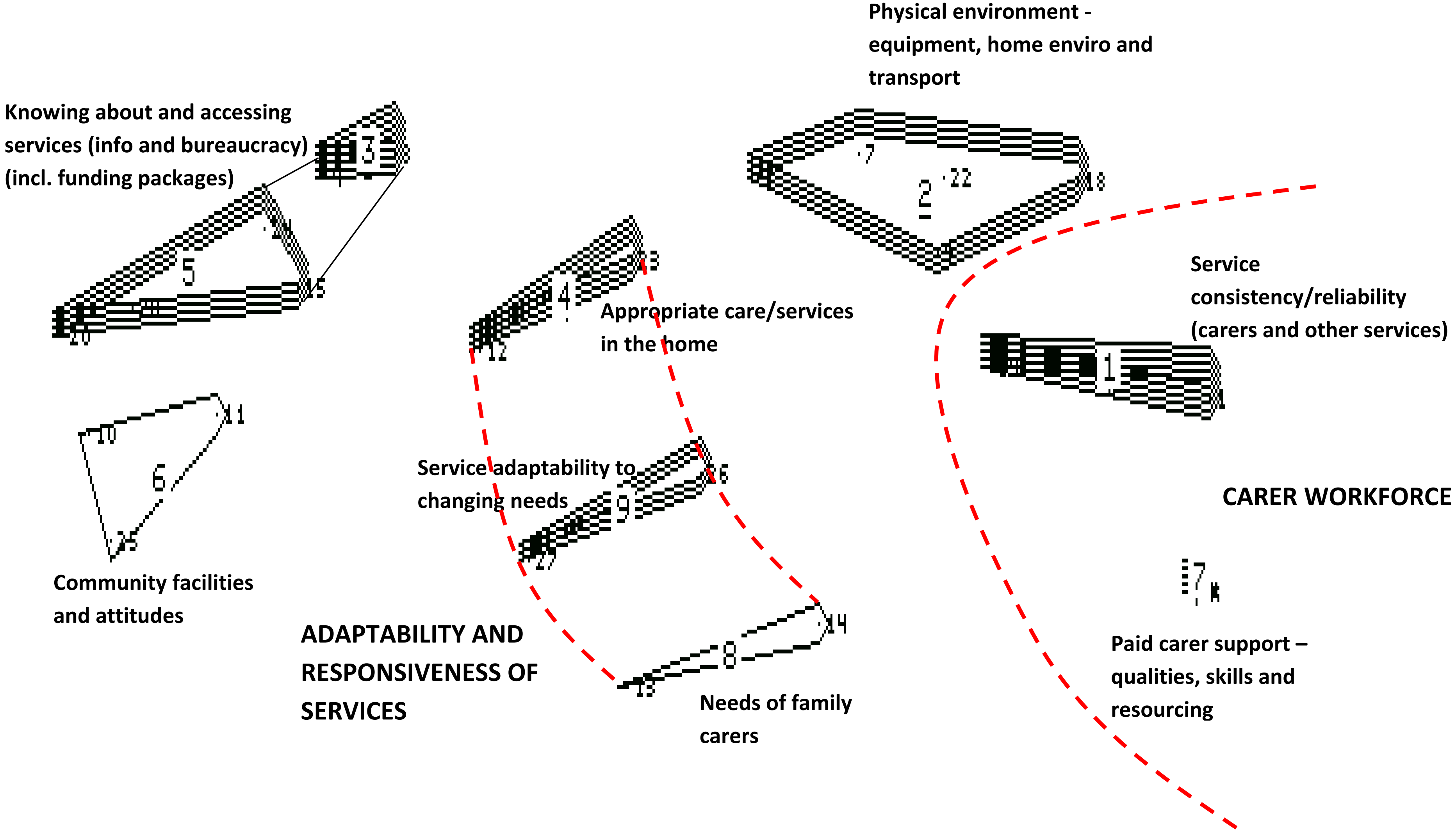


Table 3: 10 most important issues that threaten ability to remain at home (participants and carers)

Num	Statement	Imp
16	Reliability of carers	5.0
1	Need to have regularity of service giver	4.7
2	Need to have care givers who understand the conditions	4.7
5	Dependability of carers (need them to actually do their job)	4.7
3	Need for housing alterations (which can be VERY substantial)	4.5
7	Need for adequate facilities and equipment at home	4.5
8	Hard to know what packages for eligible for	4.5
24	Lack of a central source of information to know what assistance you can get	4.5
28	Difficulty dealing with forms and paperwork makes it too hard to get services	4.5
19	Consistent response to urgent needs	4.3
22	Need for communication equipment and support for communication needs	4.3
4	Need to be able to find out about all the services from different agencies (information is too disparate)	4.3
23	Need for support, psychological for carers (someone to debrief with where you know it is confidential)	4.3
26	Services don't adapt to rapidly changing needs	4.3

Table 4: Clusters in descending order of importance (participants and carers)

Cluster num	Cluster	Imp
1	Service consistency/reliability (carers and other services)	4.50
7	Paid carer support – qualities, skills and resourcing	4.47
3	Knowing about and accessing services (esp funding packages)	4.42
5	Knowing about and accessing services (incl bureaucracy)	4.25
2	Physical environment - equipment, home enviro and transport	4.23
4	Appropriate care/services in the home	4.17
9	Service adaptability to changing needs	4.08
6	Community facilities and attitudes	3.56
8	Needs of family carers	3.33

Providers Concept Mapping Group

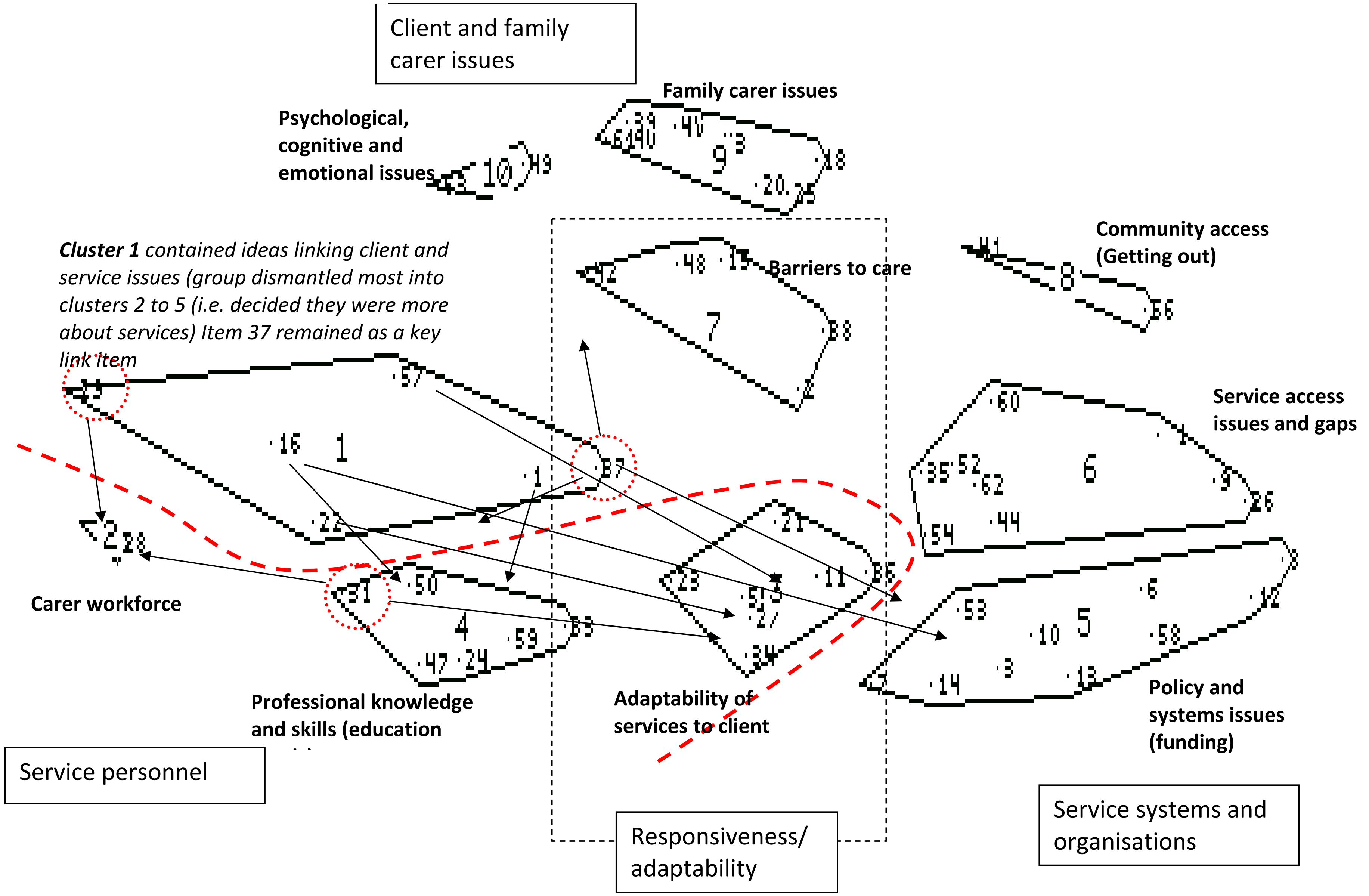
Table 5: Statements by cluster with importance ratings and immediacy of threat ratings (providers)

Num	Statement	Imp	Immed risk	Orig clus
Cl 1	*Ideas linking participant and service issues. Group decided they were more about services and dismantled most into clusters 2 to 5. Item 37 remained as a key link item*	***3.75***	***2.63***	
37	Services systems don't pay enough attention to quality of life issues of people trying to live at home	3.8	2.6	1
Cl 2	***Carer workforce***	***4.25***	***3.43***	
28	Lack of availability for trained carers for high needs participants	4.8	3.9	2
29	Restriction on what carers are able to do	3.9	3.3	1
30	Unstable carer work force linked to hospital admissions and carer support	4.1	3.1	2
32	. Some regional areas had difficulty in accessing carers	4.0	3.3	2
46	Casualisation of carer workforce leading to problems of access, reliability and continuity of care	4.5	3.6	2
Cl 3	***Adaptability of services to participant events***	***4.22***	***3.33***	
11	Ability of services provide level of services required as participant deteriorates	4.6	3.6	3
21	Contingency plans for out of hours	4.5	3.4	3
22	Risk management	4.0	3.1	1
23	What to do in the event of after hour emergencies	4.0	3.6	3
27	Availability of appropriate residential respite	4.5	3.3	3
34	Lack of access to case management services for some people	4.3	3.0	3
36	Slow access to services and slow processes due to layer of beauraucracy	3.9	3.4	3
55	Poor interface between acute health services and disability services leads to discharge to residential care when often options could have been organised	4.0	3.3	3
Cl 4	***Professional knowledge and skills (education needs)***	***3.75***	***2.80***	
1	Knowledge of the resources and how to access them for participants and carers	4.3	3.3	1
24	General lack of understanding in the sector of the unpredictably of many neurological progressive disorders	3.4	2.6	4
31	Inconsistent care delivery linked to hospital carer	3.4	3.3	4
33	Service providers have adequate understanding of accessing services	4.3	2.9	4
47	Case managers and carers don't always have adequate knowledge of neurological conditions	3.5	2.5	4
50	Lack of skills for professionals in negotiating and supporting participants and families to think about and plan for the future	3.9	2.6	4

Num	Statement	Imp	Immed risk	Orig clus
59	Lack of skills / knowledge of carers and service providers in how to deal with cultural sensitivities	3.6	2.5	4
Cl 5	***Policy and systems issues (funding)***	***4.26***	***3.13***	
3	Systemic unit cost is too low currently	4.1	2.9	5
6	Limitation of supports in terms of timely funding	4.6	3.5	5
7	Case management - needs to be ongoing	4.1	2.9	5
8	Availability of funding	4.9	3.8	5
10	Inflexibility of waiting lists	4.1	3.3	5
12	Packages - not enough	4.6	3.1	5
13	Value of packages	4.1	3.0	5
14	Policy directions - focus of broad policies are on aged care at the expense of young people with disabilities	4.3	2.5	5
16	Judgementalism	3.5	2.6	1
53	Lack of integration and coordination among service providers leading to extra burdens on participants	4.0	3.1	5
57	Lack of availability of the 24 hr care	4.5	3.6	1
58	Inequity of access to packages (dependent on the luck of the draw)	4.3	3.3	5
Cl 6	***Service access issues and gaps***	***4.24***	***3.24***	
5	Adequate equipment to support participants and carers	4.3	3.4	6
9	Limited access to services	4.5	3.5	6
26	Availability of appropriate in home respite	4.6	3.4	6
35	When people hit or fall through gaps in the care system	4.4	3.8	6
44	Lack of supported accommodation options often than nursing homes	4.3	3.0	6
51	Inability to get appropriate and timely access to home renovations	4.1	3.6	6
52	Difficulty getting timely access to medical and allied health assessments	4.5	3.6	6
54	Lack of GP care managing and referral role (not sufficiently broad or timely)	4.1	3.0	6
60	Barriers to access for certain cultural groups	3.8	2.5	6
62	Services are very fragmented	3.9	2.6	6
Cl 7	***Barriers to care***	***4.24***	***3.24***	
2	The process of accessing and coordinating care becomes too hard	4.6	3.8	7
15	Disempowerment of participant and family by professionals	3.5	2.5	7
38	Physical and social environment is an impediment to people being able to receive services	4.1	3.4	7
42	People living alone at home (without carer) paradoxically have less access to a lot of services (financial support)	4.6	3.8	7
48	Inadequate support to allow person, carers and families to forward plan (early information delivery)	3.3	2.6	7
Cl 8	***Community access (Getting out)***	***3.81***	***2.88***	

Num	Statement	Imp	Immed risk	Orig clus
41	Lack of opportunities for appropriate socialisation / barriers to socialisation	3.6	2.6	8
56	Difficulty getting transport for appointments	4.0	3.1	8
Cl 9	***Family carer issues***	***4.34***	***3.31***	
4	When conditions deteriorate, how it impacts on family and natural support networks	4.3	3.4	9
17	Family carer fatigue	4.5	3.3	9
18	Family carer stress	4.6	3.3	9
19	Family carer conflict	4.5	3.5	9
20	Loss and grief	4.0	2.9	9
25	Financial hardships for participants and families	4.1	3.4	9
39	The endurance of primary carers in their role	4.8	3.6	9
40	Lack of options / alternatives to the primary carer	4.5	3.4	9
43	Changes in family dynamics reducing families ability to offer support as they would like	4.1	3.4	9
61	Lack of financial support for carers to reduce carer commitments	4.0	3.1	9
Cl 10	***Psychological, cognitive and emotional issue***	***3.58***	***2.79***	
45	People self-belief that they wont be able to cope and will require residential care	3.4	3.0	10
49	Barriers to thinking about and planning of the future (eg: preoccupied with day to day issues, fear)	3.4	2.4	10
63	Cognitive impairment limiting peoples ability to deal with the service system	4.0	3.0	10

Figure 3: Clusters for provider group



Cluster 1 *contained ideas linking client and service issues (group dismantled most into clusters 2 to 5 (i.e. decided they were more about services) Item 37 remained as a key link item*

Figure 4: Importance ratings by providers

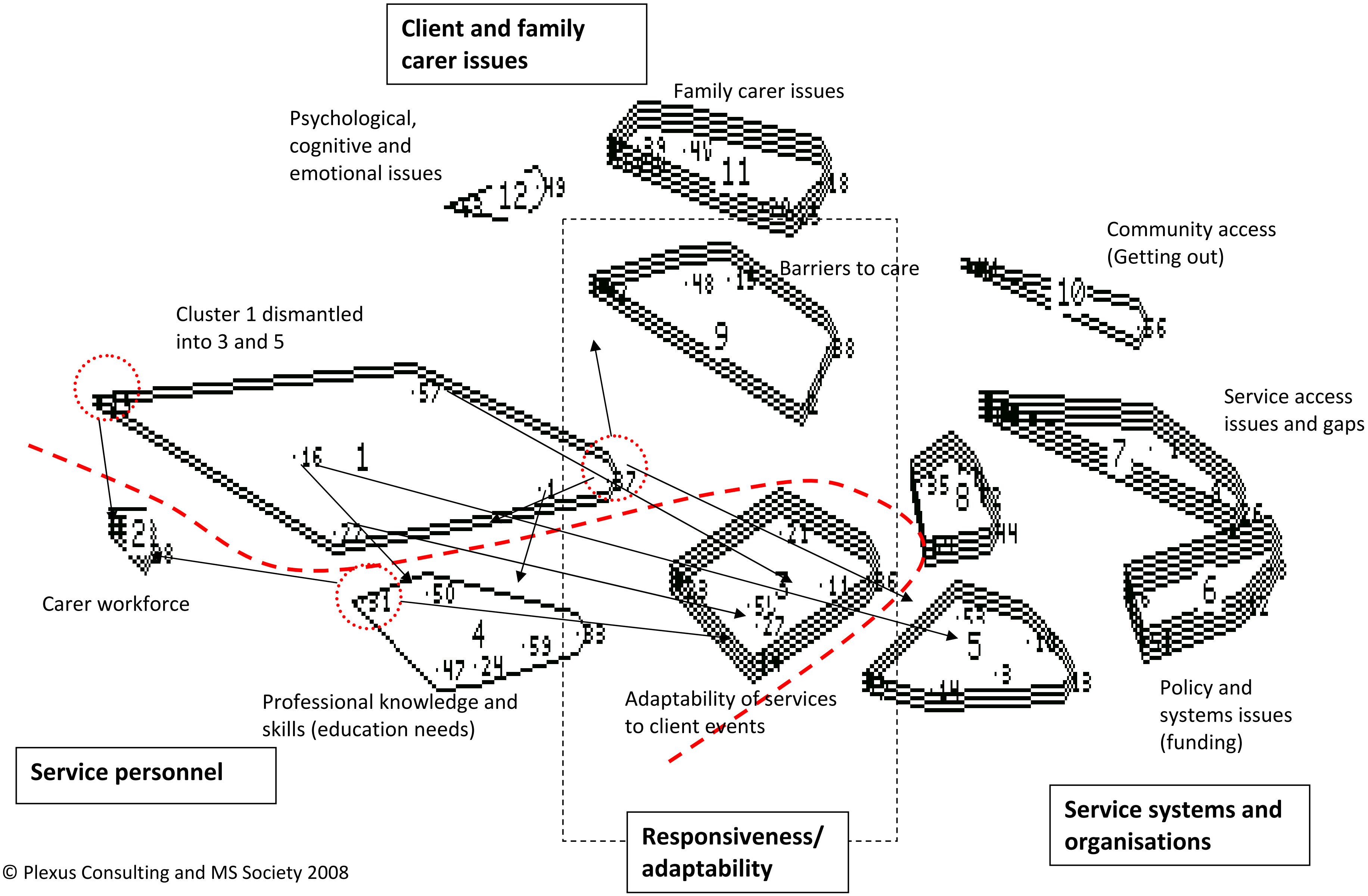


Figure 5: Provider ratings of immediacy of risk

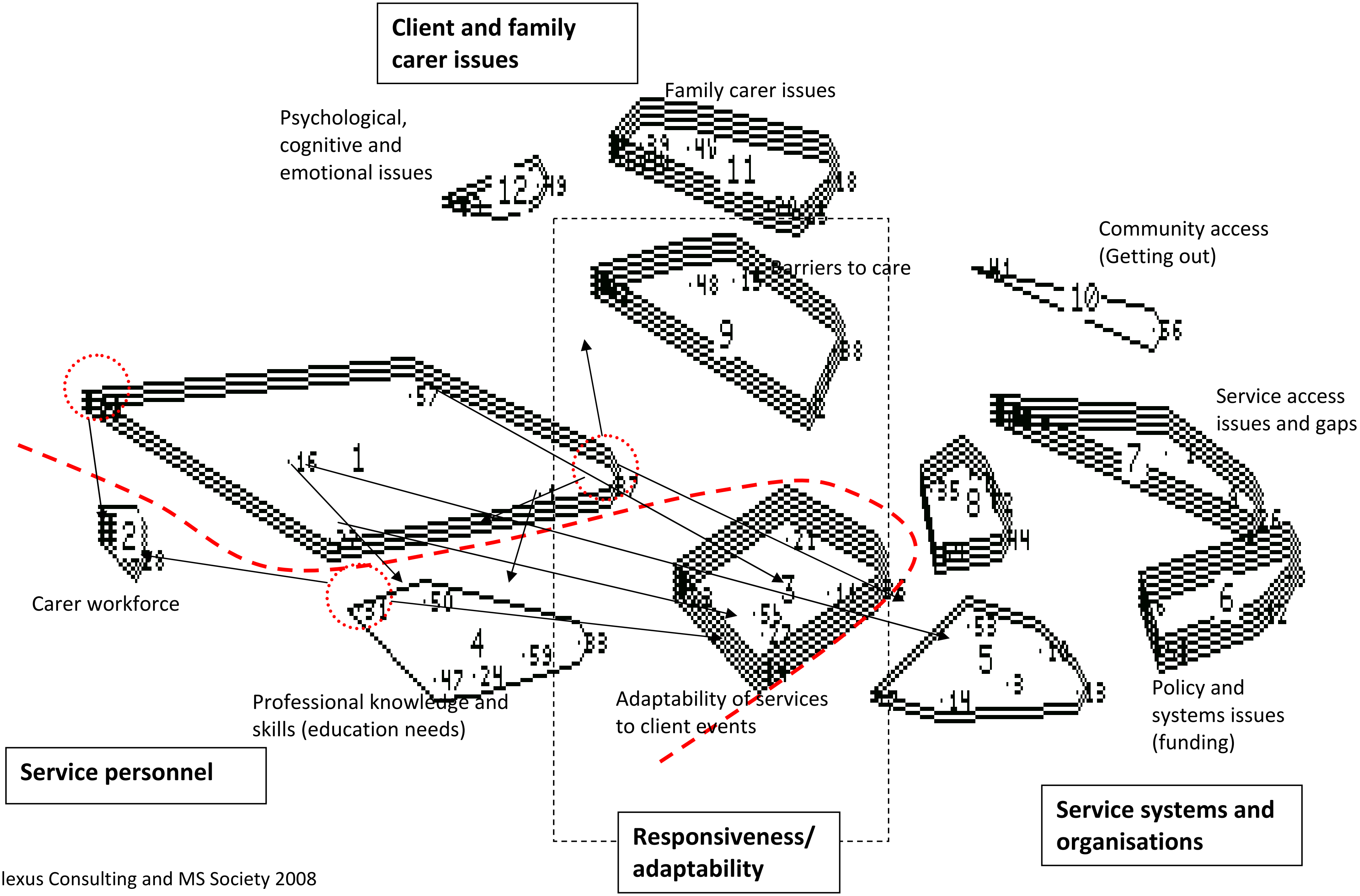


Table 6: Most important 10 statements (providers)

Num	Statement	Imp
8	Availability of funding	4.88
28	Lack of availability for trained carers for high needs participants	4.75
39	The endurance of primary carers in their role	4.75
2	The process of accessing and coordinating care becomes too hard	4.63
6	Limitation of supports in terms of timely funding	4.63
11	Ability of services provide level of services required as participant deteriorates	4.63
12	Packages - not enough	4.63
18	Family carer stress	4.63
26	Availability of appropriate in home respite	4.63
42	People living alone at home (without carer) paradoxically have less access to a lot of services (financial support)	4.63

Table 7: Top 12 statements in immediacy of risk (providers)

Num	Statement	Immed risk
28	Lack of availability of trained carers for high needs participants	3.88
8	Availability of funding	3.75
2	The process of accessing and coordinating care becomes too hard	3.75
42	People living alone at home (without carer) paradoxically have less access to a lot of services (financial support)	3.75
35	When people hit or fall through gaps in the care system	3.75
39	The endurance of primary carers in their role	3.63
11	Ability of services to provide the level of services required as participant deteriorates	3.63
46	Casualisation of carer workforce leading to problems of access, reliability and continuity of care	3.63
52	Difficulty getting timely access to medical and allied health assessments	3.63
57	Lack of availability of the 24 hr care	3.63
51	Inability to get appropriate and timely access to home renovations	3.63
23	What to do in the event of after hour emergencies	3.63

Table 8: Clusters in decreasing order of importance (providers)

Cl Num	Cluster	Imp	Immed risk
9	Family carer issues	4.3	3.3

5	Policy and systems issues (funding)	4.3	3.1
2	Carer workforce	4.3	3.4
6	Service access issues and gaps	4.2	3.2
3	Adaptability of services to participant events	4.2	3.3
7	Barriers to care	4.0	3.2
8	Community access (Getting out)	3.8	2.9
1	Ideas linking participant and service issues. Group decided they were more about services and dismantled most into clusters 2 to 5. Item 37 remained as a key link item	3.8	2.6
4	Professional knowledge and skills (education needs)	3.8	2.8
10	Psychological, cognitive and emotional issue	3.6	2.8

Table 9: Clusters in decreasing order of immediacy of risk (providers)

Cl Num	Cluster	Imp	Immed risk
2	Carer workforce	4.3	3.4
9	Family carer issues	4.3	3.3
3	Adaptability of services to participant events	4.2	3.3
6	Service access issues and gaps	4.2	3.2
7	Barriers to care	4.0	3.2
5	Policy and systems issues (funding)	4.3	3.1
8	Community access (Getting out)	3.8	2.9
4	Professional knowledge and skills (education needs)	3.8	2.8
10	Psychological, cognitive and emotional issue	3.6	2.8
1	Ideas linking participant and service issues. Group decided they were more about services and dismantled most into clusters 2 to 5. Item 37 remained as a key link item	3.8	2.6

Implications of the concept mapping results for the evaluation

For participants and family carers the most important issue was the dependability of paid carers and their ability to have confidence that services would be provided at the time they were needed and in an appropriate way. These issues were also important to providers and were considered to pose the most immediate threat when there was problems, however, providers rated issues to do with family carer needs and the ability to access appropriate funding as more important issues overall. These issue were emphasised in the discussion of the program logic that is reported in the next section.

In addition the concept mapping statements indicate specific content for the areas which have been identified as important for measurement/assessment. For example 'regularity of carers' was identified as a key issue in participant satisfaction and confidence in service provision.

Program logic

The following page presents a diagram that is the result of a workshop that was held with representatives of participants/carers, service providers, program personnel and clinical experts. All but three of the participants had also participated in the concept mapping sessions.

The framework used to develop the program logic is based on the work of McClintock in the 1980s (1986, 1988) in his studies of hospice services. The strength of this particular framework is that it explicitly focuses on both organisational and individual change processes. It is based on the question:

> *How do things we do at an organisational level bring about changes within or for individuals which are ultimately of benefit for these individuals.*

The workshop used the draft program logic presented in Attachment A as a starting point. This draft was developed by the evaluator based on program documents. The group worked through the program logic row by row, refining and extending it. Where relevant findings from the concept mapping groups were incorporated.

The result is the diagram presented as Figure 6 on the next page.

Applying the program logic

The program logic diagram is the single most important element of this evaluation framework. It defines the key processes, intermediate outcomes and ultimate outcomes that were assessed in the evaluation.

Table 10 takes the elements of the program logic and identifies key evaluation questions related to each element as well as the data sources and approaches that were used to answer these questions. This summarises what was assessed in the evaluation.

Figure 6: Program logic for the Continuous Care Pilot

People with degenerative neurological conditions who are already in need of clinical support and who have future needs that place them at some risk of aged care entry

Organisational level

Receive services guided by the following principles…

- The aim of securing and maintaining comprehensive, needs based service delivery
- Continuity of existing services as new services are introduced
- Partnership with the client in determining the need for services
- Focused on allowing people to remain in their homes as long as possible
- Individual and carers/ family are treated as 'the client'
- Enhancing the function of the whole service network (short term - coordination, long tem – workforce)

Which include…

- Detailed participatory assessment (a 'case history' as described in the project proposal)
- Active, specialist case coordination and linkages
- Provision of 'step-up services'. (Adding additional services as the client's condition requires without losing access to existing services. Requires shared protocols and appropriate financial packages)
- A 'predictive, proactive' approach to case coordination guided by a team of experts (the 'Clinical Advisory Group')
- Some brokerage funds
- Support to service providers (training, liaison, sharing info)

Client and family level

Which it is expected will lead to the following interrelated causal processes…

- Anticipatory identification of needs leading to the very timely introduction of services including preventive and maintenance services
- A more comprehensive range of services and greater continuity of service provision
- Greater client and family involvement and understanding of the services being provided and more active participation with these services. More positive and confidence enhancing experiences.
- Increased information about services available to clients and other service providers
- Early identification of, and response (at client's choice) to, issues that put a person at risk of requiring an aged placement

Which, in turn, it is expected will lead to the following beneficial client outcomes…

- Needs are identified and met in a timely manner
- Greater knowledge of and confidence in the service system and greater ability to access and use services
- Increased use of respite options (and satisfaction with respite experiences)
- Greater participation in maintenance and preventive services
- Early and more appropriate response to risks and deterioration (partially insight and future thinking, partially mechanisms for reacting to changes in circumstances)
- Rapid (re)establishment of services after hospitalisation

Which ultimately lead to…

- Greater physical and psychological well-being of clients and their families
- Less need for clients to be admitted to aged care facilities

Financial issues and workforce were identified as key barriers across all areas by both clients and providers

Table 10: Evaluation questions and data sources related to elements of the program logic

PROGRAM LOGIC ELEMENTS	EVALUATION QUESTIONS	DATA SOURCES
Clients receive services guided by the following principles: *General questions are: How, and to what extent, were these principles realised in practice? What processes and decisions show this?*		
The aim of securing and maintaining comprehensive, needs based service delivery	• Is there evidence of changes in service provision in response to identified need?	• Initial needs assessment • Service audit at commencement and service tracking through project
Continuity of existing services as new services are introduced	• Have agreements for service continuity been established with service providers? • Have services always been maintained when new services were introduced where this was appropriate in terms of participant need?	• Documented agreements • Interviews with project officer responsible for negotiating agreements • Interviews with key service providers
Partnership with the participant in determining the need for services	• To what extent and in what ways were participants involved in determining there need for services? • How were they involved in dealing with circumstances where desired services were unavailable?	• Needs assessment documents • Client interviews • Interview with project officer responsible for undertaking participant needs assessments • Interview wits with CAG members
Focused on allowing people to remain in their homes as long as possible	• How was the need for services that enable people to remain at home defined in practice (e.g. narrowly or broadly, preventively or reactively)? • Do service providers take this into account in prioritisation?	• Interviews with project officer and service providers Will also be addressed in interviews with participants related to outcomes listed below
Individual and carers/family are treated as ‘the participant’	• What evidence is there that carer/family needs were considered and addressed?	• Needs documentation • Carer/family member questionnaire • Some carer/family member interviews

PROGRAM LOGIC ELEMENTS	EVALUATION QUESTIONS	DATA SOURCES
Enhancing the function of the whole service network (short term - coordination, long tem – workforce)	• What service development needs were identified through discussions and negotiation with service providers? • What service coordination needs were identified? • What solutions, including, training were put in place to meet these needs?	• Concept mapping outcomes • Results of project officer negotiations with service providers • Documentation of training and other service capacity building activities
These services/interventions include: *General questions are: Were these services/interventions implemented? How? Was the implementation effective?*		
Detailed participatory assessment (a 'case history' as described in the project proposal)	• Was the assessment truly 'participatory'? • Did it cover all domains important to participants? • Did it meet the needs of the CAG to support their care planning role?	• Initial participatory assessment documents (as per Attachments B and C) • Interviews with participants, carers and the project officer
Active, specialist case coordination and linkages	• What was the role of the project officer and the CAG in care planning and care coordination? • Were they able to organise additional services for participants?	• Documentation of CAG outcomes • Interviews with CAG members • Interviews with project officer
Provision of 'step-up services'. (Adding additional services as the participant's condition requires without losing access to existing services. Requires shared protocols and appropriate financial packages)	• What additional services were provided to participants during the period of the trial? • Was this always achieved without causing cessation of other services? • What changes in procedures or other arrangements did service providers need to put in place to allow this to happen? • What financial packages are available and what are the barriers to accessing them? Have these been overcome?	• Service tracking through project • Interviews with project officer and service providers • Collation of information on financial packages available
A 'predictive, proactive' approach to case	• What 'predictive' decisions were made by the	• Interviews with CAG members (or focus

PROGRAM LOGIC ELEMENTS	EVALUATION QUESTIONS	DATA SOURCES
coordination guided by a team of experts (the 'Clinical Advisory Group')	CAG? On what basis? • Did the CAG have the information required to make predictive/proactive decisions? • How were these decisions discussed with participants? • How did they impact on service arrangements that were put in place?	group) • Documentation of CAG decisions • Documentation of follow-up of CAG decisions
Some brokerage funds	• For what purposes were brokerage funds expended? • What was the reason this was required (e.g. services unavailable? Ineligible? delayed?)	• Program records • Interviews with project officer
Support to service providers (training, liaison, sharing info)	• What needs were identified in order to enhance the ability of service providers to meet participants needs? What was done to address these needs?	• Interviews with project personnel and service providers (may be focus group)
Which it is expected will lead to the following interrelated causal processes: *General questions are: To what extent did these key causal mechanisms actually occur? Was the effect string enough to produce the hoped for participant outcomes?*		
Anticipatory identification of needs leading to the very timely introduction of services including preventive and maintenance services	• Were there any new services initiated immediately as a result of the assessment and the CAGs considerations? • Were any advance arrangements made with service providers to streamline participants' access to services should the need arise?	• CAG records • Interviews with project manager • Interviews or focus group with CAG
A more comprehensive range of services and greater continuity of service provision	• As previous plus… • Were new services added without impacting on existing services?	• Service tracking • Interviews with project manager • Interviews with participants/carers
Greater participant and family involvement and understanding of the services being provided and	• Do participants and their families have increased knowledge about services or no who to ask if	• Client and carer interviews

PROGRAM LOGIC ELEMENTS	EVALUATION QUESTIONS	DATA SOURCES
more active participation with these services. More positive and confidence enhancing experiences.	they need services? • Have their experiences with a) seeking to access new services, and b) the dependability and appropriateness of services improved?	• Satisfaction questionnaires • The life domains/quality of life tool
Increased information about services available to participants and other service providers	• As previous plus… • Do service providers have an increased understanding of others services and what is needed to access them ? • Do service providers have an understanding of their role as part of a suite of services that may be necessary o support a person at home?	• As previous plus… • Interviews or focus groups with service providers • Documentary evidence of agreements made with service providers and changed access policies for people with progressive neurological conditions
Early identification of, and response (at participant's choice) to, issues that put a person at risk of requiring an aged placement	• Do participants have provisional action plans and pre-arranged service plans in case of medical deterioration or other events that put them at risk? • Have long-term threats to the sustainability of a participants position at home been identified and plans made to accommodate them (e.g. carer fatigue or health issues)	• CAG documents and recommendations • Interviews with CAG, participants, carers and project officer
Which, in turn, it is expected will lead to the following beneficial participant outcomes: *General questions are: To what extent and in what ways did consumers and their primary carers experience these benefits?*		
Needs are identified and met in a timely manner	• Are new needs identified through the initial participant assessment and CAG? Were these able to be responded to immediately? • Were mechanisms established to identify and respond to newly arising needs?	• Client assessments and service records • Interviews with participants and carers • Interviews with project officer
Greater knowledge of and confidence in the service system and greater ability to access and use services	• Do participants and carers have increased confidence in a) their ability to access needed services and b) the dependability and quality of these services?	• Life Domains/Quality of Life questionnaire • Client and carer satisfaction questionnaires • Interviews with participants and carers

PROGRAM LOGIC ELEMENTS	**EVALUATION QUESTIONS**	**DATA SOURCES**
	(The concept mapping indicated that this could be coming from a very low base and is one of the critical success factors for this project.)	• *Given that this is such a critical issue consideration will be given to running a true focus group with participants and carers where this is the focus question*
Increased use of respite options (and satisfaction with respite experiences)	• Did participants use residential or day respite services during the project? • Were these new? • How satisfied were the participants and family/carer with respite arrangements?	• Service tracking • Interviews with participants/carers • Interviews with project officer
Greater participation in maintenance and preventive services	• Were needs and opportunities for maintenance and preventive services identified in the assessments? Were these addressed? • To what extent did the CAG consider these types of need in their considerations? • Were participants and carers willing to participate in these? Were there specific barriers that hindered participation?	• Assessment and initial planning records including CAG decisions • Interviews with participants and carers • Interviews with CAG • Interviews with project officer
Early and more appropriate response to risks and deterioration (partially insight and future thinking, partially mechanisms for reacting to changes in circumstances)	• Do participants have provisional action plans and pre-arranged service plans in case of medical deterioration or other events that put them at risk? Were these enacted for any participants? • Were there events that jeopardised the persons ability to stay at home? How were these solved? How confident were the participant and family that they would be able to find a solution?	• CAG documents and recommendations • Interviews with CAG, participants, carers and project officer
Rapid (re)establishment of services after hospitalisation	• If participants were admitted to hospital, was there any delay in return home due to delays in (re)establishing required services? • Were service providers satisfied with the level of communication/notification they received when	• Service tracking records • Interviews with project officer • Interviews with participants and carers

PROGRAM LOGIC ELEMENTS	**EVALUATION QUESTIONS**	**DATA SOURCES**
	a participant was in hospital? • Did participants who were admitted to hospital require new services at discharge? Were these able to be put in place?	
Which, ultimately lead to: *General questions are: Is there any evidence of these outcomes within the time frame of the trial?*		
Greater physical and psychological well-being of participants and their families	• Has participants satisfaction with critical life domains and their sense of ell-being and of being in control of their life changed (similarly for family/carers)	• Quality of life scales in the Life domains assessment (Attachment B). A tool with just the scales will be used for follow-up and with the control group • Client and family interviews
Less need for participants to be admitted to aged care facilities	*NB the question of whether there is a reduction in admissions is unanswerable given the timeframe and size of the pilot* • Do participants and carers feel that their arrangements for maintaining the participant at home are more secure? • Were there any events where an admission to residential care was likely but was averted? • Were there any events where an admission to residential care occurred but could have been averted with more adequate service provision?	• Interviews with participants and carers • Follow-up with any participants admitted to residential aged care during the life of the project • Clinical records • Interviews with project officer

Evaluation framework

Data collection activities

Based on the information needs identified and described through the program logic process and listed in detail in Table 10 a number of data collection processes were developed. During the life of the project some of the methods were modified in response to a range of issues including:

- Smaller numbers than initially anticipated
- The need to provide developmental feedback to improve project processes
- Recognition of the limited value of some of the proposed data collection methods.

The changes in approach can be summarised as an increased emphasis on qualitative data and a move to case based analysis. In addition the evaluation became more overtly formative and informative with several points of feedback into project implementation. The evaluation therefore took on aspects of an action research project.

One of the most significant changes was that case studies were developed for each participant based on:

- Interviews with the MS care coordinator
- Interviews with the participant and, where applicable, their primary carer
- Interviews with existing case managers
- Records from the clinical advisory group
- The Life Domains questionnaire.

A second major change was that participant observation became a more substantial component of the evaluation. This included attendance at three CAG meetings, observation of one of the training sessions and participation in a neurologists network workshop.

Table 11 lists the initially proposed methods and the actual methods employed.

This table is complementary to Table 10. The evaluation questions column of Table 10 indicates questions that provided the content of the specific data collection methods. So, for example, the list of questions where “participant interviews” was identified as a data source guided the content of the evaluation interviews with participants.

Table 11: Planned and actual data collection processes

Data collection processes	Proposed data collection activities	Actual data collection activities and reasons for changes
Review project documentation	Review of project proposals, tools, education materials, terms of reference	As intended but also included detailed review of all participant notes and the outcomes of CAG meetings
Concept mapping with participants/carers and providers	2 groups conducted prior to commencement of the active phase of the project	As intended
Program logic workshop	Workshop with project personnel, participants/carers and provider representatives held prior to commencement of the project	As intended
Initial participant assessment	Initial assessment interview of participant/family by project officer	As intended. Followed up with detailed interviews with the project care coordinator
Life domains satisfaction questionnaire	• Initial assessment by project officer • As a questionnaire for follow-up and also pre-post for control group	• These were not collected on all participants because some were cognitively unable to deal with it. Some participants did not have follow-ups because the initial assessment was completed less than 3 months before the end of the project • The data is used descriptively within the case studies to highlight the areas of life that were of major concern to the participants. No statistical pre-post analysis was conducted. In the follow-up interviews participants were asked in relation to each main area covered by the tool if they felt the program had benefited them in this area
Client interviews (evaluator)	• Approximately eight interviews four to five months after commencement • Interviews with all consenting participants near end of project	• The interviews with participants became a much more substantial component of the evaluation and the final interviews
Carer interviews (evaluator)	• Interviews with cares for half of consenting participants near end of project	• Carers participated in the final interviews in most cases

Data collection processes	Proposed data collection activities	Actual data collection activities and reasons for changes
Client and carer focus group	Focus group on the question of 'confidence in the ability to access services and the dependability and quality of those services' likely to be held near the end of the project	These issues were addressed in the interviews with each of the participants
Client and carer satisfaction questionnaires	All participants and carers towards the end of the project	These issues were addressed in the interviews with each of the participants
Interviews with CAG	Likely to include both individual phone interviews and a focus group. Phone interviews at both the midpoint and near the end of the project. Focus group towards the end of the project.	This was replaced by participation in three CAG meetings and a special meeting with the CAG to discuss their role
Meetings with project officer (and other key project personnel)	To be conducted at least 2 monthly through the life of the project. May involve setting up little data collection and review activities between these meetings.	This component was substantially expanded to include detailed discussions of every participant
Interviews with service providers	Approximately eight interviews to be conducted near the midpoint and 15 to 20 near the end of the evaluation. (These may be replaced with focus groups)	• Interviews at the midpoint were as intende • The interviews at the end of the project included the case-managers/key workers of each participant • Additional provider input was obtained in a provider meeting held at the end of 2008 and from the training workshops and the neurologists workshop
Early learnings workshop	A workshop with some initial evaluation findings will be held with key stakeholders approximately half way through the project	As intended
Interpretation and recommendations workshop	A workshop with key stakeholders will be held once a preliminary analysis of the evaluation data is complete. The evaluators provisional interpretation of the data will be presented and	As intended

Data collection processes	Proposed data collection activities	Actual data collection activities and reasons for changes
	participants will be invited to offer their interpretations. Key questions hat may lead to recommendations will be discussed.	

