

**Cross sector service coordination
for people with high and complex needs:
Harnessing existing evidence and knowledge**

Discussion paper



Acknowledgments

This project was supported by funding from the National Disability Insurance Agency.

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The research was greatly enriched by workshops and discussions with consumers, service providers, policy makers, research advisers and reviewers, many of whom are listed in Appendix Table 3.

Disclaimer

Any views expressed in this paper do not necessarily reflect those of the National Disability Insurance Agency or the University of Sydney.

Suggested citation:

Centre for Disability Research and Policy, University of Sydney (CDRP) and Young People in Nursing Homes National Alliance (YPINHNA) 2014. Service coordination for people with high and complex needs: Harnessing existing cross-sector evidence and knowledge.
<http://sydney.edu.au/health-sciences/cdrp/>

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List of abbreviations

ABI STR	ABI Slow to Recover Program (Victorian Department of Human Services, 2004)
BP	Better Pathways Pilot Project (Warren, 2012)
CC MND	Collaborative Care in Motor Neurone Disease in Victoria (Calvary Health Care Bethlehem, 2009)
DSO	Disability Support Organisations
LAC	Local Area Coordinator
HARP	Hospital Admission Risk Program (Victorian Government Department of Human Services, 2006)
MACNI	Multiple and Complex Needs Initiative (KPMG, 2007)
MND	Motor neurone disease
MS	Multiple sclerosis
NCCCP	Neurodegenerative Conditions Coordinated Care Program (Bahn & Giles 2012)
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NSW CCP	NSW Continuous Care Pilot (MS Australia, 2010)
PC	Productivity Commission
RAC	Residential Aged Care
SCI CPP	Spinal Cord Injury Community Participation Project (Motor Accidents Authority of New South Wales, 2007)
SCIR	Spinal cord injuries response (Griffith University, 2008)
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
Vic CCP	Victorian Continuous Care Pilot (MS Australia and Calvary Healthcare Bethlehem, 2009)
YPINHNA	Young People in Nursing Homes Alliance Australia
YPIRAC	Younger People in Residential Aged Care

Summary

The challenge

People with high and complex needs will generally need an array of supports to enable social and economic participation as envisaged by the National Disability Insurance Scheme (NDIS). As participants, these people will receive funding from the NDIS to purchase services and supports from a range of different disability sector providers, but will also need to access various 'mainstream' services including health, education, housing, justice and transport in order to pursue the life they choose. The complexity of the services system, and the interfaces between sectors, create gaps and barriers that are challenging for participants, service providers and for policy makers alike to navigate.

Cross-sector coordination is a critical scheme design element to ensure that NDIS participants get the range of services and supports they need to pursue their goals and participate in society and the economy. Any failure of other sectors to provide access to quality services will increase the costs of disability support and risk the sustainability of the NDIS. Coordination can thus also be seen as a way of addressing this fundamental risk facing the NDIS. For these reasons cross-sector coordination should be a core element in NDIS design. The disability field is actively discussing these challenges and this paper aims to provide evidence to inform policy directions now being developed.

Project aims and contents of this discussion paper

This discussion paper has been developed as a stimulus to policy development and discussion about the value of coordinated, cross-sectoral approaches in delivering supports and services to participants in the NDIS. The Centre for Disability Research and Policy at the University of Sydney and the Young People in Nursing Homes National Alliance were partners in this project.

In this paper we:

- outline key terminology and a framework for the discussion, and provide background about the current Australian context (Section 1)
- analyse available evidence on service coordination from relevant program reports and academic literature (Sections 2 and 3)
- report on four workshops conducted to gather input from consumers, service providers and policy makers (Section 4)
- synthesise this evidence (Section 5), drawing out implications for the service system emerging with the rollout of the NDIS
- conclude with a brief discussion and proposals for consideration (Section 6).

Definitions developed

The definitions for the key terms for this project are set out in Box 1. Both definitions were developed and refined progressively in the course of the research.

Box 1: Definitions

'High and complex support needs' are defined in this paper as needs for multiple changes in the environment including support in multiple areas of activities and participation, typically involving multiple service sectors.

For instance: A person may require long-term (possibly intermittent) regular personal support, high cost equipment, or behaviour support; access to various mainstream services; they may be facing challenging transitions or experiencing threats to their ability to remain in the community, such as the risk (or current experience) of institutionalisation. The complexity of need may relate more to the complexity of the services system(s) than the complexity of the person's disability.

Cross sector service coordination is a key element of NDIS design, requiring funding, and involving:

- high level inter-sectoral collaborative agreements and related infrastructure (macro level) so that system barriers do not undermine NDIS aims
- coordinators actively negotiating between sectors and services to ensure people obtain the necessary supports: a range of local and cross-sectoral mechanisms enable coordination activities
- agreed goals focussed on outcomes for people, including social and economic participation

This broad definition is elaborated in Box 2, which sets out the key components of coordination at each of these three levels.

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Findings of the research

There are two main areas of agreement in the literature and in Australian experience, demonstrated by this short-term research:

- 1. Cross service coordination (as defined) is of value. Indeed, in the current Australian context, it is needed.**
 - a. Personal outcomes are positively influenced.**
 - b. System efficiencies can be gained.**
- 2. The components of effective service coordination can be identified at system (macro), organisation or service (meso) and participant (micro) levels; both vertical and horizontal integration are required.**

The body of evidence points to positive outcomes for **people** including: greater well-being, higher levels of community participation, better social outcomes, sustainability of informal care arrangements, greater understanding of and choice

about services, better communication with service providers, reduced time in hospital, enhanced ability to remain in the community, and a greater sense of control. While the evidence on outcomes for services was more mixed, it was clear that improvements, in terms of more effective provision of services as well as efficiencies and cost savings, could be made with the right design. **Service providers** reported greater understanding of people's needs and a better ability to link and communicate with other services to meet these needs; overall service quality was enhanced. **At the systems level**, positive outcomes can include: streamlining and avoidance of duplication, reduced hospital stays, the prevention of admissions to residential care, and reductions in health expenditure.

The discussion of this broad subject and the relevant literature are themselves complex. Lack of a common understanding of key terms can make it difficult to compare existing evidence about service coordination, and different systems and disciplines use their own language to describe people's needs; our workshops in fact identified language as a potential barrier to coordination. Further challenges in comparing evidence in the literature arose because programs were varied in relation to location, structure and target group.

The key components of service coordination

Nevertheless, the reports and literature reveal the key components of effective service coordination and identify useful experience in Australia which could be adapted for use in the NDIS context. The key components are listed in Box 2, with further detail and explanation in Section 5.

In brief, a skilled service coordinator, working across sectors, would be an active negotiator, understanding the person and their needs, and understanding the human services system more broadly. They would have a positive, problem-solving attitude and would communicate and work with relevant services and systems to negotiate supports to meet the person's needs; this might involve working through and around barriers and brokering creative solutions. They would have high level support across sectors, and control of a small contingency fund to solve short-term problems, e.g., to buy equipment which would enable the person to return home earlier from hospital.

Structurally, the service coordinator would be a designated central 'linkage point', well connected to similar link points in other sectors, helping each other to navigate systems. Paramount would be their respect for the person and their autonomy, along with a commitment to work in partnership with the person and enable them to self-manage when possible (the Productivity Commission description of Disability Support Organisations (DSO) is relevant to the role of cross-sector coordination).

Box 2: Key components of a service coordination model at each level

<p>Micro: the person's experience of coordination</p> <ul style="list-style-type: none"> • A single point of contact • Being properly informed (accurate, practical and honest information) • A relationship of understanding and trust with the coordinator • Support to exercise choice and control in line with their own goals and priorities • Timely access to services and supports • Confidence that future needs will be met • Service providers with the necessary knowledge and expertise • Consistent information provided to service providers 	<p>Meso: the coordination role and enabling mechanisms</p> <p>Elements of the service coordination role:</p> <ul style="list-style-type: none"> • Advocating to enable the person to access services and supports—being a 'systems wrangler' able to overcome system blockages • Using and having access to a 'contingency fund' to broker solutions where a person's needs cannot otherwise be met. • Providing a single point of linkage—liaising within and across systems, information sharing, developing and maintaining cross-sector networks • Respecting and enabling the person • Partnering with people, families and community supports • Actively developing and maintaining cross-sector networks • Supporting the implementation and monitoring of a plan (e.g., NDIS) including <ol style="list-style-type: none"> a. facilitating choice of providers b. monitoring and reviewing the person's needs • Advising on service provider education and training needs <p>Skills and qualities needed to carry out role:</p> <ul style="list-style-type: none"> • Knowledge and understanding of the person, e.g., disability, health conditions, goals, needs, rights • 'Can-do' capabilities to work around barriers • Able to build trust and relationships • Thorough knowledge and understanding of relevant service systems • Liaison skills, e.g., building collaboration <p>Structures, processes and mechanisms (endorsed and supported at macro level) to enable coordination</p> <ul style="list-style-type: none"> • Communication and information sharing mechanisms • Formal cross-sector arrangements that enable the coordinator to secure access to services • Points of contact in relevant sectors, to facilitate linkage between disability and mainstream services • Mechanisms for training and skilling service providers in different organisations and sectors • Mechanisms to ensure access to expertise (e.g., advisory groups with specialist and cross-sectoral membership)
<p>Macro: High level commitment and agreed infrastructure</p> <ul style="list-style-type: none"> • Cross-sector formal commitment to service coordination • Shared accountability supported by structures and mechanisms, e.g., Key Performance Indicators • High level 'permission' to encourage flexibility at meso level to overcome system blockages • Funding of coordination across sectors, including linkage or focal points in sectors such as health, housing and education • Cross-sector efforts to build mutual understanding (e.g., agreement on common language and terminology; regular and purposive communication including meetings) • Workforce training and skilling to work collaboratively across sectors • Systems for shared data and information to build an evidence base (including a focus on cost-effectiveness and beneficial outcomes for people) 	

Proposals arising from the research

This paper proposes that the NDIA:

1. Include **cross-sector service coordination** as defined in this paper as an element of NDIS design.
2. Seek **high level agreement with other sectors** to work in partnership to design, trial and evaluate models of service coordination to improve outcomes for people and systems.
3. Work with other sectors to **design and fund three potential models of coordination and a method of trialling and evaluating them during NDIS rollout.**
 - a. Use the information summarised in Section 5 and Box 2 (and the study's matrix framework) to specify and design models in terms of *goals* and *service coordination components* at each of *micro, meso and macro levels*; this should include a trial in an Indigenous community. In particular, draw on this discussion paper to ensure the inclusion of evidence-based components for these models.
 - b. Involve skilled coordinators with the necessary capability to undertake the cross-sector coordination roles as defined and outlined in this paper.
 - c. Include strong participation of consumers and families in the design of the models to be trialled.
4. **Test the achievement of the specified goals at each level** (micro, meso, macro) using the suggested design for the evaluation of these models (in Section 6), examining before/after effects, as well as comparisons among different models and between NDIS trial sites and other locations.
5. In the event of positive evaluation findings, **work to achieve long-term intersectoral agreement and funding of ongoing cross-sector service coordination for people with high and complex needs.**

1. Introduction

1.1 Purpose and outline

This discussion paper is the result of a joint research project undertaken for the National Disability Insurance Agency (NDIA), with the purpose of assembling and analysing readily available evidence about service coordination for people with high and complex needs—a group needing particular attention during the establishment of the National Disability Insurance Scheme (NDIS). The paper has been developed as a stimulus to discussion about the value of a coordinated approach in service organisation, delivery and infrastructure for individuals with disability, including the capacity of such an approach to progress the NDIS’s positive engagement with other service systems — all critical to ensuring that NDIS participants get the range of services and supports they need.

The transition to the NDIS offers a significant opportunity to learn from existing evidence on coordinated services for people with high and complex needs, and to identify where there may be scope to minimise the risk that these vulnerable individuals could ‘fall through the cracks’ which exist within and across service systems. Acting on this evidence early in the scheme’s rollout will help safeguard the integrity of the Scheme’s objectives, its future financial sustainability and its ability to put individual choice at the centre of service planning and delivery.

The Centre for Disability Research and Policy at the University of Sydney and the Young People in Nursing Homes National Alliance were partners in this project. In the course of the project we:

- analysed available evidence on service coordination from relevant program reports and academic literature (Sections 2 and 3)
- conducted four workshops conducted to gather input from consumers, service providers and policy makers (Section 4); ethics approval for these workshops was obtained from the University’s Human Research Ethics Committee (2014/246);
- synthesised all this evidence (Section 5), drawing out implications for the service system emerging with the rollout of the NDIS;
- briefly discussed the findings before concluding with proposals for consideration (Section 6).

