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NSW CONTINUOUS CARE PILOT EVALUATION

EXECUTIVE SUMMARY

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Report for:

MS Australia ACT/NSW/VIC

Studdy MS Centre, 80 Betty Cuthbert Dr, Lidcombe NSW 2141

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Copies of this Summary and the Full Report are available from
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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)

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?

¹ Multiple Sclerosis Limited (MSL) is the entity that manages and operates MS Australia ACT/NSW/Vic.

² Carers include family members and friends who act as carers without pay.

- 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;
- 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.