Tools

An extensive suite of tools was developed for use in the evaluation. These were:

a. A life domains assessment tool including assessment of quality of life in these domains
b. A tool for assessing the history and trajectory of the participant's condition and service utilisation
c. Interview guides for interviews with participants, family carers, service providers, the project officer, the CAG members (these guides will outline a process and key issues rather than specific questions)
d. A 'costs to family carers' tool.

Copies of all of these tools are available on request or as attachments to the ethics proposal.

Ethics and consent

Since this project involves the release of confidential information to the evaluator it was necessary to seek ethics approval to ensure that there are adequate processes to ensure informed consent by participants and confidentiality of all information.

The evaluator has signed a confidentiality agreement with the MS Society

The participant consent form, including a plain language statement of the purpose of the project and the evaluation is attached as Attachment C.

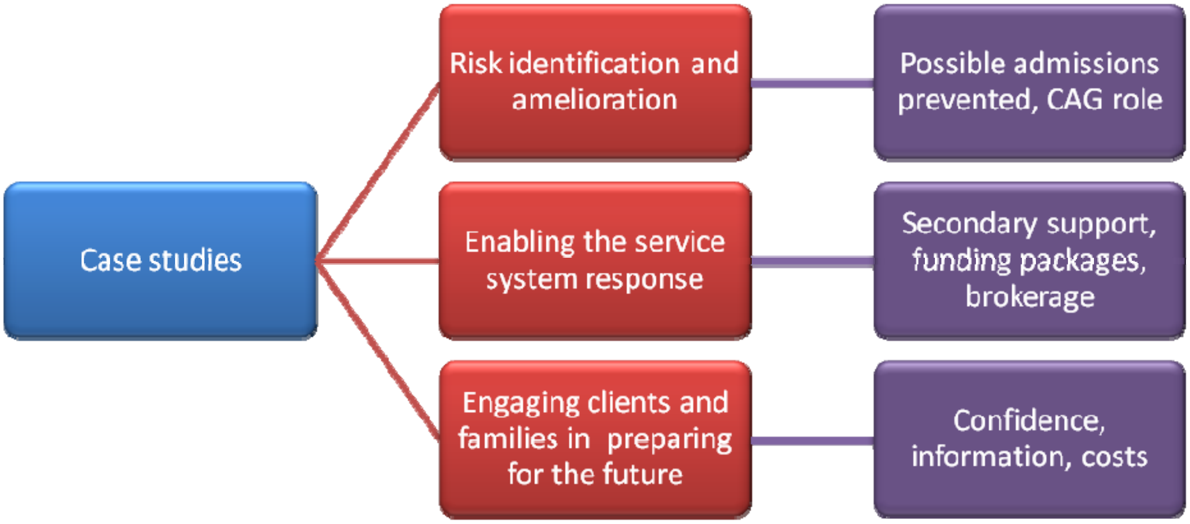
Ethics approval was obtained at the start of October.

Framework for presentation of results

One outcome of the preparation of the interim report for the project was the identification of three key areas of project impact. These areas were subsequently used to structure the development of participant case studies and are also used to structure the presentation and discussion of results in this report.

Figure 7 lists the three key areas of project impact and some of the related issues that emerged through the life of the pilot. For example key issues related to the outcome area 'risk identification and amelioration' include the assessment of the likelihood that the pilot prevented admissions to residential care and the role of the Clinical Advisory Group in identifying risk and planning amelioration strategies.

Figure 7: Outline of case studies and discussion of findings



Client descriptions and case studies

This section presents a selection of early findings from the evaluation. It is not structured according to data sources but is case oriented. Case studies drew on and integrated information from numerous sources (p 51). The sections are:

1. Overview of participants
2. Issues related to recruitment and assessment
3. Client case studies.

Overview of participants

The project included 20 participants, 11 female and 9 male. Four additional participants were recruited but have not continued for various reasons.

Four of the participants live outside of the Calvary Bethlehem catchment and the experiences of these participants was considered to be an important guide to the likely generalisability of the model.

Table 12 provides a brief summary of issues for each of the participants along with a rating of their overall level of need where (1) = 'active need', (2)= 'medium level need and risk' and (3)= 'less in need'. These ratings were determined by the project officer. Fourteen participants were rated as 'active need', three as 'medium level need and risk' and one as 'less in need'.[2]

Table 12: Brief participant descriptions

ID	Age, gender, status	Rating	Diagnosis	Risk factor / comments
1	40s, male, single	2	Myotonic Dystrophy	Elderly parents Cannot manage some of tasks at home eg: cannot do cooking as has numb fingertips Sleep apnoea & hypoventilation Future accommodation needs.
2	40s, male, married	1	MS	Lives at home with wife children. Wife is primary carer and main support. Requires full assistance with all ADL's. Mobilises in wheelchair, hoist transfer. Requires turning in night. Needs reassessment of pain / sleeping patterns. Needs support in looking at other accommodation options At risk if wife sick
4	40s, male, married	1	Advanced MND	Lives at home with wife, 1 small child and a baby. Wife is primary carer. Needs full assistance with all ADL's. Has no speech. At risk if wife sick.

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[2] The data and descriptions in Table 12 were provided by the MS project officer. All unnecessary and sensitive details have been removed in order to protect client privacy.

ID	Age, gender, status	Rating	Diagnosis	Risk factor / comments
5	40s, male, widower	2	MS	Primary carer to teenage children. Grief over loss of wife Concerns about future support of children Sleeping difficulties, pain, pins and needles, fatigue Needs future planning including financial considerations
6	40s, female, single	1	Cerebral Palsy Cervical Dystonia	Single parent with young child. Surgery on neck left nearly quadriplegic At risk of quadriplegia or death from fall. Constant pain and numbness in arms
7	40s, female, married	1	Secondary Progressive MS	Lives at home with husband and teenage children Husband is primary carer (works FT) Elderly mother & mother in law assist with ADL's RDNS 3 times a week for personal care. Loss & grief of life (pre MS) Fatigue a major issue. At risk if husband unable to sick.
8	40s, male, single	1	Secondary Progressive MS	Lives with family - mother is primary carer. Wheelchair to mobilise, hoist transfer. Young child lives with ex partner but visits alternate weekends. Need for assistance with future planning as is worried about what will happen if mother not able to continue care.
9	40s, female, married	1	Mytonic Dystrophy	Lives with husband at home. Husband is primary carer (employed FT). Multitude of health problems which have progressed. Home requiring modifications, requires electric wheelchair for mobility Requires assistance with all daily tasks. Needs monitoring due to unstable health issues.
10	30s, female, single	1	MS	Lives at home with mother and siblings. Mother is primary carer. Difficulty accessing carers to fill shifts during the week, at weekends and public holidays. At risk of long term hospitalisation as family struggling to cope with support demands Needs options for residential respite to encourage socialisation.
11	40s, female, single	1	Secondary Progressive MS	Lives with partner who is primary carer. Partner has health issues that limit physical ability to provide care

ID	Age, gender, status	Rating	Diagnosis	Risk factor / comments
				Unable to mobilise as current manual wheelchair and scooter do not provide upper body support Needs extra supports in place. At risk if partner sick.
12	40s, male, single	2	Parkinson's	Lives alone in rented upstairs flat (no lift) Dystonia with high levels of pain and anxiety Socially isolated, In need of future planning for future accommodation options.
13	30s, female, single	3	Muscular Dystrophy	Lives with sister Increasing care needs Transfers without assistance, walks. Needs assistance with future planning as will have respiratory issues Needs extra supports at home At risk if sister cannot maintain support and care.
14	30s, male, married	1	MS	Lives at home with wife and two small children. Wife tired and anxious. Ataxic, needs SPC. Works 1-2 days a week. Client and wife have low awareness of likely future needs
15	40s, female, married	1	Mitochondrial Disorder	Lives with husband and daughter; husband is full time carer. Poor vision, hearing Muscle fatigue – Continence issues Able to walk a few metres inside, cannot walk outside. Needs increased supports
16	40s, female, married	1	MS	Lives with husband & teenage children. Husband is primary carer. Non ambulant Requires full assistance to complete all personal care and ADL. Husband is primary carer and works full time. Client goes to work with husband unable to remain at home alone Husband needs education and support
17	40s, female, single	1	MSA	Single mother, lives with mother & teenage child– in mothers home, Requires light assistance with showering Uses walking frame Eyesight deteriorating.

ID	Age, gender, status	Rating	Diagnosis	Risk factor / comments
				Pain Some memory loss Finances not covering care needs
18	Male, married	1	MS	Has resided in Dept of Housing house for past 3-4 yrs Exacerbation of MS earlier this year – admitted to hosp then rehab Discharged on a Transitional Care Program High level of care now required Needs future planning as elderly parents are becoming less able to provide assistance
19	40s, female, divorced	1		
20	40s, Female			
Clients who have withdrawn from program				
	Male		MND	Deceased
	Female		MS	Diagnosis has changed, does not have MS
	Female		MS	Refused
	Female		MS	Family unable to cope with intensity of program

Issues related to recruitment and assessment

The assessment process undertaken with new participants in the project was extensive and deep, it involved:

a. A general interview by the MS care coordinator
b. Completion of the life domains assessment
c. Completion of the life stages assessment
d. Collection of data on services received and costs.

The assessment involved some time in which participants and carers are interviewed separately.

The assessment process took a lengthy period of time and often requires two or three visits. Many participants were limited in the amount they can do in a visit due to fatigue issues. This was seen as a problem by the MS care coordinator but she felt that the depth of information is valuable. Clients generally felt positive about the assessment process with several participants expressing views that the discussion had some therapeutic value in its own right; in particular a number of participants expressed appreciation of the opportunity to talk about things honestly without their carers present. Several expressed the view that they often don't express what they really feel or want to their carers out of fear of causing anxiety or further difficulties or simply because they feel dependent.

Despite its value the lengthy assessment process was seen as an impediment by at least one participant, who dropped out. It is also likely to limit future capacity and sustainability of similar projects. Means of streamlining the assessment process should be considered for any future projects.

Case studies

The following pages contain case studies of each of the participants with which the Continuous Care Pilot had a significant involvement. Two participants are not included because CCP involvement was minimal in one case because the participant was an inpatient at CHCB and then died, in another case because the participants care was being adequately managed by local services and the participant felt there were mo additional issues of concern.

The case studies are based on a wide range of data sources including:

- Deliberations and records from the CAG meetings
- All participant assessments (including the Life History and Life Domains)
- Interviews with MS care coordinator about each participant
- Interviews with the participant and, where relevant, the primary carer
- Interviews with the case manager/care coordinator/keyworker for each participant
- Records of funding packages and other funding received by the participant
- Where available, participant records on extra expenses.

The case studies utilise the structure described previously focusing on:

1. Risk identification and amelioration including:
    - Listing the main risks identified in the initial assessment, in the CAG minutes or through discussions with the MS Care Coordinator, the participant or family
    - Strategies implemented within the pilot to ameliorate risk
    - A **judgement** of the likelihood that the intervention of the pilot has prevented admission to residential care during the life of the pilot and/or whether it has materially affected the risk of admission to residential care in the near future.[3]
2. Enabling the service system response including:
    - Issues arising with service providers and/or the way in which the pilot has increased the capacity of services to meet the participants' needs
    - Issues arising with case management services and/or ways in which the pilot has increased the capacity of case managers to met the participants needs
    - Issues arising with funding sources and packages. Ways in which the pilot has sought to address funding gaps and problems including use of brokerage funds
3. Engaging participants and families in preparing for the future:
    - Family issues that have a major impact on the participant's priorities and planning for the future (commonly dependant children)

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[3] NB this is a judgement made by the evaluator and is contestable. It was partly based on 'red flag' statements in the interviews with clients and families or in the considerations of the CAG. 'Red flag' statements include things like 'I don't think I can cope anymore' or 'if s/he requires more night time care we're probably going to have difficulty providing it'. (NB these two examples are generic paraphrases of a range of statements of similar meaning.)

- Ways in which the project engaged the participant in future planning (directly-indirectly, passively-actively)
- Issues affecting the participant’s willingness and ability to engage in planning for the future.

Table 13: Case study summaries for CAG participants

Case No	Basic participant details	Risk identification and amelioration	Enabling the service system response	Client engagement in future planning
1	40s, MS, partner is main carer, requires a very supportive wheelchair **Life domains:** Happy with home life and relationships. Low rating for community participation, individual expression and enjoyment of life. No change	**Risks identified** • Increased care needs including night time care 2-3 x per night • Chronic UTIs (with hosp admissions) • Chronic pain • Depression • Impulsivity (e.g. changing services) • Stress on primary carer **Risk amelioration** • Increased night care • Trialled air mattress (not successful) • Increase day respite • Trial baclofen injections **Risk impact of program:** Very high probability would have required residential admission during or shortly after pilot. Still very high risk	**Services and providers** • Accepts regular respite • Increased night time care to 2-3 times per night but this is difficult to fund • Client felt that finding services is too dependent on chance and 'word of mouth' **Case management** • Former case manager provided services at unsustainable level. Worked with case manager to establish more adequate, sustainable funding • Very complex working out ISP with DHS…"can be like the blind leading the blind" (case manager) **Funding:** • Waiting for a long time on DSR, still no ISP • On another $3,000 package but service provider subsidising by another $9,000/yr	• 3 children, 2 dependent age. Limited participation in the lives of children is a major source of unhappiness • Anxiety about being a burden on family • No formal discussion of future needs with participant. "I don't like to think much about the future. I live life on a day by day basis" (Client)
2	40s, lives with elderly parents, walks without aids and generally independent **Life domains:** Rated highly on all life domains except participation in community and outdoor activities. Small decline in participation in life roles	**Risks identified** • Providing care to parents as well as them providing some care • Some cognitive issues (forgetfulness) **Risk amelioration** • Mostly future planning on options if parents health declines (explore housing options) • Neuropsych assessment **Risk impact of program:** Low risk of placement for participant during pilot but risk of breakdown of overall situation due to parents' health issues.	**Services and providers** • Minimal current needs, focus on monitoring and forward planning **Case management** • Case manager mainly monitoring. Client still quite independent. Asked to DSR which was confident to do after being assisted with process with another participant. **Funding:** Prepared DSR application	• Focus on investigating options if parents health declines further. (Whiteboard exercise) • Client stated that they thought the main purpose of the project was to provide a comprehensive information source re services but that this hadn't really happened
3	40s, very physically dependent **Life domains:** Rated highly on aspects related to relationships and domestic life. Rated between 3 and 5 for	**Risks identified** • Pressure care difficulties, pressure sores, hospitalisations • High risk if partner gets sick **Risk amelioration**	**Services and providers** • Rec **Case management** • On	• 2 adolescent children • Client had no recollection of the trial or the MS care coordinator, partner ha a vague recollection but no

Case No	Basic participant details	Risk identification and amelioration	Enabling the service system response	Client engagement in future planning
	community participation and sense of purpose in life. Client declined to redo life domains questionnaire.	- Revised DSR (participant had banked hours due to hospitalisations) **Risk impact of program:** Hospitalised several times including extended hospitalisation towards end of project. Returned home just after project. Remains at moderate risk due to pressure care needs despite very competent and proactive partner.	**Funding:** On approx $21,000 ISP. Been able to bank hours due to hospitalisations.	details - Partner is protective of home environment and very proactive in organising services
4	40s, lives with partner, mobilises in EC and uses hoist for transfers **Life domains:** Loss and grief issues noted in initial assessment and reflected in life domains with low scores for community participation and life satisfaction. Mood substantially improved at end of trial with life satisfaction scores increased from 2 to 10	**Risks identified** - Frequent severe fatigue - Need for exercise to maintain existing physical capacities - High risk if partner gets sick - Difficulties in relationships with some care providers **Risk amelioration** - Future planning and exploration of options “when things get tough” - Organised some exercise equipment **Risk impact of program:** Not at current risk but will be at moderate risk if physical status declines	**Services and providers** - Care provided by partner and aging parents and parents in law - RDNS 3x per week **Case management** - No case manager **Funding:** On TGA but no funding packages	- 2 adolescent children - Client felt that the opportunity to discuss future options was the main benefit of the trial. Feels more confident.
5	40s, MND, lives with partner and 2 young dependent children **Life domains:** rated low on community participation and activity but still rated very high on life satisfaction, relationships and choice (no follow-up as initial LD not complete till 2 months before end of trial)	**Risks identified** - Extremely high dependency - Respiratory and swallowing issues - High risk if partner is unwell **Risk amelioration** - Most services were in place and respite arrangements in place - Main impact of project was in organising essential equipment **Risk impact of program:** Remains at very high risk particularly if deterioration in respiratory function leads to requirement for a ventilator. Project helped participant and partner be more confident but probably didn’t affect risk level. Will need to train personal care attendants in use of ventilator if the situation arises	**Services and providers** - Client and carer stated that they had a very settled care plan that was working well **Case management** - *Client and carer aware of close collaboration between MS care coordinator and normal case manager **Funding:** Approx $61,000 in packages. Program provided $2025 brokerage for computer (eye gaze typing is only means of communication) and for botox	- 2 very young dependent children - Main concern relates to care and emergency back-up arrangements when he requires a ventilator - Been very helpful to partner just by “understanding and talking…sharing knowledge and experience”.
6	40s, lives with elderly parent. Mobilises in electric WC. Assistance required with all personal care. **Life domains:** Moderate decline in most LDs particularly	**Risks identified** - Very high care needs. Living with aging parent. - Limited finances - Distress about situation with child **Risk amelioration**	**Services and providers** - Client believes has services required and equipment necessary - Has declined respite till a respite option that enables time with child is found	- 1 dependent child. Difficulty obtaining as much access as desired. This is the main concern in the participant’s life.

Case No	Basic participant details	Risk identification and amelioration	Enabling the service system response	Client engagement in future planning
	in relation to participation in activities and enjoyment of life. Substantial declines in perceived ability to raise concerns and express opinions.	- Attempts to arrange respite declined till an option that allows time to be spent with child is found **Risk impact of program:** Remains at very high risk particularly if parent's health or capacity declines. Despite this the project hand a minimal role as participant felt services were adequate and refused respite.	**Case management** - CM said that the project assisted her to arrange extra care around school holiday time and to explore respite options **Funding:** Has around $65,000 in packages	- Primary carer unable to identify ways in which the program helped
7	40s, MS, physically mobile, fatigue and cognitive issues mean can no longer work **Life domains:** Scored high on self care domains but low on enjoyment of life, relationships and control over services. Keeps postponing follow-up interview as shifting house	**Risks identified** - Recovering from being recently widowed - Cognitive issues and decision making - Fatigue affecting ability to work - Lack of strong social supports **Risk amelioration** - Assistance with reorganising living and financial arrangements in view of reduced income **Risk impact of program:** Client and family were at risk of becoming homeless. Project provided a great deal of assistance in working through re-housing process	**Services and providers** - Project organised financial counselling and neuropsych services - Considerable liaison with estate agents and financial organisations **Case management** - CM participated in several CAG meetings and was very involved in supporting participant through processes leading up to re-housing **Funding:** $9,360 package	- 2 adolescent children - Had to work through many issues related to changed financial circumstances and work capacity. Dealing with grief over loss of spouse and lowering of expectations of what can be provided for children - Successfully worked through re-housing
8	40s, cerebral palsy and cervical dysplasia **Life domains:** Scored 7s and 8s for most activity domains indicating that it was very variable depending on pain levels. Scored 9s for items related to choice and self care.	**Risks identified** - Risk of paralysis and/or death from neck - Chronic pain - Fatigue - Some estrangement from family - Anxiety about future of child **Risk amelioration** - Main focus was to increase support levels to minimise exhaustion and the need to do activities that created a risk to neck - Provided considerable support addressing concerns re child - Wait-listed for public housing to reduce financial and overall stress **Risk impact of program:** Client remains at high risk due to exhaustion and pain. Feels that is coping much better with ISP and mind more at ease re arrangements for child.	**Services and providers** - Initially was receiving 7.5 hours from council which was cut to four then to zero when participant received ISP. This was despite very extensive negotiation - Services under ISP working well - Was unable to get funding for any child care services **Case management** - Had to divert funding from package into case management as ISP didn't include CM - CM indicated substantially increased confidence and knowledge after working with MS care coordinator. Previously CM had had conflicting advice about strategies for obtaining ISP. Greatly appreciated assistance with developing the application. **Funding:** Obtained package for less than requested, awaiting revision. Package did not	- School age dependent child - Most future considerations related to care of the child in the event of the participant's death. This involved the MS care coordinator in discussions with schools, guardianship board and adoption services.

Case No	Basic participant details	Risk identification and amelioration	Enabling the service system response	Client engagement in future planning
			include and form of support for child or parenting role or case management.	
9	Main carer is a parent with some health problems **Life domains:** No general trends in changes in LD scores. Generally high scores for home situation and relationships and low scores for community participation.	**Risks identified** • Very high care needs and no package meant participant was at imminent risk of being placed • Equipment problems with wheelchair, mattress and transfer equipment **Risk amelioration** • Progressed and obtained ISP • Organised hospital bed, new wheelchair (with rental chair while waiting) and over-bed hoist **Risk impact of program:** Was at imminent risk of being placed but with support of mother and the project has improved as is currently coping. Remains at risk if mother is unable to maintain same level of support or if condition deteriorates. Client would like to live in a residential facility with spouse.	**Services and providers** • Quite a few problems with service providers initially but now working well **Case management** • DHS planner very appreciative of assistance from the project in planning package • Initially no CM. CM started 3 months before end of project and participated with MS care coordinator in establishing services. **Funding:** Had been in process of application for ISP for a long time. Family had meeting with DHS which initially DHS did not want MS care coordinator to attend. In the end the DHS planner and the MS care coordinator worked very cooperatively in developing package. DHS planner indicated she learnt a great deal from the process. There was quite a few problems getting the services bedded down but participant and carer indicated they are now working well.	• Vey focused on spouse who is in a nursing home with a progressive neurological condition. Client's ideal future option is to live in a residential facility with spouse. • Carer "Once Ngaire [MS care coordinator] came on board it has been wonderful. She took the weight off our shoulders. She is so supportive and has the knowledge of services and what can and cannot be done." • Anxious about process of planning next 12 month package without the assistance from the pilot
10	30s, **Life domains:** Client scored 10s on most life domain questions initially and 8s and 9s at the end of the project. The exceptions were lower scores related to questions of self worth and purpose which scored 4-6.	**Risks identified** • Increasing difficulty with transfers (moved from one to two person transfer, often reluctant to use hoist) • Weight gain and loss of physical condition • Tension in relationships with service providers • Has supra-pubic catheter • Periodic depression • Primary carer in need of medical treatment and respite options not established **Risk amelioration** • Improve processes with care providers and establish problem solving process • Trialled two different respite options. Client loved both of them • Established consistent use of hoist	**Services and providers** • Client and carer reported many problems with carers not arriving, inadequate knowledge and in appropriate attitudes. MS care coordinator worked with CM to establish a process for monitoring and handling problems. Client expressed much greater satisfaction though there are still problems with consistency and knowledge. **Case management** • CM established as the contact point for all issues between family and care providers • Client and carer very confident in case manager "she is young but knows heaps of stuff"	• A priority for the family was establishing respite options to allow the family to continue to provide care • Primary carer feels much more knowledgeable about services

Case No	Basic participant details	Risk identification and amelioration	Enabling the service system response	Client engagement in future planning
		• Commenced process of considering gastric banding **Risk impact of program:** There was an imminent risk of complete breakdown of relationships with care providers due to issues of consistency (from the families side) and of occupational safety from the providers side. This would have required placement. Arrangements are now working satisfactorily. Still has moderately high risk of requiring placement due to increased difficulty of transfers and care due to weight gain and decreased mobility.	**Funding:** Mother self funded a lot of equipment and home renovations. Has a $200,000 ISP	
11	40s, **Life domains:** Scored 10s for most areas except scored 0s for questions related to community participation. Not done at conclusion due to participant fatigue and distress,	**Risks identified** • Extreme carer distress. Indicated that was past coping and needed to place participant • Disillusionment and near break down of relationship with service providers • Inadequate equipment – wheelchair, bed, transfer equipment • Postural related pain in neck **Risk amelioration** • Detailed assessment of all equipment and its use by MS care coordinator and allied health staff. WC, mattress and transfer equipment replaced with some use of brokerage funds to hasten • Increased hours of assistance to include evenings • Lots of discussion and reassurance of primary carer • Training to care providers • DSR application completed and package obtained • Botox injections for pain and spasticity in neck **Risk impact of program:** Would almost certainly have required placement in 2008 without the project. Was in hospital a t end of project and shortly after it was agreed to seek placement. Client is currently awaiting placement in a new group home approximately 3 km from spouse.	**Services and providers** • Initially the participant and carers relationship with care providers was at risk of complete breakdown • Training of care providers, better equipment and decreased stress for primary carer led to a marked improvement in relationships with care providers.) **Case management** • CM stated she was helped enormously by MS care coordinator and now better understands the nature and frequency of assessment required for people with progressive neuro disorders, how to prepare DSR. "She was invaluable to me to help me know what was coming next." **Funding:** $45,000 package at start increased to $49,000 at end. Brokerage money used to assist rapid purchase of new wheelchair.	• Client required hospitalisation for infections issues and postural related pain. Increasing weakness was making care at home increasingly difficult and participant and partner decided to seek placement. • Client and partner assisted to identify best accommodation options near partner
12	40s, lives with spouse and works part time **Life domains:** Scored 8s to 10s for most domains initially and at follow-up. Main exception was 0s for independence in self care. Increased scores of	**Risks identified** • Equipment was inadequate. Wheelchair unsupportive, bed and mattress meant that slept very little ⇨ tiredness and spouse getting up frequently • Spouse needs to travel for work occasionally • Painful spasms in arm • Continence issues	**Services and providers** • Receives few services. Most care provided by spouse though now has some personal care 2 times per week **Case management** • Client does not have a CM and feels the lack of it. Feels that has been "left dangling in the	• Main concerns are that the package hasn't been received and there is no case manager. Feels that the project gave something that has been taken away.

Case No	Basic participant details	Risk identification and amelioration	Enabling the service system response	Client engagement in future planning
	enjoyable activities and community participation – participant attributes these to new wheelchair and car	**Risk amelioration** • Organised night time care services while spouse away • Brokerage funding to fast forward provision of new wheelchair and bed • General CM support provided by MS care coordinator **Risk impact of program:** The night time situation was causing extreme stress to participant and spouse and this has largely been relieved through provision of better equipment. This may well have led to a breakdown of the situation at home.	air with no where to hang onto". That the MS care coordinator filled the gap of not being able to get a case manager and did "all those sorts of little things that have kind of disappeared" **Funding:** DSR completed and awaiting package. $17,700 in brokerage funding used for wheelchair, bed, botox and night support while spouse away	
13	40s, was living in own flat in inner urban area but due to financial issues needed top move in with parents into suburbs. Is able to walk and move about in the community. **Life domains:** Initially scored 0s for most things except for 7s and 8s for participation in making choices. Didn't do LD at follow-up interview as participant extremely distressed and teary about whole life situation and expressing nihilistic thoughts that all of life is awful	**Risks identified** • Cognitive issues affecting ability to implement and maintain services • Ongoing pain and related night time agitation and anxiety • Weight loss and loss of appetite • Social isolation (participant perceives this has worsened markedly since move to suburbs) • Risk of overburdening parents or if parents become ill **Risk amelioration** • Client found attending a pain clinic beneficial but this cannot be provided as an ongoing service • Reviewed pain medications and offered pump for nights. Client refused **Risk impact of program:** Risk is probably higher now than at start of program as participants level of distress has increased and is now producing stress for parents. Program has had little impact on risk as interventions have not been continued by participant.	**Services and providers** • Is not receiving services and has not persisted with services that have been arranged **Case management** • Had a CM when based in inner suburbs but this CM felt that she had limited success due to participants lack of willingness to persist • No current CM **Funding:** Not applicable	• Client unwilling to consider the future, perceives the present as bad enough
14	30s, MS **Life domains:** Initially scored 10s for most domains except 7-9 for items related to participating in the community. Similar results at follow-up but decrease scores re ability to express opinions and be heard.	**Risks identified** • Some services hard to access in area (e.g. continence nurse) • Social isolation • Requirement for catheter **Risk amelioration** • Put on TCGA and DSR • Assisted with some home modifications • Assessed for suprapubic catheter • Assisted to organise required house modifications	**Services and providers** • Client felt that didn't need services at present **Case management** • No local CM • Has been using MS Society for support and a level of case management • Organised private case manager to assist with DSR	• Main benefit reported by carer was opportunity to discuss options for the future and discover a broader range of options and contacts • 2 young children and spouse very concerned to keep participant is as normal a relationship to

Case No	Basic participant details	Risk identification and amelioration	Enabling the service system response	Client engagement in future planning
		Risk impact of program: Both participant and carer had difficulty remembering the MS care coordinator and distinguishing services that were specific to the pilot. Was at low risk in the short-term and remains at low-risk. Spouses willingness to provide care is limited and those aspects of the program that increased the spouses confidence and options probably helped increase this willingness	**Funding:** DSR application prepared	family as possible (not a sick role or dependent relationship)
15	40s, Muscular dystrophy **Life domains:** Lowest scores related to community participation and access to the community. Community participation scores and scores related to personal achievement declined slightly at follow-up.	**Risks identified** • No family supports in Victoria • Deteriorating health (recent chest infections, reducing respiratory function) • Discomfort in bed and poor sleeping • Issues with recruiting carer staff and staff handling skills • Social isolation • Increasing care needs • Wheelchair not appropriate (required chair that can assist standing) • Negative experience of staff handling skills when admitted to hospital • Periodic depression **Risk amelioration** • Organised new wheelchair and provided gap funding from brokerage • Provided more appropriate mattress • Review DSR, include regular health checks by nurse • Case manager encouraged to develop a pack to inform hospital staff re handling requirements for future admissions • Organised trial of respite with partner • Physio developed exercise program to assist respiratory function **Risk impact of program:** The participant's main risks for admission to residential care were respiratory illness and functional decline due to equipment that failed to support mobility and lack of opportunity to get out. These risks were largely addressed and are being more closely monitored.	**Services and providers** • Linkages package cut removing all socialisation components • Regular issues with staff knowledge/skills in manual handling of participant **Case management** • CM was very inactive before pilot and has expressed reluctance to take on some tasks **Funding: Client f**inds funding package very non-responsive. "My circumstances change from day-to-day but if I need to change anything about my package I have to go through a whole process of writing to DHS which takes way too long" Client received brokerage funding for gap in cost of wheelchair and mattress.	• Client feels that the service system has "made me feel like a beggar waiting for handouts" • Client concerned that it takes too long to change services to meet changing needs • Increased monitoring of health status and planning and preparation for hospitalisations • Developed contingency plans for periods of depression
16	40s, Diagnosis still unclear **Life domains:** Scored 9s and 10s for most aspects of well-being and ability to participate	**Risks identified** • History of mental illness, learning difficulties and dysfunctional relationships • Parents are long-term carers but get overwhelmed as more people	**Services and providers** • Has been receiving very few services. • Personal care from council for showering 5 days per week (requires 2 people)	• Adolescent child does not live with participant. Difficulties obtaining access • Parents not coping with

Case No	Basic participant details	Risk identification and amelioration	Enabling the service system response	Client engagement in future planning
	in the community. Scored 7s for most items related to choice and between 2 and 5 for items related to self expression. Didn't change meaningfully at follow-up.	become involved in care. Parents are also aging - Increasing functional difficulties with transfers and swallowing - No case manager **Risk amelioration** - Explored and encouraged respite options (parents initially reluctant) - In home respite for 6 weeks - OT and speech therapy assessments - Assessment of transfer procedures (change guidelines to 2 person transfers) - DSR and 'Making a difference' applications **Risk impact of program:** Client was not at risk of requiring residential care during the trial but parents are at the limit of their ability to cope and the participants condition continues to progress. Client is at major risk if a package and case management are not put in place soon.	- Volunteer was providing outings but withdrew. **Case management** - Has no case manager and parents are overwhelmed by the increasing complexity of care arrangements. - Parents expressed that a case manager was their greatest need - MS care coordinator submitted DSR and application for a 'Making a difference' package to try to get case management **Funding:** Has not received any funding packages and parents carry a lot of costs for equipment, supplies and transport	complexity so commenced processes for getting powers of attorney in place and connecting to Office of Public Advocate - Promoted respite options - DSR application - Critical need for case management as complexity increases
17	40s, (Only seen late in project, April 09) **Life domains:** Follow-up not done as initial LD completed just 2 months before. Scored 10s for everything reflecting extremely up-beat persona.	**Risks identified** - Not linked in with medical specialist support (previous bad experiences have led to great reluctance) - Requires ventilation overnight - Increasing requirements for night time care - Inadequate service hours (incl very limited case management) - Some relationship issues with care providers **Risk amelioration** - Client agreed to see neurologist at CHCB - Assisted in revision of ISP to increase night time care - Recommendations on equipment - Discussed "lots of ideas" with participant (participant makes most of own decisions re care and equipment) **Risk impact of program:** Client is at risk due to night time ventilation and requirements for night time care. Further deterioration of health may lead to requirements for night time care that are difficult to meet.	**Services and providers** - Has Linkages package but this is not nearly covering the cost of services being provided (esp night time care costs). Agency is providing services at a sizeable loss **Case management** - Client very positive about case manager - Case manager concerned that service providers are being overburdened to a level that is not sustainable (both financial and frequency of calls for assistance) - MS care coordinator assisted CM to revise ISP **Funding:** Has an ISP of about $42,000 and linkages package. Contention about how money is used has led to the risk of some of the funds being withdrawn	- Has adolescent child who has some grief, anger and academic performance issues - Client only wants to discuss therapies that maybe curative "I don't want to talk about making life bearable. I want to talk about therapies that may stop the condition progressing) Main aim is to visit the US to trial some therapies available there. - Case manager to do action plan for hospitals in case of admission - Assisted to consider wills
18	40s, lives in a rural city **Life domains:** Never completed	**Risks identified** - Social isolation - Anxiety about the future	**Services and providers** - Receives home help and some carer support for socialisation	- Main benefit reported by the participant was "the opportunity to talk things

Case No	Basic participant details	Risk identification and amelioration	Enabling the service system response	Client engagement in future planning
		Risk amelioration • Made some recommendations to case manager re support and socialisation options • Generally minimal involvement from project **Risk impact of program:** Low risk and minimal involvement by project. Main effect was on participant's confidence.	**Case management** • Case manager confident and participant has very high confidence in CM **Funding:** No packages, case manager to put on TGA	through…made me feel reassured that I have everything in place".
19	40s, **Life domains:** Scored 3-5s for community participation, 6s to 7s for items related to self expression and 9s and a0s for other domains. No meaningful change.	**Risks identified** • Difficulty getting out of bed • Required home modifications (esp bathroom) • Social isolation • Strained relationship with adolescent child **Risk amelioration** • Referred to and attended rehab – "helped with both physiotherapy and the mind" (participant) • Counselling for both participant and adolescent child • Bathroom modifications • Put on TGA and DSR • Referred back to GP for medication **Risk impact of program:** Client was not coping physically or mentally and was at great risk of giving up. Feels much more positive. Possibly would have required residential admission without the project.	**Services and providers** • Main care provider is a parent who was frustrated with pushing participant to get up **Case management** • Client very aware that CM was using MS care coordinator for advice • CM assisted to put participant on TGA and DSR **Funding:** Not on any packages. Brokerage used for counselling, equipment repairs and some transport costs	• Adolescent child who was having difficulties dealing with parents sickness – referred to psychologist • Felt that MS care coordinator helped break an overwhelming situation down into manageable steps "just take baby steps"
20	40s, Lived with spouse **Life domains:** Not assessed	**Risks identified** • Was in hospital with death likely from very early in the project • March to June 08 – functional decline with falls, cognitive difficulties, swallowing issues and continence issues **Risk amelioration** • June to August 08, numerous assessments and plans for home modifications. From September onwards it was recognised that participant would not return home • Numerous services provided while an inpatient in CHCB leading up to death **Risk impact of program:** Died early in life of pilot	**Services and providers** • Most services provided by CHCB including AH and home assessment till Aug 08 and medical and palliative services thereafter **Case management** • Care was coordinated through CHCB **Funding:** Most services provided through CHCB in this period	• Client and partner were supported in efforts to achieve a return home and through the palliative phase

Risk identification and amelioration

The main rationale for the project was to prevent admissions of people under 50 to residential aged care facilities by identifying and addressing issues that put them at risk. This was a major function of the Clinical Advisory Group (CAG). This section looks at:

- The outcomes of the project in terms of admissions averted
- The types and seriousness of risks identified
- The processes employed for risk identification and management (with an emphasis on the role of assessment and of the Clinical Advisory Group).

Outcomes in relation to prevention of admission to residential aged care facilities

No participants in the CCP were admitted to residential aged care facilities during the life of the project although one was admitted to and died in CHCB and two were in hospital at the time of completion of the project.

As part of the development of the case studies each participant was classified in terms of the likelihood that they would have required admission to a residential aged care facility if the program did not exist. For example participants were classified as "would almost certainly have been placed in RAC" if the primary carer expressed a definite intent to cease their role. The results of this classification are presented in Table 14. The column in the centre shows the number of participants classified in the in that way and the case study numbers of those participants (Table 13).

Table 14: Categories of participant outcome in relation to residential aged care placement risk

Category	Num	Justification
Would almost certainly have been placed in RAC if not for project	2 (9, 11)	• Primary care stating that they were at the point of giving up • Care providers withdrawing (complete breakdown in relationship)
Highly probable to have been placed in RAC without project	2 (1, 10)	• Rapidly progressing physical problems (postural, pressure, transfers, respiratory) • Extreme carer stress • Difficulty meeting care requirements (especially night time care)
Substantial risks that may have led to RAC placement during the project period or shortly after	6 (3, 5, 13, 15, 17, 19)	• Carer stress • Inadequate funding or care provision • Inappropriate equipment • Conflict with care providers • Rapid changes in requirements (e.g. transfers)
Probably not at immediate risk but required future planning to address future risk	8	
Died in hospital	1 (20)	

Classification of risks identified

As an outcome of the interim report the CAG was asked to adopt an approach that was more explicitly focused on risk identification and amelioration. To this end a tool was developed that is presented as Attachment C. The risks identified were entered into a database and a full list of risks and associated issues is presented as Attachment D.[4] In addition risks were identified by the evaluator on the basis of:

- The detailed CAG notes
- Interviews with the MS care coordinator
- Interviews with the participants and carers.

The identified risks are presented in the case studies.

Broadly speaking there were two main categories of risk identified by the CAG and by participants and their families:

1. Gradual impact risks – risks that build up over time threatening the ability of the person, their family and the service system to maintain the person at home
2. Immediate impact risks – risks that present an immediate crisis that may cause a person not to be able to remain at home. In some cases these are the accumulated endpoint of the gradually occurring risks

The most common types of risk in each category are listed in Table 15 along with an estimate of the number of people to whom that risk applied and a list of the cases as described in Table 13.

Table 15: Gradual and immediate impact risks for RAC placement

Gradual impact risks	No	Cases
• Carer stress	12	1, 2, 3, 6, 9, 10, 11, 12, 13, 14, 15, 19
• Funding and care provision not keeping up with needs	7	1, 8, 9, 12, 15, 16, 19
• Failure to update equipment as requirements change	7	3, 5, 9, 10, 11, 12, 15
• Cognitive issues leading to erratic decision making and a failure to persist with arrangements[5]	10	1, 2, 3, 6, 7, 10, 11, 13, 16, 17
• Stress on relationships with care agencies	10	3, 4, 7, 8, 9, 10, 11, 13, 15, 16
• Weight gain	2	10, 12
• Financial difficulties	3	7, 15, 16
• Erosion of participants quality of life and emotional well-being	11	1, 3, 4, 6, 7, 8, 10, 11, 13, 15, 19
Immediate impact risks	**No**	**Cases**
• Health problems requiring hospitalisation	7	1, 3, 5, 8, 11, 15, 19
• Pressure problems	6	1, 3, 9, 10, 11, 12
• Requirements for night time care, especially more than once per	6	1, 5, 9, 11, 12, 13,

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[4] Many of the 'risks' identified in Attachment B are really recommended actions while many of the associated issues are actually risks. This is discussed further in the section on processes for risk identification and amelioration (p 65).

[5] NB cognitive issues may relate to brain function or to emotional distress.

night		
• Health problems for the primary carer	7	2, 6, 9, 10, 11, 13, 16
• Serious breakdown in relationships with care agencies	3	10, 11, 13,

One of the recommendations from the Medical Specialists Workshop (p 78) was the specification of list of likely risks and of likely service requirements to guide clinicians, case managers and service planners. The issues identified in Table 15 could be used to guide the development of a risk assessment tool or approach. This could be included in guidelines and resources for case managers as discussed later.

One important risk factor is the rapidity with which equipment needs can change. Some participants required up to three revisions of wheelchair and equipment requirements in the life of the project. If there are long delays in processing equipment requests and obtaining funding people are put at high risk of requiring residential admission due to pressure problems, inability of carers to cope with transfers and care tasks and/or pain. This is discussed further in the section on the service system (p 77).

Risks associated with cognitive issues

The members of the CAG felt that overall the most significant risk factors related to cognitive difficulties experienced by participants. Cognitive difficulties can underpin many of the other difficulties that participants experience including:

- Less than optimal use of services and strained relationships with service providers
- Stress on carers
- Less than optimal participation in self-care
- Inability to participate in future planning.

The term ‘cognitive issues’ covers a broad range of manifestations and causes which are often difficult to distinguish. They may have neurological causes associated with the illness or emotional causes related to grief, guilt and/or depression (see Case Vignette 1). Typically there is a complex interaction of causes. Manifestations include:

- Memory loss,
- Failures of concentration
- Disorders of attention
- Inability to maintain a course of action and/or follow-through on decisions
- Failure of empathy
- Failures of self-monitoring of behaviour and emotional regulation
- Inability to link short term actions with longer term consequences
- Confusion
- Emotional volatility
- Fixated/inflexible beliefs and or aspirations
- Paranoid beliefs.