The rest of this first section of the paper now specifies our key terminology and a framework for the discussion, before outlining the current Australian context, including the place of service coordination, including cross-sector coordination, in the context of individualised funding, and the importance of interfaces between the NDIS and mainstream services.

1.2 Terminology and organising structure

The definitions for the key terms for this project are set out in Box 1. Both definitions were developed and refined progressively in the course of the research.

Box 1: Definitions

'High and complex support needs' are defined in this paper as needs for multiple changes in the environment including support in multiple areas of activities and participation, typically involving multiple service sectors.

For instance: A person may require long-term (possibly intermittent) regular personal support, high cost equipment, or behaviour support; access to various mainstream services; they may be facing challenging transitions or experiencing threats to their ability to remain in the community, such as the risk (or current experience) of institutionalisation. The complexity of need may relate more to the complexity of the services system(s) than the complexity of the person's disability.

Cross-sector service coordination is a key element of NDIS design, requiring funding, and involving:

- high level inter-sectoral collaborative agreements and related infrastructure (macro level) so that system barriers do not undermine NDIS aims
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This broad definition is elaborated in Box 2, which sets out the key components of coordination at each of these three levels.

Supports may vary in nature, intensity and cost. For instance behavioural challenges (not unusual in brain injury – see Tate et al., 2004) may be associated with higher costs and difficulties in finding accommodation solutions (Strettles et al., 2005). For some people, supports will be needed mainly at times of transition (e.g., the transition out of hospital for someone with spinal cord injury, initial transition into the service system for someone with motor neurone disease, transition from school to the post-school environment, or transition to higher levels of service use as needs increase with ageing or progression of a health condition).

To give some idea of the scope of what is under discussion, it was estimated that there would be some 410,000 people estimated to be eligible to receive NDIS funded services when the Scheme is fully rolled out (Productivity Commission, 2011 pages 15, 755). In comparison:

- In 2011-12 there were 3,715 people receiving disability support services who were in 'residential facilities/institutions' (large or small) or in hostels; a further 16,190 lived in group homes (AIHW, 2013, Table B59)

- In June 2010 there were 6,438 people aged under 65 in residential aged care, (*AIHW residential aged care data cubes*).
- Almost 15,000 people receiving disability support services in 2011-12 had an informal carer aged 65 or over (AIHW, 2013, Table B73).

These numbers are included to provide an approximation of scope: it is not to suggest that all these people would need or want coordination support, or that there are not others with similar needs beyond the boundaries of these groups.

Organising matrix structuring our analysis

The literature on service coordination is somewhat crowded with lists – lists of attributes, goals and outcomes of programs and systems. In order to organise and interrelate the material flowing through the different sections of this paper, we developed a simple matrix, based on a preliminary review of the key literature outlined in Sections 2 and 3.

One axis of the matrix reflects a ‘system and stakeholder’ perspective, recognising that service coordination must be planned for and can affect different areas, levels or players in the ‘system’; these levels can be characterised as ‘micro’ (the person, their family and carers), ‘meso’ (the service provider agencies and organisations) and ‘macro’ (the overall system(s)) (see e.g., Powell Davies et al., 2006; Ehrlich et al., 2009). One of the Australian reports reviewed reflects the importance of this interconnectedness or ‘vertical integration’:

‘Coordination necessitates both vertical integration (e.g., clear pathways, smooth handovers between services and coordinated plans for ongoing forward movement) and horizontal integration (e.g., networks and partnerships between services, interdisciplinary teams and consumer engagement at any one point in time). Coordination can occur at the micro-level (individual service providers and individual with chronic conditions), meso-level (services and organisations) and macro-level (system). Strategies can focus on processes to facilitate coordination (e.g., communication, supports for service providers and supports for individuals with chronic conditions) or structures for coordinating activities (e.g., shared information systems, proformas, care plans).’ (Griffith University, 2008).

The other axis of the matrix represents what is essentially a very simple evaluation framework, which has also informed our analysis of the literature. The examination of ‘goals, services/programs, outcomes’ underlies service evaluations and has underpinned biennial reports on the Australian service system for two decades (e.g., AIHW 2005). This organising matrix (Figure 1) is used to structure the analysis of literature in Sections 2 and 3, and the discussion of possible paths forward (Section 4). The consistency of approach through the report is designed to enable the

evidence underlying the main findings and directions in Section 4 to be found readily in Sections 2 and 3.

Figure 1: Organising matrix for structuring analysis

System and stakeholder	Evaluation focus			
		Goals	Services	Outcomes
	Micro			
	Meso			
	Macro			

1.3 Context

Historically, there has been fragmentation of service programs and structural barriers to delivering coordinated services to individuals with high and complex needs. In 2005 the Senate Community Affairs References Committee’s Inquiry into Aged Care reported concerns about the current system’s capacity to meet the needs of younger people with a disability who have diverse and complex care needs (Commonwealth of Australia, 2005). This client group includes people with disabilities related to catastrophic injuries from road or other traumas, people with an Acquired Brain Injury (ABI)¹, and those with progressive conditions such as Multiple Sclerosis and Huntington’s disease.

These individuals commonly require service responses from multiple arms of the service system simultaneously, something that the current configuration of the human services system struggles to deliver. As a result, many of these people are accommodated in, or are at risk of becoming residents in, aged care facilities. The Productivity Commission identified people who have been inappropriately placed in nursing homes among those ‘most disadvantaged by current arrangements’, and thus a priority group for coverage in the first stages of the NDIS (Commonwealth of Australia. Disability Care and Support, 2011, pages 60-61).

The long standing difficulty in getting service programs to collaborate with each other for the benefit of individuals has thus been acknowledged as a significant problem. The Productivity Commission recognised this in a number of its recommendations including the introduction of an individualised funding model for disability services as part of a lifetime approach to care and support for Australians with disability. The policy framework that had built up around a fixed budget

¹ Some of the needs and solutions outlined in this paper may apply also to the National Injury Insurance Scheme, also recommended by the Productivity Commission.

rationing system was shown to be not conducive to positive individualised outcomes for people, nor to deliver efficiencies in the overall service system (e.g., PC report chapters 2 and 8). This 'silo' approach has resulted in problems for people with disability and their families in a number of areas, such as school to employment transitions, hospital to community transitions and ongoing provision of rehabilitation and/or disease management services. Informed by extensive public consultation (see report by National People with Disabilities and Carer Council, 2011), the National Disability Strategy 2010-2020 sets out a unified, national approach to policy and program development to address the challenges faced by people with disability. The strategy aims to bring about change in mainstream services and programs as well as community infrastructure by addressing six priority areas, which include social inclusion and personal and community support (Commonwealth of Australia, 2011, *National Disability Strategy 2010-2020*).

The NDIS

The National Disability Insurance Scheme (NDIS) is being introduced in stages from July 2013. 'From 1 July 2013, the NDIS began in Tasmania for young people aged 15-24, in South Australia for children aged 0-14, and in the Barwon area of Victoria and the Hunter area in NSW for people up to age 65. From 1 July 2014, the NDIS will commence across the ACT, the Barkly region of Northern Territory and in the Perth Hills area of Western Australia. Roll out of the full scheme in NSW, Victoria, Queensland, South Australia, Tasmania, the ACT and the Northern Territory will commence progressively from July 2016.'

(<http://www.ndis.gov.au/roll-out-national-disability-insurance-scheme> viewed 22 May 2014).

The NDIS is the result of extensive policy development, review and community discussion. The Productivity Commission was asked to report on the practicalities and details of a 'national disability long-term care and support scheme' (Commonwealth of Australia, *Disability Care and Support*, 2011). Key points of the report included (page 2):

- 'Most families and individuals cannot adequately prepare for the risk and financial impact of significant disability. The costs of lifetime care can be so substantial that the risks and costs need to be pooled.
- The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments.
- There should be a new national scheme — the National Disability Insurance Scheme (NDIS) — that provides insurance cover for all Australians in the

event of significant disability. Funding of the scheme should be a core function of government (just like Medicare).

- The main function (and source of cost) of the NDIS would be to fund long-term high quality care and support (but not income replacement) for people with significant disabilities. Everyone would be insured and around 410 000 people would receive scheme funding support.'

The NDIS Act 2013 passed through Parliament in March 2013 with support from all sides. It continues to enjoy support from both major parties nationally, as well as from State and Territory governments and the community at large. Its broad objects are set in in Section 3 (see Box 1).

The NDIS represents a shift from a system largely reliant on a mix of government run services and block funding to services (delivered mainly by NGO providers), a system which has been devolving services from government to NGOs and which has increasingly used 'funding packages' for eligible people with disability. The NDIS system is built on a primary model of funding people with disability for a package of disability supports, judged 'reasonable and necessary', which they can then purchase from any service provider. What is 'reasonable and necessary' is carefully described in Section 34 of the NDIS Act and effectively relates to rights (to economic and social participation – also in line with the objects of the Act referring to UNCRPD), to community standards (in terms of what it is reasonable for families and the community to provide), to cost and value for money (and elsewhere to the financial sustainability of the Scheme), and to what other service sectors should provide.

The administration of the system is a responsibility of the NDIA, an Australian government agency, with the states withdrawing from the provision of disability services over the period of transition, while retaining responsibility for the direct provision of services such as health, education, transport, and justice.

Box 1: Objects of the NDIS Act

3 Objects of Act

- (1) The objects of this Act are to:
 - (a) in conjunction with other laws, give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006 ([2008] ATS 12); and
 - (b) provide for the National Disability Insurance Scheme in Australia; and
 - (c) support the independence and social and economic participation of people with disability; and
 - (d) provide reasonable and necessary supports, including early intervention supports, for participants in the National Disability Insurance Scheme launch; and
 - (e) enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports; and
 - (f) facilitate the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability; and
 - (g) promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the mainstream community; and
 - (h) raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability; and
 - (i) in conjunction with other laws, give effect to certain obligations that Australia has...

2) These objects are to be achieved by:

- (a) providing the foundation for governments to work together to develop and implement the National Disability Insurance Scheme launch; and
- (b) adopting an insurance-based approach, informed by actuarial analysis, to the provision and funding of supports for people with disability.

(3) In giving effect to the objects of the Act, regard is to be had to:

- (a) the progressive implementation of the National Disability Insurance Scheme; and
- (b) the need to ensure the financial sustainability of the National Disability Insurance Scheme; and
- (c) the broad context of disability reform provided for in:
 - (i) the National Disability Strategy 2010-2020 as endorsed by COAG on 13 February 2011; and
 - (ii) the *Carer Recognition Act 2010*; and
- (d) the provision of services by other agencies, Departments or organisations and the need for interaction between the provision of mainstream services and the provision of supports under the National Disability Insurance Scheme.

The broader service context and the place of cross-sector coordination

New directions in health and human services systems emphasise 'person-centred' services able to support people over time and across system components. There is a focus on: the needs of people experiencing health problems or disabilities, their families and communities; the maintenance of health, quality of life, participation and inclusion; an integrated approach across the continuum of care; and equitable

access by all Australians to quality services (Madden et al., 2012). There is recognition of the need to move to more integrated models of service development, delivery and management, underpinned by stronger evidence about cost-effective and successful service models.

New models of coordination are emerging in fields related to disability. In a review of literature on 'collaborative care' in mental health, the authors found many definitions and strong evidence in favour of health care coordination (Rosenberg & Hickie, 2013). They conclude:

The key challenge facing continued reform in mental health is not uncertainty regarding programs or services, but rather how to drive coordinated care for consumers across departments, governments and providers.

The structural changes now being implemented with the introduction of the NDIS are thus taking place in an evolving field. They are also made more complex because they are acting on a system which (a) was recognised to be inadequate in its reach, with much unmet need (Commonwealth of Australia 2011a. *Disability Care and Support*, page 2); (b) was itself in transition towards greater use of individualised funding packages (as previously noted); and (c) had some problems with 'coordination', particularly for people with high and complex needs, and for people at the borders of different service systems (see previously and following). In the Australian context, existing problems with coordination are perhaps best evidenced by the decision to introduce the pilots reviewed in this paper, including the Younger People In Residential Aged Care (YPIRAC) pilots that recognised that the needs of younger people either in or at risk of placement in residential aged care have not been adequately served by current systems (see more detail in Section 2).

The NDIA is itself introducing new structures (its Local Area Coordinators) and funding mechanisms (budget items for coordination services) in light of these challenges. This paper aims to provide evidence to inform policy directions now being developed.

Individualised funding and the need for coordination

The wider use of individualised funding is a feature in the new landscape of the NDIS. As was noted by the Productivity Commission there are many terms and models related to choice, control and access to the supports needed by an individual person. They accordingly focussed on principles of 'self-directed funding' (Commonwealth of Australia 2011a. *Disability Care and Support*, pages 353-4) and discussed the degree to which people would want to manage their care and their funds, or would prefer some assistance with this (Commonwealth of Australia 2011a. *Disability Care and Support*, pages 346-7).

