



NSW CONTINUOUS CARE PILOT EVALUATION

FINAL REPORT

29 NOVEMBER 2010

Report for:

MS Australia ACT/NSW/VIC

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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/carers² 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;

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 equalized 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 encountered 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:

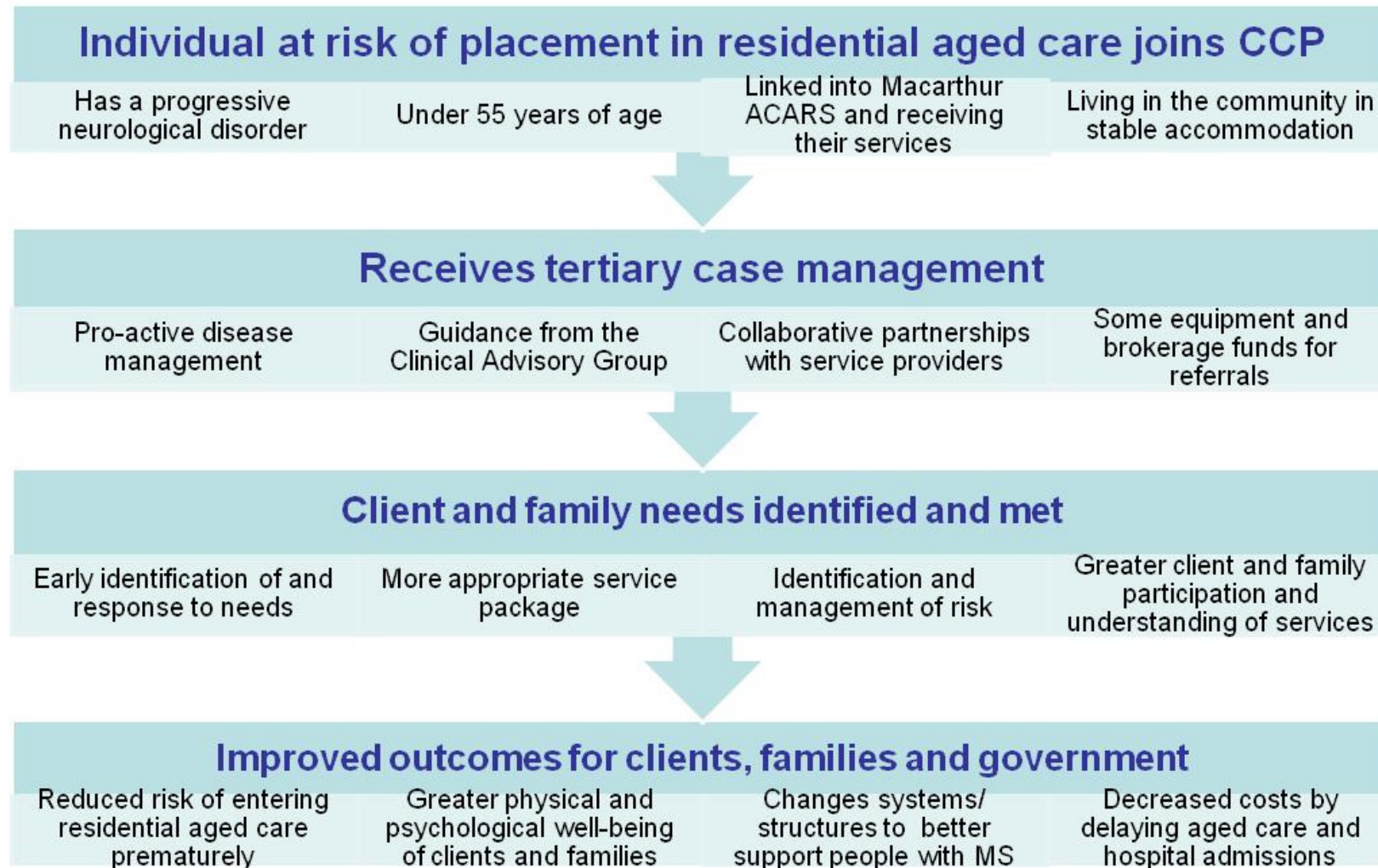
- Clients and other stakeholders involved in the CCP participated in the evaluation;
- The experience of clients informed and contextualised the analysis of other data; and,
- The findings were able to inform future policy development.