These issues can cause considerable confusion for family members, service providers, care planners and case managers, particularly when they arise in people with little or no other evidence of disability. It is a critical skill in working with this population group to be able to engage and educate all of these stakeholders about the impact of these issues.

Case vignette 1:

One participant appeared to be high functioning and, apart from fatigue, had little outward evidence of disability. The participant spoke intelligently and had considerable knowledge, awareness and insight in relation to many areas of life. The participant was widowed several years ago and was still experiencing considerable grief. In addition the participant had been unable to maintain work and so had experienced a considerable reduction in income. The participant has 2 adolescent children and is very focused on maintaining as high a quality of life as possible for these children.

Over a period of time the participant was unable to adjust the family's expenditure to fit the new income levels and accumulated debts that meant they would have to find more affordable accommodation. There were numerous faulty decisions evident both in the process of accumulating the debt and in the participant's rigid reluctance to consider any option that may require the family to leave the home. It was clear that grief and guilt played a major role in the decision-making issues demonstrated but it is also likely that these were exacerbated by neurological deficits that affected the participant's capacity to fully understand the situation and think through the implications of decisions.

Project processes and outcomes related to risk identification and amelioration

Two aspects of the project were of particular importance in relation to risk identification and planning an amelioration strategy. These were the assessment process and the Clinical Advisory Group.

Assessment of risk

It was clear from discussions with the MS care coordinator that she identified a large number of risks that had not previously been identified by the service system

- Allowing plenty of time for discussion
- Allowing participants and carers to talk separately to each other
- Physically looking at equipment and watching transfers and care provision tasks.

The role of the specific assessment t protocols that were used, particularly the extended history and the Life Domains assessment, is unclear. It is probable that there main value was in establishing rapport and allowing time for the participant to express concerns. As discussed in the previous section the catalogue of risks identified through this project could be used to develop a specific risk assessment tool.

One issue that was clearly important in the identification of risks was the Care Coordinator's physical examination of the environment and observation of transfers and care tasks. This requires a specific set of skills and has implications for the role of a case manager and core elements of the case management function as discussed later (p 75).

Role of the Clinical Advisory Group

The analysis of the role of the CAG necessarily has largely subjective elements and it is possible that some of the following comments relate to differing tastes in how meetings operate. None-the-less there are concerns related to the function of the CAG, if not for this project, then certainly as a generalisable model. The following comments are based on the evaluator's participation in three CAG meetings, reading all CAG notes and a meeting with CAG staff. Some of the more objective observations were:

- The make up of the CAG was a neurologist the MS care coordinator, the coordinator of residential services from the MS society and two social workers from CHCB
- The meetings frequently involved the participants case-manager (or similar), either in person or the phone. Those who attended reported significant value from their participation

- There was clear evidence of recommendations from the CAG being included in Disability Support Register applications
- The CAG did manage to identify means for meeting most of the needs identified. Sometimes this required a very flexible use of the service system. Reliance on the programs brokerage funds was minimal
- Where participants did not have a previous relationship with Calvary Healthcare Bethlehem the CAG sought to use local services to meet the participants needs. There were four such participants and in general they received far fewer services than the participants who had a previous connection to CHCB.
- The meetings went for a very long time—on occasion for more than 5 hours—this is unlikely to be sustainable in any future model
- The MS care coordinator expressed repeated frustration with her ability to keep the meeting on track

Some of the more subjective and debatable observations were:

- The meeting resisted efforts to impose structure on the discussion. Even after the introduction of the risk reporting and action tool (Attachment A) the tool did not structure discussion. The care coordinator was required to fit a freeform discussion into this structure after the meeting.[6]
- The discussion was frequently based on a great deal of personal involvement with the participant by multiple members of the CAG. It often had the feel of being "Bethlehem-centric". (See note above re participants without previous CHCB contact.)
- The freeform discussion meant that issues which were discussed first were discussed in great length while other issues were rushed through. The lack of structure meant there was a risk of important issues being missed altogether.
- A great deal of discussion was spent on strategies for accessing services. Often it felt more like a "service access advisory group" than a clinical advisory group. This may be an important function but it is not the function outlined in the project plan. This function would also be less necessary if there were more effective processes for developing and implementing DSR applications and ISPs as discussed later (p 76)
- There were frequent occasions when decisions were delayed pending assessment by an occupational therapist or a psychologist. The group may have operated more effectively as a 'clinical' advisory group if it had more multidisciplinary representation including and occupational therapist or physiotherapist and a neuropsychologist or psychologist.

It is difficult to see any role for a CAG, structured as it was for this project, that could be implemented broadly across the state. The CAG discussed options for a more generalisable model and agreed that a model could be developed to provide secondary and tertiary consultation support more along the lines of typical specialist clinic. These options are discussed further in the section on enabling the service system response (p 73). As a step towards this the CAG developed a discharge summary form that could be used as a communications tool for referrals that were made to this specialist service (Attachment E).

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[6] There was disagreement among CAG members as to whether the lack of structure was strength or a weakness. Some CAG members strongly expressed the view that the unstructured approach was necessary to allow adequate exploration of issues and the creative exploration of service options. They argued that this was why the CAG was able to use brokerage funds so sparingly. They recognised that this approach was unable to be sustainable but was important for the pilot as it allowed the detailed analysis of cases and the creation of new learnings about things that affect risk and risk amelioration.

Despite the concerns expressed above the CAG has contributed to developing a pool of knowledge about risks for people with progressive neurological conditions and about service needs.

Some of the positives and negatives of the risk identification and amelioration process are summarised in Table 16.

Table 16: Positives and negatives in risk identification and amelioration

Positives in processes for risk identification and amelioration	Negatives in processes for risk identification and amelioration
• Assessment process that included time and examination of the physical environment and task performance • Creative consideration of options for accessing services • Minimal reliance on brokerage funds • Case managers who attended the CAG found it beneficial	• Extremely time intensive and reliant on local and personal knowledge • Lack of system and structure for CAG meetings meant that some issues may slip through the gaps • Lack of structure of outputs make the outcomes difficult to communicate to others (a tool to enable this was developed late in the project - Attachment E)

The Clinical Advisory Group and the utilisation of brokerage funds

The CAG was judicious and conservative in the expenditure of brokerage funds. In the end it expended approximately $65,000. A substantial proportion of this expenditure occurred late in the pilot when it became clear that the participant had needs that could net be met through other means before the pilot concluded. During the first two thirds of the pilot the CAG expended considerable less than was anticipated due to its success in finding other funding sources.

Table 17 shows a breakdown of brokerage expenditures by participant while Table 18 shows expenditure by purchase type. Equipment purchases accounted for over half of the expenditure. In the majority of cases these were top-up funding to allow the rapid purchase of equipment that would otherwise have been delayed.

Table 17: Brokerage funds spent by participant

Case study Num	Brokerage amount
15	$25,012.80
12	$17,773.30
9	$4,051.00
11	$2,611.41
5	$2,025.00
1	$1,972.27
19	$577.00
10	$523.38
8	$392.85
4	$230.44
2	$0.00

Table 18: Brokerage expenditure by purchase type

Purchase type	Amount
Equipment	$33,800.65
Service gaps	$3,255.00
Medication (botox)	$1,800.00
Allied health	$1,539.80
Respite support	$600.00
Counselling	$470.00
Community access	$407.88
Transport	$346.18*
Client	$230.44
Case management	$202.77
Unspecified	$200.00
Carer support	$191.73
Care staff training	Unspecified*

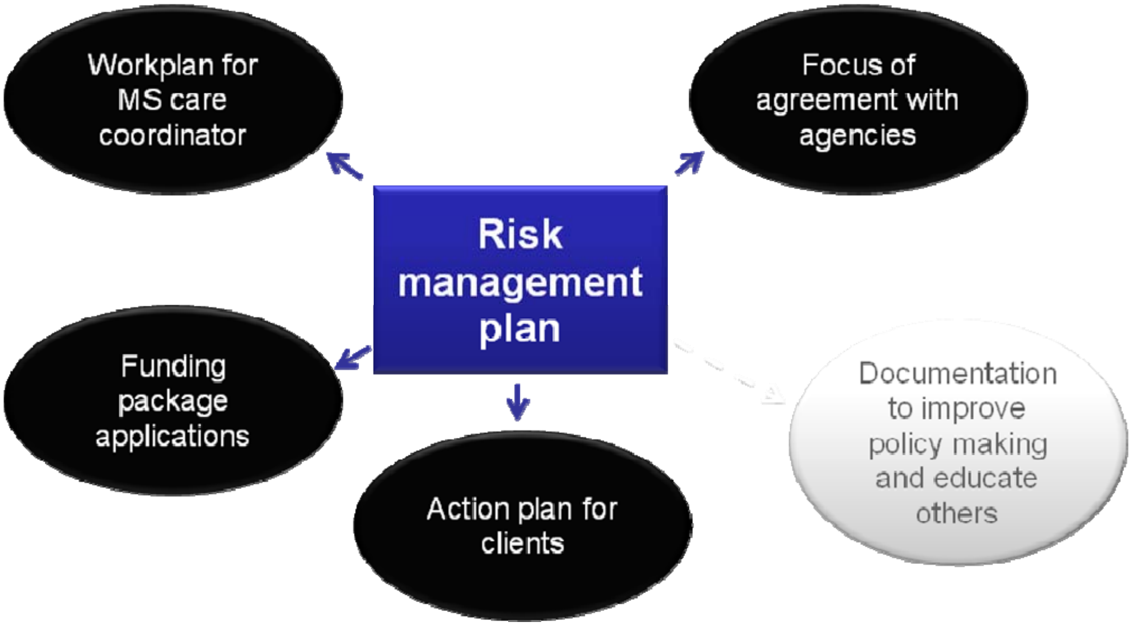
** not all invoices received so costs will change*

Enhancing the value of the CAG role

At the interim evaluation workshop held in December 2008 it was determined that a key strategy for addressing several of the issues identified above could be to ensure that the documentation of the outcomes of the Clinical Advisory Group be structured using a more explicit risk assessment/risk management approach. This would have the advantage for the pilot and evaluation of allowing clearer tracking of the way in which specific risks were ameliorated. In addition it would have benefits for the service delivery model in a number of ways which are highlighted in Figure 8 and which are discussed below.

There was some success in developing a risk assessment tool (Attachment C) and a reporting tool (Attachment E) but these were only starting to be fully implemented as the pilot concluded.

Figure 8: The centrality of a specific CAG risk management plan



Work plan for MS Coordinator:

As has been noted previously, the role of the Specialist Care Coordinator (M care coordinator) in providing secondary consultation support and education to agency care coordinators has been a major success factor in the project to date. This role builds on the guidance provided by the CAG but the value of the CAG input could be enhanced by using a framework that assists the care coordinator demonstrate the relationship between recommendations and the risks that affect this participant group.

Focus of agreement with agencies:

Care coordinators from agencies are invited to attend CAG meetings where their participants are discussed and a number have done so. The value of the CAG input into negotiating care arrangements with agencies could probably be increased, however, through a more specific linking of risk assessment with specific recommended actions and with greater specificity about the services that agencies may be called on to provide.

Action plan for participants:

To date participants have not been given a copy of the plans produced by the CAG. There may be value in providing participants a copy of the action plan in a user friendly format. Potential benefits are: to assist the participant better understand what has been arranged for them; to assist the participant to participate in decision making and in implementation of their plan; and to provide a document that the participant can use t to communicate with service providers.

Funding package applications:

The CAG recommendations have substantially informed the development of DSR applications. This process could be strengthened, however. The CAG is a highly expert group and their recommendations provide a strong basis for identifying current, preventive and likely future service needs.

Improve policy making and educate others:

The insights achieved by the CAG as they seek to plan proactively for future risks have the potential to inform a wide range of other providers and future programs (e.g. case managers, neurologists, DHS staff responsible for allocating packages, advocacy services). These learnings and deliberations were not particularly explicit in the initial form of documentation used by the CAG. In order to make the links between specific identified risks and its recommended actions more explicit Attachment C was developed as an alternative form of documentation. It was felt that this would also facilitate the benefits of the CAG in the other areas identified in Figure 8.

Future planning orientation

Initially the records from the CAG meetings indicated an emphasis on meeting existing needs rather than on future planning. In the issues lists presented to the Clinical Advisory Group in the first half of the project immediate needs outnumber medium term needs by more than 4 to1. At that time the MS care coordinator expressed the view that she felt that next year would be when she could get down to the 'real work' of the project. In the second half of the project there was a significant increase in consideration of future needs, particularly in the last two months of the project as the CAG began to produce discharge plans for participants.

There were been a number of significant areas where there was evidence of consideration of future needs. These include:

1. Circumstances where immediate and medium term needs are the same including:
    - Extreme carer stress where participant is not coping emotionally, logistically or physically
    - Specific barriers to service delivery leading to immediate risk of aged care placement (e.g. lack of hoists or participant refusal to use hoists enabling carers to provide effective care)
2. Staged introduction of respite services which:
    - Assist carers in coping
    - Produce a sense of independence and confidence for participants
3. Focus on educating care coordinators and case managers (as per previous section)
4. Supporting preparation of more appropriate DSR (funding package) applications (as per previous section)
5. Specific work with some participants about issues of future concern including:
    - Care of, and provision for, children
    - Financial planning
    - Powers of attorney.

Conclusions related to risk identification and amelioration

1. The project probably prevented admission to residential care for between 2 and 5 people

2. A number of common risks for requiring residential care were identified. These included immediate impact risks and gradual impact risks. These could form the basis of a risk assessment tool.

3. The assessment processes undertaken in the pilot were effective in identifying risks but the time spent in building rapport an giving participants the opportunity to discuss there concerns as well as observation of the physical environment and tasks were probably more important than the assessment tools.

4. The CAG provided input that was used in developing applications for funding packages and was able to identify creative options for meeting participant's needs. None-the-less there were issues related to the structure and processes of the CAG that may limit its generalisability.

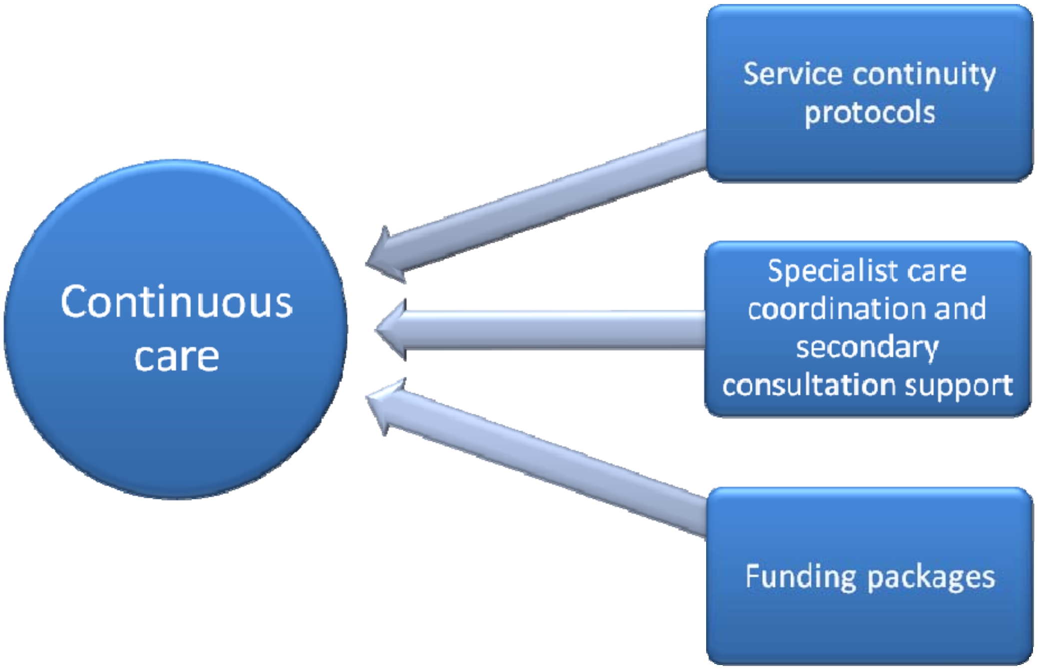
Enabling the service system response

Mechanisms for achieving continuous care

In the initial project design and in the program logic (Figure 6 page 1) the main, innovative means of ensuring continuous care for participants in the face of changing needs related to the development of specific protocols and agreements with agencies, specifically the agreement not to withdraw services if a participant obtained additional services from elsewhere. The project was not successful in obtaining agreement to these protocols. There have, however, been significant improvements in continuous care for a number of participants. These improvements have been achieved through other, more individual, mechanisms.

Figure 9 highlights three mechanisms for achieving continuous care of which, to date, the most important has been the specialist care coordination and secondary consultation role of the MS society care coordinator. These three elements are discussed below.

Figure 9: Three mechanisms for achieving continuous care



Service continuity protocols

The project did not succeed in developing service protocols with agencies. This difficulty has causes which are both internal and external to the project:

Internal reasons:

1. Time priority given to participant assessment and recruitment

2. Skills of MS care coordinator relate to care coordination more than negotiating inter-agency agreements. Lack of clarity about who has responsibility for negotiating agreements.

External reasons:

3. Agencies have been through extensive debates internally re issues about:
    - Fairness of access
    - Servicing many people versus servicing people with very high needs

    and are very reluctant to abandon policies that have already caused significant conflict and distress within the agency
4. Many agencies believe that HACC funding guidelines prohibit them from providing services to participants who are receiving other services and that they risk not receiving payment for these services.

A facilitated workshop held with MS staff and one agency representative discussed these issues and agreed that there was a need to involve DHS in the development of agreements, at least in relation to clarifying HACC guidelines and assuring agencies of funding. DHS provided the required clarifications and the project was able to negotiate the required care arrangements with agencies on an individual basis.

Case vignette 2 illustrates the problems that can occur.

Case vignette 2:

One participant was receiving 7 hours per week of HACC support. When the relevant council was approached to see if this could be extended they decided that this participant was only eligible for 4 hours per week and proposed a schedule for reducing it. In a meeting with the participant and the care coordinator the HACC representative continued to insist on the reduced hours and insisted that the participant set self-management goals for themselves. The HACC representative had no understanding of the fluctuating and progressive nature of the participant’s condition.

This episode led to extensive ongoing correspondence between the MS care coordinator and the relevant council. This correspondence made it clear that the council was working with concepts of disability derived from participant groups who have relatively stable life-long disabilities. The process of negotiation and education is ongoing.

Are service continuity protocols required?

There are two issues that suggest that service continuity protocols may not be the most important consideration in achieving continuous care for people with progressive neurological conditions. The first is that it may be unreasonable to expect agencies to give an open approval for service continuity for a group of participants. It may be more reasonable to establish an openness to service continuity based on consideration and understanding of individual need. There is evidence that willingness to accommodate individuals was achieved within the pilot.

The second issue is that while there were two agencies that attempted to withdraw or reduce services there were other agencies that were funding services to participants at a level far in excess of the funding that they received. There is a willingness on the part of many agencies to do whatever it takes. The issue then becomes one of ensuring that adequate funding is obtained as soon as possible to ensure that these agencies are able to maintain services.

Specialist care coordination, secondary consultation support

Perhaps the most important means of improving continuity of care was the work done by the MS care coordinator with other case managers to provide advice about service planning, service access and applying for funding for participants with progressive neurological disorders.

Case vignette 3:

One participant family was experiencing considerable distress due to the frequent non-arrival of personal care workers, leaving the participant and the primary carer with great difficulties. The participant was receiving personal care services from a number of agencies and when they were notified that a carer would not be attending, were distressed as they rang around trying to get someone to come.

The MS care-coordinator identified that one agency was receiving additional funding to be the overall coordinator of personal care services. An arrangement was made whereby if there were any problems the family would contact this agency. As a result the situation is much improved.

Key features of the Specialist Care Coordinator role included:

- The ability to undertake an assessment that is both comprehensive (as guided by the instruments) and insightful. Both the MS care coordinator and participants expressed the view that the assessment interview had value in allowing people to get things off their chest and to raise issues that they have been reluctant to raise in other situations
- Communicating with the Clinical Advisory Group
- Providing support and guidance to case managers and to DHS staff processing DSR applications
- Educating agencies about the need for preparatory planning for people with progressive neurological conditions
- Advocating for participants and facilitating meetings to resolve issues with service providers.

Funding packages

The rationale for introducing individual disability service funding packages is to allow participants purchase services they require from diverse sources. Most participants on the program are eligible for DHS disability support packages but many were not registered on the Disability Support Register (DSR) or had inappropriate applications completed. Many case-managers in agencies lack knowledge and confidence in how to complete the application for people with progressive neurological conditions. Similarly DHS staff often do not have the knowledge of progressive neurological conditions that is required to assess these applications and undertake service planning. The MS care coordinator has done a considerable amount of work with both agencies and DHS to improve this situation.

Many participants see the hope of obtaining a package as the only real long-term solution to their needs. The central role of packages in this project needs to be more fully recognised. The input from the Clinical Advisory Group has the potential to be particularly valuable in the process of developing packages.

Among participants who already had a package they were often not the solution hoped for. Issues that were identified by participants, carers and case managers included:

- Packages less than requested and inadequate to meet needs
- No funding for quality of life support (e.g. carers for outings)

- Lack of flexibility (need to fill in paperwork to change services, unable to redirect funds from one purpose to another)
- Poor service planning
- Unavailability of services
- No funding for activities involved in raising dependent children or other support for families and carers.

The issue of funding for support in the parenting role is discussed in the section on 'Participants role with dependent children' (p 83).

Case vignette 4:

One participant had been involved in a consultation and advisory group[7] prior to the introduction of the Disability Act 2006. The focus of this group had been to inform the development of ISPs. This participant felt that few of the recommendations of the group had been implemented.

"Overall I think that people with physical disabilities were better off under the old Act. The arrangements under this Act just require too muck paperwork and take too long to be flexible."

This participant also felt that ISPs rarely paid attention to lifestyle requirements and were focused on supports necessary for survival. (See recommendation 6 in the footnote below). Overall this participant felt that few of the recommendations of the group have been adequately implemented.

Many other participants, carers and case managers expressed similar concerns.

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[7] This group was called the 'Individualised Planning and Support Advisory Group'. It produced a final report in August 2006. Recommendations were:

1. That all planning is individualised and directed by the person with a disability.
2. That independent and peer advocacy support should be readily available to a person with a disability when they want or need it.
3. That risk management in terms of the personal choices of individuals is about the consideration, not the elimination of risk.
4. That funding principles and processes should be clarified with the aim of:
   - Reducing inconsistent decision making on what is funded
   - Streamlining the approval process and
   - Increasing the timeliness and responsiveness of the approval process.
5. That the Department of Human Services develops a comprehensive and sustainable learning and development strategy regarding IP&S that targets people with a disability, family members and carers, facilitators and disability specific support providers and considers both short and long term learning and development needs and goals.
6. Promote to people with a disability and their families the ideas and possibilities of individualised lifestyles and how these can be achieved.
7. Ensure more widespread understanding and implementation of the goals and objectives of the State Disability Plan, including the IP&S approach.
   That disability support providers reorientate their services and supports to reflect the goals and objectives of the State Disability Plan.
8. That the Department of Human Services and disability support providers seek opportunities and links beyond traditional disability services in order to build the capacity of the community to be inclusive of people with a disability.
9. That firstly, feedback is routinely sought from people with a disability on planning processes, services and supports and secondly, that information about processes for people to make complaints or raise concerns about planning or support provision is freely available.

Four key service development needs

Consideration of the areas of project success as well as the difficulties it has faced suggest that there are four key areas where service development needs to occur:

1. Access to quality, supported case management
2. Rapid and appropriate development and implementation of funding packages
3. Rapid access to equipment
4. Greater access to night-time care services.

Access to quality, supported case management

There was wide variation in the experience and approaches of people taking on a case-management role for participants of the project. This had little relationship to the severity of the participant's illness or the complexity of their need. This variation is illustrated by the four descriptions in Table 19.

Table 19: Variability in case management arrangements and performance

Case manager	Issues arising
CM with no prior experience of progressive neurological conditions and main experience with developmental disabilities	• Had attempted DSR application largely guided by rumours about how it is best to work the system • Developed 2 DSRs with support of the MS care coordinator and now feels confident she could do this on her own or could find the information and assistance required • Reports a much greater understanding of the needs of this population group and in particular an appreciation of how rapidly needs can change
CM with approx 25% caseload of progressive neurological and remainder aged care	• Confident in assessing need and developing DSR application • Appreciated input from MS care coordinator especially regarding service options
Key worked from a chronic disease management program in Community Health	• Official responsibility really limited to role with Community Health Services • Accepted a broader case management role including preparation of a DSR application with assistance of the MS care coordinator • Confident she could do this again or access required advice
Case manager funded for >$3,000/yr to provide case management	• Functioning only as a point of contact within the organisation the CM was part of • No overall care-planning or liaison with other agencies

This variability indicates a critical need to rationalise and organise the provision of case management services to this participant group. The instances described also indicate the value of having access to specialist advice when required.

At a minimum the experiences of the project suggest that it is necessary to:

1. Define criteria for when people with progressive neurological conditions should receive case-management and establish processes to ensure hat they have access to funded case management
2. Develop a set of performance criteria for case management services to this population. These should include:
    a. Requirements for initial assessment
    b. Frequency of contact and formal review
    c. Requirement for a comprehensive, multi-agency approach
    d. Specification of role in preparing applications for funding packages and in service planning
3. Develop an additional set of guidelines, resources and tools to assist case managers meet these criteria
4. Establish a means for case managers to obtain specialised advice related to clinical issues, care planning and service options
5. Ensure that the people responsible for assessing DSR applications and planning packages either have knowledge of progressive neurological conditions or have access to advice to assist them.

There are a number of possible options for achieving these outcomes. One option is to fund a support and training function within an appropriate organisation (e.g. MS Society). Another option would be to tender out the provision of case management services for this participant population and require tendering agencies to provide a certain level of expertise, training and support.

Rapid and appropriate development and implementation of funding packages

At the commencement of the project very few of the participants had funding packages that were adequate to their needs. Several were on Linkages packages that had become inadequate—in two cases these were being subsidised to a very great extent by the agencies that managed the package. This was considered unsustainable by the agencies.

A major activity of the program has been preparing or revising DSR applications for participants. As discussed in the previous section this had been a difficulty for many case managers due to lack of experience with people with progressive neurological conditions. Lack of clinical knowledge of this population group also created difficulties for the DHS staff responsible for assessing them and for planning services. As a result, for a substantial proportion of participants, the process had not progressed. There were also cases where applications had been submitted that did not match the participants requirements based on rumours about the best tactical way to go about getting a package as quickly as possible. These rumours included 'start small so you get a foot in the door then submit a revision' as well as 'put in everything possible and you may get some of it'. One of the significant achievements of the program was to significantly progress the process of applying for and implementing Individual Support Packages for many participants. Key achievements in this area were:

a. Completing DSR applications that had not been progressed
b. Building Understanding, skill and confidence in the process with a number of case-managers to the point where several of them expressed in interview that they now feel comfortable to undertake the process (NB they also indicated that they would still ring the MS Society for advice)
c. Assisting at least one DHS person to better understand the needs of people with progressive neurological conditions

d. Regularly submitting DSR reviews when the participants' needs changed (e.g. one participant had an initial DSR application and two reviews submitted in the life of the project).

The need for regular revision of funding packages reflects the rapidity of change that can occur in this population. This distinguishes this population from most other groups of people who are applying for packages and the system has had very limited success in responding. Despite the program's success in ensuring adequate and up-to-date applications most of the participants have not, as yet received packages. This delay may be tenable with people whose disabilities are relatively stable but puts people with progressive conditions at great risk of requiring admission to residential care.

This problem has been recognised for people with Motor Neurone Disease and the Motor Neurone Disease Association of Victoria has access to six packages that it can use to manage short-term needs of people with MND. While the condition of people with MS and other progressive neurological conditions may not progress as quickly as people with MND, sometimes it does. The 'clinical specialists workshop' (see below, p 78) strongly recommended that the MND model be extended to include other progressive neurological conditions.

Rapid access to equipment

In Table 15 it was noted that seven clients had substantial risks associated with faulty or inadequate equipment. A further five clients had some equipment related needs.

One of the major findings of the Neurological Complex Care Project (NCCP), a project on which the CCP was largely based, was that,

> *Equipment issues are the most significant contributor to high service activity for people with PNDs and place participants at risk of admission to acute hospitals and residential care.*

The NCCP found that participants waited for up to 10 months for equipment. For some participants in the CCP they had required three modifications to their equipment within 10 months. For this population equipment issues are critical and, if not addressed, can lead to the rapid need for hospitalisation and/or residential care placement. Equipment related risks that were seen in CCP participants included:

- Primary carer and care services unable to safely transfer participant and/or complete care tasks (sometimes this has led to the threat to withdraw services)
- Pressure problems
- Serious postural problems and associated pain and/or feeding difficulties
- Insomnia and related ill-health
- Lack of ability to leave the home.

In this project equipment needs were usually able to be met through partial funding from available sources and partial funding through the projects brokerage funds. It is critical, however, that some mechanism to allow the rapid provision of, and upgrading of equipment is established. Equipment funding programs need also to be aware of how rapidly equipment needs can change in this population and how serious the effects can be.

(See also discussion of night related equipment in the following section.)

Greater access to night-time care services

In Table 15 it was noted that six clients had substantial risks associated with requirements for night time care (by the primary carer or other services). A further four clients had some night-care related needs.

One of the issues that was most difficult for families, service providers and the CAG to address was when participants required care at night time especially where this care was required more than once per night. The three main reasons why this was required were:

a. Pressure care and pain
b. Toileting and continence issues
c. Insomnia and associated restlessness.

Provision of night care is not only expensive but is often not available more than once per night. The project was successful in arranging twice nightly care for one participant. In other cases it was necessary for the primary carer and family members to provide the required care and in some cases this was a cause of significant stress. Increasing night-time care needs pose an imminent threat to a person's ability to remain at home.

A number of participants had problems with equipment related to their night time arrangements that was inadequate, these included:

a. Pressure mattresses that were inadequate or not functioning
b. Inadequate equipment to assist transfers
c. Uncomfortable beds (e.g. too narrow, insecure leading to a fear of falling out).

The project was able to address these leading to substantial improvements in the participants' and families' ability to cope at night. All three of the cases that were classified as 'Highly probable to have been placed in RAC without project' (Table 14, p 62) had significant night-time care issues that were met through the project.

Clinical specialists forum

As part of the project Dr Susan Mathers, the neurologist on the CAG, convened a meeting of neurologists, rehabilitationists and other clinical specialists who work primarily with people with progressive neurological conditions. Dr Mather's notes from the meeting are attached as Attachment C.

One of the recommendations of the forum was to propose the development of a 'clinical hub model' of providing care similar to the model that has been developed and trialled for Motor Neurone Disease. The purpose of this model is to:

a. Provide ongoing specialist care rather than episodic care
b. Ensure that clinical care is integrated with and informs all other aspects of care.

The functions of the specialist 'hub' are illustrated in Figure 10 [8]

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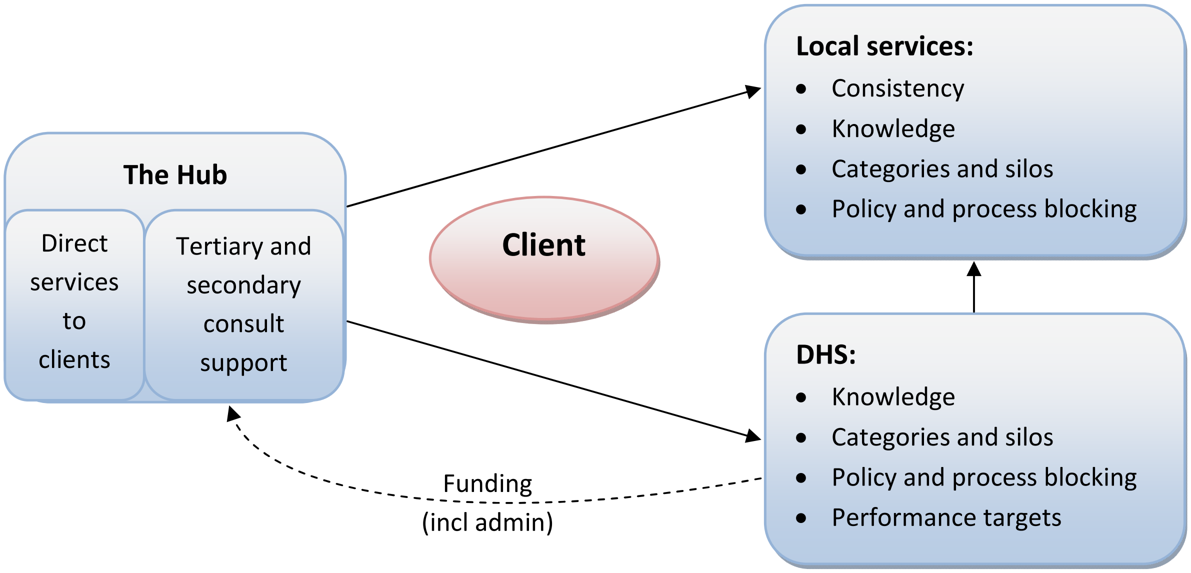
[8] NB this diagram illustrates functions but not the organisational arrangements by which these functions can be achieved. The work undertaken by the Motor Neurone Disease Association of Victoria, *Collaborative Care in Motor Neurone Disease in Victoria* (Draft Report, Dec 2008) presents detailed organisational models for the operations of a central hub and for regional services. This model is equally applicable to other progressive neurological conditions and, indeed, the regional component could be a single service for all progressive neurological conditions supported by a defined number of specialist clinical hubs.

Figure 10: Specialist hub role in supporting decision making by local service providers and DHS



Recommendations arising from the forum

The following are the agreed recommendations arising from the forum:

1. Set-up and resource a working party, with an agreed representative membership, to advise DHS on a ‘Continuous Care Model’ for people with long-term and progressive neurological conditions, in Victoria. The purpose of the model is to address:
   - equity of access to services and funding
   - prioritising of need
   - delivering specialist input to care at a distance – outreach models of care
   - case-coordination and information sharing

2. Define -
   a. criteria for admission to a program of ‘continuous care’
   b. clinical profiles of the diagnostic groups of patients likely to benefit from this model of care
   c. how an individual might transition through a Neuro-Palliative Rehabilitation model of continuous care

3. Seek support and endorsement of this initiative from
   a. Professional bodies (ANZAN, Chapters of Rehabilitation Medicine and Palliative Care, The Royal Australian College of Physicians, Australian Nursing Federation, Allied Health Professional Groups)
   b. Seek input and endorsement from Neurological Organisations and Patient support groups.
   c. Involve State and Commonwealth Government bodies to highlight need for a national focus
4. Seek to achieve recognition and integration within other State and Commonwealth Government initiatives that are seeking to provide continuous, boundary-free care for people with chronic conditions. Specifically the Hospital Admission Risk Program (which currently does not consider neurological conditions) and the Health Independence Program.

Education to service providers

The Continuous Care Pilot build upon a previous project called the Neurological Complex Care Project (NCCP)[9] which was conducted in the northern suburbs of Melbourne. One of the major achievements of the NCCP was to undertake a training needs analysis and develop a training package for health professionals and direct care workers. The training provided attendees with an understanding of key concepts in the aetiology, pathology, progression and management of progressive neurological conditions. The CCP endorses the value of this training but also recognised the need to provide more intensive, skill oriented support and development particularly to those that have a case management role with people with progressive neurological disorders.

There is little doubt that the most successful means of building capability and confidence in case managers was the opportunity that they had to work alongside the MS care coordinator on tasks which included:

- Assessment
- Monitoring and review
- Preparing DSR applications
- Identifying available services
- Problem solving and negotiation with services.

One critical issue for training and mentoring was assisting case managers, service providers and families to understand the cognitive issues that were occurring with participants.

The project also offered two formal training sessions to service providers. One of the key purposes of these sessions was to help attendees understand the differences in working with people with progressive conditions and to this end the training focused on a risk assessment and management approach using the tool in Attachment A. The training was very highly evaluated by participants.

Bringing together models of service delivery for people with progressive neurological conditions

The discussion in this section referred to two other studies that have explored the needs of people with progressive neurological conditions and systemic approaches to better meeting those needs. The first of these was the Neurological and Complex Care Project (NCCP) in the northern suburbs and the second was the Motor Neurone Disease model developed by Motor Neurone Disease Victoria and Calvary Healthcare Bethlehem[10]. This projects focused on somewhat different aspects of the service system and together they suggest an integrated model for service delivery for people with progressive neurological conditions. It is worth noting that while the NCCP noted that people with MND and Huntington's Disease have greater care needs on average than people with MS that this is not always the case. Many people with MS reach a phase in their illness where their needs are just as great and their progression just as rapid as those conditions which are more typically associated with rapid progression. Thus the needs of people with MND, late stage MS and Huntington's Disease have much in common.

Table 20 lists some of the main findings of each project. Taken together they indicate the need for a multilevel training and secondary support process. The MND project suggests a structure for delivering these services using a combination of statewide, disease specific hubs and regional 'neurology hubs'. The NPCC and this study flesh out what these services would need to achieve.

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[9] Foulsum, M. 2007. *The Neurological Complex Care Project – Final report*

[10] Source is *Collaborative Care in Motor Neurone Disease in Victoria – Draft interim report.*

Table 20: Complementary findings of the NPCC, CCP and MND model

Study	Main focus	Key findings and products
NPCC	Community services (emphasis on community health and HACC)	• Successful training package for care providers • Demonstrated value of key workers • Importance of rapid access to allied health especially occupational therapy and neuropsychology • Critical importance of rapid access to equipment
This study (CCP)	Community services and specialist planning	• Importance of high quality case management for all people with advanced disease • Role of specialist secondary consult support for case management and service planning • Framework for assessing risk • Again, access to allied health and equipment • Need for more flexible funding packages • Need to support people responsible for planning packages for people with progressive neurological conditions • Need for improved access to night time care • Need to consider needs of families with dependent children
MND model	Specialist support services	• Disease specific hubs providing assessment and tele-consultation support for all of Victoria • Regional hubs providing assessment and secondary consultation support across all progressive neurological diseases

Participant engagement in future planning

One of the key aims of the project was to engage people with progressive neurological conditions in thinking about, and planning for future needs. This was re-emphasised in the program logic workshop where one of the main outcomes was identified need for greater consumer knowledge of services and empowerment in dealing with service providers. The workshop also identified, however, that there may be participants who don't really want to think about the future for a variety of reasons.

Some of the issues related to the projects 'future orientation' were discussed in the section on Risk Identification and amelioration (p 70). This section considers specifically the ways in which participants and their families were involved in decision making in the project and specifically how they were engaged in consideration of future needs. This section has three main subsections:

1. Engagement of participants and their families in the project
2. Issues affecting engagement in future planning
3. The participants' role as parents of dependent children (and its affect on their approach to future planning)
4. Turning 50.

In relation to the third of these points, approximately half of the participants in the pilot were parents of dependent children and this fact was the dominant issue in much of their decision-making and certainly in their consideration of the future. This fact is logical when we consider the age group of the target population but it was not anticipated in the project population and it is not an issue that is widely considered in policy documents or, indeed, in the literature.

Engagement of participants and their families in the project

All participants and the family members and carers that were interviewed were asked about their awareness of the project and their understanding of what the project was about. The outcomes of these questions were:

- There was generally poor understanding of what the project was about (3 participants and 5 carers could give a general statement that it was about planning for the future)
- For most participants the project was Ngaire (the MS care coordinator)
- Most participants aware of collaboration between Ngaire and their case manager
- Only three had any knowledge of the CAG and none received any formal feedback.

Most participants indicated that they have so many people involved in their lives and that there are so many different programs and services that it is very difficult to distinguish them.

Issues affecting engagement in future planning

All participants and the family members and carers that were interviewed were asked if the MS care coordinator had assisted them to think about and plan for the future in any way. The three most common response were:

a. that the care coordinator had made them aware of more options

b. that a range of issues that had been of concern were now sorted out so that they felt more confident about the future (typically this was arrangements with service providers and/or equipment)
c. they had too much on their mind or were too anxious to think about the future.

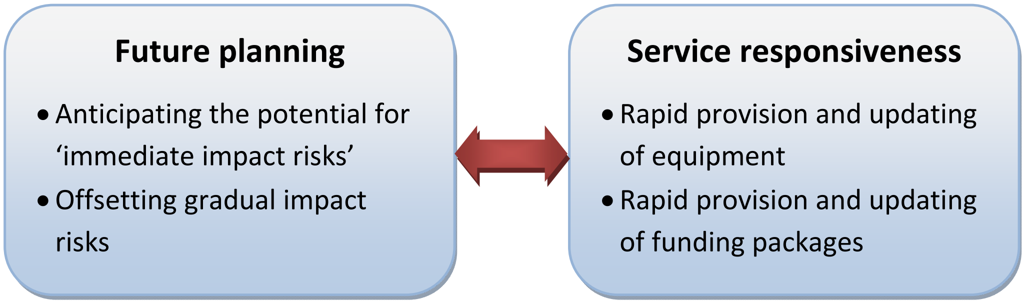
There were a number of participants who appeared not to have the cognitive capacity to think about the future. At the other end of the spectrum there were high functioning participants who just wanted information and were confident that they would be able to get their needs met when the time arose.

A number of participants expressed considerable scepticism about the willingness and capacity of services to respond to changes in their needs.

One of the areas where carers in particular (but often participants as well) recognised the need to take action today to prevent future problems was in the area of respite for the carer. Several had dealt with issues of resistance from the participant and/or previous bad experiences with respite. The CAG and the MS care coordinator put considerable effort into assisting participants find respite options that were acceptable to them.

Maximising the participant's ability to deal with circumstances that may arise in the future requires two main approaches. Prior identification of risks and mitigation of risks where possible is one component but of equal importance is ensuring that the service system is adequately responsive when needs change in ways that are unpredictable or only partly predictable. You may know that someone is likely to need a more supportive wheelchair at some stage but the prescription of the chair can only occur once the persons specific needs are known, forward planning can only go so far. (See Figure 11)

Figure 11: Two pillars of preparedness for the future



The participants role as parents of dependent children

Eleven of the20 participants had dependent aged children (in 2 cases they did not have custody and had limited access). In these cases concerns about the current and future needs of children were a priority concern that framed the whole way in which the participant thought about future planning. There were a range of common problems in relationships with children including:

- Guilt and concern about being a burden
- Guilt, anxiety and resentment in children
- Some behavioural issues in children
- Constant involvement (intrusion) of other people in the household and in the relationship
- Fear that status as a parent has been lost

- Concern for the child's future in the event of the participant's death or admission to residential care
- Inability to holiday with children.