The Productivity Commission findings were carefully researched and accord with other literature in the field (e.g., Glendinning et al 2008; Fisher et al., 2010; Lord and Hutchison, 2003). Personalised care can help manage complexity and integrate health and social care (Duffy, 2010) but its success in turn relies on suitable supports including at times of change and transition, and the presence of brokers or advocates (Duffy 2010; Manthorpe et al., 2011; National Disability Services 2013a). The Productivity Commission, consistent with this approach, proposed 'disability support organisations' (DSOs) (Commonwealth of Australia. *Disability Care and Support*, 2011, page 40):

'A new form of organisation, 'disability support organisations', would offer people brokering services, the skills and confidence to practically exercise choice, management services (such as dealing with the administrative aspects of self-directed funding, were a person to go down that route), personal planning, and orientation supports for people who are suddenly faced with the unfamiliar world of severe disability.'

This model stops short of cross-sectoral coordination, but needs to be considered when discussing coordination functions.

Cross sector service coordination and mainstream services

Mainstream services have been, and will continue to be, essential in meeting the needs of people with disabilities, particularly for those with long-term high and complex needs. That people with disability require and have the right to access the same quality mainstream services as all Australians is recognised in a range of national and international agreements, laws and arrangements (including the United Nations Convention on the Rights of Persons with Disabilities – UNCRPD; the National Disability Strategy (Commonwealth of Australia 2011b); and the Disability Discrimination Act 1992). The active involvement of programs in health, aged care, housing, education, employment and justice will be required to complement NDIS packages in order for scheme participants to activate their life choices. Strong links between the NDIS and mainstream services are critical, but these services have not always been inclusive of and accessible to people with disabilities. Many life goals will rely on services outside the boundaries of the NDIS – services to which people with disabilities have the same rights of access as do other Australians. For the NDIS to best support participants, however, the capacity to connect different services and negotiate individual delivery imperatives will be needed. Maintaining the primacy of an individual's choice and control in this systems web will be a key challenge in achieving the best possible outcomes for participants as well as the ambitious goals of the NDIS. Mediation of these interfaces will clearly need to happen at the policy level, the services delivery level and the participant level. **The form of these coordination and interface processes is at the heart of this paper.**

In its detailed analysis of the problems of the health-disability systems interface (page 182 and following) the Productivity Commission stated (page 190) that ‘a good interface between the two systems is essential’. For instance in relation to the mental health system:

‘It would be essential that the (state-based) mental health system work closely with the NDIS. In particular, there would need to be:

- clear lines of responsibility and strong communication between the NDIS and the mental health system, given the ongoing need for well-coordinated clinical and non-clinical support. To achieve good outcomes, clinical care must also be available when required and be appropriately integrated (a clear responsibility of the mental health system). This is similar to other people with significant disability who have support needs with daily living in the community, but who will also be using medical services.
- As with other types of disability, agreement from state and territory governments that they would provide complementary supports, such as public housing and clinical care, which are essential in achieving better outcomes for these groups.

The need for a better interface and expertise cuts both ways. The NSW Council for Intellectual Disability highlighted the lack of expertise in the mental health sector in dealing with people with intellectual disability who also had mental illness and the poor access of people with intellectual disabilities to clinical supports’.

The NDIS Act specifically recognises this policy and service context in which the scheme will be implemented. As well as referring to the broad context of disability reform provided for in the National Disability Strategy 2010-2020 and the Carer Recognition Act 2010, Section 3(3) (objects of the Act) refers to the need to ensure the financial sustainability of the National Disability Insurance Scheme and recognises ‘the provision of services by other agencies, Departments or organisations and the need for interaction between the provision of mainstream services and the provision of supports under the National Disability Insurance Scheme (see Box 1).

The location of the NDIS in the midst of ‘generic’ or ‘mainstream’ services is thus a challenge. NDIS is an entitlement-based scheme. Until the advent of the NDIS, support for people with disabilities has been provided by a constellation of budget-limited support programs. It will be essential for services provided through the NDIS to be integrated with mainstream services (which generally maintain budget limited funding systems)—health, housing, education, employment, aged care and transport—both to optimise outcomes for scheme participants, and to safeguard the financial sustainability of the NDIS. Mechanisms for the NDIA to interact and coordinate across sectors with mainstream services such as health, housing and education, are needed so that it can operate consistently with the Objects of its Act.

Reform in the disability sector is, on its own, not enough to ensure that people with high and complex needs get the services they need. Changes are required across the human service system, as agreed in national instruments including those referred to in the NDIS Act. To deliver on its aims and objectives, the NDIS - as a disability services funding program - will need to work directly on effective interfaces with these other program areas.

This paper explores the nature of the problems and possible solutions in providing effective and coordinated services to people whose needs span service sectors and involve collaborations working for meaningful outcomes including health, well-being and participation.

2. What can we learn from recent Australian service coordination programs?

2.1 Introduction

Over recent years there have been a number of programs and pilots in Australia that have aimed to provide better coordination of services across sectors for people with high and complex needs. Program descriptions and evaluation reports are available for a number of these, and provide a valuable source of information on the goals of cross-sector service coordination, approaches taken to implementation, and outcomes. This section synthesises the Australian experience drawing largely on reports available in the 'grey literature'.

The matrix introduced in Section 1 is used as an organising structure. After introducing the programs and pilots, Section 2.2 looks at the goals of service coordination initiatives, from micro (person and family), meso (service agencies and organisations) and macro (system) perspectives. Section 2.3 identifies the key features of the models reviewed, again at the three levels. Section 2.4 draws out evidence on outcomes at micro, meso and macro level.

Overview of the programs reviewed

Of the eleven programs reviewed here six were pilots that ran for a limited period and two are ongoing. The remaining three are reports that review the need for and propose models of service coordination for people with high and complex needs. A brief description of each is given here to provide background. (See also Appendix Table A1.)

The abbreviations in brackets are used for convenience through the text to refer to the different programs.

- **Victorian Continuous Care Pilot (Vic CCP)**. Final report and evaluation report 2009. Pilot conducted from 2008–2009 as part of the Victorian YPIRAC initiative². Service coordination was provided to 19 people aged from 33 to 49 years with a progressive neurological condition. (MS Australia and Calvary Healthcare Bethlehem, 2009)

² The Young People In Residential Aged Care (YPIRAC) program was established in 2006 with the aim of delivering sustained reductions in the number of younger people with disability in residential aged care by providing service support packages and alternative accommodation. The program operated under a 5-year agreement between the Australian Government and state and territory governments (AIHW 2009).

- **NSW Continuous Care Pilot (NSW CCP).** Evaluation report 2010. Pilot conducted from 2008–2009 as part of the NSW YPIRAC initiative. Service coordination was provided to 20 people aged under 50 with a progressive neurological condition. (MS Australia, 2010)
- **Spinal cord injuries response (SCIR), Qld.** Evaluation report 2008. Program initiated in 2005–06 to assist people with spinal cord injury transitioning from the Spinal Injuries Unit (SIU) to the community. Program is ongoing; 80 individuals had been assisted at time of review. (Griffith University, 2008)
- **Spinal Cord Injury Community Participation Project (SCI CPP), NSW.** Two year (2007) and five year (2010) evaluation reports. Pilot initiated 2004/05. Service coordination was provided to support people with traumatic spinal cord injury aged 16–65 to transition back to the community. (Motor Accidents Authority of New South Wales, 2007)
- **Collaborative Care in Motor Neurone Disease in Victoria (CC MND).** 2009 report reviewing evidence and proposing an improved collaborative care model for people with MND. Proposed model has been implemented by MND Victoria as the Regional Advisor Service. (Calvary Health Care Bethlehem, 2009)
- **ABI Slow to Recover Program, Victoria (ABI STR).** Program review report 2004. Program established in 1996 to provide slow stream rehabilitation for non-compensable Victorians under 65 years with acquired brain injuries. 124 individuals receiving services at mid-2003. Program is ongoing. (Victorian Department of Human Services, 2004)
- **Neurodegenerative Conditions Coordinated Care Program, WA (NCCCP).** Evaluation conducted in 2010. Pilot began in 2008 to provide service coordination for people aged under 65 with a rapidly degenerative neurological condition. (Bahn & Giles 2012)
- **Better Pathways Pilot Project, SA (BP).** Process and interim outcomes evaluation report 2012. Program initiated in 2009 to improve engagement, transition, and post-school outcomes for young people with disabilities and mental health issues ‘at risk’ of not making a successful transition to the post-school environment. 316 students were registered with the program at June 2012. Program is due to conclude later in 2014. (Warren, 2012)
- **Multiple and Complex Needs Initiative, Victoria (MACNI).** Evaluation report 2007. Program initiated in 2004. Provision of intensive, time limited (up to two years), care planning and service coordination intervention for people with multiple and complex needs related to combinations of mental illness, intellectual or physical disability, ABI, behavioural difficulties, family dysfunction or substance misuse—a group who typically experience poor service outcomes. Program ongoing; 56 individuals accepted into initiative as at October 2007. (KPMG, 2007)

- **Economic benefits of coordinated service delivery for YPINH.** Report prepared by ACIL Tasman for the Young People In Nursing Homes National Alliance, 2013. Cost modelling to examine the economic implications of providing cross-sector service coordination for people with high and complex needs. (ACIL Tasman, 2013)
- **Disability care at Western Health, Victoria.** 2011. Proposed strategies to improve the interface between health and disability services, in particular for people with Down syndrome and Autism Spectrum Disorder. (Thompson, 2011)

Many of the models reviewed focus on people with acquired disability. The Better Pathways project in South Australia targeted high school students with disability at risk of not making a successful transition to the post-school environment, with a particular focus on those who often fall through the gaps, such as Aboriginal students, students from culturally and linguistically diverse backgrounds, and students who live in regional areas. The MACNI program targeted ‘people with multiple and complex needs as a result of various combinations of mental illness, intellectual disability, acquired brain injury, physical disability, behavioural difficulties, family dysfunction and drug and alcohol abuse’ who often do not fit within the framework for service provision for any one disorder. The Disability Care at Western Health report focused on access to health services for people with lifelong disabilities.

Several of the models were particularly focused on periods of transition—the initial transition out of hospital for people with spinal cord injury (SCIR and SCI CPP), and the transition from school to post-school activities (BP). For people with progressive neurological conditions (Vic CCP, NSW CCP and NCCCP) there is an initial transition into the service system, followed by transitions to higher levels of service use as the condition progresses.

Many of these programs/pilots target people who have characteristics that traditional disability services models may not be well equipped to cope with, such as:

- Family contexts (e.g., dependent children)—services often focus on the needs of the individual with disability, rather than the person in their family role, and the needs of other family members.
- Progressive disabilities, where the person’s needs increase and change over time, sometimes quite rapidly (e.g., MND).
- Diverse and complex needs that span different service sectors (e.g., health, disability, housing, aged care, transport and community services).
- Reduced resilience (due to prolonged extreme stress, socioeconomic factors, etc.).

While most of the programs reviewed were time limited, SCIR, ABI STR and MACNI are ongoing. The SCI CPP pilot helped to inform the development of the current NSW

Lifetime Care and Support Scheme. The model proposed in the CC MND report has since been implemented in Victoria.

2.2 Goals

The main stated goals of the programs and pilots reviewed are as follows (some are specific to a single model, others apply across several or all of the models reviewed).

- Prevent or manage the risk of premature entry into residential aged care
- Support transition from hospital back to the community
- Promote community participation
- Reduce delays in receiving services and support
- Improve engagement, transition, and post-school outcomes for young people with disabilities
- Improve linkage of quality primary and specialist clinical care with social and emotional supports
- Provide slow stream rehabilitation services and facilitate reintegration into the community
- Support service providers to meet the needs of people with high and complex needs
- Improve coordination between government agencies
- Provide more person- and family-centred care
- Provide integrated service responses for people needing services from multiple arms of the service system

Micro: goals for people and families

Some of the reports present material relevant to identifying the goals and priorities of people with disabilities and their families. The CC MND report presents an analysis of survey responses received from 103 people with MND and carers (81% of responses were from people with MND). Results indicated that 80% of respondents wanted to remain in their own home for as long as possible, 67% preferred care to be provided locally (providing that health professionals and medical staff have appropriate expertise), and 61% commented that their local service providers would benefit from advice and training from staff with experience of MND. The ABI STR report also noted that rural families often express a preference for local service provision.