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.

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/carers⁵ 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;

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

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, accessible⁸ 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

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:

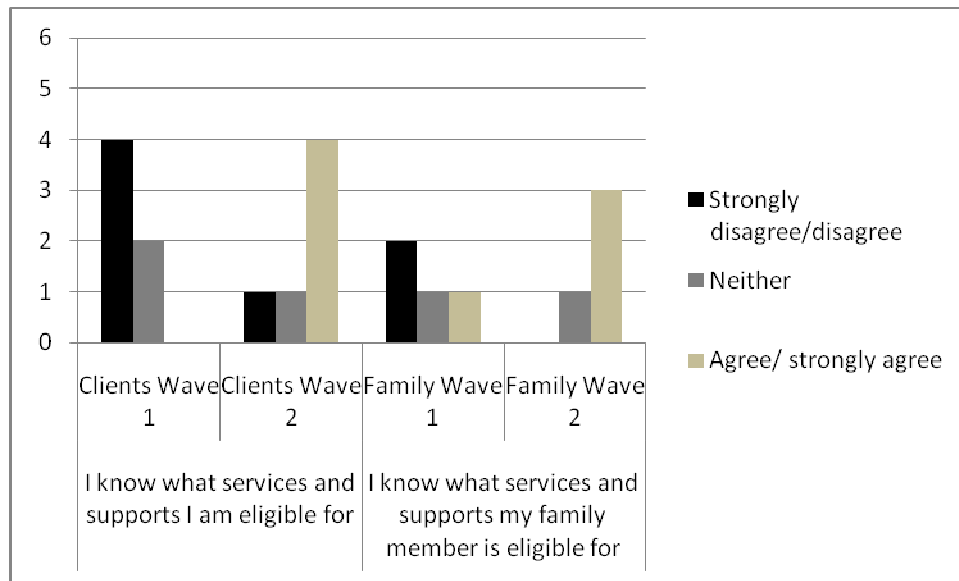
1. Service outcomes
2. Wellbeing and participation outcomes
3. Hospitalisation and aged care placement

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.

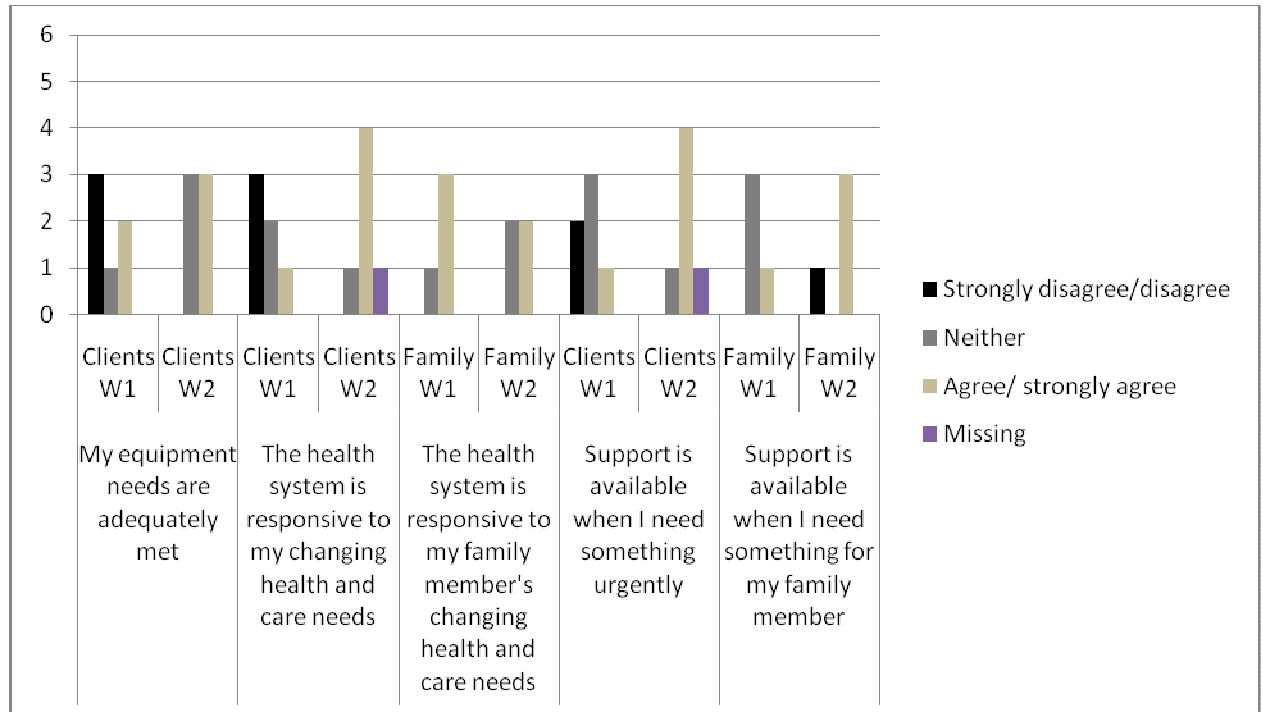
Early identification and response to needs