Several participants had sought to have services related to their parenting role included in funding packages and every case they had been unsuccessful. As one participant stated, "this really gives the lie to all the rhetoric surrounding the Disability Act and ISPs."

The pilot provided varied assistance to participants with children. Support provided included:

- Funding counselling with brokerage funds
- Liaison with schools
- Organising child care respite
- Seeking to identify respite options that would allow participant to spend time with child
- Liaising with guardianship and adoption agencies
- Lots of time spent talking and providing emotional support.

It is clear that the target group for this project is also a group that is highly likely to have parental responsibilities and all programs and services provided to this group must formally recognise and support this role.

Turning 50

A number of participants expressed concern that there options and the range of services available to them would be reduced when they turned 50. There was also evidence of this concern in the CAG that sought to get a number of measures in place before the participant turned 50. Eight participants will still have young teenage children when they turn 50 and one participant will still have children in primary school.

It is clear that the age 50 as a definition of 'young', for the purposes of service planning, is absurd. Among the pilot participants there were people in their early 40s who had more sever cognitive decline and were further adapted to a 'sick role' than many of the people who were 48 and 49. Chronological age had no relationship at all to service needs or the type of respite and/or accommodation that participants would require.

Conclusions and recommendations

The purpose of this section is to draw together and summarise conclusions that have, for the most part, been presented earlier in the document. The results are presented in three sections.

The first section focuses on Table 21, which revisits Table 10 which presented a list of evaluation questions derived from each element in the program logic (Figure 6). Table 21 presents conclusions in relation to each of these evaluation questions.

The second section summarises the most important conclusions from the evaluation. It attempts to give a sense of priority that is not present in Table 21 and also presents conclusions related to issues not covered in the program logic.

The third section presents recommendations. There are two groups of recommendations: recommendations that were derived from, or have been endorsed by the 'Interpretation and recommendations workshop' and recommendations that are suggestions offered by the evaluator but which have no status beyond this. These are clearly distinguished.

Table 21: Conclusions related to program logic elements and associated evaluation questions

Program logic elements	**Evaluation questions**	**Conclusions**
Clients receive services guided by the following principles: *General questions are: How, and to what extent, were these principles realised in practice? What processes and decisions show this?*		
The aim of securing and maintaining comprehensive, needs based service delivery	• Is there evidence of changes in service provision in response to identified need?	• The most important vehicle for securing comprehensive needs based services are individual service packages. The initiated or updated applications for many participants • There are extensive delays in the awarding of packages. This is extremely problematic in a participant group whose needs change rapidly and who may die before packages are actually awarded. While waiting for packages the project was able to assemble adequate interim care arrangements and funding. In some cases this involved using brokerage funds from the project. In all cases it was a resource intensive and expensive process that occupied a great deal of staff time
Continuity of existing services as new services are introduced	• Have agreements for service continuity been established with service providers? • Have services always been maintained when new services were introduced where this was appropriate in terms of participant need?	• There were no documented agreements however there were clarifications of definitions of terms and of HACC funding guidelines that allowed services to be continued in individual cases. There were also individual cases where agreement was made to continue services beyond organisation guidelines • There were several cases were organisations were providing services and filling gaps at a level far in excess of the funding they were receiving. This is not sustainable and indicates a need to be able to allocate adequate funding packages more quickly
Partnership with the participant in determining the need for services	• To what extent and in what ways were participants involved in determining there need for services? • How were they involved in dealing with circumstances where desired services were unavailable?	• Critical elements in assisting participants identify needed services were: o Allowing plenty of time for discussion o Allowing participants and carers to talk separately to each other o Looking at equipment, watching transfers o Being aware that participants may not always have perfect insight and may have difficulties with decision making and adhering to decisions

PROGRAM LOGIC ELEMENTS	EVALUATION QUESTIONS	CONCLUSIONS
		o Being aware that participant's may have adapted with unrealistically low expectations or may have unrealistically high expectations • Partnership with participants could have been strengthened by a clearer written explanation of the purpose of the project and by providing feedback from CAG meetings
Focused on allowing people to remain in their homes as long as possible	• How was the need for services that enable people to remain at home defined in practice (e.g. narrowly or broadly, preventively or reactively)? • Do service providers take this into account in prioritisation?	• The project had a broad focus on the issues that affect a person's ability to remain at home. It identified and addressed both short and medium term risks • There were two participants who would almost certainly have required RAC admissions if it weren't for the project and another two where RAC admission may have been required
Individual and carers/family are treated as 'the participant'	• What evidence is there that carer/family needs were considered and addressed?	• The CAG records consistently note issues related to carers and carer concerns. The need to prevent carer burnout was a major forward planning issue • Where there was a carer they consistently reported significant involvement with the project care coordinator, in many cases more involvement that reported by the participant • Experience with the initial assessment was that participants and carers were sometimes reluctant to speak completely openly in front of each other and that additional concerns were identified when they were given the opportunity to talk to the care coordinator alone
Enhancing the function of the whole service network (short term - coordination, long tem – workforce)	• What service development needs were identified through discussions and negotiation with service providers? • What service coordination needs were identified? • What solutions, including, training were put in place to meet these needs?	(See discussions in the body of the report) • The most important service development needs were universal access to high quality, streamlined provision of individual funding packages, rapid access to aids and equipment and improved availability of night-time care • The achievement of appropriate case management requires the provision of additional guidance and support to case managers. These should probably include: o Development of a set of minimum requirements for case management of people with progressive neurological conditions

PROGRAM LOGIC ELEMENTS	**EVALUATION QUESTIONS**	**CONCLUSIONS**
		o Assessment guidelines and guidelines for developing and reviewing applications for funding packages o A secondary consultation support service for advice on clinical issues and service availability • The expected issue of services wanting to withdraw when new services were introduced was an issue for a small number of participants however there were an equal number of cases where services were providing more care than they were funded for
These services/interventions include: *General questions are: Were these services/interventions implemented? How? Was the implementation effective?*		
Detailed participatory assessment (a 'case history' as described in the project proposal)	• Was the assessment truly 'participatory'? • Did it cover all domains important to participants? • Did it meet the needs of the CAG to support their care planning role?	• See notes related to partnership with the participant above • Clients report that the time spent in the assessment enabled many of them to raise issues they hadn't raised with others
Active, specialist case coordination and linkages	• What was the role of the project officer and the CAG in care planning and care coordination? • Were they able to organise additional services for participants?	• The case management and care coordination available to participants prior to the project was very variable and seemingly unrelated to need. • The support offered to case managers by the MS care coordinator was a critical success factor with may participants and built confidence in the case managers • Many additional services were organised for participants
Provision of 'step-up services'. (Adding additional services as the participant's condition requires without losing access to existing services. Requires shared protocols and appropriate financial packages)	• What additional services were provided to participants during the period of the trial? • Was this always achieved without causing cessation of other services? • What changes in procedures or other arrangements did service providers need to put in place to allow this to	• The project was not successful in obtaining agreement to service continuity protocols for the population but was, in nearly all cases, successful in obtaining needed services through negotiation on individual cases • The importance of obtaining appropriate funding packages as a means of ensuring adequate service provision was emphasised

PROGRAM LOGIC ELEMENTS	EVALUATION QUESTIONS	CONCLUSIONS
	happen? • What financial packages are available and what are the barriers to accessing them? Have these been overcome?	
A 'predictive, proactive' approach to case coordination guided by a team of experts (the 'Clinical Advisory Group')	• What 'predictive' decisions were made by the CAG? On what basis? • Did the CAG have the information required to make predictive/proactive decisions? • How were these decisions discussed with participants? • How did they impact on service arrangements that were put in place?	• The CAG's initial emphasis was on meeting backlog of unmet need • The CAG identified a range of risk issues that have an affect on a person's ability to be care for at home, these include both immediate and gradual impact issues • Participants varied greatly in their willingness to think about future needs
Some brokerage funds	• For what purposes were brokerage funds expended? • What was the reason this was required (e.g. services unavailable? Ineligible? delayed?)	• The project was conservative and targeted in the use of brokerage funds. Wherever possible funds were obtained from other sources and brokerage funds were used to supplement these funds. • The project spent substantially less brokerage money than was budgeted for • It is not necessary to have a large pool of brokerage funs to operate this project
Support to service providers (training, liaison, sharing info)	• What needs were identified in order to enhance the ability of service providers to meet participants needs? What was done to address these needs?	• Support provided to case managers and other service providers by the MS care coordinator was the most critical success factor in the project • The training events were well received but it is doubtful that they would have engendered the same level as confidence as was achieved by the case managers who had the opportunity to work collaboratively with the MS care coodinator
Which it is expected will lead to the following interrelated causal processes: *General questions are: To what extent did these key causal mechanisms actually occur? Was the effect string enough to produce the hoped for participant outcomes?*		
Anticipatory identification of	• Were there any new services initiated	• See discussion of the predictive/proactive approach above

PROGRAM LOGIC ELEMENTS	EVALUATION QUESTIONS	CONCLUSIONS
needs leading to the very timely introduction of services including preventive and maintenance services	immediately as a result of the assessment and the CAGs considerations? • Were any advance arrangements made with service providers to streamline participants' access to services should the need arise?	
A more comprehensive range of services and greater continuity of service provision	• As previous plus… • Were new services added without impacting on existing services?	• As discussed above
Greater participant and family involvement and understanding of the services being provided and more active participation with these services. More positive and confidence enhancing experiences.	• Do participants and their families have increased knowledge about services or know who to ask if they need services? • Have their experiences with a) seeking to access new services, and b) the dependability and appropriateness of services improved?	• Clients are generally more satisfied with the services they are receiving but are generally not more confident about their ability to access services in general • Some participants reported that problems they had been having with service providers have improved or
Increased information about services available to participants and other service providers	• As previous plus… • Do service providers have an increased understanding of others services and what is needed to access them ? • Do service providers have an understanding of their role as part of a suite of services that may be necessary o support a person at home?	• As discussed above
Early identification of, and response (at participant's choice) to, issues that put a person at risk of requiring an	• Do participants have provisional action plans and pre-arranged service plans in case of medical deterioration or other events that put them at risk?	• As discussed above

PROGRAM LOGIC ELEMENTS	**EVALUATION QUESTIONS**	**CONCLUSIONS**
aged placement	• Have long-term threats to the sustainability of a participants position at home been identified and plans made to accommodate them (e.g. carer fatigue or health issues)	
Which, in turn, it is expected will lead to the following beneficial participant outcomes: *General questions are: To what extent and in what ways did consumers and their primary carers experience these benefits?*		
Needs are identified and met in a timely manner	• Are new needs identified through the initial participant assessment and CAG? Were these able to be responded to immediately? • Were mechanisms established to identify and respond to newly arising needs?	• Initially a backlog of unmet need was identified and addressed • There were substantial difficulties meeting equipment needs in a timely manner. In a number of cases equipment was partially funded with brokerage funds to hasten provision • The MS care coordinator had regular contact with all participants and identified changes in care needs rapidly (e.g. one participant had three wheelchair modifications, participants had changes made to transferring arrangements, packages were revised to accommodate the need for 2 person transfers)
Greater knowledge of and confidence in the service system and greater ability to access and use services	• Do participants and carers have increased confidence in a) their ability to access needed services and b) the dependability and quality of these services?	• As discussed above
Increased use of respite options (and satisfaction with respite experiences)	• Did participants use residential or day respite services during the project? • Were these new? • How satisfied were the participants and family/carer with respite arrangements?	• Several participants utilised respite options that they had not used before. Results were generally positive. One participant developed strong friendships and regularly visits people she met in respite
Greater participation in maintenance and preventive services	• Were needs and opportunities for maintenance and preventive services identified in the assessments? Were	• The need for physiotherapy services was identified with many participants but there was difficulty accessing services in an ongoing way. This was particularly significant in the case of one participant with chronic pain who

PROGRAM LOGIC ELEMENTS	**EVALUATION QUESTIONS**	**CONCLUSIONS**
	these addressed? - To what extent did the CAG consider these types of need in their considerations? - Were participants and carers willing to participate in these? Were there specific barriers that hindered participation?	benefited from physio but was unable to access it regularly
Early and more appropriate response to risks and deterioration (partially insight and future thinking, partially mechanisms for reacting to changes in circumstances)	- Do participants have provisional action plans and pre-arranged service plans in case of medical deterioration or other events that put them at risk? Were these enacted for any participants? - Were there events that jeopardised the persons ability to stay at home? How were these solved? How confident were the participant and family that they would be able to find a solution?	- As discussed above - < The discharge plans being prepared by the CAG members are intended to function as provisional action plans > - Attempts were made with most participants to engage them in explicit forward planning but many participants were reluctant either because they saw the future as negative or because they were having difficulty getting current needs met
Rapid (re)establishment of services after hospitalisation	- If participants were admitted to hospital, was there any delay in return home due to delays in (re)establishing required services? - Were service providers satisfied with the level of communication/notification they received when a participant was in hospital? - Did participants who were admitted to hospital require new services at discharge? Were these able to be put	- Several participants had lengthy hospitalisations and a number of participants were admitted to CHCB for a period following discharge from other hospitals. The fact that CHCB acts as a buffer between the acute hospital and discharge to home is an element of the context in which the program took place that may not apply in all regions - Potentially preventable causes of hospitalisation were pressure sores and respiratory problems

PROGRAM LOGIC ELEMENTS	**EVALUATION QUESTIONS**	**CONCLUSIONS**
	in place?	
Which, ultimately lead to: *General questions are: Is there any evidence of these outcomes within the time frame of the trial?*		
Greater physical and psychological well-being of participants and their families	• Has participants satisfaction with critical life domains and their sense of ell-being and of being in control of their life changed (similarly for family/carers)	• The life domains tool did not show improvements, largely because participants scored themselves highly in many areas at the start of the project indicating that considerable adjustment of their expectations had already taken place • Client and family interviews
Less need for participants to be admitted to aged care facilities	*NB the question of whether there is a reduction in admissions is unanswerable given the timeframe and size of the pilot* • Do participants and carers feel that their arrangements for maintaining the participant at home are more secure? • Were there any events where an admission to residential care was likely but was averted? • Were there any events where an admission to residential care occurred but could have been averted with more adequate service provision?	• No participants were admitted to RAC during the life of the project although 2 died in hospital and another 2 were in hospital at the completion of the project (return to home is expected in both cases) • There were two participants who would almost certainly have required RAC admissions if it weren't for the project and another two where RAC admission was likely to have been required • Specific risks that may lead to the need for RAC admission were identified in 16 participants

Summary Conclusions

This section highlights the most important conclusions drawn previously in the report.

C1. The CCP almost certainly prevented between 2 and 5 admissions to residential aged care during its period of operation

C2. The CCP has already achieved other substantial benefits for a number of participants. These included:

   a. Resolving problems with service providers
   b. Accessing additional or more appropriate services
   c. Accessing larger and more adequate funding packages
   d. Identifying and resolving outstanding equipment issues
   e. Establishing respite arrangements that were more acceptable to participants
   f. Increasing confidence due to the knowledge that the MS care coordinator was available to contact

C3. A number of common risks for requiring residential care were identified. These included immediate impact risks and gradual impact risks.

   a. Immediate impact risks included:
      i. Health problems requiring hospitalisation
      ii. Pressure problems
      iii. Requirements for night time care, especially more than once per night
      iv. Health problems for the primary carer
      v. Serious breakdown in relationships with care agencies
   b. Gradual impact risks included:
      i. Carer stress
      ii. Funding and care provision not keeping up with needs
      iii. Failure to update equipment as requirements change
      iv. Cognitive issues leading to erratic decision making and a failure to persist with arrangements (this was considered to be a contributing factor to many of the other risks in most participants)
      v. Stress on relationships with care agencies
      vi. Weight gain
      vii. Financial difficulties
      viii. Erosion of participants quality of life and emotional well-being

C4. The assessment processes undertaken in the pilot were effective in identifying risks but the time spent in building rapport an giving participants the opportunity to discuss there concerns as well as observation of the physical environment and tasks were probably more important than the assessment tools.

C5. The CAG provided input that was used in developing applications for funding packages and was able to identify creative options for meeting participant's needs. None-the-less there were issues related to the structure and processes of the CAG that may limit its generalisability.

C6. The most important aspect in achieving these outcomes has been the role of the Specialist Care Coordinator. This role has been supported by the CAG but other additional features of the role have been:

A. The depth of assessment that has been undertaken and the open nature of the assessment
B. The secondary consult role taken by the Specialist Care Coordinator
C. Supporting the development and submission of appropriate applications for individual funding packages.

C7. Case management services provided to people with progressive neurological disorders are extremely variable and this variation does not relate to need or complexity. Means to improve access to a consistent standard of case management need to be developed. This will probably include access to a secondary consult support service.

C8. The project did not succeed in establishing *service continuity protocols* with agencies. It did, however, succeed in negotiating to maintain adequate service levels on a case-by-case basis in all but one case. Clarifications provided by DHS assisted in this.

C9. There are a number of reasons why agencies were reluctant to commit to maintenance of care and thus to *service continuity protocols*. These include:

A. A history of long-fought policy development within individual agencies that prioritises services that can be delivered to many participants over services that are provided intensively to a few
B. In some cases, the belief that continuing services with a participant who commences additional services elsewhere would constitute a breach of their funding agreement
C. In some cases, the belief that a neurological disease is not a disability
D. In most cases, service providers are more used to working with participants with relatively stable, life-long disabilities and have difficulty understanding the needs of those whose disabilities may progress rapidly.

(Clarifications by DHS in relation to point ‘b’ assisted in resolving this issue.)

C10. Brokerage funding has been expended judiciously and usually as a supplement to other funding sources. In many cases alternative funding sources have been found. This suggests that only a modest brokerage capacity is required as part of the model which bodes well for sustainability.

C11. A major focus has been on the development of submissions for individual packages through the Disability Services Register. This has required considerable support to both the case managers who were preparing the application and the DHS staff processing it. These applications have been informed and strengthened by input from the CAG.

C12. There were a number of problems identified with individual service packages (ISPs):

A. They take a long time to obtain by which time needs have often changed
B. The people responsible for planning the package are often unfamiliar with the needs of people with progressive neurological conditions and find the process difficult
C. The packages are inflexible. Modification of how money is expended requires a time consuming written process.
D. Packages usually don’t provide support to ‘lifestyle’ needs
E. Packages don’t support recipients’ parenting role and responsibilities.

C13. Many people in the target group are parents of dependent age children and there is a lack of services, information and support options for this role.

Recommendations

Please not these recommendations are opinions of the evaluator and, while they have been discussed in workshops with key stakeholders, they have no official status as views of the MS Society and Calvary Bethlehem.

These recommendations are grouped into two categories recommendations for service delivery and recommendations for future research and development.

Recommendations for service delivery

R1. A system for providing quality case management to all people with progressive neurological conditions who meet a certain threshold of need should be established. This system will need to:

1. Define criteria for when people with progressive neurological conditions should receive case-management and establish processes to ensure hat they have access to funded case management
2. Develop a set of performance criteria for case management services to this population. These should include:
    a. Requirements for initial assessment
    b. Frequency of contact and formal review
    c. Requirement for a comprehensive, multi-agency approach
    d. Specification of role in preparing applications for funding packages and in service planning
3. Develop an additional set of guidelines, resources and tools to assist case managers meet these criteria
4. Establish a means for case managers to obtain specialised advice related to clinical issues, care planning and service options
5. Ensure that the people responsible for assessing DSR applications and planning packages either have knowledge of progressive neurological conditions or have access to advice to assist them.

R2. The recommendations arising from the development of the Motor Neurone Disease (MND) model should be implemented and broadened to include all progressive neurological diseases. Indicative roles for the two levels of hubs are:

A. Disease specific hubs providing services to the whole state:
    a. Providing a tertiary consultation service including tele-consults
    b. Developing guidelines and standards for service delivery
    c. Research
    d. Advocacy
B. Regional hubs covering all progressive neurological conditions:
    a. Responsibility for implementing training including the NPCC training package and also training, mentoring and secondary support to case managers

   b. Offering general secondary consultation support especially around service issues
   c. Holding a number of service packages that can be used in whole or in part to meet emergency needs
   d. Holding a modest pool of additional brokerage funds
   e. Participating in the development of service packages
   f. Coordinating linkages between health and community services
   g. Service planning in the region.

R3. Processes to improve the timeliness, quality and flexibility of individual support packages need to be developed, these processes should include:

   a. Mechanisms for providing advice to those responsible for making decisions about and planning packages
   b. More uniform access to case management and empowering of case managers or the designated package manager to quickly redirect funds
   c. Guidelines that allow the use of funds to support recipients in their parenting roles and responsibilities where these apply

R4. Consider means to increase the potential and speed of access to aids and equipment programs and night time care programs

R5. The 50 year age limit should be abandoned for all services and programs where it applies. It serves no function for the community and merely serves to hide need and window-dress government programs.

Recommendations for future research and development

R6. A major forum should be held involving relevant medical specialties and organisations involved in advocacy and community service delivery for people with progressive neurological conditions. This forum should seek to build on and broaden the work undertaken in the development of the MND model and elaborate the role and requirements for statewide specialist hubs and regional hubs as described in recommendation R2. The forum should consider the outcomes of the NPCC, the CCP and the Motor Neurone Disease model and seek to achieve an integration as discussed on p 81 (see particularly Table 20).

R7. Out of this forum a progressive neurological consortium should be established under the auspices of the Australian and New Zealand Association of Neurologists, the Royal Australasian College of Physicians and related bodies. This consortium should have a leading role in:

1. Defining common risks and standard care requirements
2. Defining standards for care provision including case management
3. Advising governments on policy and program development
4. Seeking means to achieve closer collaboration between the health and community services sectors

R8. A major project should be funded to investigate the needs of people with neurological conditions who are parents of dependent children and the needs of these children. The terms of reference should include the development of guidelines for incorporation of the needs of parents and children in funding packages.

Attachments

Attachment A: Life Domains assessment tool

Attachment B: Life History assessment tool

Attachment C: Clinical risk reporting and action tool for Clinical Advisory Group

Attachment D: CAG identified risk and associated issues

Attachment E: CAG discharge summary form

Attachment F: Noted from the Clinical Specialists Forum

Attachment A: Life Domains assessment tool

Section 1: What I do

NAME:

DATE:

LIFE DOMAINS

	Disagree As strongly as possible					**Unsure**					**Agree** As strongly as possible
1. Culture											
• I am able to participate in communities of interests e.g. church, football	0	1	2	3	4	5	6	7	8	9	10
• I feel that I can maintain my cultural i.e. interests & beliefs	0	1	2	3	4	5	6	7	8	9	10
• I am still able to express my individuality	0	1	2	3	4	5	6	7	8	9	10
2. Enjoyment in life											
• I spend my time doing things I enjoy	0	1	2	3	4	5	6	7	8	9	10
• In general, I enjoy my days	0	1	2	3	4	5	6	7	8	9	10

NAME: **DATE:**

LIFE DOMAINS

	Disagree As strongly as possible		**Unsure**		**Agree** As strongly as possible

3. Moving around

• I am still able to attend activities & events in the community	0 1 2 3 4 5 6 7 8 9 10
• I am able to access amenities in the community	0 1 2 3 4 5 6 7 8 9 10
• I can spend time out of doors	0 1 2 3 4 5 6 7 8 9 10

Are there any barriers that stop you from getting out and about

4. How to live

• I still feel that I am achieving things in my life	0 1 2 3 4 5 6 7 8 9 10
• I feel that I participate in my life roles	0 1 2 3 4 5 6 7 8 9 10
• I feel I have purpose in my life & a reason to get up	0 1 2 3 4 5 6 7 8 9 10

NAME:	**DATE:**				
LIFE DOMAINS					
	Disagree As strongly as possible		**Unsure**		**Agree** As strongly as possible
Do you perceive that there are barriers that may stop you from realising your goals?					
5. Doing valued work					
• I am still able to contribute skills in paid employment • I feel I can share my skills & ideas • I see work as important?	0 1 2 3 4 5 6 7 8 9 10 0 1 2 3 4 5 6 7 8 9 10 0 1 2 3 4 5 6 7 8 9 10				
6. Always learning					
• I am able to learn new things • I want to develop personally • I see learning / study as important	0 1 2 3 4 5 6 7 8 9 10 0 1 2 3 4 5 6 7 8 9 10 0 1 2 3 4 5 6 7 8 9 10				

NAME:			**DATE:**		
LIFE DOMAINS					
	Disagree As strongly as possible		**Unsure**		**Agree** As strongly as possible

Are there any other issues in your life to do with the things you do and how you spend your time?

(e.g. Things that get in the way of you doing the things you like. Things you'd like to do that you don't get to do)

Section 2: Relationships

NAME: **DATE:**

LIFE DOMAINS

	Disagree As strongly as possible					**Unsure**					**Agree** As strongly as possible
7. Building relationships											
• I have a good relationship with my family & friends	0	1	2	3	4	5	6	7	8	9	10
• I feel I can still contribute to relationships	0	1	2	3	4	5	6	7	8	9	10
• I still feel I can assist people	0	1	2	3	4	5	6	7	8	9	10
8. Communicating											
• I feel free to voice my opinion and raise concerns	0	1	2	3	4	5	6	7	8	9	10
• I feel my interests, experience and opinion are valued	0	1	2	3	4	5	6	7	8	9	10
• I feel I have a say in everyday decision	0	1	2	3	4	5	6	7	8	9	10
• I am able to make choices and decisions	0	1	2	3	4	5	6	7	8	9	10
• I get to say what I want or need to say, to those around me	0	1	2	3	4	5	6	7	8	9	10

NAME:			**DATE:**		
LIFE DOMAINS					
	Disagree As strongly as possible		**Unsure**		**Agree** As strongly as possible

9. Being part of a community											
• I participate in community activities & events	0	1	2	3	4	5	6	7	8	9	10
• I feel I have remained connected to my communities	0	1	2	3	4	5	6	7	8	9	10
• I feel involved in my interests and activities	0	1	2	3	4	5	6	7	8	9	10
• I still feel I have the energy for community involvement	0	1	2	3	4	5	6	7	8	9	10
• I feel I have good support to into the community and stay involved	0	1	2	3	4	5	6	7	8	9	10

Are there any other issues in your life to do with relationships with other people or with the community?

Section 3: Living arrangements

NAME: **DATE:**

LIFE DOMAINS

	Disagree As strongly as possible				**Unsure**				**Agree** As strongly as possible		
10. Where to live											
- I can still have a choice where I live	0	1	2	3	4	5	6	7	8	9	10
- I feel safe and secure where I live	0	1	2	3	4	5	6	7	8	9	10
- I enjoy my environment	0	1	2	3	4	5	6	7	8	9	10
Are there changes you would like to consider to your current living arrangement?											
11. Paying for things											
- I have sufficient money to fund my interests/lifestyle	0	1	2	3	4	5	6	7	8	9	10
- I make choices & decisions about my money	0	1	2	3	4	5	6	7	8	9	10

NAME:						**DATE:**				

LIFE DOMAINS

	Disagree As strongly as possible		**Unsure**		**Agree** As strongly as possible

Do you manage your own money? If not, do you want to?

12. Being safe											
- I am able to enjoy my home	0	1	2	3	4	5	6	7	8	9	10
- I still feel it is my home	0	1	2	3	4	5	6	7	8	9	10
- I feel involved in my interests and activities	0	1	2	3	4	5	6	7	8	9	10
- I feel secure in my surrounds	0	1	2	3	4	5	6	7	8	9	10
- I still feel safe moving about in the community independent or assisted.	0	1	2	3	4	5	6	7	8	9	10

Do you have any concerns about your safety?

Are there any other issues to do with your living arrangements?

Section 4: Choice and self-direction

NAME:	**DATE:**
LIFE DOMAINS	
	Disagree As strongly as possible **Unsure** **Agree** As strongly as possible
13. Looking after self	
• I take control of my physical health & wellbeing i.e. exercise program, choice of healthy foods	0 1 2 3 4 5 6 7 8 9 10
• I take control of my emotional health i.e. share feelings	0 1 2 3 4 5 6 7 8 9 10
• I take control of my spiritual health i.e. find purpose	0 1 2 3 4 5 6 7 8 9 10
• I take control of my social health i.e. networks & friends	
Are there any changes you would like to consider to improve your well being?	
13b Looking after self – control and self determination	
• I am still included in choice & decisions about most aspects of my life	0 1 2 3 4 5 6 7 8 9 10
• I am able to look after myself	0 1 2 3 4 5 6 7 8 9 10
• I feel I am seen as an individual	0 1 2 3 4 5 6 7 8 9 10
• I still feel I have a degree of independence	0 1 2 3 4 5 6 7 8 9 10

NAME:	**DATE:**				
LIFE DOMAINS					
	Disagree As strongly as possible		**Unsure**		**Agree** As strongly as possible
Do you feel you have a level of partnership with people in your health management?					

14. Choosing support	
I feel I choose the services I need	0 1 2 3 4 5 6 7 8 9 10
I still feel I am involved in who provides my care	0 1 2 3 4 5 6 7 8 9 10
I still feel I choose when to have the support	0 1 2 3 4 5 6 7 8 9 10
I feel I choose where I receive the supports	0 1 2 3 4 5 6 7 8 9 10

Are there any other issues in your life to do with your ability to make choices about your life and look after yourself?

Attachment B: Life History assessment tool

Name:

Early Life: Primary school

Your memories of school in your young years, likes, dislikes, interests

Early Life: Secondary School

Your memories of adolescent years; likes, dislikes, interests, achievements

Name:

Tertiary Education / Employment

How would describe your tertiary education and or first experience in paid work.?

What did you enjoy in your studies?

What were your achievements and or difficulties?

What employment have you, or are you involved in?. What did / does employment offer you?

Select no more than 3 issues that were prominent at this time in your life

- ☐ Social Isolation
- ☐ Relationship issues
- ☐ Financial issues
- ☐ Employment issues
- ☐ Motivation issues
- ☐ Loss / grief /anger
- ☐ Pain
- ☐ Fatigue
- ☐ Anxiety
- ☐ Communication

Continuous Care Pilot: Evaluation progress report

Name:

First Symptoms, Date of Diagnosis, Age *Brief account of the situation at this time i.e. place of residence, studying, working, in a relationship etc* *Need for informal or formal supports or services in this time i.e. family, partner, counselling, neurological organisation (information)*	Select no more than 3 issues that were prominent at this time in your life ☐ Social Isolation ☐ Relationship issues ☐ Financial issues ☐ Employment issues ☐ Motivation issues ☐ Loss / grief /anger ☐ Pain ☐ Fatigue ☐ Anxiety ☐ Communication

Name:

Major exacerbation: physical and emotional impact on you, your family and significant others

Brief account of the situation at this time i.e. place of residence, studying, working, in a relationship etc

Need for informal or formal supports or services in this time i.e. family, partner, counselling, neurological organisation (information)

Select no more than 3 issues that were prominent at this time in your life

☐ Social Isolation
☐ Relationship issues
☐ Financial issues
☐ Employment issues
☐ Motivation issues
☐ Loss / grief /anger
☐ Pain
☐ Fatigue
☐ Anxiety
☐ Communication

Name:

Memory of change in your role;- Impact on employment, tertiary education, family, household, significant others	Select no more than 3 issues that were prominent at this time in your life ☐ Social Isolation ☐ Relationship issues ☐ Financial issues ☐ Employment issues ☐ Motivation issues ☐ Loss / grief /anger ☐ Pain ☐ Fatigue ☐ Anxiety ☐ Communication

Name:

## Memory of Change in Status:- requiring someone to do for or need to access external assistance Impact: • Family, significant others • Place of abode • Relationships • Employment • Community connectedness • Physical, social and emotional being Services: Need for informal or formal supports or services. what, when, who, why, how long, challenges, benefits etc)	Select no more than 3 issues that were prominent at this time in your life ☐ Social Isolation ☐ Relationship issues ☐ Financial issues ☐ Employment issues ☐ Motivation issues ☐ Loss / grief /anger ☐ Pain ☐ Fatigue ☐ Anxiety ☐ Communication

Name:

First Admission:

- Hospital
- Respite
- Relocation of residence

- *Impact on social, emotional and physical being of you, your family and significant others.*
- *Need for informal or formal supports or services. what, when, who, why, how long, challenges, benefits etc)*

Select no more than 3 issues that were prominent at this time in your life

☐ Social Isolation
☐ Relationship issues
☐ Financial issues
☐ Employment issues
☐ Motivation issues
☐ Loss / grief /anger
☐ Pain
☐ Fatigue
☐ Anxiety
☐ Communication

Name:

Last 6 months; • What are the difficulties you have been experiencing in the last 6 months • What has been put in place to support you and your family (explore all the questions around services, what, when, who, why, how long, challenges, benefits etc)	Select no more than 3 issues that were prominent at this time in your life ☐ Social Isolation ☐ Relationship issues ☐ Financial issues ☐ Employment issues ☐ Motivation issues ☐ Loss / grief /anger ☐ Pain ☐ Fatigue ☐ Anxiety ☐ Communication

Attachment C: Clinical risk reporting and action tool for Clinical Advisory Group

Client: ___________________________________ **Date:** __________________

Risk	**Likelihood/severity/ timeframe**
1.	
2.	
3.	
4.	

Risk 1: ____

Immediate issues affecting risk	Recommended actions	Who responsible

Contingency arrangements should risk eventuate	Who responsible

Risk 2: ____

Immediate issues affecting risk	Recommended actions	Who responsible

Immediate issues affecting risk	Recommended actions	Who responsible

Contingency arrangements should risk eventuate	Who responsible

Risk 3: ____

Immediate issues affecting risk	Recommended actions	Who responsible

Contingency arrangements should risk eventuate	Who responsible

Risk 4: ____

Immediate issues affecting risk	Recommended actions	Who responsible

Contingency arrangements should risk eventuate	Who responsible

Attachment D: CAG identified risks and associated issues

CAG identified risk	Issues affecting risk
Air mattress overlay and bed frame need review	
Application for brokerage funding	• Request for brokerage funding to support primary carer to have holiday while participant in respite • Request to brokerage for cooling vest as participant unable to regulate temperature when in community • Request to brokerage to fund foam blocks to assist participant remain in position thru night
Apply for linkages package/DSR	
At risk of loss of home	Has moved home with elderly parents for support
Bathroom modifications	
Bathroom modifications	Assessment of bathroom by OT, funding request to VA&EO
Botox injection	
Carer shifts not full in place yet	
Case mgr linked to linkages package - limited CM hours available due to case load	
Consider supra-pubic catheter	• Incontinence - wears continence aids • Risks to participants and carers when changing continence aids - repeated hoisting and stretching to assist turning
Constant pressure area break down - risk of hospitalisation	
Continence	Recurrent UTIs and incontinence issues
Current mannual wheelchair needs replacing	Wheelchair not supporting upper body adequately
Current wheelchair needs review	
Current wheelchair needs review	
Dehydration	
Dehydration	
Dehydration	
Deteriorating health	• At risk of chest infections • Discomfort while in bed • Client in MMC with pneumonia last year. Found that acute hosp staff do not know how to hoist or assist participants with disabilities • Client has no family support in Victoria, all friends have disabilities. Only support is partner.
DSR need to be updated	
DSR review	Check when DSR review last done
DSR review	ISP doesn't cover all mornings and evenings
Emergency plan	
Employment	
Employment	

CAG identified risk	Issues affecting risk
Excessive spending of Moira funds	
Facing legal action	
Fear of infection	
Finances	
Finances	
Financial assistance for sons school needs	
Financial hardship	
Financial issues/hardship	Expenditure 3 times more than income
Funding doesn't cover needs adequately	Access Southern substantially supplementing needs
Funding doesn't cover needs adequately	Funds don't cover overnight care. Nightline and RDNS needed to reposition participant
Future planning	
Future planning	
Future planning	
Future planning	
Future planning	Where does participant see themselves if anything happens to parents?
Future planning (e.g. Trusts)	
Hair washing	
Hair washing	
High levels of anxiety	• Pain • Concern about what the future may bring and loss of independence
House mate- someone to be around overnight	
House modifications	
House modifications	Requires passage and bathroom modifications for WC accessibility
Independently living at home with full care package, at risk of failing	
Isolated	
Isolation	• Can only access community when pain levels are low • Reliant on others for transport • Unable to socialise, focus is on pain only
Isolation	• Unable to speak, uses eye gaze computer • Limited social network though large family network
ISP does not adequately cover increased needs	• Offer of ISP 19/12/08 in planning stages - shortage 2 hrs • ISP planner to forward plan to panel for extra hours • Many instances where chosen service provider not reliable
Lack of resources in LGA	
Lack of resources in LGA	Lack of expertise in complex catheter management
Linkages package	
Loss of home	
Loss of home	Unable to pay mortgage due to limited income

CAG identified risk	Issues affecting risk
Medication review and change	
Medium	
Mini exercise cycle / stretching exercises	
Neck deteriorating	
Neck deteriorating	Lack of neck and trunk control
Need carer controls for new power wheelchair	Client having difficulty negotiating uneven surfaces in the community. Need carer controls that can be used from back of chair.
Needs stretching exercises to remain flexible	
Needs stretching exercises to remain flexible	
Needs to be on TGA & DSR	
Neuropsych assessment	
Neuros psych assessment	
Night management/bed mobility/ assessment of bed, mattress, air mattress overlay	Nightline does not cover area
Not known to staff at CHCB	
Ongoing pain	• Medication needs review • High levels of anxiety increase pain • Unable to get enough sleep/rest
OT assessment	
Pain issues/pain clinic	• Unclear of current status of pain issues • Client enjoyed stretching exercises from physio at pain clinic (now ceased)
PEG	Relies on wife to monitor this and set it up
Physio assessment	
Physio assessment	
Primary carer requires break	• To prevent primary carer burn out, carer going away for 4 weeks • Client and primary carer do not know what staff are attending shifts • Service providers still experiencing problems filling shifts
Recurrent funds for respite	Requires top-up in home respite funding to relieve husband of burden
Reduced fluid intake	
Relationship issues	
Relationship issues	• Spouse uncomfortable with carer role • Pressure on family if has to stop driving
Relationship issues	
Requesting extra care to support with recovery after health issues	
Requesting extra health care to support with recovery after health issues	
Requires emergency plan	
Requiring assessment of	• Currently using manual hoist for all transfers, assessment for ceiling hoist • Single bed too small, gives participant sore back and feels at risk of rolling

CAG identified risk	Issues affecting risk
equipment at home	out - Unable to use mattress overlay, too noisy
Residential respite information	
Review and update exercises - staff training	
Review of carer rosters	Manual handling assessed as 2 person job
Rights of access to son	
Shortage of carer staff	- Service provider having difficulty recruiting staff - Client is physically fragile, feels carers are too rough
Shoulder pain	
Social isolation	Reliant on carers to drive van - time constraints and funding for employment of carers for this purpose
Socially isolated	
Socially isolated	
Socially isolated	- Can't leave house due to unsteadiness - Lives in isolated area - Fatigue - Neighbours houses are not wheelchair friendly - Fear of infection
Some services less than person centred	
Some services provided to the participant are less than person centred	
Son frustrated	
Son frustrated	- Client reports son is angry and has bought punching bag - he doesn't know why he is angry - Meeting of clinical psych with participant and son and with son. Son said was positive
SPC care	
Stress on family at home	
Stresses at having to ask cleaner to do tasks	
Support needs increased	- Requiring Night Life every night, sometimes 2-3 times - Service provider funding extra care. Service provider applied for ISP, advised could get $5000 support and choice package but unwilling to accept small package as may be detrimental to ISP app - Client impulsivity causing concern (e.g. Ringing VA&EP to change orders on equipment ordered by OT) - Chronic UTIs (?impact cognition and impulsivity)\ - Client depresseddue to recent deaths in family (CM feels participant is suicidal)
Swallowing assessment (issues)	Deterioration of swallowing due to Botox
Swallowing issues	
TGA & DSR	Eastern DHS won't allow TGA and DSR till all other options exhausted. Investigating Linkages
TGA & DSR	
TGA & DSR	

CAG identified risk	Issues affecting risk
TGA & DSR	
TGA & DSR	Requires application
TGA & DSR	
TGA and DSR	
TGA and DSR	
Transport costs (taxi vouchers)	Unable to afford travel to and from CHCB for respite
Travel allowance	
Travel allowance	
Unable to feed self	
Unable to get out of bed	
Unable to get out of bed	• GP reduced Effexor and Zyprexa doses after enquiry from participant and mother. Client feeling low so advised to tell GP who has increased meds again • Client wants to remain in bed, not have shower or go to community activities. Will get up for toilet and meals at mother's insistence. • Discussion with participant re possible admission to Royal Park for assessment and rehab
Uses ventilator overnight	• Back up battery limited to 4 hrs if power fails • Check that has emergency contacts including neighbours • Check that machine is regularly checked
Weight	• Impact on health - fatigue escalating - at risk of diabetes, hypertension, heart disease • Has trialled various weight loss products and seen dietician to no avail • Out of pocket expenses from surgery (gap) • Client has expressed concern as to whetehr she could stick with opfast diet
Weight	Weight contributes to risk to participant and carers during ADL
Weight loss/loss of appetitie	Pain and nausea due to medication
Wheelchair assessment	Discomfort in lower back from wheelchair

Attachment E: CAG discharge summary form

Continuous Care Pilot:- discharge summary

Client name: D.O.B Male / Female

Address:

Next of Kin: Relationship:

Neurology group:

Client consent to share details with:

-
-
-
-

Admission to CCP:	CCP Discharge:

General Practitioner (GP):	
Neurologist:	
Neurologist:	
Neurological Group:	

Communication plan:

Continuous Care Pilot:- discharge summary

Social situation / support systems

Summary / overview: interventions, actions, services

Continuous Care Pilot:- discharge summary

Identification: need / support	Recommendations	Interventions likely to be required	Contact / Person responsible
			Name & contact details

Attachment F: Notes from clinical specialists forum

Introduction:

The forum began with a discussion of the policy context for chronic care delivery, in Victoria, Australia and overseas. This included –

- **The National Service Framework for Long-term Conditions.**
  Department of Health. London: DH, 2005.
- **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
- **Care in your community; DHS 2007**
- **The Victorian Health Independence Program Guidelines DHS(2008)**
- **Victorian State Disability Plan: Implementation Plan 2006-2008**
- **Strengthening Palliative Care Policy 2004-2009. A policy for health and community care providers**

The aims of the Continuous Care Pilot and the Clinical Specialists Forum were outlined.