The Victorian CCP evaluation lists the issues of greatest importance to consumers and carers, based on an analysis of two 'concept mapping' sessions involving program participants. The highest ranking issues can be summarised as:

- Reliability, regularity and dependability of carers and service providers
- Service providers who understand the person's condition
- Housing alterations, and adequate facilities and equipment at home

- A central source of information about what assistance is available (including eligibility) and help with paperwork
- Consistent response to urgent needs
- Communication equipment and support for communication needs
- Confidential psychological support for carers
- Services that can adapt to rapidly changing needs

The MACNI initiative emphasised the importance of achieving stability and consistency in the lives of people with multiple and complex needs (as defined for that target group), and creating a platform for long-term engagement within the service system—shifting the focus from responding to a series of crises to planned intervention to achieve long-term goals. Care plan goals focused on promoting stability of health, housing, safety and social connectedness.

Meso: goals and priorities for provider agencies

For service providers, goals of service coordination centre on resources, systems and mechanisms that enable them to better meet the needs of service users. Several reports discuss problems and structural barriers in the current services system that hamper providers in meeting needs, particularly those of people who do not fit neatly within one program area. In essence, the programs and pilots described here aimed to find ways of overcoming or circumventing these problems in order to more fully meet people’s needs.

Service barriers and gaps identified in the Victorian CCP report, and echoed in several of the other reports, included:

- **Fragmentation** of service provision and inability to draw down from the full range of relevant services across sectors to achieve integrated care delivery
- **Limited understanding** on the part of disability service providers regarding disease trajectory and how to manage complex health needs
- **Lack of knowledge** about specialist networks and when to refer
- **No clear pathways** to enable integrated, multidisciplinary health and disability services
- **Long waits** for packages and inadequacy of the funding provided (delays in accessing equipment received particular emphasis in several of the reports)
- **Poor communication** between individual/family/health providers/community care providers.

One of the aims of the Victorian CCP was to identify and address **unmet needs** and aspects of need where **no forward planning** had occurred for the person with a progressive neurological disability. Among participants, unmet needs were frequently identified for disability support packages (often because the person and/or their case manager had **difficulties with the application process**), community services, case management, health care, social support, and ‘at-risk’ behaviours.

The Disability Care at Western Health report highlighted a lack of access to health professionals and **inadequate management of health issues** in community settings experienced by people with disabilities, and inadequate support for carers working in disability services group homes and day programs to manage the risk of health deterioration (e.g., risk of pressure wounds following seizures).

The CC MND model aimed to provide access to necessary services and expertise for people living in non-metropolitan areas, especially in response to an identified lack of neurology and respiratory physicians in regional areas. **Limited access to local services with appropriately skilled workers** for people outside metropolitan centres was an issue raised in several of the reports. The ABI STR report pointed out that a **lack of rural travel budgets** can effectively reduce the amount of service delivery to individuals, as case managers are reluctant to travel regularly to rural areas.

Access to services for people with high and complex needs can also be limited by **narrowly specified eligibility criteria** (e.g., based on age, diagnosis, disability type) (CC MND, BP, MACNI), **service rationing** (e.g., such that a person loses hours from one provider when they access support from another provider), and **inadequate resources** (e.g., inadequate disability support packages, unavailability of social housing, etc.).

The MACNI initiative focused on people who were marginalised within the service system because they **did not fit within the legislative framework for service provision for any one disorder** and the existing service system was unable to meet their needs. There was a perception that services often have a **'silo' mentality**, and do not take a holistic approach to assessment and intervention.

The CC MND report noted **financial disincentives** to service providers taking on more complex individuals, because of the way occasions of service are counted. Also, many of the activities that constitute an allied health intervention for a person with MND are unfunded (e.g., discussion with equipment/home modification providers and local therapists).

The ACIL Tasman report examines economic benefits of coordinated service delivery and discusses the shortcomings of the current state-based disability systems. It highlights service fragmentation and a lack of support for people and their families in finding their way through the system. The duplication of assessment, along with a general under-provision of services, can mean that people often receive a lot of assessment relative to the other services they receive. The report notes that the current disability system is not well equipped to cater to people with a mix of health and disability support needs, who have therefore often had to be supported in the aged care sector. However, residential aged care facilities are staffed and funded to respond to the needs of frail older people, for whom average stays range from 6

months to 2 years. Because of this, they struggle to support younger people with high and complex needs.

Macro: goals and priorities at system level

A major objective of the MACNI Initiative is to develop a regional service framework that ensures a coordinated and collaborative response to individuals with multiple and complex needs.

Many of the reports articulate goals at the meso level (i.e., for the program), rather than system level and whole-of-government goals. However, the following broad macro level goals for cross-sector service coordination can confidently be inferred from the reports:

- Provision of quality services to meet the needs of people with disabilities—this is a primary objective of disability service systems.
- Efficient use of resources—reduced duplication and over-servicing, and ‘joined up’ services and programs across sectors
- Enabling people to remain living in the community for as long as possible, and thus reducing demand for more expensive service responses in the acute care and residential aged care sectors.

It is worth also mentioning here the Hospital Admission Risk Program (HARP), a Victorian initiative developed in response to unprecedented growth in demand for public health services (Victorian Government Department of Human Services, 2006). There was a large investment to develop new approaches to patient management, providing more appropriate care for individuals known to have a high risk of potential health deterioration and thus preventing future avoidable hospital use—a clear systems level goal. The HARP initiative was based in the health sector and did not specifically target people with high and complex needs, as defined for this project, so it is not included as one of the key programs reviewed. However, some of the projects delivered under the initiative involved strategies for cross-sector collaboration and service coordination, and relevant points from the HARP report are included in this section. HARP has now evolved to a mainstream model of care with a focus on chronic disease management.

2.3 Features of cross-sector service coordination

This section identifies the key features of service coordination, outlined in the reports reviewed, looking in turn from the perspective of the person (micro), service provider (meso), and service system (macro).

Micro: what coordination looks like for the person

Based on descriptions given in the various reports, the experience of person-centred service coordination for people with disabilities and their families involves the following:

- Help with navigating the service system across relevant sectors, understanding which services are available and relevant, and being assisted to apply for services.
- Not having to tell their story repeatedly to different providers, and not wasting time and energy trying to find out what services are available and how to access them.
- Receiving services and supports when they are needed (i.e., no long delays), seamlessly and without having to negotiate awkward interfaces between services in different sectors.
- Feeling confident that the necessary services will be available to meet future needs (i.e., that there is the flexibility for services to change as their needs change).
- Service providers who understand their needs and have the necessary expertise to meet them (e.g., because relevant information about the person has been communicated, and/or the service provider has received training and skilling to enable them to meet the person's particular needs).
- Being kept properly informed—open and effective channels of communication between the person/family, the coordinator, and service providers.
- Having a single point of contact—someone to go to with questions, or when there are problems or issues with services.
- Having a relationship of trust with their coordinator, and feeling that the coordinator properly understands their issues and needs.
- Having genuine input into the process of service planning, so that the plan is shaped by the person's own goals and priorities (e.g., for a person who is a parent, supporting their parenting role may be of foremost importance to them)

Disability services are a means to an end rather than an end in themselves. For most people, more effective access to the supports they need and less time and energy spent on trying to find out what is available and how to access it enables them to get on with living their lives.

Meso: components service coordination

While the programs reviewed differ in detail, this section endeavours to set out the key common components of cross-sector service coordination, providing brief information on the ways in which they were operationalised and some illustrative examples. It should be noted that these programs were, on the whole, operating as 'islands', outside of but interacting with standard program structures and systems, a situation that has no doubt impacted on aspects of their design and operation.

a) Coordination function

This function involves facilitating communication horizontally and vertically (i.e., between the person, case manager, service providers, higher level structures in the

program, and other stakeholders including other relevant programs and organisations), and securing the services needed for the person. In several of the models, the coordinator was the lynch pin—being the central point of contact for the person and family, service providers, and other stakeholders (e.g., clinical experts), and also taking the lead role in goal development and planning for the person (e.g., CCP Vic, BP, SCI CPP).

Important qualities for carrying out the coordination function include having the necessary skill set for liaising with the various stakeholders, knowledge of the relevant service systems, and an understanding of the disabilities or health conditions of the program's target group. The coordinator also typically had some form of imprimatur within the context of the program to enable them to be effective in securing the services needed.

The work of the coordinator often included service planning in partnership with the person, navigation of the service system, helping the person/family to apply for services or funding, and providing information and support to the person and family.

Liaison and advocacy are key aspects of the coordination function, to facilitate better access to mainstream services, such as community health; and to forge linkages with services and other organisations in the community. This was a strong component of the Better Pathways model—examples of advocacy work undertaken by Pathways Workers include assisting a family to obtain a house through Housing SA, and helping a young person into an apprenticeship with local council. In the MACNI regional coordinators work with service providers to foster information sharing and identify and develop collaborative and coordinated solutions, helping to build and strengthen local service networks.

In some models case management was provided separately to the coordination role, while in others the coordinator undertook case management activities as part of their broader role. In the MACNI a Care Plan Coordinator may take on case management in addition to their care plan coordination responsibilities, or case management may be undertaken by a separate provider.

In the SCIR model there is a coordinator for each region in Queensland. When a person with spinal cord injury is referred to SCIR, the coordinator makes contact with the person, talks to the family and the clinical team, undertakes needs-based planning with the person, and appoints a case manager. The case manager looks after day to day issues with services and supports for the person, reviews care needs, and seeks approval for any changes through the coordinator. Over time, as their rehabilitation progresses, the person typically takes more responsibility for organising services and the case manager may no longer be needed. The person remains in the program and relates directly to the coordinator to arrange changes to services and supports.

In the SCI CPP, Community Participation Coordinators assisted with discharge from hospital and resettlement into the community by developing a community participation plan for each participant, which addressed their social, family, work and leisure goals, and then assisting the person to access and co-coordinate services and equipment to achieve the plan. The coordinator worked with relevant agencies to ensure there were no system blockages such as delays in services. The three main types of activities undertaken by coordinators were (i) individual and family support, (ii) liaison and advocacy, and (iii) goal development and lifetime planning. Coordinators had extensive experience supporting people with spinal cord injury in the community and a good knowledge of available support systems.

The NSW CCP used the term 'tertiary case management' to describe its model, which provided participants with 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 and collaboration with an area health service. A coordinator was appointed to run the pilot and set up a Clinical Advisory Group (CAG). The coordinator followed through on decisions made by the CAG in relation to individual service plans, and worked closely with case managers to ensure continuity of care by facilitating information flow between health professionals and service providers, timely and appropriate referral to services, identification of service gaps, and the practical application of available resources. Four of the seven participants had case managers. The NSW CCP evaluation recommended that the coordinator should have formal health training, a good working knowledge of the health and disability service systems, and strong organisational and communication skills.

The ABI STR model is different again. The STR program contracts the coordination function out to case management organisations. For each individual a rehabilitation plan is formulated, in communication with the person and family. External providers are engaged to deliver therapy and attendant care services. The case management organisations also link with equipment services and accommodation providers, and advocate for access to mainstream services.

b) Facilitating access to relevant skills and expertise

Several of the programs reviewed had a mechanism for ensuring access to or input from specialists, including specialist clinicians and professionals with an in-depth knowledge of the particular disability/condition, associated needs and how these were likely to change over time. These mechanisms were intended to facilitate ongoing input from relevant organisations across sectors into the assessment, service planning and review processes for participants.

In the case of the Better Pathways project, interagency teams within each of the designated communities comprised representatives from government departments, service agencies, and schools peak bodies. An Aboriginal Education Coordinator was

included, as the program had a particular focus on aboriginal young people with a disability. A relationship with Disability SA Aboriginal Cultural Advisors, both locally and centrally, facilitated linking with service providers, recruiting Aboriginal Pathway Workers, and supporting Better Pathways workers to engage with Aboriginal young people with disabilities. The program also linked with a range of Aboriginal services, agencies and groups regarding referral pathways.

In both the Victorian and NSW CCPs a Clinical Advisory Group (CAG) was central to the model. Clinicians on the CAG had access to clinical information for each of the participants and liaised with treating health professionals. The CAG clinicians provided secondary consultation advice, supporting and guiding case coordination and decision-making for each participant. At regular meetings they discussed the needs of participants and their carers, evaluated potential risks (in particular relating to risk of entry into residential aged care), developed disease management plans, and provided clinical advice and assessment. In both pilots the coordinator was the common thread through both the clinical and social components of the trials and was also a person with an in-depth understanding of the needs of people with progressive neurological conditions.

In the SCIR model each participant has a multi-disciplinary transition rehabilitation team. The participant's 'key worker' is a member of this team (e.g., may be a social worker based at the hospital). The key worker coordinates meetings of the team about the person's rehabilitation and transition planning, and facilitates information sharing between participant, family and other members of the team. All members of the multidisciplinary team contribute to the development of the participant's plan.