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 health and care needs (n⁹=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

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)



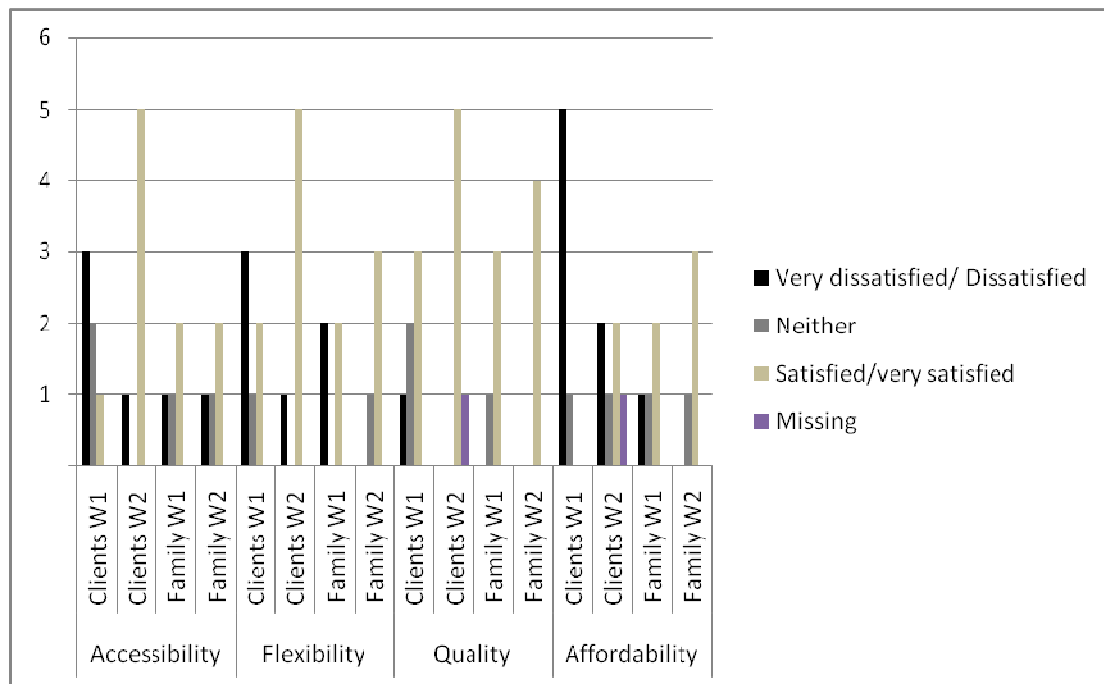
It is important to note, however, that by Wave 2 some clients neither agreed nor disagreed that their needs were met. Family members were also less likely to feel that the health system was responsive to their family members’ needs in Wave 2 (Figure 4.2).