Participants' forum:

Participants were invited to present issues concerning their particular patient diagnostic groups, and open discussion occurred. Concerns which were raised included –

- **Equity of Access**
  - Patients disadvantaged by -
    - Distance from metropolitan specialist services. Lack of specialist regional or outreach services.
    - Lack of clarity about what, how and where services could be accessed (by patients/families and health professionals). No clear pathway or program for continuous care delivery for people who meet the criteria for this model of care.
    - General understanding, but no documented and agreed criteria / clinical profiles of patients requiring such a program.
    - No clear provision for managing cognitive and behavioural changes in patients with neuro-psychiatric conditions (eg Huntington's Disease, Fronto-temporal dementias, and complications of many other neurodegenerative conditions) - buck passing between medical and psychiatric services
    - Complexity of care needs. Generic service providers lack confidence / reluctant to get involved
  - Patients with rapidly progressive diseases particularly disadvantaged by -
    - Lack of fast-tracking of service delivery / funding means many patients miss out completely and die before service is offered
    - patient may not be able to stay in residence of choice
  -

- **Community Care Packages**
    - Poor knowledge of what is available and how to apply, amongst many health professionals, and even case managers
    - Inadequate supply of funding packages to meet patient/family needs
    - Long waiting times for most packages / funding
    - Needs become more critical as delays lengthen
    - Expensive health professional time is wasted following-up applications and emphasising urgency with DHS, or managing consequences of failure to provide support services to patient.
    - Opaque internal DHS processes in deciding priority of package allocation
        - ? level of clinical input into decision-making process
        - ? DHS internal contacts, to whom clinicians could escalate their concerns in urgent cases
    - Confusing array of support packages and eligibility criteria
        - Need for streamlined, flexible system, preferably linked to patient.
- **Failure to provide continuous care, despite a strong evidence-base for this model of care for people with long-term neurological diseases**
    - Inflexible funding and service agreements for health care providers
    - No HARP. Chronic Disease Management stream for chronic neurological care.
    - Most specialist neurological services in the tertiary-level setting are not resourced to provide a multidisciplinary team-based paradigm of care to non-inpatients.
    - Specialist centres are not resourced or funded to provide secondary consultation and support to local health care providers and case managers
    - Many Community Rehabilitation Centres and hospital-based Rehabilitation Services restrict their practice to ‘episodes of care’ rather than ‘continuous care’. This is driven in part by –
        - Funding and reporting requirements
        - In this chronic setting, an inappropriate mindset, which views ‘the goals of rehabilitation’ as ‘effecting improvement’ rather than efforts to maintain and support the independence, comfort and quality of life of an individual with a progressive disability

Conclusions:

It was agreed that the current system often failed to meet the reasonable needs of people and families living with long-term and progressive neurological illnesses. System review is needed to address frustrations and barriers outlined above, which prevent a more streamlined and effective model of care.

The current system leads to -

- fragmented rather than integrated care delivery
- poor communication and sharing of information and knowledge between stakeholders (patient /family /health care providers / community care providers etc)
- failure to monitor care needs and support early decision-making
- poor anticipation of predictable problems
- failure to minimise risk of complications and crises

Recommendations:

1. **Set-up and resource a working party, with an agreed representative membership, to advise DHS on a 'Continuous Care Model' for people with long-term and progressive neurological conditions, in Victoria.**

To address –

- equity of access to services and funding
- prioritising of need
- delivering specialist input to care at a distance – outreach models of care
- case-coordination and information sharing

2. **Define -**
    a. **criteria for admission to a program of 'continuous care'**
    b. **clinical profiles of the diagnostic groups of patients likely to benefit from this model of care**
    c. **how an individual might transition through a Neuro-Palliative Rehabilitation model of continuous care**

3. **Seek support and endorsement of this initiative from**
    a. **Professional bodies (ANZAN, Chapters of Rehabilitation Medicine and Palliative Care, The Royal Australian College of Physicians, Australian Nursing Federation, Allied Health Professional Groups)**
    b. **Seek input and endorsement from Neurological Organisations and Patient support groups.**
    c. **Involve State and Commonwealth Government bodies to highlight need for a national focus**

NSW CONTINUOUS CARE PILOT EVALUATION

FINAL REPORT

29 NOVEMBER 2010

Report for:
MS Australia ACT/NSW/VIC
Studdy MS Centre, 80 Betty Cuthbert Dr, Lidcombe NSW 2141

Prepared by:
Disability Studies and Research Centre, Faculty of Arts and Social Sciences,
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Copies of this report are available from http://www.msaustralia.org.au/advocacy.asp or by calling MS Connect: 1800 042 138 (freecall). You can also contact Kristy Muir

Acknowledgements

Thank you to the people who contributed to the research including the clients of the NSW Continuous Care Pilot, family members and carers, service providers, stakeholders and MSL staff. This evaluation was made possible by funding from the NSW Department of Ageing, Disability and Home Care (ADHC) and MSL.

All names have been left out of the report to protect privacy and confidentiality.

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Abbreviations

CAG	Clinical Advisory Group
CCP	Continuous Care Pilot
ADHC	Ageing, Disability and Home Care, NSW
DSRC	Disability Studies and Research Centre
ACARS	Aged Care and Rehabilitation Services
MS	Multiple Sclerosis
MSL	Multiple Sclerosis Limited
RAC	Residential Aged Care
UNSW	University of New South Wales

Executive Summary

The NSW CCP was set up by Multiple Sclerosis Limited (MSL)[1] in conjunction with Macarthur Aged Care and Rehabilitation Services (ACARS) in Camden. It was funded by the NSW Department of Ageing, Disability and Home Care (ADHC) as part of the Young People in Residential Aged Care Program (YPIRAC) together with a contribution from MSL.

Program description

The main objectives of the CCP were to:

- Actively prevent premature aged care placement through pro-active disease management and service partnerships;
- Trial and evaluate a model of combining complementary funding programs to manage the health and community care needs of participants;
- Locate timely/appropriate services, including direct purchasing where no other option exists.

It was expected that the CCP would work to achieve the following key outcomes, to:

- Minimise the number of preventable admissions to RAC;
- Articulate a disease management model for CCP participants and the broader target group.

The CCP was set up to provide ‘intensive case management and coordination, and other assistance, to twenty persons aged less than 50 years with a progressive neurological condition who are at risk of inappropriate entry into residential aged care’ (DADHC, 2008). They had to be clients of Macarthur PDS (Physical Disabilities Service) outreach operating out of Camden hospital.

The CCP was designed to provide the following services:

- Intensive case management and coordination;
- Pro-active disease management and clinical support;
- Referral to services; and
- Provision of equipment and non-recurrent services through brokerage. (DADHC, 2009)

---

[1] Multiple Sclerosis Limited (MSL) is the entity that manages and operates MS Australia ACT/NSW/Vic.

The brokerage funds were $150,000 for the purchase of non-recurrent services and/or equipment for clients where ‘there is no other service response available and the service purchase can be shown to mitigate a present risk of disability exacerbation’. MSL was tasked with administering these funds.

The CCP had a Steering Committee for the overall governance of the pilot. A coordinator was appointed to run the pilot and set up a Clinical Advisory Group (CAG) to develop and monitor the implementation of care coordination plans for CCP clients.

The evaluation approach and methodology

The Disability Studies and Research Centre (DSRC), based at the University of New South Wales, was commissioned by MSL to conduct an evaluation of the CCP. The evaluators developed a program logic model (based on the one used in the evaluation of a similar pilot in Victoria) to outline the following evaluation questions:

1. To what extent has the CCP been implemented as intended? How effective is the tertiary case management model used in the CCP?
2. What have been the outcomes for clients on the pilot?
    a) How many clients have avoided premature entry to residential aged care or unnecessary hospitalisation?
    b) Have clients and their families/carers’[2] well-being changed?
    c) Are clients receiving a better managed and more appropriate service package?
3. What systemic/structural changes have occurred to better support people with progressive neurological conditions?
4. Are there cost savings and other benefits to government arising from the CCP and potential savings and benefits of the disease management model it is piloting?

The evaluators used mainly qualitative but some quantitative methods to answer these questions. The methods included:

- a review and analysis of background information on the Program;
- collection and analysis of client case file and program financial data for the CCP;
- a pre- and post-program wellbeing and satisfaction survey of all clients who use the CCP;
- a pre- and post-program survey of clients’ family members/carers;

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[2] Carers include family members and friends who act as carers without pay.

- case studies of a sample of clients , involving in-depth interviews with the client, family member/carer, case worker, and one of the client's service providers; and
- stakeholder interviews with representatives from the CAG, hospital and CCP.

Findings

The Report contains three main sections dealing with the evaluation findings:

- Client outcomes
- Program effectiveness (the process evaluation)
- Costs Analysis

The report found that the CCP was an important and valuable program that provided support and assistance to all of the program clients. It met most of its objectives, although for a smaller number of clients than was originally intended. It met some but not all the objectives and outcomes set out in the funding proposal.

Client outcomes

The CCP had positive outcomes for all of the clients who participated. Some clients had reduced hospital admissions following their involvement in the pilot, despite the natural progression of their diseases. Some clients appear to have been kept at home for longer than they might have had the CCP not been involved. None of the clients were admitted to residential aged care (RAC) during the period of the CCP and all remain within the community with supported services as a direct result of the CCP. The CCP was able to reduce waiting times for services for clients and link them to new medical and non-medical services across the health and disability systems of which they were not previously aware.

Family members who cared for clients also all seem to have benefited from the CCP due to improvements in the client's health and psychological state and as a result of practical assistance such as respite, child care, home care and mobility assistance. In some cases they received direct benefits such as young carer information and training, child care and relationship counselling.

While the CCP played an important role in coordinating services and supports for clients, the role of case managers and service providers in providing these services and supports was also critical to positive outcomes for clients and carers.

Program effectiveness

The CCP, despite some early issues, functioned effectively according to the objectives of the program. However, there were some establishment issues due to the lack of guidelines and procedures that meant that the CCP took time to reach full functioning. The CAG functioned well, met regularly and was run well, ethically, and sensitively. It was able to evaluate client risk and develop plans to manage this. It was also able to monitor ongoing implementation of these plans. The coordinator was effective and was able to follow through on decisions made in the CAG.

Costs analysis

The total cost of the pilot was $160,740, which was roughly offset by a reduction in hospitalisation ($158,850) when the equivalized annual number of hospital days was compared before and during the pilot. The brokerage funds were not adequately used and only came into play quite late in the pilot. The lack of transparency about the funds and the restrictive use of them was a problem for the functioning of the CAG and for the effectiveness of the pilot as a whole.

Recommendations

The following are the evaluation recommendations:

1. The CCP is an effective and important intervention that should be developed for broader use within the health system. By bringing together a professional team to develop coordinated and improved patient management, clients get access to better services and have improved outcomes for themselves and their families.

2. The CCP did not reach its full capacity and if the pilot is further rolled out consideration should be given to location and eligibility criteria.

3. There should be clearer guidelines on the role of the Steering Committee, the CAG and the coordinator. Procedures for meetings and case coordination should be developed. There should be a chairperson appointed who is not the coordinator so as to keep a separation of the two roles.

4. The nature and role of brokerage funds must be better communicated.

5. Risk identification protocols should be developed.

6. Communication materials and communication strategies should be developed in advance of program commencement.

7. With regard to the above points 3, 4 and 5, the need for guidelines, role descriptions and protocols should be used in a balanced fashion so as not to detract from the flexibility and lack of formality that was a positive feature of the pilot.

8. Ideally, the coordinator should have formal health training as well as a good working knowledge of the health and disability service systems. Strong organisational and communication skills are also needed.

9. Involvement of government should be continued in future programs. Additional government departments could be included in meetings where information is needed, for example, the housing department can

be invited to discuss ways of accessing appropriate housing and home modifications.

10. Where appropriate clients and family should be more actively involved in discussion and planning of their own case management.

11. With regard to the wind up of the pilot, it is recommended that remaining brokerage funds be used to develop discharge plans for clients. However, there is a concern that the ending of the pilot may bring some risks to the ongoing health and well-being of clients and their carers. It is recommended that the positive features of the pilot be considered in developing a broader program to support people with progressive neurological conditions. Key features of such a program should include:

    - The efficient use of existing services by creating a better understanding of client need and the services available to meet this need;
    - Linking clients to new medical and non-medical services and speeding up service provision;
    - Coordination of the various levels of case management through a Clinical Advisory Group and a coordinator together with case managers and with the participation of clients and their families;
    - Training and education of program participants, their families and service providers on the nature of PND and its progression;
    - Effective use of brokerage funds to speed up access to services and provide for services and supports that would not otherwise be available.

1 Introduction

The need to keep young people out of residential aged care (RAC) is a federal government priority. RAC is inappropriate for younger people who should optimally be able to remain with family and in the community. This type of care is also a very costly approach for government. One group who are particularly at risk of entry into RAC are people with progressive neurological conditions who face growing needs as their diseases worsen. This group does not fit well within the disability services system and it thus becomes vital to link up their clinical health services with disability and social or community services. A 'continuum of care' approach attempts to bring together services within health, disability, aged care and community services to better address people's needs and to encourage efficiency by ensuring that existing resources are used in a timely and more efficient way than is currently occurring. This ensures a focus on proactive and preventative measures to avoid the risk of frequent hospital admission and earlier than necessary admission to RAC. Linking the medical with the non-medical services in a coordinated and intensive case management model is an innovative response to the difficulties encounters by this client group.

Following the success of the CCP in Victoria run by MSL in partnership with Calvary Health Care Bethlehem (MS Australia, 2009b), the NSW CCP was set up by MS Australia in conjunction with Macarthur Aged Care and Rehabilitation Services (ACARS) in Camden. It was funded by the NSW Department of Ageing, Disability and Home Care (ADHC) as part of the Young People in Residential Aged Care Program (YPIRAC) together with a contribution from MSL.

The NSW CCP was set up to provide advanced case coordination by identifying risk of entry into RAC and developing disease management strategies in conjunction with project partners. This would lead to formal transition pathways for managed access to a range of services. The Pilot was expected to reduce client entry to RAC through an "articulated pathway in the community", combining:

- community support with pro-active disease management;
- collaborative partnerships with service providers;
- referral and brokerage within an intensive case management structure;
- identification of issues for clients and for the service system in this transition phase;
- demonstration of pathways and options for improved management of these clients that allow them to remain in their home setting for as long as possible (MS NSW, 2009).

The Disability Studies and Research Centre (DSRC), based at the University of New South Wales, was commissioned by MSL to conduct an evaluation of the CCP. The evaluation was funded out of the CCP funds and was seen as an integral feature of the pilot to ensure that lessons were learned from the NSW CCP for comparison with the Victoria CCP and future possible replication of a continuous care program elsewhere at state or national level.

The evaluation considers client, family and structural/systemic outcomes, appropriateness of the pilot's design, and effectiveness of its implementation.

This report sets out the evaluation findings and makes recommendations for improvement of future programs based on the findings.

The report is structured as follows:

Section 2 describes the program and some of the background to its set up.

Section 3 outlines the evaluation approach and methodology.

Section 4 discusses the outcomes for CCP clients and their families.

Section 5 contains a discussion of the program's effectiveness.

Section 6 involves a costs analysis of the CCP.

Section 7 sets out the main findings and recommendations of the evaluation.

2 Program Description and Background

The NSW CCP was first funded by ADHC for the period 29 May 2008 to 30 September 2009. This timeline was later extended. The funding will end when the pilot ends in late 2010 or early 2011. The CCP took some time to set up and effectively began in early 2009, making it a two year program.

2.1 Program objectives and outcomes

The objectives of the CCP were to:

- Actively prevent premature aged care placement through pro-active disease management and service partnerships;
- Trial and evaluate a model of combining complementary funding programs to manage the health and community care needs of participants;
- Locate timely/appropriate services, including direct purchasing where no other option exists
- Develop service networks and responses to meet the changing needs of Pilot participants in a timely and clinically effective way;
- Evaluate the intervention model and report on key risk factors for this group for aged care placement;
- Develop a specific regional network of clinical and other services utilised by this group to promote referral pathways and other opportunities;
- Provide data on the specific service requirements of participants for service planning; and
- Evaluate the cost savings and emotional impact of preventing long stays in acute/sub acute services through the pilot's intervention to locate services earlier. (DADHC, 2008)

The expected outcomes of the CCP were to:

- Minimise the number of preventable admissions to RAC;
- Articulate a disease management model for CCP participants and the broader target group
- Define and establish training for service providers dealing with people with degenerative diseases;
- Generate a model regional services network for neurological health/disability management;
- Establish mentoring and education about the impact of degenerative diseases for staff in related services;
- Provide data that supports the development of dedicated service pathways for people with complex needs associated with progressive neurological conditions. (DADHC, 2009)

2.2 Target group

The CCP was set up to provide 'intensive case management and coordination, and other assistance, to twenty persons aged less than 50 years with a progressive neurological condition who are at risk of inappropriate entry into residential aged care' (DADHC, 2008). The eligibility criteria required participants to be 'persons with a disability' but not an intellectual disability or primary diagnosis of an ageing related condition and not already living in RAC. They had to be clients of the Macarthur Disability Service Community Outreach program operating out of Camden hospital.

2.3 Services and supports provided

The CCP was meant to provide the following services:

- Intensive case management and coordination;
- Pro-active disease management and clinical support;
- Referral to services; and
- Provision of equipment and non-recurrent services through brokerage. (DADHC, 2009)

The brokerage funds were $150,000 for the purchase of non-recurrent services and/or equipment for clients where 'there is no other service response available and the service purchase can be shown to mitigate a present risk of disability exacerbation' ie: 'when a timing or service gap cannot be resolved, or a key service (such as an equipment assessment) is needed urgently' (DADHC, 2009). These funds would be administered by MSL.

2.4 Management and Governance

The CCP was to be governed by a Steering Committee comprising members of ADHC, MSL, and Macarthur ACARS. The Steering Committee was meant to 'provide governance, strategic oversight and advice' to the CCP to ensure that the objectives of the pilot were met. (MS Australia, undated b). The roles and responsibilities were defined as follows:

- Provide strategic advice in relation to the implementation of the project as outlined in the Project Proposal
- Provide high-level advice to address critical issues that may impact on the progress of the project and achievement of outcomes, including the management of any high level risks
- Provide a range of views and perspectives from members and their related networks to inform and enhance the progress of the project
- Provide advice on the development of the project's products including the development of policy, guidelines and implementation strategies and recommendations
- Assist in promoting the operation and achievement of the project wherever possible
- Monitor the evaluation process
  (MS Australia, undated b)

The CCP employed a Coordinator on a 0.6 FTE basis who was managed by MSL. The Coordinator was to work closely with Macarthur ACARS case managers to ensure continuity of care for CCP clients by ensuring:

- Improved information flow between health professionals and service providers;
- Timely and appropriate referral to services;
- The identification of service gaps; and
- The practical application of available resources.

(DADHC, 2009)

The coordinator and Macarthur ACARS medical professionals set up the Clinical Advisory Group (CAG) which met regularly to discuss the ongoing needs of the CCP participants and their carers. The CAG's main role was to evaluate potential client's risk of entry into RAC, to develop disease management plans, to provide clinical advice and assessment, and to support and guide case coordination and decision-making around each patient.

3 Evaluation Approach and Methodology

Concurrent evaluation of the CCP was a component of the funding agreement between ADHC and MSL. The evaluators were required to work with the CCP to determine whether or not the pilot:

(a) delivers significant benefits to clients and their families above and beyond what usual practices/services deliver,

(b) changes systems/structures available to support people with progressive neurological conditions, and

(c) decreases usual overall costs by reducing the use of acute/sub-acute health care services and delaying residential care admissions (MS Australia, 2009).

Program theory was used, in conjunction with an outcomes-based accountability approach and broad consultations with key stakeholders from the CCP, to develop the evaluation framework.[3]

The methodology was designed to ensure that:

- Clients and other stakeholders involved in the CCP participated in the evaluation;
- The experience of clients informed and contextualised the analysis of other data; and,
- The findings were able to inform future policy development.

Based on a review of the materials and consultations with key pilot stakeholders, a program logic model was developed to assist in understanding the ideas that have informed the CCP (Cooksy, Gill & Kelly, 2001; Figure 3.1). This is a somewhat simplified version of the Victorian pilot's program logic (Batterham, 2008) and is specific to the approach being followed in the NSW pilot.[4] The program logic model has been used to design the methodology.

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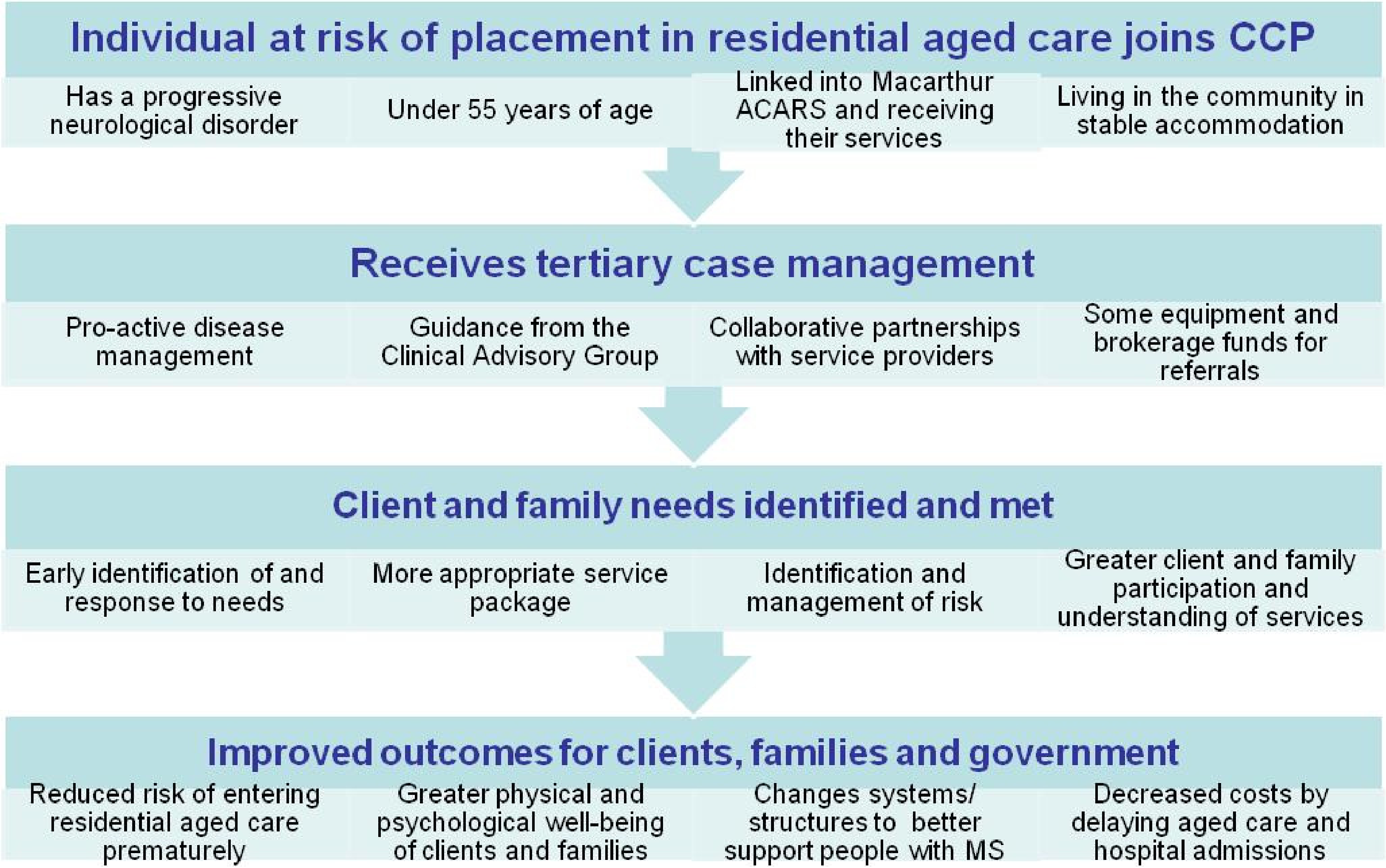
[3] Some of the program documents used in the NSW pilot including forms and communication materials were provided to the researchers. The researchers consulted with three staff members from MSL in NSW in developing the evaluation approach. In addition, some of the documentation from the evaluation of a similar pilot in Victoria was made available to the researchers who also had discussions and correspondence with the MS Australia Senior Policy Advisor, and the Victorian evaluator.

[4] Optimally, this program logic should have been developed at the start of the pilot with stakeholders so as to ensure a common understanding of and commitment to the program objectives. However, stakeholders appear to have been brought on board in other ways by the CCP staff. For the purpose of this evaluation it has been used to design and conduct the evaluation and not as a program tool.

Figure 3.1: Program Logic Model



The program logic informed the evaluation approach. A set of key evaluation questions were developed that flowed from the pilot's objectives. These questions were used to evaluate how effectively the pilot was meeting its objectives. The central evaluation questions were:

1. To what extent has the CCP been implemented as intended? How effective is the tertiary case management model used in the CCP?
2. What have been the outcomes for clients on the pilot?
    a) How many clients have avoided premature entry to residential aged care or unnecessary hospitalisation?
    b) Have clients and their families/carers'[5] well-being changed?
    c) Are clients receiving a better managed and more appropriate service package?
3. What systemic/structural changes have occurred to better support people with progressive neurological conditions?
4. Are there cost savings and other benefits to government arising from the CCP and potential savings and benefits of the disease management model it is piloting?

The methodology was designed on the basis of the program logic and the evaluation questions that arose from this program logic. Methods were chosen to best address these questions. Primarily qualitative as well as some quantitative data instruments were developed to collect outcomes and process data (see Appendix B: Schedule of Instruments). The researchers took a partnership approach with the CCP staff so that certain evaluation data was collected through the program operation. The evaluation ran from November 2009 to November 2010 with the fieldwork occurring between July and September 2010.

3.1 Methods

The evaluation used qualitative and quantitative research to assess changes to systems as well as individuals. Data was triangulated to meet the evaluation objectives, measure changes over time, and provide information to contribute to program improvements. The following methods were used:

- a review and analysis of background information on the Program;
- collection and analysis of client case file and program financial data for the CCP;
- a pre- and post-program survey of all clients who use the CCP;
- a pre- and post-program survey of clients' family members/carers;

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[5] Carers include family members and friends who act as carers without pay.

- case studies of a sample of clients , involving in-depth interviews with the client, family member/carer, case worker, and one of the client's service providers; and
- stakeholder interviews with representatives from the CAG, hospital and CCP.

Client case file review

The evaluators examined 7 client case files. In some cases these contained completed 'Life Domains' forms. The coordinator explained that these forms were developed in the Victorian evaluation and used initially by her in her introductory meetings with clients. She said that clients found these forms 'invasive, irrelevant and taxing' and decided, in consultation with her MSL manager, to stop using them. The coordinator kept a record of service use, hospital admissions, and brokerage costs for each client. This information has been used to inform the evaluation regarding changes in service provision, case management and client outcomes.

Cost analysis

The evaluation examined whether the CCP has resulted in a decrease in the usual overall costs to government of the clients on the program by reducing their use of acute health care services and delaying their admission to residential aged care (MS Australia, 2009). Due to time, budgetary and data constraints the evaluators have undertaken a simplified costs analysis.

An approximate amount for one day of in-patient hospitalisation (based on NSW Health figures) was used as the working figure for this analysis. Clients' previous hospitalisations in the two years leading up to the pilot were extracted from their medical records. An aggregate annualised amount of hospital days was calculated for this period. It was then compared to the number of hospitalisations equivalized to one year in the pilot. The reduction in the number of hospital days during the pilot has been given a dollar amount based on the government figures available. While it was not meaningful for the evaluation to examine days and costs in relation to residential aged care avoidance, such avoidance was tracked qualitatively.

The costs to government of the CCP have been compared to the hospitalisation costs during the pilot. Findings do not include the additional costs of community based care; this was beyond the scope of the evaluation.

Primary Data Collection

Primary data collection methods were used to collect data about the CCP and its clients. Research instruments measured the range of outcomes and process experiences required for the evaluation. This data was supplemented by program data provided by the CCP coordinator and the MSL NSW Services Manager.

The evaluation had a strong focus on qualitative instruments as these were best suited to studying the small group of clients and stakeholders. The qualitative data obtained from the interviews was used to understand the perceived outcomes and factors that facilitate and hinder the effectiveness of the tertiary case management model used by the CCP. Data collection instruments can be found in Appendix B. The following table sets out the various data collection methods used the number of participants for each method.

Table 3.1: Number of evaluation participants by method

Participants	Number	Method	Appendix
Clients	7	Survey (pre evaluation)	B6
	6	Survey (post evaluation)	B6
	7	Face-to-face interviews (case study)	B1
Family/carers	5	Survey (pre evaluation)	B7
	4	Survey (post evaluation)	B7
	5	Face-to-face interviews (case study)	B2
Case Managers	5	Telephone interviews (case study)	B4
Service Providers	15	Telephone interviews (case study)	B5
	5	Telephone interviews (additional)	B5
CAG members	6	Telephone interviews	B3
Hospital staff member	1	Telephone interview	B3
MSL CCP staff	2	Interviews	B3
Total surveys	Pre	Post	Total
	12	10	22
Total interviews			46

Pre and Post Surveys (Appendix B6 and B7)

The CCP coordinator collected pre and post client and family member/carer data. This provided semi-longitudinal data on the satisfaction of clients with their case management and the satisfaction of family members/carers over the same period. Together with the interview and case study methods discussed below, the surveys assisted to answer the evaluation question regarding improved physical and psychological well-being of clients and their families. The surveys used the Personal Wellbeing Index to measure client and family members' quality of life (International Wellbeing Group, 2006). The family member/carer survey also included one section of the Burden Assessment Scale (Reinhard, Gubman, Horwitz, & Minsky, 1994).

The survey was administered as close to the beginning of the evaluation as possible (Wave 1 in January 2010) and at the end of the data collection stage of the evaluation (Wave 2 in September 2010) so that the longest possible period of time elapsed between the two collection dates. These surveys were administered by the CCP coordinator. Twelve pre-surveys were collected comprising 7 clients and 5 carers. Ten post-surveys were collected comprising 6 clients and 4 carers (Table 3.1). To ensure only clients with completed pre and post-surveys were included in the analysis, only 6 clients and 4 family members have been included in the survey findings throughout the report. The results have been reported as numbers rather than percentages because of the small sample. Given this small sample, the survey results should be treated with caution; the results only provide an indication of change for a very small number of clients and family members.

CCP client interviews (Appendix B1)

The evaluators used an in-depth interview schedule to obtain client data on physical and emotional well-being, case management, care and service provision, and perceptions of the CCP and its impact on their lives. The semi-structured interview allowed the evaluators to gain an in-depth understanding of client perceptions, concerns and wishes about their service needs, care and family position, case management and changed outcomes (if any). The interviews helped to demonstrate causal links between improved well-being and the intervention of the pilot so as to address the evaluation questions regarding both the value of the CCP model, its implementation and its impact on clients. The evaluators conducted the interviews face-to-face with clients.

It must be noted that the interview schedules and surveys for clients and carers asked people to comment on the effectiveness of the CCP in addressing their circumstances. This may have led to some conflation of the positive benefits of the CCP and the contribution of service providers. Clients and carers are not always able to distinguish the various people, services and structures that provide them with assistance. Given that the CCP involved collaboration with service providers the comments from clients and carers should not be taken to mean that the CCP must be given sole credit for improvements. The important roles of the various professionals and providers within the cooperative framework of the CCP should be acknowledged and borne in mind throughout the report.

Case Studies

The evaluation intended to obtain data on all 20 CCP clients and to conduct in-depth case studies with five of these people and their carers, case managers and service providers. However, only 12 clients were recruited onto the CCP and five of these clients were no longer part of the pilot at the time of data collection. Therefore, case studies were conducted on all seven of the remaining CCP clients.

Six of the seven clients included in the evaluation joined the pilot before January 2010 and one joined in March 2010. Six remained on the pilot until the end of the primary data collection period (August 2010) and one was discharged in April 2010 but agreed to be part of the evaluation. The evaluation was able to consider the impact of the pilot on clients who had been involved in the CCP for an average of 10 months. The range of time spent on the CCP was a maximum of 14 months and a minimum of 5 months.

A case study approach was chosen as an effective method of gaining detailed insight into the lives of the clients and the processes involved in the pilot. Interviews were conducted with clients, their case managers, family members/carers, and service providers to provide a complete picture of the clients' care, treatment and management and the impact of the CCP. In two cases, clients did not have family members or carers and in three cases clients did not have case managers. In a number of cases, additional service providers were interviewed so as to obtain as full a picture as possible of each client.[6] The number of family, case managers and service providers interviewed for each client can be found in Table 3.2.

Table 3.2: Number of family, case managers and service providers interviewed for each client and service provider types

	Family/ Carer	Case manager	Service provider	Service provider type
Client 1	-	2	2	psychologist; physiotherapist
Client 2	-	1	3	community support worker; neuropsychologist; physiotherapist
Client 3	1	-	3	community support worker; private occupational therapist; physiotherapist
Client 4	1	-	1	physiotherapist
Client 5	1	1	1	physiotherapist
Client 6	1	1	3	respite provider; community support worker; physiotherapist
Client 7	1	-	2	community support worker; physiotherapist

The aims of both the case manager and service provider interview schedules were to gather their perceptions of: the tertiary case management model; whether or not their client's needs and risks have been identified and addressed; and outcomes for the client. In contrast, the aim of the family member/carer interview schedule was to gain their perceptions of whether or not their family member/client's needs and risks had been identified and addressed through the CCP and the impacts the CCP has had on their family member/client and on them as a carer. Family member interviews were conducted face-to-face where possible. The case worker and service provider interviews were done telephonically.

Stakeholder Interviews (Appendix B3)

The evaluators conducted face to face and telephone interviews with a range of people involved in governance of the CCP including six CAG members, two MSL/CCP staff members (the CCP coordinator and the Regional Services

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[6] See Appendix A for a brief write up of each of the case studies. The interview schedules can be found in Appendix B.

Manager, Northern Region MS Australia - ACT/NSW/VIC) and a hospital staff member. See Table 3.1 above for a description of data methods and numbers of participants interviewed. These interviews were based on the ‘Governance Interview Schedule’ (in Appendix B3). This interview schedule addressed the evaluation questions on the effectiveness of the tertiary case management model as well as the changes to clients’ outcomes that resulted from the CCP. The questions were designed so that individual perceptions could be compared and assessed and given appropriate weighting by the evaluators. Over and above the service providers interviewed as part of the case studies, an additional five service providers who had knowledge of one or more of the clients on the CCP were also interviewed to provide responses regarding specific clients as well as general views regarding the CCP. The service provider interview schedules (Appendix B5) were used for these interviews.

Individual interviews provided detailed and specific information on processes within the CCP as well as providing a contextual framework. The interviews also complemented the case studies as certain specific clients were discussed with appropriate stakeholders from the CAG and the CCP. These interviews were important in assessing systemic/structural changes.

Analysis

The qualitative data was analysed thematically. The survey data was analysed quantitatively (although the survey group was very small). All the data sources were triangulated in the analysis for this report. The report draws out key findings, as well as lessons and recommendations. The case management model used in the CCP including its component features is reviewed here. The effectiveness of the pilot is assessed and recommendations have been made for improvements in design and implementation should the pilot be replicated elsewhere.

3.2 Ethics

The evaluation research was approved by the Human Research Ethics Committee (Western Zone) for the Sydney South West Area Health Service on 15 June 2010.[7] The evaluators also received ratification of this approval from the University of New South Wales Human Research Ethics Committee.

Clients were recruited by the CCP and introduced to the evaluators so that the research was at ‘arms length’. Prior to participation in the research, all participants were provided with clear, accessible[8] information about participating in the research, voluntary consent to participate (with continuous opportunities to withdraw from the research), respect for individuals’ rights and dignity, reimbursement for participation (clients and carers) and confidentiality. Where permission was granted, responses were recorded for

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[7] HREC reference number HREC/10/LPOOL/21; SSA reference number SSA/10/LPOOL/69.

[8] Plain English approach letters were used to accompany the official forms for those whose illnesses may have caused cognitive difficulties.

accuracy. All data is stored in a locked office at DSRC and can only be viewed by the research team. It will remain confidential and be destroyed after seven years.

4 Client and Family Outcomes

The CCP worked with 12 clients over the two year period of its operation. Of those, 4 exited: two died, one moved state and one decided to stop participating in the pilot. Of the 8 remaining, 7 joined the CCP in time to be part of the evaluation. These 7 clients were interviewed as part of in-depth case studies. See Table 3.2 above for a description of case study interview numbers and types. The case studies also involved interviews with a family member/carer, a case worker and a service provider. (The case studies can be found in (Appendix A: Case Studies). In addition, the clients were surveyed in January and in September of this year. This section uses the interview and survey data to examine the impact of the CCP on the clients and their families.

Client Profiles

The CCP was set up to provide 'intensive case management and coordination, and other assistance, to twenty persons aged less than 50 years with a progressive neurological condition who are at risk of inappropriate entry into residential aged care' (DADHC, 2008). The seven clients evaluated matched the intended target group of the CCP and met the eligibility criteria of the pilot: all were under 50 at the start of the CCP, had a progressive neurological condition, lived in the community, were clients of Macarthur ACARS and were at risk of premature entry to RAC. Table 4.1 lists the clients' family/community situations, age ranges and disease types.

Table 4.1: CCP clients, disease type, family/community situation, age range

Client	Disease type	Family/community situation	Age at start of CCP
1	MS	Lives alone (Department of Housing modified property)	43
2	Chronic inflammatory demyelinating polyneuropathy	Lives with husband in Department of Housing home	47
3	MS	Lives alone (Department of Housing property)	31
4	MS	Lives with elderly parents in private rental accommodation	40
5	HERNS	Lives with wife and three children in own home	40
6	MS	Lives with husband and two young children in own (unmodified) home with mortgage	29
7	MS	Lives with teenage son in private rental accommodation	49

The initial proposal prevented people over 50-years from being eligible for the CCP, which affected the initial recruitment of the full cohort of participants. This was changed to allow more flexibility in recruitment of clients, but the full capacity was not reached. While CAG members understood that the presence of a progressive neurological condition was another eligibility criterion for the CCP, many felt that the pilot could have benefitted people with other disease types.

Evaluation approach and summary

The Program Logic Model (Figure 3.1) set out the elements of tertiary case management that clients should receive which include:

- Pro-active disease management
- Guidance from the CAG
- Collaborative partnerships with service providers
- Equipment and brokerage funds (where needed)

These four elements link the clinical and disability components of the service delivery system as there is often a lack of convergence between the two.

This case management approach should ensure that the clients' and families' needs are identified and met through the CCP, including:

- Early identification of and response to needs
- More appropriate service package
- Identification and management of risk
- Greater client and family participation and understanding of services

Clients and families should experience improved outcomes from this intervention including:

- Reduced risk of entering residential aged care prematurely
- Greater physical and psychological well-being

Based on the above, this section of the report sets out the evaluation findings on client and family outcomes in the following areas:

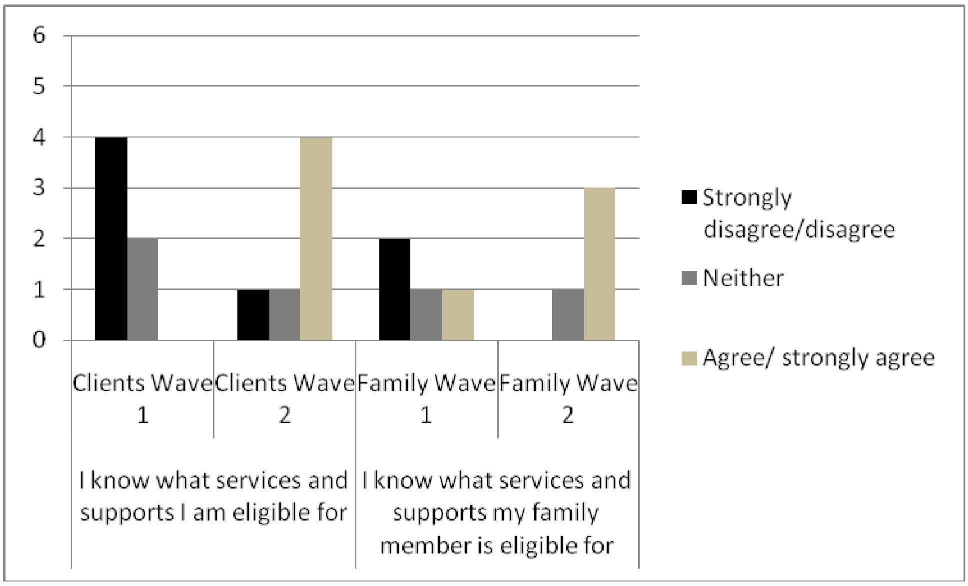
1. Service outcomes
2. Wellbeing and participation outcomes
3. Hospitalisation and aged care placement

4.1 Service outcomes

Improved understanding of services

Clients and family members who were interviewed and surveyed reported an increase in their understanding of the services and supports that were available to them. While in the pre-surveys (Wave 1), none of the six clients surveyed knew what services and supports they were eligible for, by the post-surveys (Wave 2) four clients agreed that they knew about appropriate services and supports. Family members' understanding also increased (Figure 4.1).

Figure 4.1: Understanding of available services and supports by number of clients and family member / carers Wave 1 and 2



Some clients and family members also discussed having an improved understanding of services in the interviews. One client said: ‘It’s [the CCP] a good way of introducing the patients to the care that is available to us at the times we need them’. Other stakeholders also identified improvements in people’s understanding of services:

> ... now they [clients and their family members] realise that there are people out there who are able to help them, because they are specialised ... and its provided them with support as well: where to go if things go wrong? What do they do if things seem to be crumbling around them? (CAG member).