A key feature of the collaborative care model proposed for people living with motor neurone disease (MND) in Victoria was a 'hub' of expertise, set up as a collaboration between organisations that have specialist knowledge of MND and the needs of people living with the disease (including respiratory support). Working in conjunction with local service providers the hub would provide tertiary services to people with MND. It would also provide outreach tools, as specialist resources for people with MND, families and service providers across the State—education material, consultancy services for patients, families and health professionals, case conferencing and telehealth facilities, and an outreach team.

The Victorian CCP evaluation report endorsed this model, and proposed the establishment of disease specific hubs to provide tertiary consultation services (including tele-consults), develop guidelines and standards for service delivery, and undertake research and systemic advocacy. There would also be regional hubs covering all progressive neurological conditions, which would provide training, mentoring and secondary support to case managers.

The Victorian and NSW CCPs and the CC MND model located the coordination function within a specialist organisation, and also linked in other relevant services

from other sectors. Likewise the MACNI 'regional gateways' provide links to a range of other relevant organisations and specialist services; there is an emphasis on finding local service solutions for participants and facilitating collaborative service planning across agencies .

c) Individualised approach to planning and anticipating needs

All the programs reviewed were based on an individualised approach to cross-sector service coordination. Common (though not universal) features included:

- Anticipation of future needs to enable early intervention and ensure that services and supports can be in place when they are needed. Anticipation and management of risks (i.e., potential threats to health, wellbeing, and informal care arrangements) is central to future-oriented planning.
- Involvement of the person and family in planning and goal setting.
- Holistic assessment, taking account of the broader context of the person's history, family life, home environment, and goals
- Regular review in order to be responsive to the person's changing situation and needs. (In the case of the CCPs, a capacity for on demand review and response.)

In many of the models the coordinator played a key role in the planning process; the models varied as to the degree and the directness of input from other parties, including case managers, service providers, and clinicians.

The Victorian CCP used a 'biographical' approach to planning, considering all life domains, the history of service usage, and future expectations. A physical examination of the person's home environment and observation of transfers and care tasks was an important component. This in-depth approach to planning also helped the coordinator establish a rapport with the person, which was seen as a valuable aspect of the model.

The CAG also had a role in the process, undertaking detailed, future oriented planning based on their understanding of risks affecting the participant. Here, risks were primarily understood as threats to a person's health and well-being and ultimately, their ability to remain living in the community. Risks were categorised as 'gradual impact risks' that build up over time and threaten the ability of the person to remain living at home; and 'immediate impact risks' that present an immediate crisis. As well as identifying and managing risks for individuals, there was a strong emphasis on identifying systemic risks, to inform the improvement of service provision for people with progressive neurological conditions more broadly.

The CC MND model also emphasises the importance of forward planning and anticipation of needs in order to achieve timely and equitable access to information, services and treatment. It is critical to allow time for decision making and choice in order to avoid crises and unnecessary hospitalisation or unwarranted medical interventions, particularly for people whose condition and needs can change rapidly.

In the SCIR model, the person's needs for personal care, equipment, home modifications and social housing are assessed before discharge from hospital, and the person does not leave hospital until adequate supports are in place. There is scope for a staged transition process, allowing a person to leave the spinal injuries unit for a short period to try out living in the community before making the final transition back to community living. This enables the transition plan to be fine-tuned.

In the Better Pathways model the Pathways Worker is responsible for developing and implementing student Transition Plans, and monitoring progress until one year post-school. Pathways Workers are trained to use Person Centred Thinking tools in developing transition plans, to ensure that the plan is centred, aspirational and steered by the young person. Planning meetings involve the student and 'stakeholders' of the student's choosing, and wherever possible this will include family and school representatives. Plans and progress are reviewed quarterly, with stakeholders.

d) Timely access to services and equipment

The broader context in which the pilots and programs reviewed were operating is one characterized not only by fragmentation and service 'silos', but often by chronic under-resourcing, systemic unmet demand, and 'red tape'. For service coordination to be effective there must be attention to ensuring that the required services, as identified in service plans, can actually be provided when they are needed. In the models reviewed there were two broad approaches to achieving this within the broader system context of a less than optimal funding and resource environment.

These were:

- Direct purchasing of services from a pool of brokerage funds to enable immediate access to supports while longer term funding was sourced and brought online
- Agreement/commitment among partner organisations to provide services to program participants

The SCIR focuses on getting services and supports in place before discharge from hospital. Sometimes this takes time (equipment trialling, in particular, was identified as a source of delay), but the person is not discharged until everything is in place. The cross-sectoral partnership agreements underpinning the program have been instrumental in facilitating access to necessary services. SCIR partnership organisations agree to give priority to SCIR participants. For example, SCIR participants have access to a greater range of fully funded aids and specialised equipment, and funding specifically allocated by the Department of Housing has allowed the social housing needs of SCIR participants to be prioritised.

To help ensure more timely access to services for participants, the Better Pathways program 'mandated' service collaboration between schools, disability and health services, and further education and training agencies. Under this arrangement participating service agencies granted extra effort and longer lead times to program participants.

In many of the programs brokerage funding was available to allow direct purchase of services/equipment. In the Victorian and NSW CCPs brokerage funds were used to purchase non-recurrent services (disability and other) and/or equipment only when no other response was available to meet an urgent, identified risk. Similarly, SCI CPP coordinators had access to funds for purchasing services and/or equipment on an interim basis where waiting times or other limitations had a direct impact on resettlement in the community. In the MACNI brokerage funding is used to allow a response to be customised to the person's individual needs, e.g., by enabling the provision of extended hours services, access to specialist counselling services, or support to increase engagement in the community (such as education and training).

The ABI STR program provides funding for contract purchasing of a range of core services, including allied health services to deliver slow-stream rehabilitation, case management, and the management and provision of aids, equipment and home modifications. Physiotherapy, occupational therapy and speech pathology are the main therapy services funded. The program also funds provision and training of support workers to deliver participants' individual rehabilitation programs under therapists' supervision. Case managers advocate for individuals and their families to access other services in the community to meet recreational, psychological, support and social needs. In WA, the NC CCP also used direct purchasing, with expenditure per individual capped at \$80,000 per year or \$10,000 per month for two consecutive months.

e) Cross-service and cross-sectoral commitment

All of the programs and pilots reviewed aimed to achieve service coordination both within and across sectors, and implemented various structures, mechanisms and protocols to support this. The SCIR model is based on a partnership network among key organisations. Cross-sector commitment between disability, health, and housing was initially formalised in memoranda of agreement. As mentioned above, SCIR partnership organisations agree to give priority to SCIR participants. Agencies worked together to establish shared expectations, met regularly to reflect on their processes and refined their operational models in response to experiences.

In a similar way, the Better Pathways Interagency Team Charter underpinned cross-sectoral collaboration by requiring Interagency Teams to comprise representatives of specified agencies across the disability, health, housing and community sectors. Responsibility for providing timely responses to young people identified at risk of not making a successful post-school transition was vested in these Interagency Teams.

While more formal community partnerships were not achieved, referral relationships with a variety of agencies, services, and groups were established. A small Department of Education and Child Development Central Office team implemented a range of strategies to encourage and support schools, service providers and agencies to work in partnership to achieve the objectives of the project and address identified issues.

Another element in the Better Pathways model that promoted cross-sectoral collaboration was the requirement that each school designate a key contact person who coordinated the program across the school and was the point of contact for project 'key workers' (coordinators).

The MANCI is underpinned by the Human Service (Complex Needs) Act 2003; the purpose of the Act is 'to facilitate the delivery of welfare services, health services, mental health services, disability services, drug and alcohol treatment services and housing and support services to certain persons with multiple and complex needs by providing for the assessment of such persons and the development and implementation of appropriate care plans.'

In outlining a proposed model of service coordination for people with high and complex needs, ACIL Tasman (2013) makes the point that connections between programs (disability, health, aged care, housing etc.) are needed at two key levels:

- Participant level—a suite of services coordinated at the community level into a coherent model of support that makes sense to the person and meets their needs comprehensively. ('Micro' level, in terms of our structuring matrix)
- Systems level—service programs actively engaging with each other around their key responsibilities, and having the capacity to develop boundary protocols and joint-funding initiatives. ('Meso' level, but facilitated by imprimatur from 'macro' systems level)

The Disability Care at Western Health report outlined strategies for improving the interface between health and disability services, particularly focusing on people with Down syndrome and autism spectrum disorders. Among other strategies, it proposed a cross-staffing approach, involving a disability consultation liaison role within the health team, and health outreach services to provide education and support for disability workers in group homes to help them manage health issues. The proposal recognised the need to engage senior staff in both disability and health sectors to scope interest, develop joint strategies and engage potential facilities and participants. The focus was on service level connections across the health and disability services in the health catchment region.

f) Communication

Communication and information sharing are critical to effective service coordination. Channels of communication run horizontally (between the person/family and service

providers, and between different service providers within or across sectors) and vertically (between different organizational levels within a given agency or sector).

Mechanisms for promoting or supporting communication include identifying points of communication within different organisations (e.g., designated key contacts), scheduled meetings involving representatives of partner organisations, and communication tools such as telehealth and electronic information sharing. Improving communication can also be a matter of organizational culture change.

The Victorian CCP evaluation states 'Central to the model is a communication process, pathways and a coordination role that will facilitate collaboration, a transfer of knowledge and effective responses from all sectors to deliver an integrated approach to disease management for the progressive neurological sector.'

The CC MND model proposes a suite of outreach tools, including a telehealth service, an e-health record, and teleconferencing between services, and an overarching communication /coordination strategy.

The importance of good communications between Better Pathways Workers and school key contacts emerged as a strong message from that report. The Better Pathways model included information resources (a website and newsletter) and communication strategies (regular phone and face-to-face meetings). A protocol for information sharing was developed at state government level to ensure the privacy of individuals was protected.

As mentioned above, the model proposed by Disability Care at Western Health included 'outreach' and 'inreach' strategies to improve communication and understanding between health and disability service providers.

Many of the 'system-level' interventions delivered under the HARP initiative emphasised communication and information sharing as key to providing effective service responses across the continuum of care, so that patients could experience a seamless transition between care settings (Victorian Government Department of Human Services, 2006). Information sharing was enhanced through regular forums, newsletters and clinical meetings to establish system-wide, local and cluster-specific HARP networks. Service linkages and partnerships were strengthened to connect services and facilitate coordinated service provision across and within acute and primary care services. One agency developed the capacity to flag HARP patients on their patient administration system so that a HARP patient who presented to the emergency department could be identified and their agreed emergency care plan implemented.

g) Training and skilling disability and mainstream service providers

Mechanisms to 'up-skill' service providers are built into several of the service coordination models reviewed. These include approaches to skilling generic service providers so that they can provide effective services for people with specific

disabilities/conditions. Peer education and support is an important means of improving workforce skill levels.

Training for service provider agencies to increase their understanding of and ability to address the needs of people with progressive neurological conditions was a component of the Victorian CCP. The evaluation report states that 'the most successful means of building capability and confidence in case managers was the opportunity that they had to work alongside the MS care coordinator on tasks which included assessment, monitoring and review, preparing DSR applications, identifying available services, problem solving and negotiation with services.' The project also offered two formal training sessions to service providers.

The ABI STR program model is based on therapists developing and establishing treatment programs with individuals, training and supervising attendant carers to deliver the program, and regularly reviewing and adjusting the program.

Under the MND service coordination model now in place, one of the roles of the Regional Advisor is to provide peer support for service providers and expert advice on MND and individual-specific issues impacting on service delivery.

The Disability Care at Western Health model identifies the need for training and support to help improve the non-verbal communication skills and engagement skills for health staff working with people with disabilities. A number of nursing and allied health staff expressed an interest in learning more about disabilities, related behaviour issues, and being more effective in engaging non-verbal patients.

Macro: requirements for coordination between different service sectors

Where it was part of the model, high level support and imprimatur within each sector was critical in ensuring that cross-sectoral collaboration and cooperation could happen.

The MACNI was supported by the Human Services (Complex Needs) Act 2003, which provided a legislative basis for individual eligibility and entitlement. The Act also enabled the exchange of information between service providers to facilitate effective, co-operative and collaborative assessment and service planning around the needs of each individual.

Mandates and formalised processes provided impetus for the communications and collaborative processes at lower organisational levels that really made service coordination work (see 'e. Cross-service and cross-sectoral commitment', above). Joint, cross-sectoral funding arrangements were also an effective way of getting all players 'on board' (e.g., SCIR, ACIL Tasman model). Management and advisory groups with cross-sectoral representation can be an important means of improving communication and fostering a mutual understanding of philosophies, structures, funding mechanisms, and services across sectors (e.g., the Better Pathways interagency teams).