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.

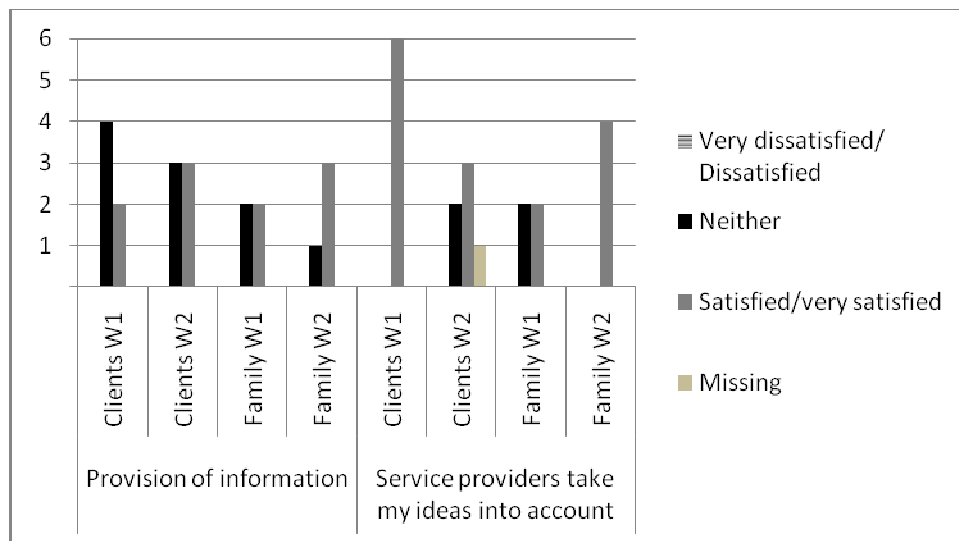
The CCP assisted another client who was on a 14 month waiting list for an occupational therapy mobility assessment. The CCP brokerage funds were used to obtain a private assessment which significantly speeded up her application for an electric wheel chair. This client was also linked to other services 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

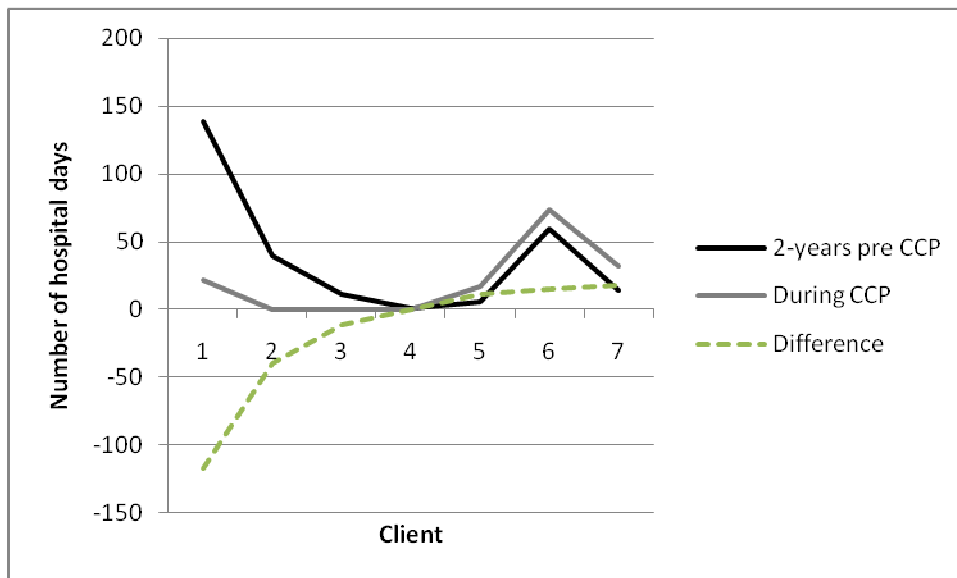
The hospitalisation data supports stakeholders' broad perception that the CCP was keeping clients out of RAC and preventing some hospital admissions. The hospital data were collected by the MSL CCP coordinator who used the NSW Health hospital records to track the number of days clients were hospitalised 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 equalized 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

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

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 administrators.