However, while most clients and family members were acutely aware of changes in their understanding of available services, two clients and one family member had little understanding of available services and/or which providers were providing support and who these providers were affiliated with. This is a significant finding as it points to the important knowledge transfer involved in the CCP and the valuable empowerment that follows from greater client and carer understanding of the range of possible services that they can draw on.

Early identification and response to needs

There was a general increase in clients and family members reporting an improvement in the service system responding to their needs between Waves 1 and 2 of the survey. CCP clients’ were more likely to agree that the health system was responsive to their changing heath and care needs (n[9]=1 in Wave 1 compared to n=4 in Wave 2); that support was available when it was urgently needed (n=1 to n=4); and that their equipment needs were being met

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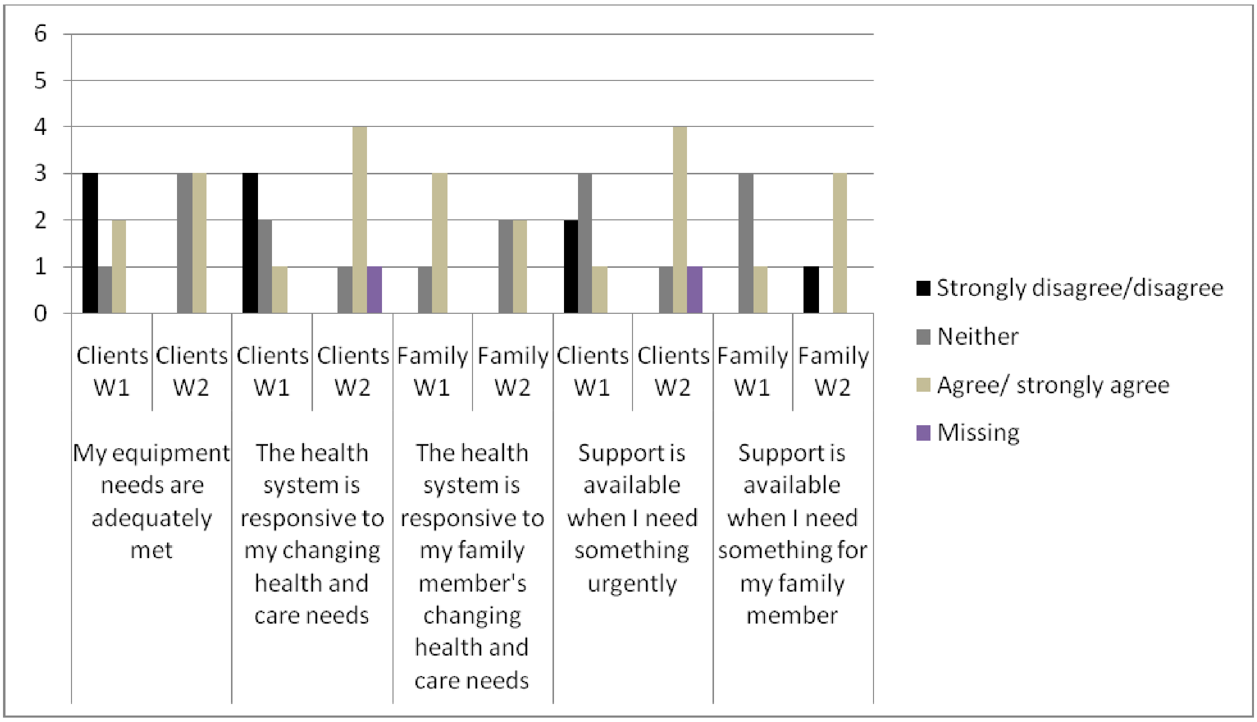
[9] ‘n’ represents the total number of people who responded.

(n=2 to n=3). Family members were also more likely to report that support was available when needed (n=1 to n=3; Figure 4.2).

Figure 4.2: Clients and family members' perceptions of the extent to which their needs were met (Wave 1 and Wave 2)



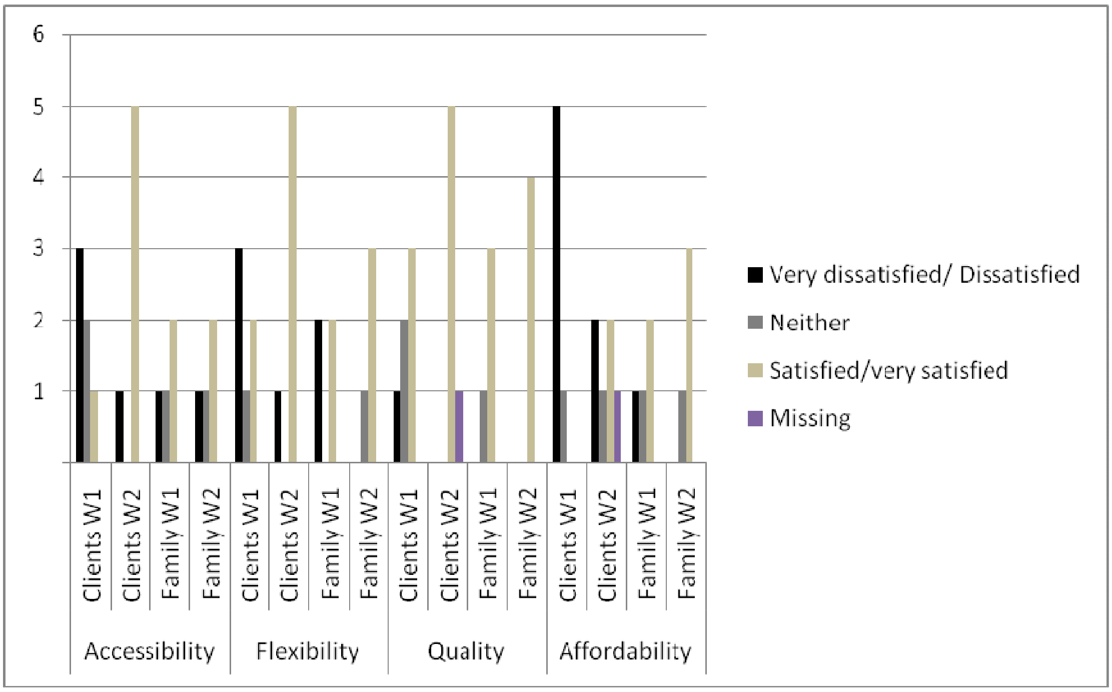
It is important to note, however, that by Wave 2 some clients neither agreed nor disagreed that their needs were met. Family members were also less likely to feel that the health system was responsive to their family members' needs in Wave 2 (Figure 4.2).

In general, client needs were more likely to be met because of a change in the availability and appropriateness of services and in how the services were delivered. These aspects are discussed below.

Availability and appropriateness of service packages

Client satisfaction increased with the accessibility, flexibility and quality of services during the CCP pilot. Figure 4.3 shows that by Wave 2 five of the six clients were satisfied or very satisfied with the accessibility, flexibility and quality of the services they were receiving. While affordability had improved for clients, only two were satisfied with the affordability of services at Wave 2. Family members were more satisfied at the outset of the CCP than clients. However, there was still a small improvement in the number of family members who were satisfied with the flexibility quality and affordability of services (Figure 4.3).

Figure 4.3: Client and family member satisfaction with service accessibility, flexibility, quality and affordability at Wave 1 and Wave 2 (n=6)



The interviews with clients, family members and other stakeholders further demonstrated increases in the number and breadth of services clients received and improvements in the appropriateness of supports. All seven clients involved in the evaluation case studies had improved services as a result of the CCP. Clients' needs were highlighted by the CCP and appropriate services were identified. The intervention of the CCP reduced waiting times for services. The types of services received varied significantly depending on the needs of each client. They covered a range of life domains and specific services:

- Physical health
    - Physiotherapy
    - Occupational therapy
- Mental health
    - Counselling
    - Other psychological services
- Service coordination
    - Case manager
    - Information provision
- Social and community
    - Community activities
    - Gym program

- Equipment for improved independence
    - Wheel chairs
    - Access to transportation
    - Home modifications
- Domestic and family support
    - Home care
    - Child care
    - Respite
    - Weekend away
    - Support regarding pets

Most clients (4 out of 7) had case managers. Case managers assisted clients to identify and access the most appropriate supports. As one client explained:

> When I called around to find out what sort of help I could get when I needed it, I always got the door slammed shut in my face. There wasn't the help out there that I needed at a full time basis. So if it wasn't for the CCP intervening - getting me a case manager, getting Home Care on to it - I wouldn't be getting these services, and I'd still be stuck with fortnightly domestic assistance and that's it.

Generally, the service packages facilitated by the CCP have been holistic and tailored to the specific needs of the clients involved. Many clients and family members appreciated that the supports organised by the CCP were broader than just physical health services. For example, as many of the clients have mental health issues related to their diseases, counselling, community support and psychological services were important additions to their service packages. There was also a focus on broader community and family support. For example, child care was provided to assist one of the clients and her partner and a young carer was provided with information and training to assist him in his role. These were seen by the clients and carers as valuable supports. However, one client felt that more could be done to enhance her community involvement. She recommended that there be recreational programs to complement the services clients are receiving to enrich their lives and help them to get out of the house and into the community:

> What would be great is if there were more ... social and recreational programs out there that people like myself who can't do much, but would like to get out of the house, do something, keep the mind enriched ... I think that if enough of the organisations got together... it might help. Or if they could start up something ... like a recreation officer ... Like they could organise on different days of the week – one day would be art, one day would be swimming ... Because that would sort of enrich our lives that much more – we wouldn't just be surviving, we'd be living ... It's things like that that would really enrich everybody's life, not just mine, like everyone on the CCP. At the moment we've got all the services we need; we haven't got the recreation that we need though.

Several people felt that the CCP was beneficial to clients simply for allowing them to feel like there was a proper effort to look out for their interests by people with a variety of skills. There was also reassurance about the future: '[The CCP has] made us feel more at ease because we know someone is looking out for us ... and thinking of the future ... as the illness progresses'. However, it is not known whether this reassurance will persist once the pilot concludes.

The involvement of ADHC and MSL has created greater awareness among hospital staff of potential services and funding for clients. Some service providers did however note that the CCP could not overcome all the problems within the health system, the lack of funds for case management and allied health services, and other issues such as lack of transport and appropriate housing. Similarly, CCP clients were aware that the pilot could not help them with everything that they needed. Some clients were aware that the CCP could not solve all of their housing and accommodation needs because of structural difficulties within the disabilities services system.

Case studies: services received as a result of the CCP

One client's case manager helped to increase his access to physiotherapy and to gain funding for a gym program. This support helped him and his carer to better manage his condition, to decrease his boredom and give his carer more space. The client was also assisted with community activities and counselling and he and his family received brokerage funding to have a weekend away.

Another client's case manager and community support worker assisted her and her family by providing information and reducing their anxiety. Various social and community supports were also put in place, which led to a noticeable reduction in her hospital presentations which she had previously used as an 'escape'.

The case manager was able to assist another client with young children to access child care, relationship counselling, social activities, psychological services and respite. She was not however able to access all of the services she was referred to such as transport and home care. The CCP was able to arrange for a case manager to be quickly appointed, which improved the coordination of her services. The CCP was involved in advocacy for home modifications but these have not yet occurred due to their significant cost and other obstacles such as building regulations. A service provider explained that without the intervention of the CCP, the client's family 'would have totally disintegrated – her husband would have walked out, her parents would have taken the children and she would have been left with nothing'.

In another case, the CCP helped a client to access increased physiotherapy, community support and some services from MSL. Although the client has been reluctant to accept many services, she now has a better understanding of her condition and is less resistant to services and support. The client was discharged from the CCP earlier this year as the CAG felt that she was no longer at risk of RAC following the interventions of the pilot.

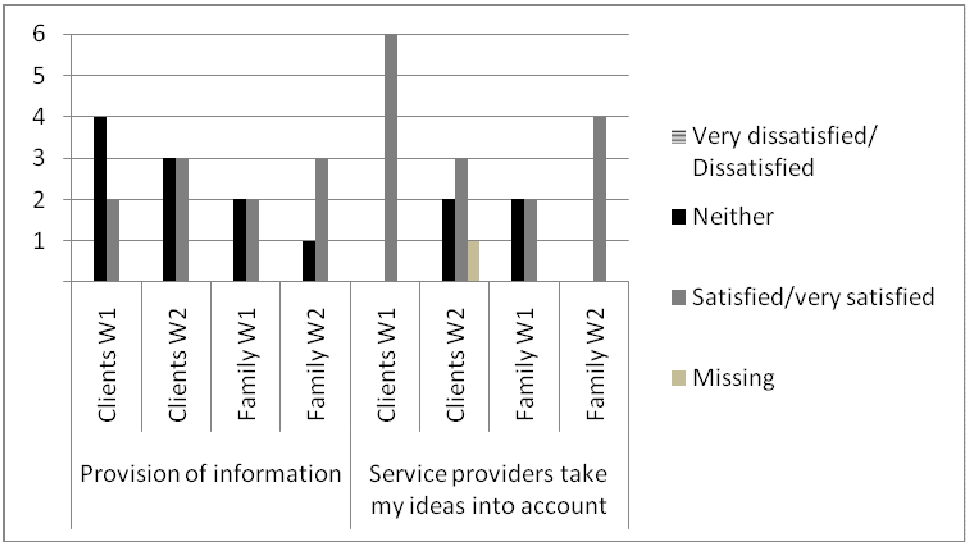
The CCP assisted another client who was on a 14 month waiting list for an occupational therapy mobility assessment. The CCP brokerage funds were used to obtain a private assessment which significantly speeded up her application for an electric wheel chair. This client was also linked to other services and respite. The client and her family member were not entirely clear about what had come about due to the CCP as opposed to help from the hospital system. In this case, the CCP was able to obtain community support for the client from MSL but the client still does not have a case manager.

One client was able to remain with, rather than lose her services. One of her service providers explained: '[The CCP] enabled us to show [the agency providing case workers] not to close her case management file because of the length of time she's been on it.' Although this client was linked to a lot of services before the CCP, the pilot has allowed her to maintain these rather than being forced into self-management, which she was not capable of doing. This may have enabled her to stay in her own home.

Relationship between clients and service providers

Not only was there an increase in the services clients had access to, but also some clients and family members perceived an improvement in their relationship between service providers. There was an increase in the amount of information provided to clients and family members as a result of the CCP. Clients and family members reported getting 'more information' and the survey findings showed increased satisfaction (Figure 4.4).

Figure 4.4: Client and family member satisfaction with service providers' provision of information and willingness to take on ideas at Wave 1 and Wave 2 (clients: n=6; family members: n=4)



Clients and family members also appreciated the coordinated care approach, which prevented them from having to repeat the same details of their care to different providers/medical personnel and reassured them that there was someone to contact who was familiar with their case. A number of clients and their families also said that the CCP made them feel more supported, more 'in control' and better able to articulate and have their views heard. As a service provider said, the support of the CCP coordinator and her community based care staff made the client:

> ... more able to express her needs and wants, and [she] has thus been more empowered to speak up to get her needs met better. I doubt that would have happened without the CCP pilot.

All family members at Wave 2 reported that they were satisfied or very satisfied with service providers taking their ideas into account. Despite these positive findings, fewer clients believed that their ideas were taken into account at Wave 2 compared to Wave 1 (n=2 and n=6 respectively; Figure 4.4)

4.2 Wellbeing and participation outcomes

Beyond improving clients' services, the CCP also brought a range of positive outcomes for all seven clients and for the five family members and carers associated with them. These included improvements to clients' psychological and physical wellbeing, family wellbeing, and participation and community.

Outcomes for clients' psychological and physical wellbeing

Reducing stress and associated psychological benefits

The most common outcome in terms of psychological wellbeing cited by CCP clients and their families was that participation in the program reduced their stress levels. This was described within five of the seven case studies. For several, this was attributed to increased communication between their service providers and resulting in less of a need for them to coordinate and communicate between these services themselves. The outcome of this was less stress and a feeling of support.

For others, stress levels were reduced as a result of having a more appropriate service package, resulting in outcomes related to feelings of physical safety and inter-personal security. For one client who lives alone, physical safety was related to having an increased amount of in home support which meant that she was no longer as fearful about what would happen in a medical emergency, as she felt that there would be people there to discover the problem and assist her within a reasonable timeframe. For another, an outcome of inter-personal security was gained through stress reduction, in that increased services allowed less stress on her family relationships due to feeling less of a need to ask her family members to care for her. Thus a reduction in stress as a result of the CCP appeared to link to outcomes of feeling supported, physically safe and inter-personally secure.

Physical wellbeing

For some clients, less stress also flowed into physical wellbeing and with the psychological benefits brought into effect by the CCP, clients' felt that physically these relapses were under more control and that they were at less risk of 'decline':

> I've noticed that since CAG's been involved, yeah, I have had a lot of relapses still, but I'm finding that it's reduced my stress, so I'm not, you know, struggling at home as much, because there are some strategies put in place. So it's kind of prevented me from declining, I think (Client).

Other improvements to physical wellbeing were also evident. For example, for one client, the CCP assisting to provide more appropriate equipment, including an electric wheelchair and an arm chair that will help her to stand up independently, which will increase the client's independent movement and exercise: 'It will make me get up and move a lot more and try and help myself'.

Further improvements to physical wellbeing for other clients include more assistance and services decreasing their physical fatigue levels, including connecting one client to a fatigue management course, resulting in greater energy for other areas of value in their lives. This may ultimately flow into psychological outcomes as well. For one client there was the benefit of spending more quality time with her children, and for another being able to access the community – aspects which contribute to the psychological factors of independence and inter-personal security.

Outcomes for family wellbeing

Outcomes for family members and carers

The CCP increased family members' and carers' wellbeing by putting specific supports in place for them. In several families, this involved arranging access to formal overnight respite care or day recreational activities, allowing family members to have a few days' break from caring responsibilities. In these cases, the outcome of the break for families or carers may not only be the time out from responsibilities and the emotional strains of caring, but also improving their relationship with the person for whom they care:

> He's not always under my feet. Like, he'll go out for the day, on Wednesday, and he'll come home and he's tired. And [I] can sit down and watch television and do what [I] have to do. He was tired [before starting the recreational activities], but he used to follow me around. I was like, 'Leave me alone, will you?' (Family member)

For another family, the client's son – and main carer – was given access to young carer support services and information through the CCP that were not previously available to him. This has the potential outcome of increasing his support systems, particularly in terms of balancing his schooling and carer responsibilities.

Comments by the husband of the client who received the electric wheelchair described above also show that the CCP may have physically benefited families:

> If she wasn't getting the assistance with the electric wheelchair, there would be days where I just can't take her out... [now] it won't be a strain on my back – I've had back problems for a number of years... (Family member)

Thus, in addition to relieving caring responsibilities, the CCP seems to have had flow on outcomes for the health of family members and carers, even while primarily addressing the physical needs of the clients themselves.

Outcomes for whole families

In some instances the CCP was able to benefit families as a whole. This is evidenced in the CCP arranging for one couple and one family each to have a holiday, giving families something to look forward to together:

> The CCP coordinator] organised that [the weekend away]. I haven't told the kids yet. I was surprised. I'm looking forward to it. The kids will be so excited. (Family member)

The possibility of such events may give families a welcome relief from daily caring responsibilities and routines, and allow them to enjoy each others' company in a relaxed context, allowing rejuvenation within their relationships. This may ultimately have the outcome of allowing families to remain caring for the clients for longer.

In one case study, the case manager arranged for by the CCP was also able to systematically organise a range of supports to increase the wellbeing of the family as a whole. This included addressing the needs of all family members in their various constellations:

> It's not just [my spouse], yeah, like I said, they're looking at the broader spectrum and, you know, working things out for our kids, [my wife] and I's relationship, and also looking at [my spouse] as an individual, and now they're starting to work out a few things for me as an individual. (Family member)

For this family, the case manager was able to organise marriage counselling for the couple, childcare for the children, access to respite care benefiting both the client and her husband, access to a support group for the client and is beginning to address support for the husband. The combined outcome of implementing these supports has been that the case manager within the framework of the CCP has been able to prevent family and marriage breakdown:

> Because I suppose there's a real risk too that my husband might say, 'Okay, that's it, I've had enough, I'm leaving with the kids'... I think the problem with a lot of services too is that they focus on the client, they don't focus on the family... the CAG has been really good [in addressing them as well]. (Client)
>
> Without the CCP her family would have totally disintegrated – her husband would have walked out, her parents would have taken the children and she would have been left with nothing. (Service provider)

Thus, beyond creating good outcomes for clients and carers individually, the individuals and systems put in place and coordinated by the CCP also appear to have improved family wellbeing.

Outcomes for participation and community

Reducing social and personal isolation through participation

For several clients, the CCP, in collaboration with case managers, connected them to a range of support groups, social coffee mornings and other recreational activities, such as gym membership. For some, this reduced their feelings of social isolation by providing them with activities within the community to participate in and social contact.

For another client, the CCP connected her with activities and facilitated an opportunity to participate in disability advocacy. These activities reduced her social isolation, which had increased after having to medically retire due to frequent MS relapses.

As mentioned earlier, there was a sense from one client that more could have been done in regard to this area. The CCP focused more on functional rather than social outcomes:

> What would be great is if there were more ... social and recreational programs out there that people like myself who can't do much, but would like to get out of the house, do something, keep the mind enriched... It's things like that that would really enrich everybody's life, not just mine, like everyone on the CCP. At the moment we've got all the services we need; we haven't got the recreation that we need though. (Client)

Accessing the community

The CCP was also able to assist clients with their transport and mobility requirements associated with being unable to drive or move around without the appropriate equipment. The outcome of this was to increase the access these clients had to their local communities. The CCP assisted one client with an assessment and funding to receive an electric wheelchair. This client anticipated that this action would flow on to outcomes of allowing her to access the local community independently of her husband:

> [My spouse] doesn't have to push me anymore. It gives me independence – I can go and shop when I want to shop. Just to get myself around easier – not have to be pushed. (Client)

The CCP also enhanced access to the community for other clients in terms of organising assistance with transport through applications for taxi vouchers. This was particularly significant to one client who was unable to drive and could not always depend on her family for transport due to difficult family dynamics. However, in one case, the CCP was unsuccessful in assisting a client to access transport subsidies.

Independence and remaining in the community

Finally, an outcome of the CPP was that it allowed clients to remain in the community. This relates to the CCP objective of keeping clients out of hospital and residential care (which is discussed in more detail in Section 4.3), but for one client this was framed in terms of independence, and the way that the CCP's actions had enhanced her independence to the extent that she is free to participate and live in the community:

> The pilot is giving me independence and still allowing me to stay home to do as I like, to live independently. (Client)

While articulated by one client, this is perhaps an outcome that may apply more broadly across those accessing the CCP. Enhancing independence may be seen as the outcome of a number of CCP actions combined, including the provision of more appropriate services and equipment.

Personal wellbeing scores

The positive outcomes that emerged in the case studies were also reflected in the survey data. While caution should be used when examining the personal wellbeing scores of clients and family members because of the very small sample, there was an increase in the personal wellbeing scores of both the client and family member groups between Waves 1 and Waves 2.

When the Personal Wellbeing Index was calculated, clients (n=6) scored 48.4 (out of a possible 100) in Wave 2 compared to 32.1 in Wave 1. Despite the improvement, CCP clients' wellbeing is still much lower than other Australian adults, which normally ranges between 73.4 and 76.4 (Cummins et al. 2007). Family members' (n=4) Personal Wellbeing Index scores increased from 60.3 to 69.6 (Table 4.2).

Table 4.2: Personal Wellbeing Index of CCP clients and family members/ carers at Wave 1 and 2 compared to adult and carer population groups

Group	**Personal Wellbeing Index**	
	Wave 1	Wave 2
CCP Clients	32.1	48.4
Family members/carers of CCP clients	60.3	69.6
Average adult range in the population*	73.4-76.4	
Average carer score in the population*	58.5	

* Source: Cummins et al. 2007

Change was more likely for clients than family members across different individual life domains between Waves 1 and 2. When clients were asked to rate their satisfaction with 13 areas of their lives on a scale of 0 (most dissatisfied) to 10 (most satisfied) there was a 1.5 or greater increase in mean satisfaction in 8 areas between Waves 1 and 2. Increases in satisfaction were recorded for life as a whole, future security, standard of living, feeling part of the community, feelings of safety, personal relationships, free time and financial situation (Table 4.3).

Table 4.3: Mean satisfaction with individual life domains by client (n=6) and family members/ carers (n=4) Wave 1 and Wave 2 (on a scale of 0 most dissatisfied to 10 most satisfied)

	Clients (n=6)			Family members / carers (n=4)		
	Wave 1	**Wave 2**	**Difference**	**Wave 1**	**Wave 2**	**Difference**
Life as a whole**	1.8	4.8	3	6.3	6.2	-0.1
Future security**	2.2	5	2.8	5.5	7	1.5
Standard of living**	3.3	5.2	1.9	5.8	6.5	0.7
Feeling part of the community**	1.8	3.7	1.9	5.3	7.8	2.5
Safe you feel**	4.7	6.4	1.7	6.3	7.5	1.2
Personal relationships**	4.7	6.3	1.6	7	7	0
Amount of free time you have	3.2	4.8	1.6	4.3	4.8	0.5
Financial situation	2.7	4.2	1.5	3.5	4.8	1.3
Physical health	1.7	3	1.3	4.8	6.8	2
Psychological health	1.7	2.7	1	7	7.8	0.8
Health**	2	2.8	0.8	5.8	6.5	0.7
What you have achieved in life**	3.8	4.5	0.7	6.5	6.5	0
Employment and/or educational opportunities	1.2	1.3	0.1	4	5	1

**Domains included in the Personal Wellbeing Index (see Table 4.2)

4.3 Hospitalisation and residential aged care placement

It is difficult to determine the precise impact of the CCP on clients' hospital admissions and their admission to RAC because of a lack of a control group and the very small sample size. In general, however, most interviewees felt that the CCP had been a very positive, innovative and necessary intervention which was assisting to keep clients out of long-term hospitalisation and residential aged care, as the following quotes demonstrate:

> ... through this program all these patients have managed to live in their own home environment without the need for residential care, and the patients are happier and feel more satisfied ... And they are able to move on with their own goals in life – one of the patients has started writing a book. Those things wouldn't have happened if the program didn't exist. (CAG member)
>
> The pilot is giving me independence and still allowing me to stay home to do as I like - to live independently... I'm more comfortable

> now knowing that I have people coming and making sure I'm okay; being able to eat is a major thing; being able to have a shower is a major thing... I've got more services that I can actually afford; I'm getting more help in sectors that I need than what I was getting before. (Client)
>
> I think it's wonderful and will make a huge difference to a person with MS or any other illness, and I really believe it will reduce going to hospital more. Prevention is a lot better than cure, and I think the mind also plays a big role in the health and welfare of a person. If they know they have some back up in the community, then I think it would halve the hospital admissions ... if people feel supported in the community then it does prevent them from seeking help in an institution. (Service provider)

Some of the clients interviewed did not seem aware that they were at risk of RAC but acknowledged that the CCP was planning for future eventualities that they had not considered or did not have knowledge of. Understandably, their service providers have tried to be optimistic in their dealings with clients while also giving them a realistic understanding of their disease course and management. All 7 clients remained in the community during the CPP. The fact that none of the CCP participants went into RAC during the period of the pilot is a very positive indication of the success of the CCP in providing supported services to keep participants in their homes.

Hospitalisation of CCP clients

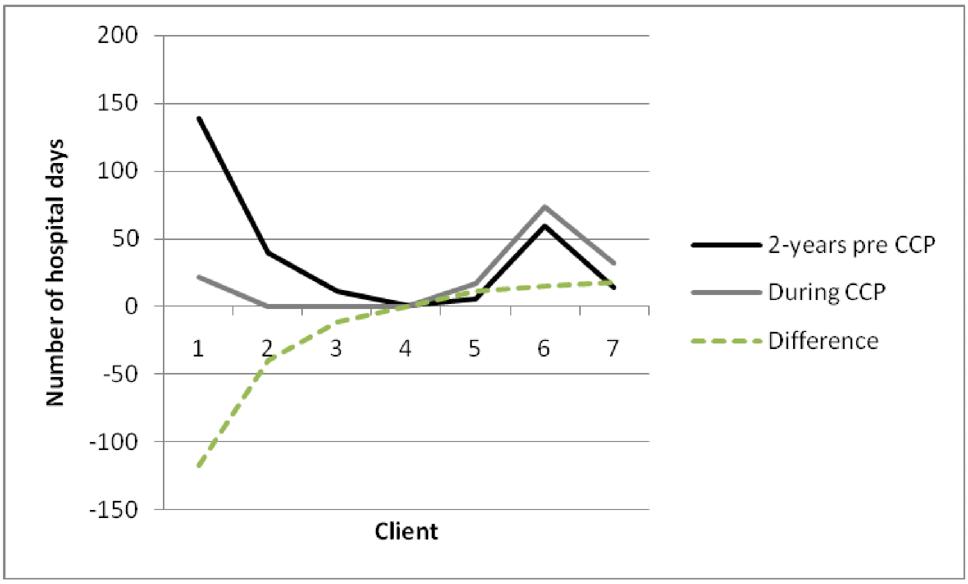
The hospitalisation data supports stakeholders' broad perception that the CCP was keeping clients out of RAC and preventing some hospital admissions. The hospital data were collected by the MSL CCP coordinator who used the NSW Health hospital records to track the number of days clients were hospitalised from two years prior to joining the pilot to the 30 June 2010. The records were analysed by determining the date clients entered the pilot, comparing the total number of admissions before the pilot (two years prior to joining the pilot to the day before entering the pilot) to hospitalisations during the pilot (from the day the client entered the pilot to the 30 June 2010 when the data were collected). Where data was recorded in hours, it was rounded up to one day of admission. All data was equivalized to a twelve month period for comparison.

The hospital data should be treated with caution because:

- data were only available for the seven clients involved in the evaluation;
- raw data was collected two years prior to clients joining the program but a shorter period of time had passed between joining the pilot and the end of the data collection period;
- the time clients had spent in the pilot varied; and
- the results assume that patterns of hospitalisation would be similar across a year, which is not always likely to be the case. Indeed, given the client group, it would have been more likely that hospitalisations increased given natural disease progression.

Although the hospital data should be treated with caution, the findings suggest that the CCP may have been successful in decreasing the total number of days clients spent in hospital. As a group the total number of days clients spent in hospital in a year decreased by 125 days (from 296.5 to 144.2 days). This was a result of decreases in hospital days for four of the seven clients and small increases in hospitalisation for the other three clients (Figure 4.5 and Table 4.4).

Figure 4.5: Equivalized annual days spent admitted to hospital before and during CCP and the total difference by client



The 125 day decrease across the group of CCP clients reflects a small decrease in the number of admissions (from 31.5 to 29 separate admissions per year). The change was mostly a result of the decrease in the amount of time clients spent in hospital once they were admitted (Table 4.4).

Table 4.4: Equivalized annual days clients spent admitted to hospital before and during CCP

Client	Total number of days in hospital			Total number of hospital admissions		
	2-years pre CCP	During CCP	Difference	2-years pre CCP	During CCP	Difference
1	139	21.8	-117.2	18	6.4	-11.6
2	40	0.0	-40.0	3.5	0.0	-3.5
3	11	0.0	-11.0	1	0.0	-1.0
4	0.5	0.0	-0.5	0.5	0.0	-0.5
5	5.5	16.6	11.1	1.5	3.7	2.2
6	59	73.8	14.8	4.5	13.2	8.7
7	14.5	32.0	17.5	2.5	5.7	3.2
Total	**269.5**	**144.2**	**-125.3**	**31.5**	**29.0**	**-2.5**

Source: NSW Health hospital data provided by MS Australia

Where clients were hospitalised as in-patients, the planned admission approach assisted to keep these as ‘short admissions’. Importantly, when clients were discharged, the CCP played an important role in linking clients to the appropriate services so their sound health management continued after they returned home, which helped prevent admissions to RAC. It was also believed that CCP had reduced preventable admissions to RAC through early identification of risk and by providing respite to resolve stresses. On the medical side, treatment was identified early and, where possible, was undertaken with clients remaining as outpatients.

It was also reported that hospital admissions were decreased in at least one case because the CCP had provided more holistic support, which decreased the ‘social’ admissions to emergency departments:

> The CCP actually enabled her to be sent home from an extended hospital stay through more supports going in. Because there are more linkages between the people working with her it has again seriously dropped the number of her presentations at the emergency department - from presentations of three a fortnight down to one in a couple of months. (Service provider)

While these findings should be treated with caution because of the small sample size, they are positive. They show that despite the expectation that hospitalisation would have increased as a result of the progressive degenerative nature of the clients' conditions, time spent in hospital decreased across the group.

4.4 Conclusion

All clients and their families experienced improved outcomes following their participation in CCP. There was a small overall reduction in hospital admissions, no client entered RAC and all clients seem to be in a better position with regard to future RAC admission. Clients’ service packages have improved and families have benefited directly and indirectly from these and additional services. There have been practical, medical and psychological benefits for clients as well as improved opportunities to participate in the community. Many of the positive outcomes arose from the effective work of case managers and service providers but these would not have been as effective without the collaborative process involved in the CCP. Further support in relation to social and recreational activities may have been beneficial for some clients.

5 The Continuous Care Model

This section contains a process evaluation of the effectiveness of the CCP. It examines the CCP based on the following four functional areas:

1. Pro-active disease management model
2. CAG guidance
3. Brokerage
4. Governance

In general, the CCP functioned as intended and was able to achieve most of its objectives and outcomes (as listed in 2.1 above). There were however, some early establishment issues in the set up of the pilot and some ongoing issues around procedure, brokerage and communication that were not resolved.

This section discusses the way in which the proactive disease management model was taken forward by the CAG so as to link clinical health services with disability and community services. The CAG was supported by the work of the coordinator, the steering committee and MSL in working across the two service systems to achieve improved outcomes for pilot participants.

5.1 Proactive Disease Management Model

The CCP involved a model of early identification of client risk and the development of disease management planning to alleviate this risk and bring together services and supports in a more appropriate service package to improve outcomes for clients and their families. Relatively simple approaches to risk and disease management occurred within the CCP and these were generally effective. According to a member of the CAG, the CCP:

> ...allowed them to understand the disease, be able to manage certain things and be able to implement plans in terms of crisis.

Risk identification

Clients were recruited to the CCP largely based on their likely risk of entering RAC. This risk identification process occurred via the CCP coordinator consulting with Macarthur ACARS staff about potential clients and discussing this information with the CAG. Clients were then grouped as to their appropriateness and eligibility. The CAG used the ACAT (Aged Care Assessment Tool) in their assessment of client risk of premature entry to RAC but also considered risk more broadly. A CAG member explained that risk depends on a number of factors:

> Lack of social and family support; difficulties in financial sustainability; may be at medical risk due to ongoing medical condition, such as ongoing MS relapses; ongoing disability – for example being in a wheelchair in a non-wheelchair accessible home.

CAG members seemed to be in general agreement about what risk entailed and there was emphasis on the social circumstances surrounding people as a major contributor to risk. One CAG member explained that risk assessments were done using a bio-psycho-social model, which considered if clients were at risk psychologically or socially as well as medically. Another CAG member, however, noted that there was sometimes disagreement about whether someone was at risk of residential aged care placement.

The coordinator acknowledged that clearer criteria would have been helpful but said that there was a common understanding in the team of the definition of risk. The MSL services manager felt that a firm protocol on risk might not be flexible enough.

It seems the CAG was able to function without clear guidelines on risk assessment, however these might have assisted debate within the CAG and encouraged consistency and efficiency. It is recommended that risk identification protocols should be developed for any future continuous care program.

Disease management

The focus of CCP was around risk identification and management and disease prevention. With this in mind, the CAG's initial focus was around clients' physical issues and then their psychological and social concerns and carer stress. The CAG developed individualised plans to address these different dimensions. The implementation of each plan was re-evaluated at each CAG meeting and the team working with the client dealt with new issues as they arose.

The CCP operated quite loosely without the introduction of clear guidelines or documentation to clarify the functions of the various structures and individuals involved. This was a sometimes a limitation, for example, permanent and ad hoc CAG members would have benefited from clearer definitions of roles and functions. But it did not prevent the CCP from functioning reasonably well in terms of disease management. If protocols or guidelines were developed for future similar programs they would need to be very flexible to accommodate the diverse needs of the clients. A good balance needs to be found that includes informality that by-passes an overly administrative model and good systems that make structures, individuals and processes function well.

Intensive case management and coordination

The coordination of services was seen as a critical component of the CCP's tertiary case management model. Coordination ensured a common goal which was more effective than 'everyone doing their own thing' (CAG member). It brought together a multidisciplinary team which allowed for ongoing reassessment of the order of priorities for each patient. It improved communication, allowed for new ideas and addressed service gaps. Many of the positive outcomes experienced by clients and their carers resulted from the hard work of their case managers and service providers but this was strengthened and extended by the involvement of the CCP in intensive case management and coordination. The coordinated approach linked medical and non-medical service providers which proved beneficial for some of the clients. It also prevented one of the clients from 'manipulating' service providers and 'playing people off against each other' as communication between her providers increased. It also allowed issues to be raised between groups of providers and to have the most appropriate or qualified provider address the issue.

The holistic nature of the tertiary management model was praised by some CAG members and other stakeholders. A doctor pointed out that because of the complex needs of the patients on the CCP who have multiple physical and psychological issues, a range of allied health care providers needed to work together to address all of these issues. A service provider said that coordination highlighted options that people had not thought of before (such as different funding sources) and that proved to be 'extremely effective' for clients. A CAG member said that the coordination of services had been beneficial for clients as it reduced the number of people they needed to talk to and hence reduced client stress. It was recommended that to further improve collaboration, CCP should involve shared electronic clinical records so all health workers have up to date notes on service plans and health issues.

Coordination appears to have worked effectively within the intensive case management of the CCP. Regular monthly meetings allowed for ongoing follow up on the progress of clients. These meetings also allowed for detailed discussion of each client with a group of relevant service providers (the client's own and additional knowledgeable people). These discussions resulted in specific planning for each client. The coordinator played an important role in taking forward decisions of the CAG and ensuring that CAG members acted on the decisions that related to them. These elements are effective and would be enhanced by the addition of documentation setting out the roles and responsibilities of all people involved in the CCP and the procedures to be followed.

Services packages and networks

The CCP was able to provide clients with more appropriate service packages in all cases as evidenced by the case studies (see Appendix A) and client outcomes (Section 4 above). The CCP appears to have realised its objective of developing service networks and responses to clients' changing needs. The coordination of services by the CAG and the coordinator strengthened existing networks within Macarthur ACARS and Liverpool Hospital and between these hospitals and private case managers and private service providers. This was not formalised beyond the inclusion of relevant service providers into CAG meetings on an ad hoc basis.

One of the stated objectives of the CCP was to 'generate a model regional services network for neurological health/disability management'. Again, no formalised regional network was developed, although the CAG was able to draw in service providers from Liverpool hospital and in private practice. This has strengthened relationships and existing networks and may have created new informal networks between health professionals, community workers, the hospital and external groups and individuals.

Communication

A clear understanding of the purpose of the CCP and its functioning was important for Macarthur ACARS, external service providers and for clients and their families. This placed a responsibility on the coordinator and MSL to communicate properly with all stakeholders in the setting up and running of the pilot. This was important for building relationships with hospital staff and service providers for the effective running of the CCP. It was also important for the participation of clients and their families and for their understanding of their services. There were some establishment and ongoing implementation problems in regard to communication. It is recommended that for future continuous care programs communication materials and communication strategies should be developed in advance of program commencement and implemented and distributed more effectively.

Hospital

The relationship between Macarthur ACARS at Camden hospital and the CCP seems to have been good. The coordinator was housed within the hospital which allowed for close contact between her and the various medical professionals. The hospital supported the pilot actively by participating on the CAG and Steering Committee and by providing facilities for meetings. The MSL services manager and the coordinator seem to have played a positive role in communicating the aims of the CCP in its establishment and functioning.

Hospital staff did not however feel that communication was as good as it should have been. One hospital employee reflected on the late launch of the CCP (‘18 months into the program’) and what she felt was a disjointed relationship between MSL and local health area. She observed that it was not until ADHC representatives joined the CAG that everyone became more aware of what the CCP was trying to achieve. Another doctor was much more critical of the communication regarding the establishment and running of the CCP. She said that she had never been made ‘formally aware of the CCP’s existence’ and MSL did not consult with her or ask for her advice in the design of the pilot. The CCP coordinator said that she was in fact invited to attend CAG meetings but declined to do so.

Service Providers

There was some concern raised about the lack of information and documentation on the CCP. The failure to launch the CCP at the start of the pilot and to provide all new CAG members and service providers involved in the CCP with ongoing information was a limitation. An information workshop about the CCP was held in May 2010 for the community, clients, service providers and others connected to the CCP. An earlier workshop, targeted at service providers would have been beneficial.

The information workshop as well as the CAG meetings and the coordinator’s work with various service providers had a positive impact in developing a greater understanding among stakeholders of progressive neurological diseases and service responses to these. A service provider said that her involvement in the CCP had benefited many of her other clients because she was ‘far more aware of other services available in this area’.

A service provider suggested that the CCP should be more widely advertised and another suggested better engagement about it with the community. A further service provider recommended better communication about the CCP. There was also a suggestion that the roles and responsibilities of all stakeholders be identified at the start of the program to avoid confusion including among case workers who felt that they were sometimes being managed by the CAG or its members.

Clients and Families

All of the clients and their families were appreciative of the CCP and felt that it had assisted them in a range of ways. This included providing information to them about disease progression and available services and funding to assist them.

However communication problems were raised as a concern by two clients. One client said that it was not clear to her what she could and could not ask the CCP for. She recommended that there be better communication about the CCP and who is involved in it. It was also suggested that clients be involved in the relevant parts of the CAG meetings and/or involved in some group discussions with stakeholders. While it may not be appropriate to include clients in CAG meetings, in some cases clients and family should be more actively involved in discussion and planning of their own case management.