Among key factors reported by HARP project staff as important in facilitating establishment of individual HARP projects, were:

- key government policy initiatives or specifications,
- local funding flexibility,
- administrative arrangements that promoted innovative practice and facilitated communication between different service providers,
- active involvement of multiple service providers, and
- linkages and networks with other HARP consortia.

(Victorian Government Department of Human Services, 2006).

2.4 Outcomes

The reports provide a rich source of information on the outcomes of service coordination. The nature of the outcome information available in each of the reports is briefly summarised in Table 2.1.

Table 2.1: Summary of nature of outcome data presented in each of the reports

Program / Pilot	Nature of outcome data
<p>Victorian Continuous Care Pilot – Final Report (+ Evaluation report)</p> <p>Pilot conducted 2008–2009</p> <p>19 people aged 33–49 years with progressive neurological disability</p>	<p>Descriptive information on outcomes for participants, confidence in the service system and satisfaction with the project based on interviews with all participants and primary carers (where relevant).</p> <p>Descriptive information on program design and implementation outcomes based on interviews with service providers, key project personnel, and the CAG.</p> <p>Assessment of the pilot’s success in preventing inappropriate admission to RAC, based on assessment of likelihood that each participant would have required admission to RAC if the program did not exist.</p>

Program / Pilot	Nature of outcome data
<p>NSW Continuous Care Pilot Evaluation</p> <p>Two year program starting early 2009</p> <p>20 people aged < 50 with a progressive neurological condition</p>	<p>Descriptive outcome data:</p> <ul style="list-style-type: none"> • a pre- and post-program survey of all participants who use the CCP; • a pre- and post-program survey of family members/carers; • case studies of a sample of 7 participants, involving in-depth interviews with the participant, family member/carer, case worker, and one of the participant’s service providers; and • stakeholder interviews with representatives from the CAG, hospital and CCP.
<p>Review of the spinal cord injuries response (SCIR) (Qld)</p> <p>2008</p> <p>Program initiated 2005–06</p> <p>Evaluation began mid-2007</p>	<p>21 SCIR participants compared with 15 people who did not receive support from SCIR.</p> <p>Qualitative interview which included verbal administration of a structured survey questionnaire that incorporated reliable and validated measures of life satisfaction, participation, self-efficacy, and coping.</p> <p>Interviews with key informants in senior management positions in stakeholder organisations. Three focus groups for staff members directly involved in the implementation of SCIR.</p> <p>Network analysis to investigate the extent and nature of linkages and collaboration between partner organisations.</p> <p>Cost analysis: 8 SCIR participants and 8 people who did not receive support from SCIR— total cost per person for hospitalisation, transitional rehabilitation, equipment and personal care support for the first 6 months post-discharge from hospital.</p>

Program / Pilot	Nature of outcome data
<p>Evaluation of the Spinal Cord Injury Community Participation Project (NSW)</p> <p>Pilot Initiated 2004/05. Two year report and Five year follow-up (2007; 2010)</p>	<p>Participants (n=31) compared with control group (n=27).</p> <p>Range of outcome measurement tools used and data statistically analysed (measuring community integration/participation, psychological health, quality of life, environmental barriers, care needs and self-efficacy, vocational outcomes, satisfaction with social support received).</p> <p>Hospital readmission rates.</p>
<p>ABI Slow to Recover Program (Vic)</p> <p>Program started 1996 (ongoing)</p> <p>Program review 2004</p> <p>181 participants over life of program; 124 receiving services at mid-2003.</p>	<p>Analysis of services provided through the program.</p> <p>Residential status of participants.</p> <p>Program cost analysis</p>
<p>Neurodegenerative Conditions Coordinated Care Program (WA)</p> <p>2012</p> <p>Pilot began in 2008. Evaluation conducted in 2010.</p>	<p>Qualitative data collected through semi-structured face-to-face interviews, and telephone interviews. For the stage one data collection (2009) 5 participants and 11 carers were interviewed. For stage 2 (2010), 8 participants and 11 carers were interviewed.</p>
<p>Better Pathways Pilot Project: Process and interim outcomes evaluation report (SA) (2012)</p> <p>Program initiated in 2009; 316 students registered at June 2012</p>	<p>Qualitative outcome data gathered through: Student interview/surveys; 12 themed case studies; 4 parent focus groups; Project stakeholder surveys (Pathways workers, School key contacts, Interagency team representatives and key contacts).</p>

Program / Pilot	Nature of outcome data
<p>Economic benefits of coordinated service delivery for YPINH</p> <p>Prepared by ACIL Tasman for the Young People In Nursing Homes National Alliance.</p> <p>2013</p>	<p>Cost modelling to examine the economic implications of moving towards a more coordinated approach in the provision of services for people with high and complex needs, using eight case studies based on the experiences of real life individuals (people with acquired disabilities and complex health and other support needs that change over time).</p>
<p>Multiple and Complex Needs Initiative (MACNI) evaluation conducted by KPMG (Final report 2007)</p>	<p>Administrative data on program activities</p> <p>Interviews and surveys of key stakeholders to identify the effects of the initiative on individual and system outcomes</p> <p>16 case studies based on detailed file and document review and consultation with relevant stakeholders</p> <p>Operational budgets and expenditure reports (a preliminary assessment of cost effectiveness was undertaken).</p>

Micro level outcomes—ways in which coordination makes a difference for people

The pilot and program evaluations provide evidence on a range of outcomes for people with disabilities and their families. Because of their limited timeframes, the reports cannot provide information on long term outcomes, and in some cases an evaluation was conducted relatively soon after the program was established (e.g., 2 years in the case of NCCCP). Numbers of participants for whom outcomes were assessed ranged from 7 in the NSW CCP to 181 in ABI STR. Only two of the reports (SCIR in Qld, CPP in NSW) were able to compare outcome data for intervention and control groups. Keeping these limitations in mind, the reports nonetheless provide valuable information on outcomes for people who received service coordination.

The case studies included in several of the reports provide powerful illustration of the real life situations and challenges for people living with complex disability and health needs, and the crucial difference that coordination can make for them and their families.

Access to appropriate services and support

A primary aim for cross-sector service coordination is to assist people with disability and their families to find and access the services they need to enable them to live

their lives in the community. On the whole, positive outcomes were reported for all the pilots/programs reviewed in terms of better access to services.

Outcomes reported included people having their previously unmet needs met, reduced waiting times, and improved understanding of the services available. For example, the NSW CCP evaluation found that most participants and family members reported an increase in their understanding of the services and supports available to them, and an improvement in the service system responding to their needs. There was an increase in the number and variety of services received, improvements in the appropriateness of supports, and reduced waiting times for services. Likewise, the SCI CPP in NSW reported positive feedback from participants about the value of coordination and the funding available for direct purchasing of services.

The SCIR review compared outcomes for 21 SCIR participants with 15 people who had not received support from the program. Results showed that SCIR made a big difference for people with spinal cord injury transitioning back to the community. Compared with a control group who did not receive support from the program, SCIR participants reported less financial hardship, greater access to equipment and support, less frustration as a result of unmet needs, greater choice about where to live and how to live, and increased levels of independence. All participants believed that they would have been worse off without SCIR to support their transition from hospital to community.

People who did not receive SCIR support were reliant on self-advocacy and spent a lot of time completing complicated service applications with uncertain outcome; these people and their families or friends often had to undertake fund raising activities to supplement the basics they needed to return to the community. Fund raising consumed much energy, and distracted from rehabilitation, and people often felt humiliated about their dependence on the charity of others.

In some programs/pilots improved relationships with service providers were reported. In its second year of operation the NCCCP in WA employed 40 part-time care support workers to provide personal care instead of contracting agency staff as in the previous year. Participants preferred this arrangement because of better continuity in the staff providing personal care—staff got to know their specific requirements and they did not need to repeatedly explain to new staff how to care for them. Several participants in the NSW CCP also perceived an improvement in their relationship with service providers.

Other aspects of coordination valued by individuals and families included having a point of contact, and increased certainty about accessing services and supports into the future. In Better Pathways (SA), the anticipated 4 year length of the program, and the development of a relationship with the 'key worker' was seen as very important by parents. In the Victorian CCP, participants reported increased confidence due to knowing that they could contact the care coordinator. Similarly,

participants and family members in the NSW CCP valued having someone to contact who was familiar with their situation; they appreciated not having to repeat the details of their care to different providers and medical personnel. A number of participants and their families also said that the CCP made them feel more supported, more 'in control' and better able to have their views heard.

The evaluation of Better Pathways in SA found that, while few participants had achieved 'post school status' at the time of the evaluation, many had improved their 'learning or earning' status, and almost all said they believed they are being supported to stay on track to achieve their goals and will have improved future opportunities.

In taking a more holistic approach, and assessing needs in a more contextualised way, several of the programs provided supports for family members and carers, such as access to formal overnight respite care, marriage counselling, and childcare (NSW CCP). For about three-quarters of Better Pathways participants, Pathways Workers also provided support for the student's siblings and parents and/or carers.

However, remaining service gaps and issues were identified in some reports. The SCIR evaluation reported that, despite having access to the necessary equipment, housing and support services, once participants were back in the community there was a lack of ongoing physical rehabilitation and therapy, psychosocial support, and vocational support. Participants said that the support offered was not always responsive to their changing needs. SCIR is quite strongly focused on transition into the community, rather than taking a long term view of people's support needs.

The WA NCCCP evaluation found that supplying in-home care and respite to participants in country areas remained problematic due to lack of appropriately skilled staff. The program relied on brokering other service providers to perform in-home services and participants had to travel to the metropolitan area for respite.

Quality of life and wellbeing

Improvements in quality of life and wellbeing for people with a disability and their family members were important outcomes of service coordination about which many of the evaluations provided valuable data.

Based on results from a verbally administered survey questionnaire that incorporated reliable and validated measures of life satisfaction, participation, self-efficacy, and coping, the SCIR evaluation found substantially higher quality of life for SCIR participants immediately post-transition compared with those who did not receive support from SCIR. SCIR participants had higher levels of overall life satisfaction, fewer health problems, and were more likely to be employed and less likely to be separated or divorced. No significant differences were found between the two groups in coping ability, perceived control over their lives, or problems experienced.

Evaluation of the SCI CPP in NSW used a range of validated outcome measures to compare health and well-being, daily functioning, community integration, activity, participation, and service use for the intervention and control groups (each split into high and low impairment). At 2 years post discharge, CPP participants had higher levels of community participation and self-efficacy than the control group. No significant differences in quality of life or rates of employment were found, although some aspects of personal satisfaction were better for participants. At 5 years post discharge CPP participants had higher levels of community participation (high impairment group only) and better quality of life (low impairment group only) compared to the control group.

Five of the seven NSW CCP participants for whom outcome data were collected reported reduced stress levels, which appeared to link to feeling supported, physically safe and inter-personally secure. The report noted an interplay between physical and psychological benefits. For some participants, less stress led to a sense of improved physical wellbeing, for example feeling that their physical relapses were more under control. Decreased fatigue because of access to more assistance and services also had benefits—one participant reported being able to spend more quality time with her children, and another was more able to access the community.

Family members benefited from improvements in participants' health and psychological state, and as a result of practical assistance such as respite, child care, home care and mobility assistance. In some instances supports primarily addressing the physical needs of the person with disability were noted to have flow on benefits for family members and carers—e.g., for one participant in the NSW CCP the provision of an electric wheelchair alleviated a spouse's back problems—potentially contributing to the sustainability of informal caring arrangements. In one case it was felt that the supports provided had averted family and marriage breakdown.

The NSW CCP evaluation reported increases in the personal wellbeing scores of participants and family members. For participants, results indicated increases in satisfaction 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. Due to the very small sample these results should be interpreted with caution.

The MACNI evaluation reported that about half of the participants showed behavioural improvements and a further one-quarter showed a greater level of engagement with care managers and other supports in the community. Stakeholders noted that the frequency of adverse events had diminished as a result of the Initiative. Although functional improvements were not seen during the period of evaluation, it was anticipated that gradual functional improvement would result over time—for many in the target group it was considered that progress would be slow, with periods of relapse and deterioration. Standard pre and post functional

assessments were not applied to participants; the evaluation recommended that specific measurable outcomes for individuals should be developed to enable progress to be assessed.

Less time spent in hospital

The CCP NSW evaluation included data comparing annualised days of hospitalisation for participants before and during the pilot. The total number of days participants (collectively) spent in hospital per year decreased by 125 days, mainly due to reduced lengths of stay—where participants were hospitalised, the CCP’s planned admission approach helped to keep these as ‘short admissions’. Similarly, evaluation of the SCI CPP found that participants had lower rates of readmission to hospital due to secondary complications—19%, compared with 44% for the control group. The MACNI also reported reduced emergency department presentations, hospital admissions and bed days for participants during the MACNI period compared with the pre-MACNI period.