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 Affairs¹² 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

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

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	30.8%
	Wheelchair contribution	\$ 6,000.00	
	Shower access equipment	\$ 572.50	
	Total	\$ 6,712.50	
Professionals	Counselling	\$ 1,920.00	16.6%
	Occupational therapist	\$ 1,700.65	
	Total	\$ 3,620.65	
Family/social/lifestyle	Family respite weekend away	\$ 1,214.00	6.7%
	Pet trainer	\$ 250.00	
	Total	\$ 1,464.00	
Home modifications	Access modifications	\$ 10,000.00	45.9%
	Total	\$ 10,000.00	
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

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

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 services 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)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Availability (e.g. services you need are available when you need them most)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Accessibility (e.g. services are available in a location you can get to)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Staff are aware of your cultural needs (e.g. services are culturally relevant and recognise different practices and values)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Affordability (e.g. you can afford the services you need and/or the services are free)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Quality (e.g. services are good quality with well-trained staff)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Provision of information (e.g. translated materials or interpreters)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Service providers/health workers taking your ideas/concerns into account (e.g. service providers listened to you)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Thinking generally about your support needs 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. The health system is responsive to my changing health and care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I am concerned about the capacity of my family member/carer to continue caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

for me					
d. I would like more choice about the types of services that I get	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. My equipment needs are adequately met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. My views and those of my family are taken seriously by the health workers who work with me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. My family members/carers value my views on my care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I know what services and supports I am eligible for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. My care situation is not flexible enough to work around my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Support is available when I need something urgently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. How satisfied are you with your standard of living?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. How satisfied are you with your health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. How satisfied are you with your psychological health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. How satisfied are you with your physical health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. How satisfied are you with what you have achieved in life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. How satisfied are you with your personal relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. How satisfied are you with how safe you feel?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. How satisfied are you with feeling part of the community?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. How satisfied are you with your future security?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. How satisfied are you with your employment and/or education opportunities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. How satisfied are you with your financial situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. How satisfied are you with the amount of free time you have?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix B7: Family/carer questionnaire (completed Jan 2010 or when client joined the program and Aug/Sept 2010)

1. Thinking about the support services your family member/friend uses 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)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Availability (e.g. services your family member/friend needs are available when they most need)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Accessibility (e.g. services are available in a location your family member/friend can get to)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Staff are aware of cultural needs (e.g. services your family member/ friend uses are culturally relevant and recognise different practices and values)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Affordability (e.g. your family member/friend can afford the services they need and/or the services are free)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Quality (e.g. your family member/friend receives good quality services with well-trained staff)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Provision of information (e.g. translated materials or interpreters are available if my family member/friend needs them)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Service providers/health workers taking your family members' ideas/concerns into account (e.g. service providers listened to your family member/friend)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Service providers/health workers taking your ideas/concerns into account	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(e.g. service providers listened to you)						
--	--	--	--	--	--	--

2. Thinking generally about your family members' support needs 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. The health system is responsive to my family members' changing health and care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I am concerned about my capacity to continue caring for my family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Support is available when I need it for [person's name] care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. My views are taken seriously by the health workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I know what services and support my family member is eligible for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. My family members' care situation is not flexible enough to work around my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. My needs as a carer are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I can access respite when I need to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. How satisfied are you with your standard of living?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. How satisfied are you with your health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. How satisfied are you with your psychological health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. How satisfied are you with your physical health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. How satisfied are you with what you have achieved in life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. How satisfied are you with your personal relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. How satisfied are you with how safe you feel?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. How satisfied are you with feeling part of the community?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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 past six months 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I have missed days at work or school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I have found it difficult to concentrate on my own activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I have had to change personal plans like taking a new job or going on vacation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I have cut down on leisure time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I found the household routine was upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I had less time to spend with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I neglected other family members' needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I experienced family frictions and arguments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. I experienced frictions with neighbours, friends or relatives outside the home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. I found it difficult to manage my time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. I experienced poor health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>