Training and system change

One of the required outcomes of the CCP was to ‘define and establish training for service providers dealing with people with degenerative diseases’. Another was to ‘establish mentoring and education about the impact of degenerative diseases for staff in related services’. This appears to have been achieved in a limited form. The coordinator arranged for a training session for home care staff on cognition issues as clients often complain about the problems with these services. She felt it would have been good to have additional sessions (for example on equipment) but limitations of time and budget meant these did not occur. She noted that ‘there was nowhere to raise this’ and she was not sure ‘how much of a priority it was’. The MSL services manager said that education and training was not part of the conception of the CCP and that the lack of it was also a resource issue. This seems at odds with the training session that was held and the stated aims of the pilot in the funding proposal which mentioned the need to:

- Define and establish training for service providers dealing with people with degenerative diseases;
- Establish mentoring and education about the impact of degenerative diseases for staff in related services
  (DADHC, 2009)

Some of the service providers felt that they gained a better understanding of the service system through the pilot and the options available to clients. One CAG member said that it had been a 'learning curve' for the therapists who had become more aware of existing funding. She said 'there is more information flowing from various directions to the professionals'. Some also felt that they had learned more about MS and other progressive neurological conditions through their involvement with the CCP. A stakeholder recommended that case workers be trained about MS, mental health, and disease progression at the start of the program. A number of service providers felt that their clients had benefited from improved coordination and hoped to continue with this beyond the pilot. Most indicated a hope that the CCP or programs like it would be continued as part of the health system.

5.2 CAG Guidance

The CAG was the operational centre-piece of the CCP. Its role was to evaluate potential client's risk of entry into RAC, to develop disease management plans, to provide clinical advice and assessment, and to support and guide case coordination and decision-making around each patient. It was meant to regularly monitor and revise management plans as needed with a range of service providers involved with the client concerned.

The CAG was set up by the coordinator in June 2009. It comprised a representative of ADHC, various staff of Macarthur ACARS (including a physician and various allied health professionals),[10] the CCP coordinator and her immediate manager at MSL (although he stopped attending when he left the organisation). The CAG had a core of regular members but also invited particular service providers from Macarthur ACARS, MSL, other agencies or from private practice to attend those parts of the meeting where their own clients were to be discussed. The CAG met regularly for monthly meetings of approximately three hours each.

The CAG functioned effectively and played a positive role in fulfilling its intended functions. The external service providers also played an important role and contributed significantly to the success of the CCP. Overall, the meetings were perceived as informal, open, honest and constructive:

> CAG works well in that it is multi-disciplinary and the attendance is very good. The people work towards inter-disciplinary goals and aims, and agendas are quite similar across the board for each patient. It works well because it is an open forum, and because everyone is relaxed about giving their own ideas and opinions... each patient has a 20 minute slot which is allocated as part of the agenda. I think all of those things work well.

However there were aspects of the CAG that could have been strengthened. Better guidelines, procedures and terms of reference would have streamlined

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[10] The health professionals included a physiotherapist, speech pathologist, occupational therapist, and rehabilitation specialist physician.

the activities of the CAG and clearer definition of roles and responsibilities would also have enhanced the work of the individuals within the CAG. There were also challenges in engaging private sub-contractors in meetings when there was no remuneration for their time. Furthermore, meetings were criticised for their length, lengthy discussions without decisions, and lack of teleconferencing options.

There were also some issues raised regarding the composition of the CAG and the skills available to assist the members. The CAG learned a lot from having an ADHC representative as this person brought important knowledge of the disability service system. The representative changed three times during the two years as a result of staff movement within and out of ADHC. Involvement of government and additional government departments should be continued in future programs where needed. For example, the housing department could be invited to discuss ways of accessing appropriate housing and home modifications. It was also pointed out that the CAG could have benefited from a permanent social worker, which would have assisted with the holistic approach to clients, recognise patterns of behaviour and the impact of family relationships on clients.

There was also criticism about the attendance of case managers at the CAG. The lack of attendance may also relate to the issue mentioned above about case managers possibly misunderstanding the role of the CCP. A CAG member said that all clients on the CCP should have a community case manager to improve the flow of the tertiary level management. The issue of scarcity of case managers appears to be a systemic problem that the CCP could not entirely overcome.

Despite these challenges, the CAG was able to develop clear management plans for clients and their families and was able to monitor the implementation of these and adapt them when client needs changed or other issues arose.

5.3 Governance

The NSW CCP was run by a Steering Committee and was administered by the NSW office of MSL. A coordinator was appointed to take forward the decisions of the CAG and work with clients, their families and their service providers. MSL based in NSW administered the CCP (including the brokerage funds), managed the coordinator and convened the Steering Committee.

Governance was generally effective, the structures were appropriate and the individuals involved were, in the main, sufficiently skilled and suited to the tasks involved. However, the CCP faced some establishment problems. The choice of the site, along with other criteria, and poor communication about the pilot meant there were insufficient patients to meet the eligibility criteria. While Liverpool hospital would have provided a greater pool of potential clients, Camden benefited from the existence of Macarthur ACARS, a specialist rehabilitation centre and enabled the pilot to be tested in a regional rather than urban area. It is possible that the MSL services manager may have been unnecessarily inflexible in turning down potential pilot participants, thus resulting in the small client numbers. There were also initial relationship challenges between hospital and MSL staff, which were resolved, and confusion around the need for ethics approval delayed the start of the pilot.

The existence of a previous pilot in Victoria meant that the NSW CCP could use those elements that were deemed useful and disregard those that were not. For example, Victoria's life domains questionnaire, which was seen as 'invasive' was not used in NSW. The NSW CCP developed a memorandum of understanding with the Area Health Service which was not done in Victoria. The NSW CCP also developed more formal protocols around confidentiality and prepared its own consent forms. However, as mentioned above, the CCP lacked guidelines, procedures and protocols for some of its areas of work such as the running of the CAG and risk and disease management. It also failed to communicate or publicise some of its processes such as the brokerage guidelines. These concerns go beyond establishment issues and point to problems with implementation of the pilot and some of the difficulties facing the personnel involved, though many of the issues were resolved over time.

The Steering Committee

The Steering Committee was meant to 'provide governance, strategic oversight and advice' to the CCP to ensure that the objectives of the pilot were met. (MS Australia, undated b). The Steering Committee met four times (12 February 2009, 11 November 2009, 10 February 2010 and 14 September 2010).

The Steering Committee was made up of representatives from ADHC, MSL (the MS services manager chaired the Committee), and Macarthur ACARS at Camden Hospital. Some of the representatives have changed since then. The Steering Committee was made up of 'more senior decision makers' while the CAG contained the 'operational people'. The Steering Committee worked well as it contained a 'diverse field of disciplines' and included individuals who were committed to the concept of the CCP and keen to see it succeed. They were also experienced people who understood the hospital, health and service system more broadly.

The Steering Committee played an oversight role and monitored the progress of the CCP. One Steering Committee member described this as 'the overall plan of where the CCP is heading'. It ensured that the key agencies involved in the pilot were kept informed about the CCP and could offer advice and assistance if problems arose. The Steering Committee also considered applications for brokerage funding although the chairperson (the MSL Manager) approved funding. The Steering Committee also discussed transition of clients out of the CCP and the wrap-up of the pilot. An example of the Committee's role was the changing of the eligibility age and introducing flexibility in this regard. The Steering Committee also raised the issue of brokerage funds being restrictively controlled by the MSL services manager. Despite this being raised, it still took a long time to convince MSL to use these funds. This points to the possibility that the Steering Committee was not as effective as it could have been in holding MSL to its obligations in the pilot. It also might have played a larger role in encouraging MSL to launch the CCP or hold information sessions earlier than it did. The Steering Committee appears to have played a limited but important role in ensuring that the funders (ADHC) and the hospital remained committed to and involved in the CCP. It performed the functions that it was intended to but could possibly have been more forceful on the issue of brokerage funding and communication/awareness of the pilot.

It is recommended that in future programs of this nature a session is held to discuss the role of the Steering Committee, the functions of the individuals on it, and the terms of reference for its operation. This might make it a stronger and more effective body.

The Coordinator

The coordinator's role was to work with case managers to ensure continuity of care for CCP clients by ensuring:

- Improved information flow between health professionals and service providers;
- Timely and appropriate referral to services;
- The identification of service gaps; and
- The practical application of available resources.

(DADHC, 2009)

The coordinator appears to have performed all of these functions through her work on the CAG and her work with the clients, their families and their teams of service providers. She also set up the CAG, chaired the meetings, prepared the minutes and was responsible for following up the actions between CAG meetings. She was employed by MS Limited on a 0.6 FTE basis, which seems to have been sufficient time to allow her to perform her functions adequately.

Although the MSL offices are in Lidcombe the coordinator was based in an office in Camden hospital. This proved to be positive as it meant that she was able to build good working relationships with the Macarthur ACARS staff and keep in regular contact with them around client case management. It did however mean that the coordinator was somewhat isolated from support from MSL staff and support was poorly provided in the early stages.

The coordinator's medical skills (registered nurse) were important in helping her to understand the complex conditions of clients and their treatment.

The coordinator was also required to bridge ideological divides where certain medical staff saw the CCP in tension with their own medical approaches to disability. For example, a doctor based at the hospital but not involved with the CCP, expressed some concerns about the ideological basis of the CCP and its impact on clients. She said the CCP's client orientated approach might be creating patient dependency and getting other professionals involved unnecessarily. She felt a doctor-patient model was more appropriate for clients with cognitive difficulties than a client orientated one where clients make choices and initiate everything themselves. While this view was rare in this evaluation, it is not that unusual within the health system. A skilled coordinator needs to be able to show that a social model of disability that encourages patient participation and self-determination is more appropriate than a medical model that places most of the decision making with doctors.

Generally, the coordinator was praised for her hard work and good coordination. There were however a few issues in relation to her role, including blurred lines between her overall coordination role and her need to take on some case management functions for clients without case managers:

> Sometimes I wonder if there was a good understanding of the role of the Coordinator of this Pilot. Many people saw her as a Case Manager. It would have been good to have a very clear understanding of what her roles and responsibilities were, and if that was made very clear to the people on the CAG.

There should have been a clearer introduction of the coordinator and her roles and responsibilities prior to the setting up of the CCP structures.

One CAG member felt that the coordinator should have more power to insist that actions coming out of CAG meetings are taken forward by the CAG members responsible. While most people were doing what they were supposed to, there were some members who did not always complete their tasks in time for the next meeting which held up progress for clients. Given the cooperative model of the CCP and the fact that various agencies and individuals are involved over which the coordinator has no authority, this does not seem to be an appropriate suggestion. The coordinator was able to find ways of working with a range of people and encouraging them to make their contribution to a particular clients plan. As a whole, there was a high level of cooperation from all involved and much goodwill and hard work from service providers within and outside of the hospital.

MSL Management

MSL initiated the CCP, jointly funded it, and employed the coordinator to run the pilot. The MSL services manager convened and chaired the Steering Committee and was responsible for the allocation of brokerage funds and the overall management of the pilot including its finances. As mentioned, the MSL services manager did not work closely with the coordinator due to time and geographical constraints and this left the coordinator somewhat unsupported. This was to some extent addressed when an MSL person was sent to sit on the CAG and assist the coordinator. By the time this person left MSL the coordinator was managing more independently. As noted, the MSL services manager responsible for the CCP played an overly conservative gate keeping role with regard to the brokerage funding, regardless of the fact that these were to be ‘last resort’ funds and existing resources and/or funding sources were identified and utilised.

The role of MSL in the pilot was valuable as a number of MSL resources such as training programs and community support providers were able to be accessed by people who were not previously linked in to these services. In one case, a client who did not have MS was able to be supported by MSL with some services and this is unlikely to have happened without the CCP.[11] The organisational and other resources of MSL were important in ensuring the effective running of the CCP. It is unlikely that a pilot of this sort could have been run from within the health system as effectively. The involvement of a private outside organisation appears to have bypassed government bureaucracy and allowed for a more informal and efficient approach. Service providers noted that they had learned a lot about MS and similar diseases from their involvement in the pilot and this had assisted them in their work with clients and their families.

5.4 Conclusion

Most CAG members and service providers felt that the CCP was an excellent and much needed model and should be continued and made more widely available across the service system. This should involve including other illness types experienced by people at risk of premature entry to RAC. It was also suggested that the age eligibility be extended as people under 65 were ‘still young’. The CCP encountered some establishment problems that were largely resolved within the first six months of the pilot. The CCP had appropriate structures and personnel that functioned effectively. Communication regarding the purpose of the CCP could have been stronger. Brokerage funding was too tightly controlled and should have been used sooner and more expansively. The pilot would have benefitted from clearer guidelines, procedures and risk and disease management protocols. However, the flexibility of the CCP and its independence from the administrative structures of either the health or disability service system allowed for decisions and processes to happen quickly and efficiently without undue responsibility falling on participants. The balance between clear guidelines, procedures and role definitions and a flexible and ‘easy to use’ model is an important one. Despite these shortcomings, the CCP was able to perform its central functions and achieve many of its objectives and outcomes. The strong performance of the coordinator, CAG members and service providers highlights the commitment of health and allied health professionals to the idea of continuous care and improved service pathways to overcome some of the shortcomings of the health system.

The four elements of the tertiary case management model (as set out in the Program Logic Model (Figure 3.1) include: pro-active disease management, guidance from the CAG, collaborative partnerships with service providers and equipment and brokerage funds for referrals. These process components came together effectively in the CCP to achieve positive outcomes for clients. The collaboration between the CAG and service providers allowed for disease management planning and risk identification. These plans were then taking forward by the coordinator together with service providers. The CAG case discussions that brought in the particular providers for each client helped to facilitate intensive case discussion and sound planning and led to more effective management and cooperation. Clients and their carers were

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[11] It should however be noted that MSL regularly supports a wide range of people without MS such as through the flexi-respite service in NSW that MS administers.

encouraged to participate in their own service planning and were able to feel supported in seeking more appropriate service packages and supports. The brokerage funds, where used, filled important service gaps; however many of the clients were able to benefit from new or more timely services without much additional money being spent.

6 Cost analysis

6.1 Pilot funding

The NSW Continuous Care Pilot was funded by the Australian Government Department of Families, Housing, Communities and Indigenous Affairs[12] and NSW Government Department of Ageing Disability and Home Care as part of the Young People in Residential Aged Care Program.[13] Between 2008 and 2010 the MSL received $265,240 in government funding to implement and manage the CCP pilot (Table 6.1).

Table 6.1: NSW CCP government funding received in 2008/09 and 2009/10

Financial Year	Government funding
2008/09	$ 41,870
2009/10	$ 223,370
Total	$ 265,240

Source: MSL financial reports 2008/09 and 2009/10.

6.2 Pilot expenses

Based on the MSL's financial reporting, less than two-thirds (60.6%) of the government income was spent on the pilot during the 2008/09 and 2009/10 financial years. In total, $160,740 was spent on operating costs, salaries (including on-costs) and direct and indirect administration (Table 6.2).

Table 6.2: NSW CCP expenses 2008/09 – 2009/10

Expense	Financial year		Total	Per cent of total
	2008/09	2009/10		
Operating costs	$ -	$ 127	$ 127	0.1%
Salaries and on-costs	$ 29,328	$ 48,818	$ 78,146	48.6%
Direct admin	$ 1,442	$ 31,226	$ 32,668	20.3%
Indirect admin	$ 11,100	$ 38,699	$ 49,799	31.0%
Total	$ 41,870	$ 118,870	$ 160,740	100%

Source: MSL financial reports 2008/09 and 2009/10.

Over half (51.3%) of all expenses were administration based (including direct costs such as consultant fees, travel, telephone, insurance and general administration costs such as stationary and printing and indirect project, finance, IT and other corporate costs). Salaries and on-costs accounted for

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[12] Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (2009), Mid-term review Younger People in Residential Aged Care (YPIRAC) Program, FaHCSIA, 1 April 2010, http://www.fahcsia.gov.au/sa/disability/pubs/policy/ypirac/Pages/program_impl.aspx.

[13] ADHC (2008), Contract between ADHC and MS Society for the NSW Continuous Care Pilot, unpublished.

most of the remaining expenses (48.6%), while the operating costs (brokerage costs) were only listed as accounting for $127 (or 0.1% of all expenses) (Table 6.2). Although brokerage funding is barely evident in the financial reporting, according to internal CCP data received in August 2010, over $20,000 of brokerage funding has been approved and allocated (see Section 6.4).

6.3 Income compared to expenditure

According to the MSL financial data, the CCP spent only 60.6 per cent of all government funding received during the financial years 2008/09 and 2009/10. This left a surplus of $104,500 by the 30 June 2010 (Table 6.3).

Table 6.3: NSW CCP income compared to expenditure

		2008/09		2009/10		Total
Income	$	41,870	$	223,370	$	265,240
Expenses	$	41,870	$	118,870	$	160,740
Surplus/loss	$	-	$	104,500	$	104,500

Source: MSL financial reports 2008/09 and 2009/10.

The surplus is a result of a number of factors including, the smaller number of clients recruited to the pilot than envisaged, the delay in clients joining the pilot and the slow allocation of brokerage funding. It is important to note that some of the surplus has already been spent because the pilot has continued beyond 30 June 2010 and brokerage funding has been allocated (see Section 6.4).

6.4 Brokerage funding

A key component of CCP was the availability of brokerage funding. The brokerage funds were for the purchase of non-recurrent services and/or equipment for clients where ‘there is no other service response available and the service purchase can be shown to mitigate a present risk of disability exacerbation’ ie: ‘when a timing or service gap cannot be resolved, or a key service (such as an equipment assessment) is needed urgently’ (DADHC, 2009). The ‘Guidelines and Procedure: CCP NSW Brokerage Funds’ describes the purpose of the funds as follows:

> … to provide financial assistance to support a timely purchase of equipment or services, where there is a timing or service gap which has the potential of placing a participant of the pilot at imminent risk of not being able to remain at home or to return home from a hospital admission. (MSL Australia, undated c)

The CCP had a sizeable budget for brokerage - $150 000 out of the total budget of $250 000 or about $7,500 for each of the proposed 20 clients on the CCP. However, according to the MSL financial reporting, only $55,000 was budgeted for brokerage costs in 2009/2010. Given the trend towards increased expenditure at the conclusion of the evaluation period it seems likely that quite a lot more of these funds will have been spent by the time the CCP is wound up.

Brokerage funds were intended to be discretionary, limited and non-recurrent. They were not intended to replace the role of other funding avenues and therefore clients were required to demonstrate that no other funding was available for the requested service or equipment (MS Australia, undated c). While there was no set limit to individual funding, requests over $7,000 required additional explanation and processing.

These funds were to be administered by MSL. Funding requests could be generated by clients, the CCP Coordinator, primary carers, case managers and the CAG. Each request required the submission of a brokerage fund application form to the CCP Project Coordinator, which was approved by the CCP Program Manager (MS Australia, undated c).

Funding distributed

Despite the predicted $55,000 that was to be spent on brokerage costs in the 2009/2010 financial year, according to the financial data, only $127 was spent. This seems to have been due to overly zealous gate keeping on the part of the MSL manager and a coordinator and CAG members who did not have information on the extent of brokerage funding or access to guidelines as to how it should be spent, which limited the number of funding applications. It was the CAG members who pushed the Steering Committee to start spending the brokerage funding:

> It's only in the last couple of months that they have actually considered using brokerage dollars. I think that is quite a flaw. Sure you don't want to use all that money in the first month, but you also want it to be a fair process and for the funds to be used to help the clients. I kept saying, 'You need to put in a request for brokerage and we frame it in such a way, that says, "If we don't use this service or get this piece of equipment, then this person has a higher chance of having to enter residential aged care"'.

Funding did start to get spent during the second year. Data received from CCP in August 2010 indicates that almost half of the brokerage funding had been approved and allocated. A total of $21,797 in brokerage funding has been allocated to six current CCP clients.[14] Of the six clients who received brokerage funding, funding ranged from $360 to $10,000 and averaged at $3,633 per person (Table 6.4).

Table 6.4: Summary of brokerage funding allocated

Description	Number/$
Number of clients who have received brokerage funding	6
Average number of items funded per client	1.3

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[14] The five clients who have exited the program did not receive any brokerage funding. The remaining current client has not yet submitted an application for funding.

Range of funding received per client	$390 - $10,000
Average funds received per client	$ 3,632.86
Total brokerage funds allocated	$ 21,797.15

Source: MSL financial reports 2008/09 and 2009/10.

Funding was allocated across a range of areas to meet the individual needs of CCP clients. Brokerage funding can be categorised into equipment, professional service, family/social/lifestyle and home modification costs. Although only one client has thus far received home modifications these costs accounted for almost half (45.9%) of all the funding allocated. Equipment costs, including a contribution to purchasing a wheelchair, shower access equipment and a cooling vest, accounted for 30.8 per cent of the funding allocated. The remaining funding was provided for professional counselling and occupational therapy sessions (16.6%) and to contribute to family and lifestyle benefits, such as a weekend away and training for a client's pet (6.7%) (Table 6.5).

Table 6.5: Brokerage costs by category and description as at August 2010

Category	Description	Cost	Proportion of funding allocated
Equipment	Cooling vest	$ 140.00	
	Wheelchair contribution	$ 6,000.00	
	Shower access equipment	$ 572.50	
	Total	$ 6,712.50	30.8%
Professionals	Counselling	$ 1,920.00	
	Occupational therapist	$ 1,700.65	
	Total	$ 3,620.65	16.6%
Family/social/ lifestyle	Family respite weekend away	$ 1,214.00	
	Pet trainer	$ 250.00	
	Total	$ 1,464.00	6.7%
Home modifications	Access modifications	$ 10,000.00	
	Total	$ 10,000.00	45.9%
Total		**$ 21,797.15**	**100%**

Source: MSL CCP Project Coordinator, August 2010.

The brokerage funding should have been used earlier in the pilot and discussed more transparently with the coordinator and CAG and Steering Committee members. There should have been clearer guidelines on what the funds covered and how to access them and these guidelines should have been more widely available. The extent to which all the brokerage funds should have been expended is not known. The evaluation was not tasked to determine whether the amount of funds allocated to brokerage was appropriate to meet the objectives of the CCP. This issue should be considered for future continuous care programs.

6.5 Cost per client

It is difficult to summarise the cost of the program per client because, with the slower than expected establishment and implementation of the pilot it is difficult to differentiate establishment and recurrent costs. Therefore the total expenditure between 2008/09 and 2009/10 has been used to estimate the cost of the pilot per client. Table 6.6 shows the total cost per all clients engaged with the pilot (n=12) and the cost for the current client cohort (n=7). It also includes the cost per day based on the total number of days clients have spent in the pilot between joining and either their exit or as at 30 June 2010 to align with the financial year data.

Table 6.6: Estimated cost of CCP per client

Description	Cost
Total pilot cost 2008/09 – 2009/10	$ 160,740.00
Cost per all clients (n=12)	$ 13,395.00
Cost per current clients (n=7)	$ 22,962.86
Cost per day (based on total days clients have spent in pilot, from joining to exit or 30 June 2010, n=2227)	$ 72.18
Cost per client per annum (based on day rate across a year)	$ 26,344.90

The cost per client is relatively small given the benefits of improved supports, better services and perceived improvements in client wellbeing. Furthermore, the total cost of the pilot ($160,740) was roughly offset by the decrease in hospital admissions over a one year period ($158,850) (Table 6.7).[15]

Table 6.7: Equivalized annual hospitalisation cost by days admitted prior to and during CCP

	2 years pre CCP	During CCP	Difference
Total hospital days per year	269.5	144.2	-125.3
Hospital cost per year (daily rate of $1,267.94)	$341,709.83	$182,859.83	-$ 158,850.00

6.6 Conclusion

The NSW CCP received $265,240 in government funding between 2008 and 2010. By 30 June 2010 only $160,740 had been spent. Almost all expenses were related to salaries and administration. The extent to which all the brokerage funds should have been expended is not known. Despite this, poor communication between the coordinator and her manager, an insufficiently informed CAG, the coordinator's lack of knowledge about the guidelines or procedures and late applications resulted in low expenditure of brokerage

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[15] In addition to this none of the seven clients were admitted to Residential Aged Care facilities.

funding. While brokerage costs were not visible in the financial year data, they did start to get allocated late in the pilot. The cost of the pilot per client is relatively small given the benefits of improved supports, better services and perceived improvements in client wellbeing. The total cost of the pilot ($160,740) was roughly offset by the decrease in hospitalisation ($158,850 over 12-months).

7 Findings and Recommendations

This section sets out the main findings of the evaluation and the evaluators recommendations.

7.1 Main evaluation findings

General

1. The CCP was an important and valuable program that provided support and assistance to all of the program clients. It met most of its objectives, although for a smaller number of clients than was originally intended. It met some but not all of the objectives and outcomes set out in the funding proposal.

Client outcomes

1. The CCP had positive outcomes for all of the clients who participated. Some clients had reduced hospital admissions following the involvement of the pilot. All clients remained out of RAC during the pilot period and seem to have an improved chance of staying at home for longer than they might have had the CCP not been involved. The coordinated supported services across the health and disability systems that they received as a result of the CCP contributed to their improved outcomes.

2. Clients had reduced waiting times for services and were introduced to services of which they were not previously aware.

3. Other positive outcomes for clients included mental health benefits as they felt more supported by the CCP and their improved services and supports. These included medical, psychological and social.

4. Family members who cared for clients also seem to have benefited from the CCP due to improvements in the client's health and psychological state and as a result of a practical assistance such as respite, child care, home care and mobility assistance. In some cases they received direct benefits such as young carer information and training, child care and relationship counselling.

5. Clients without case managers would have been more effectively assisted by the CCP had such managers been available.

6. Clients did not always fully understand what the CCP was and what it was doing for them. However, clients and their family members have become better informed about their likely disease progression and the planning needed to address this.

Program effectiveness

1. The CCP, despite some early issues, functioned effectively according to the objectives of the program.

2. The lack of guidelines and procedures meant that the CCP took time to reach full functioning.

3. Communication regarding the purpose and nature of the CCP could have been better and the launch of the CCP should have occurred much earlier.

4. The choice of location, poor communication about the CCP and eligibility requirements meant that there were insufficient clients to reach the targeted number of 20 clients. A total of 12 clients participated in the pilot.

5. The initial decision to restrict the age of eligibility to the pilot at 50 years limited the number of potential participants. This was later relaxed.

6. The limitations of the health and broader service system could not always be overcome by the CCP. The CCP did manage to help clients find ‘short cuts’ around long waiting lists and link clients to new medical and non-medical services of which they were previously unaware but was not always able to obtain case management or other services for clients.

7. The CAG functioned well, met regularly, was run well, ethically, and sensitively. It was able to evaluate client risk and develop plans to manage this. It was also able to monitor ongoing implementation of these plans.

8. The support of Macarthur ACARS and hospital staff was invaluable to the effective functioning of the CCP. Hospital staff took the pilot seriously, worked hard for it to succeed, and were committed to the idea of tertiary case management. External service providers also performed an important role and involved themselves positively in the CCP.

9. The coordinator was effective and was able to follow through on decisions made in the CAG. The difficulty of separating the coordination function from a case management function was sometimes an issue. Locating the coordinator in the hospital was very helpful as it meant she was in daily contact with hospital-based service providers working with CCP clients and could follow up on CAG decisions more easily.

10. The brokerage funds were not fully used and only came into play quite late in the pilot. The lack of transparency about the funds and the restrictive use of them was a problem for the functioning of the CAG and may have had some impact on the effectiveness of the pilot as a whole.

11. The total cost of the pilot was $160,740, which was roughly offset by the decrease in days spent in hospital over a 12-month period

($158,850; when the equivalized annual number of hospital days were compared before and during the pilot).

12. Many of the clients benefited from the additional services offered by MSL and may not have accessed these if not for the pilot.
13. The involvement of ADHC on the CAG and Steering Committee was valuable as it provided access to information on funds and services that people were not previously aware of.
14. The independence of the CCP from government meant that it was able to work flexibly and effectively without bureaucratic constraints.
15. Service providers benefited from the CCP as it allowed for good links to be made between all those people dealing with particular clients. It improved communication and cooperation between the different providers.

7.2 Recommendations

1. The CCP is an effective and important intervention that should be developed for broader use within the health system. By bringing together a professional team to develop coordinated and improved patient management, clients get access to better services and have improved outcomes for themselves and their families.
2. The CCP did not reach its full capacity and if the pilot is further rolled out consideration should be given to location and eligibility criteria.
3. There should be clearer guidelines on the role of the Steering Committee, the CAG and the coordinator. Procedures for meetings and case coordination should be developed. There should be a chairperson appointed who is not the coordinator so as to keep a separation of the two roles.
4. The nature and role of brokerage funds must be better communicated.
5. Risk identification protocols should be developed.
6. With regard to the above points 3, 4 and 5, the need for guidelines, role descriptions and protocols should be used in a balanced fashion so as not to detract from the flexibility and lack of formality that was a positive feature of the pilot.
7. Communication materials and communication strategies should be developed in advance of program commencement.
8. Ideally, the coordinator should have a medical training as well as a good understanding of the disability service system. Strong organisational and communication skills are also needed.

9. Involvement of government should be continued in future programs. Additional government departments should be included in meetings where information is needed, for example, the housing department can be invited to discuss ways of accessing appropriate housing and home modifications.

10. Where appropriate clients and family should be more actively involved in discussion and planning of their own case management.

11. With regard to the wind up of the pilot, it is recommended that remaining brokerage funds be used to develop discharge plans for clients. However, there is a concern that the ending of the pilot may bring some risks to the ongoing health and well-being of clients and their carers. It is recommended that the positive features of the pilot be considered in developing a broader program to support people with progressive neurological conditions. Key features of such a program should include:

    11.1 The efficient use of existing services by creating a better understanding of client need and the services available to meet this need;

    11.2 Linking clients to new medical and non-medical services and speeding up service provision;

    11.3 Coordination of the various levels of case management through a Clinical Advisory Group and a coordinator together with case managers and with the participation of clients and their families;

    11.4 Training and education of program participants, their families and service providers on the nature of PND and its progression;

    11.5 Effective use of brokerage funds to speed up access to services and provide for services and supports that would not otherwise be available.

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Appendix A: Case Studies

Client 1

This client is a single woman in her early 30s. She has little social support or family relationships, and lives alone. She has a diagnosis of MS and associated mental health issues, uses an electric wheelchair and only has movement in one hand.

The main issue she identified to the CCP was the need to receive enough services to remain living in her own home by herself. Her ability to maintain her independence, her own home and her lifestyle with her pets were paramount concerns for her.

Once engaged, the CCP was able to link her to a range of disability services, including secondary case management, as well as engage brokerage funding to help her with other areas of concern important to her, such as training for her pets and for some equipment.

Before the CCP

Prior to her involvement in the CCP, the client identified as only receiving domestic assistance once a fortnight, despite a significant need for more services, particularly personal care and more frequent domestic assistance:

> *Client: "I can't cook my own meals, I can't get into the shower by myself, and I can't afford full-time personal care or anything like that. The way I was ... I only had domestic assistance once a fortnight ..."*

She was on a waiting list for mental health services, and had tried to access some other support services herself, but had been unsuccessful. This was a source of considerable stress for her, as she was socially isolated and in the event of an accident or medical emergency, no one would necessarily know that she was experiencing a problem until the situation had escalated.

The client had had 73 presentations at emergency and three lengthy hospital stays in the period 2005-2010, including one stay of a period of several months, as well as a short-term admission to a residential aged care placement. For all of these reasons, she was considered at serious risk of nursing home or residential aged care placement. As her previous placement had been a very negative experience and indeed cut short, she was not keen to return. When approached by the CCP at the end of June 2009 and accepted to the program, her primary objective was to remain living in her own home with her own lifestyle.

Since the CPP

The CCP's role for this client has been predominantly about organising access to a range of disability, mental health and support services. The program has been able to organise case management, increased domestic assistance, Home Care twice a day, psychological treatment, access to some social events through the MSL support group, access to respite care and assistance with inquiries regarding getting a ‘helper dog’. Additionally, the CCP was able to use brokerage funding to arrange for the client to receive training for her pets that her physical disability restricts her from completing herself.

Furthermore, the coordination between her different service providers and the involvement of a secondary level case manager has gone some way to managing the client’s relationships with particular service providers, with whom she has a history of disagreements. While this is not always successful, it does mean that the client has some advocacy support when making a complaint.

Outcomes from the CCP

At a service level, the CCP has allowed the client to access a range of new services, which she had not been successful in gaining entry to previously, despite efforts:

> *Client: “When I called around to find out what sort of help I could get when I needed it, I always got the door slammed shut in my face ... So if it wasn’t for the CCP intervening – getting me a case manager, getting Home Care on to it – I wouldn’t be getting these services, and I’d still be stuck with fortnightly domestic assistance and that’s it”.*
>
> *Client: “Pretty much all the services I’m getting now, I never had before the pilot, so I attribute it all to the pilot program”.*

This implies that the CCP as a program may be able to advocate for individuals due to the expertise and knowledge brought in by a range of players, to achieve results that individuals would not be able to achieve on their own:

> *Case manager: “If the client had not had this advocacy and support they might not have been able to access the services or even been aware of what is available to them”.*
>
> *Social worker: “With all the expertise in the CCP everybody has knowledge of other services or other organisations and facilities ... within the community that one individual didn’t have, so they were able to have a broader view of stuff, of what’s out there, rather than an individual searching for something”.*

The benefits of these services for this client are however more broad-ranging. As a young woman, it is particularly significant to her that the services allowed her to maintain her independence:

> *Client: “The pilot is giving me independence and still allowing me to stay home to do as I like, to live independently”.*

However, on a more practical level, the increased range of services also contributes to her safety (in the context of social isolation) and stress reduction:

> *Client: "I had a lot of stress before CCP... I'm more comfortable now knowing that I have people coming [to my house] and making sure I'm okay".*
>
> *Allied health professional: "I think it has helped alleviate stress and burden to have more services available".*

The benefits of increased coordination and communication between her service providers were also significant for this client. She cited the benefits of the communication between her providers in terms of not having to explain her medical or service details quite as frequently to different medical or service providers, which allowed her to be less anxious.

In addition, the communication between her case manager, organised by the CCP, and some of her other service providers, allows her advocacy support and potentially a mediator when she is having difficulty with certain providers. Although the client remains unsatisfied with some aspects of her service provision from specific providers, this role of her current case manager in helping her to speak with the organisations involved and make a complaint is something she commended. She did however express dissatisfaction with the turnover rate of case managers throughout her time on the CCP, as she had had three different case managers in her first 6 months on the program. While this may relate to a problem beyond the scope of the CCP, it does suggest that the most effective relationship for the client between the secondary and tertiary case management levels will occur when there is consistency in the case manager, rather than a need to 'get to know' successive case managers anew.

Coordination and communication between the client's service and medical providers was also cited by two providers as beneficial in managing the client's relationship with the service system and a variety of providers:

> *Medical service provider: "I suppose what happened is that everyone started talking to each other... and there's almost a point where if she knows that people are all talking to each other, she can't play people off against each other".*
>
> *Social worker: "One of the things that [the client] did really well was that by having everyone disjointed, she was able to manipulate each other, and one of the things that happened because of the CCP is that that then got reduced, because everybody knew what everybody else was doing".*

The client's previous behaviour may have stemmed from her frustrations about receiving only a very small amount of uncoordinated and inappropriate services. Improved service management has possibly allowed her to have greater confidence in those services being provided, and thus not feel the need to act in the ways she had previously.

Several service providers felt that the client's involvement in the CCP and the new services it has provided has reduced her hospital admissions. Supporting documentation shows only seven hospital visits since her participation in the CCP, with several of these for only one or two days, and only one for longer than a week. In addition, some were planned visits rather than emergency presentations. This is significant, as she had had 73 hospital admissions in the five years prior to the CCP, including some for a period of months. As one explained:

> *Medical service provider: "The CCP actually enabled [the client] to be sent home from an extended hospital stay through more supports going in. Because there are more linkages between the people working with her it has again seriously dropped the number of [her] presentations at ED (emergency department) ... From presentations of three a fortnight down to one in a couple of months is pretty good".*

Another service provider felt this was due to the CCP recognising that this client had used hospital for 'social admissions' in the past, when she was having trouble with family or services, and accordingly putting other more appropriate services in place:

> *Social worker: "With [the client] they've been able to put in the booked respite. In the past, she ... would come into hospital, and now with the CCP what it's done is booked respite ... – that's now prevented her from coming into hospital".*

Seen from a broad perspective, less frequent hospital admissions combined with the option of respite care and the independence within the client's own home, as described above, may ultimately delay the client's entry to residential care, as she will be able to remain in her own home with the supports in place that allow her temporary residential support when she needs it, rather than permanent placement.

However, there was still a feeling among some players that more could be done to support the client in staying out of hospital:

> *Community worker: "So some hospitalisations have occurred [for her] and she was suddenly discharged from hospital without an adequate support system and there was no quick access for financial assistance to cover needed attendant care services for her".*

Although there is some question of whether attendant care does require financial outlay, or whether the client had not received this service due to other reasons such as waiting lists, the quote above shows that implementing supports to keep clients out of hospital may be a particularly complex area for the CCP to address, requiring navigation of external service system factors, such as finances/funding or waiting periods. This is a point supported by one of the CAG members, who cited the difficulty that the CAG sometimes had in getting around waiting lists.

Further areas for improvement were also identified by the client herself. Whilst she was very satisfied with the range of services that had been put in place to assist her with functional activities and daily living, she felt that the CCP could do more to address her social isolation and need for increased social contact:

> *Client: "What would be great is if there were more ... social and recreational programs out there that people like myself who can't do much, but would like to get out of the house, do something, keep the mind enriched ... I think that if enough of the organisations got together... it might help. Or if they could start up something ... like a recreation officer ... Like they could organise on different days of the week – one day would be art, one day would be swimming ... Because that would sort of enrich our lives that much more – we wouldn't just be surviving, we'd be living ... It's things like that that would really enrich everybody's life, not just mine, like everyone on the CCP. At the moment we've got all the services we need; we haven't got the recreation that we need though".*

The client also expressed interest in attending a CAG meeting herself, to assess the way her interests were being represented by different players. She did not necessarily wish to attend every meeting, but suggested that the option should be there if she wished to pursue it. One of her medical service providers supported the idea of clients *"being part of the ongoing discussion"*.

Client 2

The client is a woman in her early 40s who lives alone in a fully modified Department Of Housing property and finds it difficult to manage financially. She was diagnosed with relapsing remitting Multiple Sclerosis (MS) over ten years ago and has had several admissions to hospital over the intervening years with exacerbations of her MS. Her physical skills are now those of a quadriplegic. In addition the client also has non insulin dependent diabetes, obesity, cellulitis and uses a catheter. The client is dependent on services for personal care, domestic tasks, meal preparation, shopping and transport. According to one of her service providers:

> *From a physical perspective, [the client] has had increasing difficulties in completing her activities of daily living with or without assistance. Showering and transferring to her bed for drying, dressing and so on has been a particular challenge. She is at significant risk of being admitted to an aged care facility if she is not provided with additional resources to assist her in living in the community [and with] activities of daily living.*

Furthermore, according to her case manager she is 'an isolated woman with no peers or friends. She has no company, apart from visiting service providers'. This lack of social support also puts her at significant risk of premature entry into residential aged care.

Before the CCP

Prior to her involvement with the CCP, the client's needs were met by the Home Care High Needs Pool, who provided (and continue to provide) 35 hours of assistance a week and an elderly community worker who assists her with shopping on a regular basis. She also attends physiotherapy weekly and accesses an occupational therapist for equipment assessment as required. The client has a Community Support Worker from Multiple Sclerosis Limited, as well as access to a MSL Clinical Nurse specialist for information and support to manage continence issues. Over the years there have been several services that have refused to assist this client as she has not met their eligibility criteria. This has left her feeling isolated and frustrated.

Since the CCP

The client commenced the CCP in July 2009. Whilst she was linked in to a lot of services prior to the CCP, the CCP has allowed her to maintain these services, in particular her case management through Community Options. Prior to her involvement in the CCP, Community Options were looking to close her case management files due to the length of time she had been utilising this service and due to their motivation to train clients to become self-managing. Community Options, following collaboration with the CCP, has agreed to keep the client on their books until she is either admitted to RAC or similar due to her complex needs. In addition, her case manager feels that the CCP has been:

> *"... very good at tapping into rehab for [the client] – in collaboration with all parties we successfully got her into rehab for two weeks. She's got quite a few referrals for specialist appointments and the outcome has been that she's been able to link into that".*

The CCP has also enabled the client to continue receiving home visits from her counsellor to assist her with her depressive tendencies, social withdrawal and isolation. The client was originally paying for these appointments but was unable to continue to do so; however the CCP accessed its brokerage funds so that the client could continue to receive this service for another 12 months. Recently, the client received emergency counselling through the same service following a traumatic event which almost caused her to not return home. The CCP brokerage funds also recently paid for additional equipment to prevent her falling out of her wheelchair.

Outcomes of the CCP

The client's physiotherapist feels that one of the major successes of the CCP is that the client has been able to continue living in her own home, as 'she [the client] would be distraught at any other option'. Her case manager feels that 'maybe' the CCP could help to prevent the client from entering residential aged care prematurely.

The CCP's funding of home visits from her counsellor has been most beneficial as the clients feels that she 'connects well with the counsellor'. This is a significant achievement as the client finds it difficult to trust and open up to people. According to one of her service providers, the client has told her that the counselling sessions have: '... helped to lift her anxiety about changes, her feeling of isolation and depression'. This service provider elaborated that the counselling sessions have provided:

> *"... her [with] a sense of stability and continuity. Also, this regular counselling service [helps her in] alleviating her tension [and] gives her opportunity to discuss her fears or difficulties on a more practical level and with the counsellor's help [and to] make more realistic plans to approach challenging situations in her life".*

The liaising with services providers that comes from being part of the CCP has had spin-off effects on the client. Her case manager commented that the client has '... enjoyed the social engagement of everyone being involved – the additional phone calls and so forth of services' and her Community Support Worker believes that the client, possibly for the first time in her life, feels 'listened to'. Her neuropsychologist feels that the support of the CCP and other service providers has enabled the client to: 'express her needs and wants, and (she) has thus been more empowered to speak up to get her needs met better'. However her case manager flags that the conclusion of the CCP poses a possible risk: 'For [the client] it has meant more people have come into her life ... she will find it difficult once people start exiting again'.