The SCIR evaluation reported that the overall average hospital length of stay was 26 days longer for people who did not receive SCIR support. However, there was variation by severity of injury—compared with those who did not receive SCIR support, average hospital stay was 60 days shorter for SCIR participants with paraplegia, and 31 days longer for SCIR participants with quadriplegia. For those with quadriplegia, discharge delays continued as a result of difficulties with the coordination of complex equipment and housing needs.

Ability to live in community settings

For both the Victorian and NSW CCPs, no participants were admitted to residential aged care during the course of the pilots, which achieved one of the pilots’ aims. For the Victorian CCP, it was concluded that between 2 and 5 participants would probably have been admitted to residential aged care without the program (assessment of ‘residential aged care placement risk’ was based on the identification of combinations of key risk factors, such as carer stress, inappropriate equipment and rapid changes in requirements). The CCP’s achievements resolving problems with service providers and outstanding equipment issues, providing additional or more appropriate services, more adequate funding packages, and more acceptable respite arrangements were seen as important in enabling participants to remain living in the community. The NSW CCP evaluation identified the linking of participants with appropriate services to provide management of health issues in the community post-discharge important in preventing admissions to residential aged care. Most of the stakeholders interviewed believed that the CCP had assisted in keeping participants out of long-term hospitalisation and residential aged care.

The ABI STR report concluded that ‘without the program it is fair to surmise that a significant proportion of the target group would be inappropriately residing in aged

care residential facilities or, inappropriately staying for extended periods in acute hospitals.³ The SCI CPP evaluation suggested that at least one participant would not have been able to return to community living in absence of the program.

Meso level outcomes—what works and what doesn't work for service providers and agencies

The reports provide a wealth of information on which aspects of the service coordination models worked well, where problems remained, and what could be improved. All the programs were in fairly early stages at the time of evaluation. In many cases adjustments to the program had been made along the way, in response either to formal interim reviews or ongoing feedback from participants and stakeholders (e.g., NCCCP, BP, SCIR).

On the whole, the evaluations found that service providers were positive about service coordination in terms of better outcomes achieved for participants and improved service delivery processes, particularly due to enhanced linkages between organisations and sectors, and better communication and information sharing. For example, the MACNI evaluation found that the initiative delivered benefits at meso level through providing support for services and professionals, boosting their confidence in working with the target group and engendering a sense of shared responsibility among providers. A summary of 'what worked and what didn't work' is presented below, for each of the meso level components of service coordination identified in Section 2.3, above. Some other key issues are also identified.

a) Cross-sector coordination function

The coordination function generally appeared to work well in all programs reviewed. The strength of the relationship of the coordinator with the person and family was identified as an important positive quality in several of the programs (e.g., BP, CCP Vic).

The role of the specialist care coordinator was seen as the most important aspect in achieving outcomes for participants in the Victorian CCP. Of particular value was the support provided by the care coordinator to case managers and other service providers, and the time the coordinator spent in building rapport and discussing participants' concerns, as well as observing them in their homes.

³ It should be noted that placement in residential aged care is not an inherently negative outcome. ACIL Tasman (2013) makes the point that residential aged care can sometimes provide a good interim accommodation solution, as long as the person has access to the additional supports required to meet their needs. See also National Disability Services 2013b for discussion of the disability-aged care interface.

Similarly, the NSW CCP evaluation reported that the coordinator was effective following through on decisions made in the CAG, though it was noted that there was sometimes difficulty separating the coordination function from a case management function. Locating the coordinator in the hospital facilitated communication with hospital-based service providers working with CCP participants. It was recommended that the coordinator should ideally have formal health training as well as a good working knowledge of the health and disability service systems, and strong organisational and communication skills.

The SCIR evaluation noted that while SCIR did provide individual-level coordination of services for participants, the focus was on transition to the community, with less emphasis on coordination support once the participant was established in the community. Processes to facilitate coordination were developing but not yet formalised, and structures to support them were not yet in place (e.g., a shared care plan and records).

In the MACNI a challenge for coordinators was having the requisite authority when dealing with services in order to find solutions and make things happen; this often required support from more senior officers. The point was made that a coordinator should be a leader rather than as a manager, engaging services through building relationships and understanding, and resolving issues through discussion and negotiation. It was suggested that the roles of coordinator and case manager should be more clearly separated (e.g., provided by different organisations), with the coordinator role focused on advocacy for the individual and bringing people together to find innovative options of care, rather than the 'nitty gritty detail' of case management.

b) Facilitating access to relevant skills and expertise

In the SCIR program, the multi-disciplinary team approach to resource and transition planning appeared to work well in terms of ensuring that all relevant professionals had input into the planning process. The participants 'key worker', who was a member of their multi-disciplinary Transition Rehabilitation Team, was responsible for ensuring all relevant information was brought together, and facilitated information sharing between the individual, family and other members of the team.

In the Victorian and NSW CCPs 'Clinical Advisory Groups' (CAGs) were the means of bringing the relevant skills and expertise, including specialist clinical input, to bear in the planning process for individual participants. The NSW CCP evaluation reported that the CAG functioned well, and was effective in evaluating individual risk, developing plans to manage risks, and monitoring ongoing implementation of plans. These plans involved interventions that were not only clinical in nature but included other professional and community contacts.

There were some problems with the functioning of the Victoria CCP CAG, and it was not recommended to implement more broadly. It was acknowledged, though, that the CAG did contribute to developing a pool of knowledge about risks for people with progressive neurological conditions and about service needs. It was suggested that a more effective approach to ensuring that clinical care was integrated with other aspects of care would be to implement a 'clinical hub model' similar to that developed for Motor Neurone Disease. The 'hub' model proposed in the CC MND report places a strong emphasis on developing skills of local professionals to manage MND.

The Better Pathways evaluation reported that key stakeholders believed that the collective knowledge and experience of members in and across relevant disciplines and agencies is the primary strength of the Interagency Teams.

c) Individualised approach to planning and anticipating needs

The programs and pilots all took an individualised approach, but placed varying degrees of emphasis on person-centred practice. In some, this was central to the model—for example the Victorian and NSW CCPs and the Better Pathways program.

Stakeholders interviewed for the MACNI evaluation reported that working at the individual's own pace, considering their needs in a holistic way, and maintaining and building upon their existing relationships with services in the community were important factors in achieving good outcomes.

Some of the evaluations noted that person centredness was not achieved to the extent envisaged. For example, the SCIR evaluation reported that participants were not always fully involved in decision making, and families were often not significantly involved, despite their inclusion in the program model. Some staff felt there was a need to develop guidelines to support flexible, individualised decision-making, including clarifying what the SCIR is able to provide and ways of determining what is essential for participants' wellbeing.

Both the NSW CCP and ABI STR reports identified a need for participants and family to be more actively involved in discussion and planning. The ABI STR review recommended a number of strategies to increase involvement and empowerment, including: 'Ensure case management and decision making is based on a philosophy of mutual partnership with clients and carers, and that this is reflected in contracts with the case management agencies'. It also suggested the need for a more holistic, flexible model not so focused on physical needs.

Achieving a real shift towards person-centred practice may require specific efforts to skill staff in this approach, perhaps including the use of protocols and provision of resources for education and training. The Better Pathways program had a strong emphasis on person-centred practice, and Pathway Workers were trained in the use of 'Person Centred Thinking tools', intended to help them to see the person

differently, and develop the ability to listen more deeply and carefully, and act upon what they learned.

d) Timely access to services and equipment

This was a key goal, and while coordination did improve access to services and supports for participants in all the programs, in many cases system blockages remained so that it was not always possible to provide the planned services in a timely way. Reasons included resource constraints (e.g., lack of available places in appropriate services or social housing), and eligibility criteria and application processes that hampered access to existing services. This is not surprising given that, to a large extent, the service coordination programs reviewed were islands, operating in the broader context of a 'business as usual' service system.

The CCP NSW evaluation reported that the program had created greater awareness among hospital staff of potential services and funding for participants. However some service providers did 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.

Administrative processes remained a source of delay in some of the programs. The ABI STR evaluation outlined some problems with care planning, including the time consuming nature of the planning process and lack of ability to respond quickly to changing needs. The care plan review and the wait for a response to it often created stress for families. The Better Pathways evaluation also reported delays in students registered with the program becoming fully engaged. Various reasons were identified, including inadequate program resources.

Lack of consistency in staffing was seen as a source of confusion and delays in organising and receiving services and supports for SCIR participants. Rotational staffing models and staff leave arrangements contributed to this issue. The ABI STR evaluation also noted that staff changes and staff rotations can jeopardise continuity and create additional work, as new staff are often unfamiliar with processes.

Some programs noted ongoing access issues for people in rural areas. This was the case for ABI STR, where metropolitan based case managers reported difficulties in engaging with rural mainstream services. Similarly, the NCCCP program experienced difficulties supplying in-home care and respite to people living in country areas; it was more successful in providing equipment.

For several programs, the availability of a funding pool for direct purchasing of services and equipment was seen as key to achieving better outcomes. For example, in the SCI CPP, 'interim funding' to meet the costs of items and services not funded by other agencies played an important role in achieving better community integration and quality of life for participants. The MACNI evaluation emphasised the value brokerage funding in enabling coordinators, case managers and care teams to

try creative and innovative approaches, 'outside of the box'. The Victorian CCP evaluation identified 'planning to meet contingencies, including brokerage funds' as a critical element for a model of continuous care for people with progressive neurological conditions.

e) Cross-service and cross-sectoral commitment

Formal cross-sectoral commitment to service coordination can be beneficial in helping to break down 'silos' and boundaries between programs, and encouraging partnerships and collaborative approaches to the provision of services across sectors.

As mentioned above, the MACNI is underpinned by the *Human Service (Complex Needs) Act 2003*, which aims to facilitate the bringing together of services from all relevant sectors to support people with multiple and complex needs. The evaluation found that the legislation supported improved service coordination through: 'providing the imprimatur for sharing information and engaging stakeholders; conferring authority for Regional Directors to prioritise complex clients; imposing a timeframe requiring a focused response; and creating a process for coordination and collaboration.'

The Better Pathways program was developed by the SA Social Inclusion Board, a body established with a cross governmental mandate to look at impacts of policy on social inclusion, and was implemented as a joint initiative of the Ministers for Education and Disability in partnership with the Social Inclusion Board. The program was later transferred to the Department of Education and Child Development when the Social Inclusion Board ceased to exist. According to a workshop invitee who was closely involved with the Better Pathways project from its inception, high level support for Better Pathways diminished after the transfer to the education sector. Although the interagency teams have been effective in building linkages in the community and assisting school staff and the main service provider agency to support referred students, and despite strong support from workers and participants that the program is making a significant difference to young people with disability realising their goals, the program is not being continued beyond the 5-year period initially funded.

The SCIR program was based on a formal partnership between health, housing, and disability departments. The evaluation report noted that, in practice, the partnership approach was dependant on personnel, rather than being 'embedded in the system and part of institutional practice across organisations'. However, a network analysis to investigate the extent and nature of linkages and collaboration between partner organisations found that there was a 'moderately integrated structure', with evidence of joint problem-solving, working agreements and policy formulation across organisations, and ongoing commitment from the agencies because of the value they saw in the initiative. It was noted that SCIR would 'continue to require

high level support (managerial and ministerial) and commitment from all partner agencies to implement the initiative as it was intended'. According to a workshop participant who has had significant involvement with SCIR, having a dedicated budget, with funding from various sources, has been important in achieving a real willingness for partner organisations to work cross-sectorally.

In the Victorian CCP it was intended that 'Service Continuity Protocols' would be established with service provider agencies—agreements to provide continuing services even if the person started receiving additional, supplementary services. The project did not succeed in establishing service continuity protocols with agencies (various reasons were outlined in the report), but was able to negotiate to maintain adequate service levels on a case-by-case basis in all but one case.

The ABI STR evaluation identified the need for more formalised arrangements with a select group of accommodation providers to facilitate identification of appropriate accommodation for people ready for discharge from hospital.

As one workshop attendee said, it is no good having excellent person-centred service coordination if there is no housing available to enable people to live in the community. The same is true of other crucial services, such as equipment, home modifications, and attendant care. Unless all the necessary supports a person needs can actually be accessed, putting money into skilled, professional coordination is a poor investment. Lack of service in one area will undermine investment in the other areas.

f) Communication

Both formal and informal communication pathways are important, and can complement each other. Communication between organisations and sectors can foster improved mutual understanding regarding what each provides, and who is responsible for different aspects of care.