Client 3

This client is in her late 40s, living with her de facto partner, who also identifies as her carer. The couple live in a low socio-economic area, and would appear to have poor knowledge of how to navigate the disability service system. The client is diagnosed with a variant of Gullaine Barre Syndrome, known as chronic inflammatory demyelinating polyneuropathy (CIDP), and has an additional diagnosis of depression.

The client uses a manual wheelchair, and both she and her de facto partner identify most of the functional issues around her disability as involving mobility – both within the home and within the community, such as using public transport. Mobility issues were identified as particularly pertinent as these related to both the client's independence and her husband's health, as without the proper equipment assisting his wife with mobility was becoming increasingly difficult and straining his own 'bad back'.

Once engaged, the CCP played a role in addressing these mobility issues for the couple, as well as putting in place initiatives to address their service support and better coordinate their services.

Before the CCP

Prior to becoming a part of the CCP in mid-January 2010, the couple had no case management strategy in place and were lacking the correct equipment to assist the client's mobility needs, although she was receiving physiotherapy services. The client was using a manual wheelchair which she was unable to push herself, and thus required her husband's assistance with all movement in the home and community.

The client was on a 14-month waiting list for an occupational therapy assessment to address her mobility needs, but the couple were not able to push for a quicker assessment. With little assistance in navigating the disability service system and increased client medical needs, their stress levels were rising.

When the client was admitted to hospital in mid-January 2010, she was approached about being part of the CCP.

Since the CCP

Once the client became part of the CCP, the program worked to address two main issues – firstly, mobility, and secondly, to engage support services.

In May 2010, the CCP engaged brokerage funds to employ a private occupational therapist to conduct an assessment for the client to receive either an electric scooter or electric wheelchair. This allowed the couple to deal with their mobility issues without having to remain on the 14-month waiting list and without having to pay for the private OT themselves, a cost they would have been unable to cover. When interviewed in July 2010, the application for an electric wheelchair had been submitted – half paid for by CCP brokerage funds and half paid for by other funding – and the client is expecting to receive the wheelchair shortly. The CCP was also able to arrange for assessments for an arm chair that would help her stand up independently and preliminary discussions around home modifications.

The CCP was also able to link the couple in with a range of support services. This included arranging for a key community worker to be assigned (although still no case manager); arranging for the client to become a member of MSL and thus receive access to the MSL support group and respite services, despite not having a diagnosis of MS;[16] and arranging for the couple to have their first weekend away in many years through flexi rest, something which they were both greatly looking forward to, but would not have had the economic resources for without the support of the program. In addition, the couple cited the communication between their service providers – primarily their physiotherapist, private occupational therapist and community worker – as another key aspect that the CCP provided for them.

Outcomes from the CCP

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[16] The client has CIDP which, as a demyelinating condition is recognised as similar to MS, and allowed for her registration with MSL. There are not adequate services due to lack of funding available to the CIDP support group and their workers are volunteers. Therefore, registration with MSL opened many doors by allowing access to services (respite, flexi-rest, community support workers, psychologists, incontinence clinic etc).

Overall, one of the main outcomes of the CCP for this couple was that they were able to receive the assessment for the equipment that would be beneficial to both of them without having to remain on the 14-month waiting list. The client's husband recognised that the process of receiving the electric wheelchair had been fast-tracked due to the CCP's involvement:

> *Husband: "I think having the involvement in the CCP has sort of sped up the process, knowing who to go and see, who has got funding, that sort of stuff".*

From a personal and equipment perspective, the CCP addressing the issue of mobility through arranging for the electric wheelchair will allow the client greater independence and less reliance on her husband:

> *Client: "Well, [the electric wheelchair] changes that [my husband] won't have to push me anymore. It gives me independence – I can go and shop when I want to shop. Just to get myself around easier – not have to be pushed".*
>
> *Client: "It will make me get up and move a lot more and try and help myself".*
>
> *Private OT: "Independence will improve with more mobility. This gives her a more hopeful future – something she can look forward to; hope for [her husband] – he got very excited about the wheelchair ..."*

This also feeds into benefits for the husband's health, as he was becoming increasingly unable to assist her due to his own 'bad back':

> *Husband: "If she wasn't getting the assistance with the electric wheelchair, there would be days where I just can't take her out, you know, we might miss an appointment, something like that ... Yeah, she will be able to make it because it won't be a strain on my back – I've had back problems for a number of years ..."*

This has reducing carer stress and taken the pressure off her partner. Speeding up the process of receiving the wheelchair allowed these benefits to be in place earlier, preventing further deterioration of her husband's health and promoting independence in their relationship. Furthermore, this may allow the client to live with her husband for longer, as they have adequate equipment to address her needs within their home, as well as increase her access to the community, as she will be able to go out without her husband's assistance, reducing the strain on him. This is a direct result of the CCP, as one service provider observed:

> *Service provider: "The CCP has enabled us to get essential equipment for [the client] that we would not be able to get through any other source".*

The CPP brokerage was used to purchase a mask and tubing to assist with the client's breathing caused by sleep apnoea.

From a service perspective, the provision of a key worker for the couple is significant, especially given the lack of a secondary level case manager – however, the couple did appear to remain unclear about when they could ask this worker for assistance, as well as unclear on the actions and workings of the CCP and how this interacts with other aspects of the healthcare system:

> *Client: "Well, I wouldn't know what to contact [the worker] about".*
>
> *Client: "I didn't know what [the CCP] could do for me. I'm not quite sure what they'd do for me ... or what can they do for me".*
>
> *Husband: "To be honest I can't really tell whether it's due to her participation in the CCP or whether it's due to the hospital system ..."*

Further clarification for the couple around the way the CPP works and roles of their service providers is an area for future improvement. It should be noted however, that this client had little memory of being visited by the CCP coordinator. Her high level of stress and depression did not allow her to take much information in. The lack of clarification of these points may also relate to her being one of few clients on the CCP to remain without a case manager at the secondary management level. The addition of a secondary case manager for this couple may have provided a link between the tertiary management achieved by the CCP and the day-to-day experiences of disability services by the client and her husband, allowing the couple to better link the changes they were noticing in their lives with the actions taken by those involved in the CCP:

> *Husband: "[Has anything improved since she's been part of the pilot?] Again, too hard to identify. I haven't really noticed anything that's a direct result of being on the Continuous Care Pilot ... [Do you think the amount of services has changed?] Yes, well, it's definitely changed, because with the MS registration ... That's what's enabled her to get respite if she needs it and also the holiday she's looking forward to".*

As identified above, linkage to MSL is also a significant outcome of the CCP for this couple, as it allows access to a support group and respite services – key to emotional support for the client and her husband. Her carer was referred to a carers' groups which advise on services available in the area and how to go about getting referrals. The client was also referred to a urologist at MSL for continence issues affecting her quality of life. She was able to receive an appointment fairly quickly free of charge with a specialist urologist who deals with patients with neurological conditions.

The client was also referred to a GP for an extended care plan to receive counselling.

The coordination between their services and medical appointments was also identified as relieving stress for both the client and her husband, as they did not have to repeatedly explain aspects of the client's medical situation as this information had already been passed along. This created a feeling that others were looking out for them:

> *Client: "[How has your life changed as being part of the program?] Getting a bit more help than what I've ever had in my life".*
>
> *Husband: "So everyone knows where she's at ... if she went to something, say physio, physio already knows; someone from the other department that she was about to mention has already told them what's going on with her and stuff like that ... It certainly relieves a lot of stress... makes us feel more at ease, because we know someone's looking out for us, more or less, you know, doing things, trying to get things in place ..."*
>
> *Key community worker: "[She has] reported of 'feeling that I am being cared for'..."*

Overall, the CCP should be considered of benefit to this couple, although there is room for improvement around the interaction between secondary and tertiary case management for this specific couple and clarification of the workings of the program. The identification of this issue in one of the few cases where the CCP client did not have a secondary level case manager suggests that the CCP model may work best where there is a secondary case manager to liaise with the tertiary management of the program.

Client 4

The client is a 40 year old male who has a rare inherited syndrome that has neurological manifestations. The client's brother recently passed away from the same syndrome. The client's health issues have had a significant impact on his overall day-to-day functioning. The client reports of a depressed mood and withdraws from engaging with his young family – two daughters of high school age and one son in primary school. According to his wife he spends most of the day in front of the television and is at very high risk of diabetes and stroke due to his increased weight which is an ongoing issue as a result of his condition.

The client's memory is declining and he is no longer able to drive due to a recent seizure. He also requires constant prompting and support from his wife to get things done. Due to the client's condition, work is impossible for him as well as his wife who is his sole carer. Consequently the client is on a disability support pension and the family have experienced financial difficulties from time-to-time.

Before the CCP

Prior to his involvement in the CCP, the client had no case management and his wife received no assistance with his care and was significantly stressed. She explained:

> *I do everything. Basically I get his meals, medication, help him get in the shower, and get dressed. At the moment he has an ulcer on his leg, so I'm looking after that. I have to organise him too, to do his exercises and stuff. I have to do all that.*

The client is at risk of admission into an aged care facility if his wife ceases to cope with caring for him at home. She explained: ‘If he gets lesions on the brain I won’t be able to lift him or put him on the toilet or shower’. According to one service provider:

> *“This disease is a progressive debilitating neurological condition that will continue to affect both his physical health and his cognitive abilities. It is expected that he will continue to deteriorate over time and he is at considerable future risk of premature placement in residential aged care if additional supports are not available for his care”.*

Since the CCP

Since the client first came into contact with the Pilot in June 2009 he has been linked up with an organisation that provides him with some degree of case management. The CCP coordinator worked in conjunction with the Brain Injury Association acting like a case worker in the absence of one. He has been referred for case management services but still remains on the waiting list as he is not considered a high priority. The CCP coordinator negotiated with the Brain Injury Association that when his need becomes desperate and he requires a proper case manager, he will be considered as an urgent case. So far his needs have been adequately met without a case manager.

He has also received funding for a more intensive and normalised gym program as well as weekly physiotherapy. The CCP coordinator was able to apply for his gym membership funding through the Brain Injury Association. Through the Extended Care Plan the client has received twelve sessions of counselling to help him with his depression. The CCP has also arranged for the client to attend day activities and outings with a local organisation, and he is currently being assessed for his eligibility to receive Community Transport. The CCP Brokerage Funding has also paid for a weekend away for the client and his family. It also paid for a private occupational therapist to assess his home modification needs.

Outcomes from the CCP

The client’s involvement in the CCP has had a number of positive outcomes for him and his family. In particular, his wife feels that her husband has benefitted enormously from his outings and access to the community that the CCP has instigated. This has had ramifications for her as well:

> *He’s not always under my feet. Like, now he’ll go out for the day and come home tired. And I can sit down and watch television and do what I have to do. He was tired [before starting the recreational activities], but he used to follow me around. I was like, ‘Leave me alone, will you?’ I don’t know if it was because he was bored, or had nothing to do.*

The CCP has had an impact on his wife’s ability to cope with caring for her husband. The client’s physiotherapist noted that, ‘His wife is far less frenetic and far more relaxed. She is no longer desperate for respite and is aware of the resources available to her’. The client’s wife also feels that now she ‘has someone to ask, because before I had no idea where to look if I wanted to find out something. I know now that if I have a problem I can ring up [the Pilot Coordinator] and they can find out'. She also expressed her gratitude to the CCP Coordinator for the impact they had had on her and her husband's life:

> *Honestly [the CCP coordinator] has helped me a lot. [They] turned up one day, we [the client and carer] were just sitting here like two loners, watching television, even the blinds were closed the day [they] turned up ... I was just a bit depressed and didn't know what to do. [The CCP Coordinator] came at the right time, it's like someone up there was helping me. I was pretty down.*

The family also had preconceived ideas from their past experience of watching another family member pass away with the same disease; however the CCP has allowed the family to see that other services can be involved and other scenarios are possible. The client's physiotherapist observed that:

> *Because there was now another person [the Pilot Coordinator] involved, the CCP was able to convince them [the client and his partner] that they were truly entitled to support. They were and still are resistant to accepting services which may be taking something away from someone else, but the CCP has allowed them to accept more.*

Client 5

The client is in her early 40s and has MS, a mental health disorder and is experiencing cognitive decline. She is divorced and her ex-husband and young daughter live overseas. She lives with her elderly parents for whom English is their second language. Her parents have very little knowledge of what services are available and struggle to meet the needs of their daughter. Consequently the client's brother and sister-in-law help all three with their administrative needs, including banking, paperwork, paying bills and medical appointments. They also assist financially with their rental payments. The client's parents are very over-protective of her and she has little to no independence – she is not allowed to shop or cook for herself or engage in her preferred social outings, namely going to coffee shops alone. Prior to the CCP, the client had a number of emergency department presentations and the CCP Coordinator was under the impression that the client used hospital as an escape from her family. However, the client's physiotherapist argues that the client would never acknowledge this herself, and would rather always emphasise the need for her to be grateful to her family.

Before the CCP

Prior to her involvement in the CCP the client received very little services and support, however she attended physiotherapy regularly. According to one service provider, the client and her family desperately required ongoing regular assistance from a case manager, due to the client's double diagnosis and problems with her cognition, as well as her parents' lack of English. However, due to the high demand for this service the client was placed on a substantial waiting list.

Since the CCP

Since the client commenced the CCP in March 2010 she has received case management from Community Options. The CCP negotiated with Community Options on the basis of the client's urgent need for a case manager. Once appointed the case manager was able to link the client to appropriate services. The CCP has also linked her up to the Neighbourhood Aid program which takes her on shopping expeditions and she now attends coffee mornings and meditation meetings which enables her to have contact with people in similar positions to her. She has also received increased access to Community Transport which has assisted her in getting to and from her extra-curricular activities and medical appointments.

Outcomes from the CCP

The CCP has had a tremendous impact on the client's parents. Knowing that there is support there (if needed) and that their daughter's situation is continually being monitored relieves their stress. The client herself has noted the impact this has had on her parents:

> *[My family] are grateful that there are people to assist, because it is not all on their shoulders. So that helps.*

If the client was not part of the CCP, her sister-in-law believes that:

> *The stress levels of all those around her would be higher and this would affect her ... A happier family means a happier [client's name].*

The client also feels that the CCP has linked her and her family to support services. She states:

> *Prior to it [the CCP] I didn't realise there was such wonderful services that can be of help, not only to me but also my parents as well*.

According to her physiotherapist, these community supports the client has accessed through the CCP have enabled her to feel better supported - not only in the community but also in the home - and therefore the client uses hospital as an escape less often. She has had no emergency department presentations since March, which was when she was last 'properly' admitted into hospital.

However, the client's sister-in-law feels that the CCP will not prevent the client from entering aged care prematurely:

> *I don't think that [staying at home] will be possible if she was to become a permanent wheelchair user, along with being cognitively challenged ... if 24 hour care is needed I would hazard to say [the CCP's] involvement will not result in her staying at home longer.*

Client 6

This client is in her early 30s, and lives with her husband and two young children. She is tertiary educated and was previously working, but has been recently medically retired due to unstable MS and associated depression. The client is currently trying to balance her family obligations as a wife and mother with fairly frequent MS relapses.

The main issues identified by the client to the CCP were around assistance with childcare and family support, as well as the need for equipment and home modifications to assist in times of relapse, where the client's mobility rapidly decreases.

Once put in place, the CCP was able to coordinate a range of personal and family support services, and has assisted the client with advocacy around the need for home modifications. This client had a very thorough case manager whose collaboration with the CCP ensured that the issues were covered and that everyone was working towards the same aim.

Before the CCP

Prior to the client's participation in the CCP, she considered herself and was considered by some service providers as at risk of nursing home placement, as her husband and family were finding themselves unable to deal with her frequent MS relapses in the context of a lack of services and proper equipment being provided:

> *Client: "I remember back when I wasn't part of the program, didn't have any support, and it was hell, absolute hell, and I think there was a big risk back then of me being put into some kind of care or being hospitalised all the time".*
>
> *Case manager: "[What is your understanding of why she was offered a place in the program?] Because she was at risk of going into a nursing home, and she's young and she's one of these people who's in between all the services ... [Also] home modifications – that hasn't been resolved, so she's still at risk of going into a nursing home ..."*
>
> *Community worker: "We recognised quite early on if those [family] relationships were to break down that she would very much be at risk, because she wouldn't be able to care for herself at the times she was undergoing relapse".*

The client's home was not equipped for the mobility issues that came with the relapses nor did she have proper mobility equipment or aids, and she had very little social or practical support beyond her immediate family who were already feeling strained. In mid-September 2009, she was approached about being part of the CCP and gained entry to the program with a view to resolving some of these issues.

Since the CCP

Since her involvement in the CCP, the client has been linked to a range of services to provide practical and emotional support to both herself and her other family members. It must be noted that in this case, the client's case manager arranged and following up on many of these services. The CCP did however negotiate the quick appointment of the case manager and assisted in ensuring efficient communication and that all the issues, current and potential risks were highlighted and dealt with in a timely manner through good collaborative team work. The case manager arranged for childcare and relationship counselling in collaboration with CAG members. She also received psychology services, social coffee mornings with other MSL members, stress management training and access to respite care. These operate in addition to her pre-existing physiotherapy and medical services. The case manager was able to access much of the child and family support due to the client's husband's Aboriginal background. The client was also referred by the CCP to other services, but was not successful in her subsequent application for subsidised transport.

The CCP attempted to address the client's mobility issues by assisting with advocating for home modifications, however when the client was interviewed in July 2010 this issue had not yet been resolved. Since then, the brokerage funds have paid for an external access ramp to her house which is currently being arranged.

Both the client and her husband identify the provision of childcare and assistance with home modifications advocacy as the key aspects that the CCP has provided for them, as well as coordination and communication between the different services.

Outcomes from the CCP

Both the client and her husband identified the CCP improving their service situation as well as improving her personal wellbeing and their collective family wellbeing. For the client personally, the coordination provided by her secondary level case manager and the communication between the CCP players at CAG meetings reduced her stress levels, which had previously acted as a trigger to her declining health situation:

> *Client: "I've noticed that since CAG's been involved, yeah, I have had a lot of relapses still, but I'm finding that it's reduced my stress, so I'm not struggling at home as much, because there are some strategies put in place. So it's kind of prevented me from declining, I think".*

The services put in place to reduce the client's stress also acted to improve her family's wellbeing, as did the CCP's ability to recognise that family supports would also be required in addition to personal supports:

> *Client: "Helping me out with my children would reduce the stress on my partner, thus reducing the stress on our relationship, reducing his stress at work".*

> *Husband: "... it's not just [my wife] ... they're looking at the broader spectrum and, you know, working things out for our kids, [my wife] and I's relationship, and also looking at [my wife] as an individual, and now they're starting to work out a few things for me as an individual".*

Ultimately, this was assessed by one allied health provider as preventing family breakdown:

> *Allied health provider: "Her condition hasn't medically stabilised, and without the CCP her family would have totally disintegrated – her husband would have walked out, her parents would have taken the children and she would have been left with nothing".*

The coordination and communication provided by the tertiary level of management was also identified as beneficial both for and by this client. It was seen as allowing quicker identification of her medical needs and a more efficient and useful flow of relevant information about her:

> *Doctor: "[Her case management is] just coordinated at a much more efficient level now. There's several people ... that I believe all work quite well together in looking at [her] needs and current situation. What I've found is that if something does go wrong, specifically in terms of [her] psychological welfare, then I've been notified quite promptly and have been able to act really well ..."*

> *Client: "... they do really have such a good understanding of my medical history, because they're communicating not only amongst themselves, but they're communicating with doctors. [The CCP coordinator] can ring Dr [X], and talk to Dr [X] about my situation or she can contact Dr [Y] and talk about my rehabilitation, or [my secondary level case manager] can get access to that information. A lot of the time that [secondary case management organisation] probably wouldn't be given access to that kind of medical ... history, which has I think enabled her to go 'Okay, this could happen, we need to do this'".*

This suggests that the tertiary level of case management may provide useful contextual and medical information to secondary level case managers, something perhaps not available to them in their usual role independent of the CCP.

The CCP's assistance in advocating for home modifications has the potential to keep the client living at home, as unsuitable housing would ultimately be her main reason for entering residential care. The home modifications issue has however been one which the CCP has been attempting to address for some time, yet has encountered difficulties due to external building regulations and funding options to subsidise the significant $80,000 cost this would incur. (A contribution has been made through the CCP brokerage for an access ramp):

> *Client: "The doctor said, 'You need to go away and get your home modified, because next time we won't let you home'".*

> *Client: "They [the CCP] are acting the advocate and trying to push for these [home modifications], but so far they haven't happened ... they are working towards it".*
>
> *Allied health provider: "We still have an incredible amount of issues around home modifications ..."*

The CCP therefore has potential to prevent the client from entering residential care prematurely, but this ultimately depends on the outcome of their advocacy efforts. This suggests that the actions possible from the CCP may be limited by external regulations, assessments and requirements. These have been a major limitation of this client's CCP experience, and have prevented movement towards home modifications and have prevented her from accessing subsidised transport. The client expressed her frustration at the CCP referring her to services she was ultimately unable to receive. She recommended that she would like to see the CCP be independent of the hospital system, as she perceived that the hospital system did not always act on the CAG's recommendations, and may be a source of some of the regulations or requirements that the CCP was unable to navigate.

Her husband also recommended that the CCP increase their focus on implementing flexible services that could be accessed only in times of relapse or crisis. He was particularly keen for extra domestic, childcare and transport assistance during these times. This may suggest the need for the CCP to focus on the balance between regularly scheduled and flexible crisis services, particularly in the context of a sporadic condition like MS where relapses and crises may escalate within a very short timeframe.

Client 7

The client is a female in her late 40s who has MS and lives with her high school aged son, who is her sole carer. They live in a low socio-economic suburb and manage to get by on a Disability Support Pension. The client is independent with her personal care; however her mother has employed a cleaner to clean the bathroom fortnightly. The client has no plans devised for if she was to experience a worsening of her health. The only 'plan' that she referred to in the interview was moving in with either her parents or her brother if she was unable to live independently. Consequently MSL felt that it was necessary to assist with support and services in order to ensure that the client can remain in the community should her son be unable to continue to care for her.

Before the CCP

Prior to becoming involved in the CCP the client received very little assistance, although she did attend physiotherapy on an ad-hoc basis. Shopping and food preparation was done with her son's assistance and she received one hour of Home Care a fortnight.

Since the CCP

Since taking part in the Pilot, the client regularly attends physiotherapy. It has taken the client a long time to accept physiotherapy and that was her greatest need. She has also been linked up with a MSL Community Support Worker and has received the Flexi Rest package through MSL. The client is now linked in better to MSL and because of these linkages she is able to get her continence issues addressed. Apart from that she is mostly choosing to not be linked into services as she feels it is her family's duty to support her and her son. However, she also feels that her family should not have to care for them as much as they do.

Outcomes of the CCP

The client was initially very cautious of becoming involved in the pilot and according to one service provider "She was initially very reluctant to accept anything that would change her level of independence". However, the major outcome of her involvement in the CCP is that it has reassured her that there are people 'out there' who care. This is evident in her statement: "With a group of people helping me, I don't feel isolated anymore". Furthermore, her son believes that this change in his mother's attitude will help her to stay at home for longer:

> *Mum is more open now, and is able to ask for help. She's willing to let other people 'in' to her life to help – realising that she can't do it all by herself and that it's okay to ask for help. She is not as stubborn and pig headed as she used to be. I feel this will help her to stay at home longer because she will be able to get assistance if she needs it. Before the Pilot Mum didn't ask for help, now she feels that it is okay to do so.*

The CCP has also strengthened her son's belief in his capacity to care for his mother. The CCP arranged for him to attend a free First Aid course for young carers and has also given him information as to what services and supports are available to him. Consequently he is confident that he is able to get assistance if required in the future.

Following CAG discussion the client was discharged from the pilot in April 2010 as she was not at risk of residential aged care entry. The CAG decided that the risks had been diverted due to her involvement in the CCP. To prevent this client from falling back into the risk category she is interviewed on a regular basis to ensure that there are no services required by her. Recently, the client has agreed to accept the assistance of a volunteer for shopping and similar tasks. Her son is due to do his HSC this year and a volunteer will help to alleviate carer stress.

Appendix B: Schedule of Instruments

1 Clients Interview Schedule

2 Family member or carer (unpaid) Interview Schedule

3 Governance Interview Schedule

(CAG members, MSL staff, hospital staff member)

4 Case Managers Interview Schedule

5 Service Providers Interview Schedule

6 Client pre and post survey

7 Family member/carer pre and post survey

Appendix B1: Clients Interview Schedule

As you may be aware, you have been selected to be part of a program looking at new ways to manage the care of people with MS, called the Continuous Care Pilot. This program involves having a case manager [in your case, Coordinator's name] to support your access to doctors, other health professionals you see (e.g. physiotherapists, occupational therapists) and other supports. The Continuous care program aims to reduce people's need to enter residential aged care. I am from UNSW and we have been asked to see if the program is improving things for you and other clients.

Background

- When did you first meet [Coordinator's name] and how did they explain their role?
- After [Coordinator's name] became involved did you expect there would be changes to your care situation? If so, what kinds of changes did you expect to happen?

Effectiveness of the case management model

- Since [Coordinator's name] has been involved what aspects of your care have changed? Is this what you had hoped for?

Prompts:

- Home help
- Personal care
- Equipment
- Information
- Planning for the future
- Support for the family

- Has anything not improved? If so what?
- Since [Coordinator's name] has been involved, is there anything you haven't liked about how things have been done?
- If these changes hadn't happened how would things be different for you?
- Since [Coordinator's name] involvement in your care has communication amongst the different people who treat you improved?

Risks and needs identified and met

- If your health worsened, who would you contact to access services?
- What do you perceive to be the main risks or problems for the future? Have you discussed these with [Coordinator's name]? If so, what kinds of things did you discuss?

- Since [Coordinator’s name] came on board, have you been to hospital at all? If so, how many times? Have you been satisfied with the care arrangements for when you return home?
- Do you think the changes you have put in place with [Coordinator’s name] will enable you to stay in your own home for longer? Why?
- What are your main concerns for your needs and those of your family when you think about the future?
- Are you confident that you will get the help you need when you need it?

Outcomes

- Since meeting [Coordinator’s name] in what ways, if any, has your life changed? Prompts:
    - greater participation in services
    - family/carer participation in services
    - your physical and psychological well-being
    - your family’s well-being

Lessons and recommendations

- Is there anything else that could be done to improve how your care is managed?
- Do you have any other questions or comments?

Appendix B2: Family member/carer Interview Schedule

As you may be aware, [person's name] has been selected to be part of a program looking at new ways of managing the care of people with MS, called the Continuous Care Pilot. This program involves having a case manager [in your family members' case, Coordinator's name] to support access to doctors, other health professionals (e.g. physiotherapists, occupational therapists) and other supports. The Continuous care program aims to reduce people's need to enter residential aged care. I am from UNSW; we have been asked to see if the program is improving things for [person's name] and other clients and the impact it has had on your role as a carer.

Background

- What is your relationship to [person's name]?
- What kind of support do you provide for [person's name]? (Prompts: emotional; domestic; community; social).
- When did you first meet [Coordinator's name] and how did they explain their role?
- After [Coordinator's name] became involved did you expect there would be changes to [person's name] care situation? If so, what kinds of changes did you expect to happen?

Effectiveness of the case management model

- Since [Coordinator's name] has been involved what aspects of [person's name] care have changed? Is this what you had hoped for?

Prompts:

- Home help
- Personal care
- Equipment
- Information
- Planning for the future
- Support for the family

- Has anything not improved? If so what?
- Since [Coordinator's name] has been involved, is there anything you haven't liked about how things have been done?
- If these changes hadn't happened how would things be different for [person's name]?

Family member or client's risks and needs identified and met

- If [person's name]'s health worsened, who would you contact to access services?

- What do you perceive to be the main risks or problems for [person's name] future? Have you discussed these with [Coordinator's name]? If so, what kinds of things did you discuss?
- Since [Coordinator's name] came on board, has [person's name] been to hospital at all? If so, how many times? Have you been satisfied with the care arrangements for them on their return home?
- Do you think the changes put in place by [Coordinator's name] will enable [person's name] to stay at their home for longer? Why?
- What are your main concerns for your needs and those of your family when you think about the future?
- Are you confident that [person's name] and your family will get the help you need when you need it?

Outcomes for CCP clients and their family members and carers

- Since meeting [Coordinator's name] in what ways, if any, has [person's name] life changed? Prompts:
    - greater participation in services
    - family/carer participation in services
    - your physical and psychological well-being
    - your family's well-being
- How has your relationship changed with [person's name] since the CCP?
- In what other ways, if any, has you and your family's life changed since [person's name] has been linked up with [Coordinator's name]?

  Prompts:

  Participation in services

  Physical and psychological well-being

  Financial well-being
- Overall, do you think the approach (the CCP) currently taken to [person's name] care is beneficial? Why? What would you change/improve?

Lessons and recommendations

- Is there anything else that can be done to improve how [person's name] care is managed?
- Do you have any other questions or comments?

Appendix B3: Governance Interview Schedule

(Use for Clinical Advisory Group members; hospital staff and MSL staff)

Background: the CCP and the CAG

- What is your role in the CCP?
- What is your organisation's role in the CCP?
- Could you please explain to me how the CAG is set up?

Documenting and managing risk

- How do you identify whether clients are eligible for the CCP or not?
- What makes an individual at risk of entering residential aged care prematurely?
- How do you manage risk? (Prompt: risk management plans. Key factors accounted for in this planning)
- How effectively do you think the CCP manages client risk?

Effectiveness of the CAG

- In what ways does the CAG work well?
- What parts of the CAG are not working well?
- What has the CAG done to identify and respond to newly arising needs?
- Do you feel that the brokerage funds work well? Why or why not?
- What kind of financial monitoring is in place for the brokerage funds?
- How effectively do the CAG members work together? What factors help and hinder good working relationships within the CAG?
- To what extent are the services and supports the CAG recommends coordinated?

What contribution do you think the CAG has made to the CCP?

Effectiveness of the case management model

- What aspects of the CCP have worked well/ what has not worked well?
- How effective is the CCP compared to other services CCP clients have received in the past?
- What contribution do you think the different stakeholders have made to the CCP program? (Prompts: CAG, case managers, service providers, MSL staff, family/carers) What has been valuable/what has not?
- How effectively do you think the CCP resources have been used?
- What role can education and training play in improving the case management model?

Outcomes of the CCP

- Do you think that clients receive a more appropriate service package as a result of the CCP?

- What impact do you think the CCP has had on clients and their families? (Prompts: client and family participation and understanding of services; physical and psychological well-being of clients and families; risk of entering residential aged care prematurely).
- Do you believe that the CCP minimises the number of preventable admissions to residential age care? Why or why not?
- Does the CCP assist in 'heading off' other problems that client's face?
- Do you think this program is having/will have an impact on how services are coordinated and delivered more generally?
- Overall, do you think the CCP is beneficial as a strategy?

Lessons and recommendations

- Overall, what changes do you feel need to be made to improve the CAG?
- If the CCP was to be rolled out further, what three key aspects of the program would you recommend to be continued? What would you change/improve?
- Do you have any other questions or comments?

Appendix B4: Case Managers Interview Schedule

Background

- What is your role in the CCP?
- Did you assist [client's name] prior to them participating in the CCP?
- What is your understanding of why [client's name] was offered a 'place' in the CCP? (Prompts: has a progressive neurological disorder; under 55 years of age; linked into MAC&RS and receiving their services; living in the community in stable accommodation).
- What makes [client's name] at risk of a residential aged care placement and why?
- How do you manage this risk?
- Since the advent of the CCP what changes have been made to [client's name] case management?

Effectiveness of the case management model

- In what ways does the CCP work well? Why? (Prompts: disease management; Clinical Advisory Group; partnerships with service providers; equipment and brokerage funds for referrals).
- What parts of the CCP do you think are not working well? (Prompts: disease management; Clinical Advisory Group; partnerships with service providers; equipment and brokerage funds for referrals). How could these be addressed?
- How effectively do all the CCP 'players' (e.g. case managers, service providers, the CAG, etc) work together? Do all of the players understand each other's roles and responsibilities? Why or why not?
- What factors help/hinder good working relationships between the players?
- To what extent are services/supports coordinated?
- What have the different stakeholders contributed to the CCP program? (Prompts: case managers, CAG, service providers, MSL staff, family/carers) What has been valuable/what has not?
- How effectively do you think the CCP resources have been used?
- What role can education and training play in improving the case management model?

Client risks and needs identified and met

- How effective has CCP been at identifying and managing client risks?
    - Does [client's name] have a provisional action plan and pre-arranged service plan drawn up in case medical deterioration occurs or another event puts them at risk? How did this process work and was it effective?

  - During the course of the CCP, have there been any events that have jeopardised [client's name] ability to stay at home? If so, how effective was CCP support?
  - Do you think that the CCP can prevent or delay [client's name] entry into residential aged care?
  - Does the CCP assist in 'heading off' any other problems [client's name] faces?

Outcomes

- Do you think that clients receive a more appropriate service package as a result of the CCP?
- What impact do you think the CCP has had on clients and their carers and families? (Prompts: early identification of and response to needs; client and family participation and understanding of services; physical and psychological well-being of clients and families; risk levels of entering aged care prematurely)
- Do you think this program is having/will have an impact on how services are coordinated and delivered more generally?
  - Has the CCP changed the way you work?
  - What impact do you think the CCP has had on Case Managers?
  - What impact do you think the CCP has had on service providers?
  - Are you going to continue to use any of features of the pilot after it ends?
  - Are there likely to be any lasting impacts on case management at Macarthur ACARS?
- Overall, do you think the CCP is beneficial as a strategy?

Lessons and recommendations

- If this program was to be rolled out further, what three key aspects of the program would you recommend be continued? What would you change/improve?
- Do you have any other questions or comments?

Appendix B5: Service providers Interview Schedule

Background

- What is your role in the CCP?
- What is your organisation’s role in the CCP?
- What do you think makes [client’s name] at risk of entering residential aged care prematurely?
- How should this be taken into account in their case management?
- Did you assist [client’s name] prior to their involvement in the CCP?
- Since the advent of the CCP what changes, if any, have you noticed to [client’s name] case management?

Effectiveness of the case management model

- Has [client’s name] received any new services as a result of the CCP? Why or why not?
- How effectively do all the CCP ‘players’ (e.g. case managers, service providers, the CAG, etc) work together? Do all of the players understand each other’s roles and responsibilities? Why or why not?
- What factors help/hinder good working relationships between the players?
- To what extent are services/supports coordinated?
- What contribution do you think the different stakeholders have made to the CCP program? (Prompts: CAG, case managers, service providers, MS staff, family/carers). What has been valuable/what has not?
- How effectively do you think the CCP resources have been used?

Client needs identified and met

- Do you know if [client’s name] has made plans for obtaining services if they were to experience a worsening of their health? How did this process work and was it effective?
- During the course of the CCP, have there been any events that have jeopardised [client’s name] ability to stay at home? If so, how effective was CCP support?
- Do you think the CCP will help [client’s name] stay at home for longer? Why or why not?
- Does the CCP assist in ‘heading off’ other problems that client’s face?

Outcomes

- What impact has the CCP had on clients and their families? (Prompts: early identification of and response to needs; client and family participation and understanding of services; physical and psychological well-being of clients and families; risk levels of entering aged care prematurely).

- Do you think this program is having/will have an impact on how services are coordinated and delivered more generally?
    - Has the CCP changed the way you work?
    - What impact has the CCP had on service providers?
    - Are you going to use any features of the pilot after it ends?
- Overall, do you think the CCP is beneficial as a strategy?

Lessons and recommendations

- If this program was to be rolled out further, what three key aspects of the program would you recommend be continued? What would you change/improve?
- Do you have any other questions or comments?

Appendix B6: Client questionnaire (completed Jan 2010 or when client joined the program and Aug/Sept 2010)

1. Thinking about the support <u>services</u> you use most often, how satisfied are you with the:	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
a. Flexibility (e.g. services are available at different times of day or can be used at different frequencies)	☐	☐	☐	☐	☐
b. Availability (e.g. services you need are available when you need them most)	☐	☐	☐	☐	☐
c. Accessibility (e.g. services are available in a location you can get to)	☐	☐	☐	☐	☐
d. Staff are aware of your cultural needs (e.g. services are culturally relevant and recognise different practices and values)	☐	☐	☐	☐	☐
e. Affordability (e.g. you can afford the services you need and/or the services are free)	☐	☐	☐	☐	☐
f. Quality (e.g. services are good quality with well-trained staff)	☐	☐	☐	☐	☐
g. Provision of information (e.g. translated materials or interpreters)	☐	☐	☐	☐	☐
h. Service providers/health workers taking your ideas/concerns into account (e.g. service providers listened to you)	☐	☐	☐	☐	☐

2. Thinking generally about your <u>support needs</u> to what extent do you agree or disagree with the following:	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree
a. I have clear plans for my future care	☐	☐	☐	☐	☐
b. The health system is responsive to my changing health and care needs	☐	☐	☐	☐	☐
c. I am concerned about the capacity of my family member/carer to continue caring	☐	☐	☐	☐	☐

for me					
d. I would like more choice about the types of services that I get	☐	☐	☐	☐	☐
e. My equipment needs are adequately met	☐	☐	☐	☐	☐
f. My views and those of my family are taken seriously by the health workers who work with me	☐	☐	☐	☐	☐
g. My family members/carers value my views on my care needs	☐	☐	☐	☐	☐
h. I know what services and supports I am eligible for	☐	☐	☐	☐	☐
i. My care situation is not flexible enough to work around my needs	☐	☐	☐	☐	☐
j. Support is available when I need something urgently	☐	☐	☐	☐	☐

3. Please tick the number that best describes your answer to the following statements.

Thinking about your own life and personal circumstances:	Completely dissatisfied				Mixed						Completely satisfied
	0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
a. How satisfied are you with your life as a whole?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
b. How satisfied are you with your standard of living?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
c. How satisfied are you with your health?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
d. How satisfied are you with your psychological health	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
e. How satisfied are you with your physical health	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
f. How satisfied are you with what you have achieved in life?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
g. How satisfied are you with your personal relationships?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
h. How satisfied are you with how safe you feel?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
i. How satisfied are you with feeling part of the community?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
j. How satisfied are you with your future security?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
k. How satisfied are you with your employment and/or education opportunities?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
l. How satisfied are you with your financial situation?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
m. How satisfied are you with the amount of free time you have?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Appendix B7: Family/carer questionnaire (completed Jan 2010 or when client joined the program and Aug/Sept 2010)

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1. Thinking about the support services <u>your family member/friend uses</u> most often, how satisfied are you with the:	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	Don't know/NA
a. Flexibility (e.g. your family member/friend can access services at different times of day or at different frequencies)	☐	☐	☐	☐	☐	☐
b. Availability (e.g. services your family member/friend needs are available when they most need)	☐	☐	☐	☐	☐	☐
c. Accessibility (e.g. services are available in a location your family member/friend can get to)	☐	☐	☐	☐	☐	☐
d. Staff are aware of cultural needs (e.g. services your family member/ friend uses are culturally relevant and recognise different practices and values)	☐	☐	☐	☐	☐	☐
e. Affordability (e.g. your family member/friend can afford the services they need and/or the services are free)	☐	☐	☐	☐	☐	☐
f. Quality (e.g. your family member/friend receives good quality services with well-trained staff)	☐	☐	☐	☐	☐	☐
g. Provision of information (e.g. translated materials or interpreters are available if my family member/friend needs them)	☐	☐	☐	☐	☐	☐
h. Service providers/health workers taking your family members' ideas/concerns into account (e.g. service providers listened to your family member/friend)	☐	☐	☐	☐	☐	☐
i. Service providers/health workers taking *your* ideas/concerns into account	☐	☐	☐	☐	☐	☐

(e.g. service providers listened to you)						

2. Thinking generally about your family members' <u>support needs</u> to what extent do you agree or disagree with the following:	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree
a. Clear plans have been made for my family members' care in the future	☐	☐	☐	☐	☐
b. The health system is responsive to my family members' changing health and care needs	☐	☐	☐	☐	☐
c. I am concerned about my capacity to continue caring for my family member	☐	☐	☐	☐	☐
d. Support is available when I need it for [person's name] care	☐	☐	☐	☐	☐
e. My views are taken seriously by the health workers	☐	☐	☐	☐	☐
f. I know what services and support my family member is eligible for	☐	☐	☐	☐	☐
g. My family members' care situation is not flexible enough to work around my needs	☐	☐	☐	☐	☐
h. My needs as a carer are met	☐	☐	☐	☐	☐
i. I can access respite when I need to	☐	☐	☐	☐	☐

3. Please tick the number that best describes your answer to the following statements.

Thinking about your own life and personal circumstances:	Completely dissatisfied				Mixed			Completely satisfied			
	0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
a. How satisfied are you with your life as a whole?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
b. How satisfied are you with your standard of living?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
c. How satisfied are you with your health?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
d. How satisfied are you with your psychological health	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
e. How satisfied are you with your physical health	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
f. How satisfied are you with what you have achieved in life?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
g. How satisfied are you with your personal relationships?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
h. How satisfied are you with how safe you feel?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
i. How satisfied are you with feeling part of the community?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

j. How satisfied are you with your future security?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

4. Please state to what extent you have had any of the following experiences in the <u>past six months</u> *because of your caring responsibilities*:

	(1) = Not at all	(2) = A little	(3) = Some	(4) = A lot	N/A
a. I have had financial problems	☐	☐	☐	☐	☐
b. I have missed days at work or school	☐	☐	☐	☐	☐
c. I have found it difficult to concentrate on my own activities	☐	☐	☐	☐	☐
d. I have had to change personal plans like taking a new job or going on vacation	☐	☐	☐	☐	☐
e. I have cut down on leisure time	☐	☐	☐	☐	☐
f. I found the household routine was upset	☐	☐	☐	☐	☐
g. I had less time to spend with friends	☐	☐	☐	☐	☐
h. I neglected other family members' needs	☐	☐	☐	☐	☐
i. I experienced family frictions and arguments	☐	☐	☐	☐	☐
j. I experienced frictions with neighbours, friends or relatives outside the home	☐	☐	☐	☐	☐
k. I found it difficult to manage my time	☐	☐	☐	☐	☐
l. I experienced poor health	☐	☐	☐	☐	☐