Specific issues to do with communication processes and mechanisms were identified in many of the reports, usually accompanied by suggestions of improvements that could be made. While informal communications between service providers are fundamental, it seems that formal communication structures and mechanisms are very important in establishing and enabling a culture of communication and information sharing. Vertical channels of communication are important for ensuring that program level goals are communicated to operational levels, and that operational level issues can be effectively fed up to higher levels.

The SCIR evaluation reported that inter-agency integration had been improved by achieving collaborative problem-solving between agencies, communication between departments, and greater trust between nongovernment organisations and the government sector. It was noted that, although personal relationships were critical, formalising those relationships encouraged interagency communication: 'by having

the formalisation, we were actually all able to get together and say this is what we can and can't do'. The evaluation noted that providers involved in the partnership felt the need to work towards greater levels of collaboration through increased levels of communication, shared decision-making, mutual trust, consensus and streamlined systems. It was suggested that the development of tools to support information sharing, such as a shared care plan and records, would be helpful.

SCIR participants reported being provided with inconsistent and inaccurate information about the program. Some said that staff were often unclear about SCIR funding guidelines, which caused confusion and stress for participants and families. Results of the network analysis suggested that while at the strategic level of the advisory and reference groups there was a clear understanding of SCIR and a strong commitment to full integration across services, this may not have always been communicated effectively to operational staff.

A 2011 review of Better Pathways (summarised in the 2012 evaluation report) noted the lack of established methods of communication between project stakeholders as an issue affecting project capacity and sustainability. In response, a website was established to promote effective communication and help develop a sense of shared understanding among participating schools' personnel, service providers and agencies, and a sense of project cohesion. Various resources were made available on the website, including links to professional learning opportunities and Better Pathways newsletters (also distributed in hard copy). A Better Pathways conference was held in December 2011, bringing together schooling sector managers, school leaders, key school contacts, service providers, Interagency Panel representatives, and schooling sector representatives for the first time; the conference was judged to be a valuable learning and networking opportunity.

The ABI STR evaluation noted that there was a lack of knowledge about the program among key acute personnel, and a need for families to be better informed about the program. Suggested strategies for improving communication included regular updates about the program for hospitals (to improve awareness of the program) and clear information for families about program policies and procedures. Case managers commented that a training program for new ABI STR case managers would be helpful.

The importance of communication and networking between service providers, including good interpersonal relationships (involving face-to-face meetings), was emphasised in the MACNI evaluation, and the initiative was seen as successful in providing the framework for supporting this. It was noted that the benefits of the shared understanding and improved service networking fostered by the initiative extended beyond the individuals involved: 'Services have expanded their knowledge of what else is available and have built up their own professional networks'. However, there was scope for improvement, including better processes for

transparent and timely information sharing (to ensure that information about the person and their care plan is shared with all the necessary professionals in a care team), and information sharing mechanisms for coordinators to develop their skills and share learning.

g) Training and skilling service providers

The value of opportunities for peer education was noted in several of the reports. For example, in the Victorian CCP the coordinator assisted case managers, service providers and families to understand the cognitive issues that were occurring with participants. The MACNI evaluation mentioned a case in which liaison with local police led to the provision of training for police in dealing with people with a mental illness and community policing.

More generally, the MACNI evaluation found that the initiative had contributed to capacity within the sector, including workforce skills development. Coordinators reported feeling that they had developed a significant body of skills. However, it was noted that some coordinators had experienced a ‘rapid learning curve’, and that some of the smaller, non-government organisations showed a lack of real understanding of risk management. Skills development for staff engaged in care planning and management and additional support and information for coordinators were recommended.

The need for skills development was also noted in the ABI STR evaluation, particularly for rural areas. Therapists involved with the program suggested that a skilled therapy team should visit country areas on a regular basis to support local therapists and attendant carers. The ability to work as part of an inter-disciplinary team was seen as important.

In the context of providing services to people with high and complex needs that are dynamic (e.g., related to progressive conditions), and of staff turnover in provider agencies, there is likely to be a need for mechanisms that facilitate an ongoing program of training for professionals involved in cross-sector service coordination.

Resource constraints and workforce issues

In some instances service coordination was perceived as placing extra burden on already stretched service providers. For example, a 2011 review of the Better Pathways program found that there was a diminishing level of goodwill among school personnel—workload, time, and human resources demands associated with their participation in the program were impacting on levels of school engagement. The program was seen as an ‘add on’ and ‘something else to do’, there was little understanding of how the project related to existing school priorities. These issues were addressed by providing extra program support for participating schools, and school engagement improved over the following 12 months.

Increased workload was also an issue for SCIR providers, because of paperwork and coordination associated with a wider range of services and supports available to SCIR participants. For many staff, care planning was a new and time consuming activity.

Transparency versus flexibility

An issue that emerges from several of the evaluations is the tension between a need for clarity and certainty (in terms of articulating and formalising roles, responsibilities, eligibility criteria, etc.) and a need for flexibility, to enable needs to be met in creative ways.

The NSW CCP evaluation recommended that there should be clearer guidelines on the role of the steering committee, the clinical advisory group and the coordinator, and the development of procedures for meetings and case coordination, risk identification protocols, and communication materials and strategies. However, these should not detract from the flexibility and informality that were positive features of the pilot. The report noted that the independence of the CCP from government meant that it was able to work flexibly and effectively without bureaucratic constraints.

Issues identified in the ABI STR evaluation included lack of clarity about program eligibility, need for consistency in decision-making, and better transparency and accountability. Conversely, some family members felt that the model of moving participants from 'intensive' to 'maintenance' level of support after approximately 2 years lacked the flexibility required to respond to individuals' needs.

The MANCI evaluation identified a number of areas in which transparency and accountability could be strengthened (e.g., 'Improve the consistency and detail of information collected at assessment'), but noted the need to balance standardised approaches across the program against allowing the regions to develop innovative approaches and solutions. 'The evaluation noted that processes to ensure the transparency, governance and assessment of cost effectiveness for brokerage expenditure were not well developed.'

Clear protocols need to be developed and put into place for brokerage of services, to ensure that services are provided in a coordinated and timely manner and remain responsive to the individual's needs.

Macro outcomes—service quality and cost effectiveness

Outcomes for individuals and families—including improved health and wellbeing, better access to appropriate services, ability to remain living in the community, and return to work—are very important at a system level as indicators of service effectiveness and quality. As these outcomes have been discussed above, they will not be repeated here.

The MACNI provides an example of how a service coordination initiative can have broader system benefits. The MACNI 'Regional Gateway' model provided an impetus

for the establishment of frameworks for collaborative and coordinated care and the development of holistic assessment and planning for individuals who do not meet the initiative's eligibility criteria. These advances within the regions have meant that processes are now in place to address the gaps in service that originally led to the development of the Initiative. The initiative was seen to have contributed to a 'paradigm shift', and to have impacted on a far greater number of individuals than those directly participating. The process of care plan coordination was judged to have enhanced the perceived value of the community sector with other service providers and increased the level of engagement between government and non-government service providers.

Some of the reports present information relevant to estimating system level cost savings due to improved service coordination. The point should be made, however, that cost savings, where they can be identified, often accrue to sectors other than the disability sector (e.g., health, aged care), which underlines the need for cross-sectoral commitment to and investment in service coordination. It is also important to emphasise that the programs reviewed here were motivated by the recognition that existing programs and structures were failing to properly meet the needs of individuals—saving money was not a primary goal.

Several of the reports provide data that may be useful in developing indicative costings for the various components of a potential service coordination model under the NDIS. For example, the MACNI report gives the cost of each of the major program components, including the average amount spent per individual on multi-disciplinary assessment and care planning. The SCIR, ABI STR, Vic CCP and NSW CCP reports also provide some cost data.

Both the Victorian and NSW CCP evaluations concluded that some participants would have been admitted to residential aged care in the absence of the program, with consequent savings to the aged care sector. In addition, the NSW CCP evaluation reported that the total cost of the pilot was roughly offset by a reduction in hospitalisation when the equivalised annual number of hospital days was compared before and during the pilot (the additional costs of community based care were not included in the evaluation).

The SCIR cost analysis compared a matched sub-sample of 8 SCIR participants and 8 people who did not receive support from SCIR. The total cost per person was calculated by summing the total cost for their hospitalisation, transitional rehabilitation, equipment and personal care support for the first 6 months post-discharge from hospital. Compared with those who did not receive support from SCIR, average hospital stay was 60 days shorter for SCIR participants with paraplegia, and 31 days longer for SCIR participants with quadriplegia. Reflecting this, average total cost was lower for SCIR participants with paraplegia and higher for SCIR participants with quadriplegia. However, overall, for the SCIR sub-sample, reduced

length of hospitalisation was calculated to represent a saving of approximately \$160,784.

Increased costs of community supports for SCIR participants, and longer hospital stays for those with quadriplegia, were due to the availability of options, the focus on having optimal services and equipment in place prior to discharge, and the inclusion of more factors/players in the decision-making process. That is, these costs were associated with providing better services and supports than those available to people who did not receive support from SCIR. Nonetheless, it was concluded that, although difficult to demonstrate with certainty due to the small sample size and the incomplete cost data, the analysis suggested that SCIR has the potential to result in a significant saving to government.

The MACNI evaluation reported reductions in hospital emergency department presentations (down 75%), hospital admissions (down 35%) and bed days (down 57%) for participants during the MACNI period, compared with the pre-MACNI period. Similarly, the HARP initiative was reported to have had a positive impact on the level of hospital utilisation in Victoria, with participants experiencing 35% fewer emergency department attendances, 52% fewer emergency admissions, and 41% fewer days in hospital. The reduced need for hospital services was equivalent to approximately one emergency department attendance, two emergency admissions, and six days spent in hospital each year for every HARP participant (Victorian Government Department of Human Services, 2006). Savings to the acute sector were also reported in the ABI STR evaluation, due to a decrease in hospital bed days. It was also suggested that the program has resulted in reduced costs for residential care, because of the number of people the program has supported to remain living at home.

A modelling exercise to examine the cost benefits of coordinated service delivery for people with high and complex needs took the approach of costing care over the life course for 8 case studies under 'business as usual' and service coordination scenarios (ACIL Tasman, 2013). The two scenarios for each case study gave costings for:

- Medical treatment
- Home modifications
- Other equipment (e.g., wheelchair, pressure mattress)
- Cost to family (foregone work earnings, travel costs, etc.)
- Foregone earnings of individual
- 'Excess' disability burden—the pain and suffering that could have been avoided with better and more timely treatment
- Value of life years foregone due to premature death due to sub-optimal care

The modelling indicated that, in 5 of the 8 cases, service coordination results in net savings to society over the lifetime of the individuals, with an average saving of \$1.36 million per case (ranging from -\$0.18 million to \$8.40 million). Service coordination delivered substantial savings in medical treatment costs and in costs incurred by family members. The cost of external care was higher because of the improved levels of care, and home modification and other equipment costs were also slightly higher. Service coordination resulted in much reduced suffering (an average lifetime disability burden reduction valued at \$0.46 million) and longer lifespan (valued on average at \$1.61 million).

The report also cites the following figures, relevant to an assessment of the costs associated with not providing cross-sector service coordination:

- The Productivity Commission estimated the annual costs to hospitals of long stay patients at between \$38 million and \$84 million. Data from the NSW respite system suggests that each blocked bed results in more than 7 people missing out on respite services.
- In 2001 it was estimated that \$350 million was spent on caring for patients with pressure ulcers, with the cost of each pressure ulcer estimated at \$61,000. Many pressure ulcers are preventable and occur as a result of inadequate equipment and care by providers who do not have the necessary skills.

The NCCCP evaluation reported that provision of quality care through the program was thought to have prolonged the life of some participants. The individuals depicted in the case studies of the ACIL Tasman cost modelling also lived longer with service coordination. This underlines the importance of using established methodologies to properly value additional years lived, and improvements in health and wellbeing, when assessing the cost benefits of service coordination.

It is important to make the point that some cost increases are very likely to be associated with implementation of person-centred service coordination. To a large extent these will be associated with more adequately meeting previously unmet needs. These costs may be more visible and quantifiable than the cost savings and the social returns on investment that will ultimately flow from service coordination.

It should also be noted that the costs associated with starting up a new program are often different to the costs of an established program. Many of the programs reviewed had a particular emphasis on linking people with relevant services in the community; making better use of existing services to meet people's needs helps to reduce the cost burden on the disability sector. Reduced duplication and over-servicing because of better communications between service providers and between sectors should also lead to reduced costs in the long term.

However, cost savings will be dependent on cross-sector service coordination actually working across the micro, meso and macro levels. Often the effectiveness of

one service or support is dependent on the other necessary services and supports being in place. For coordination to work there needs to be a culture of collaboration, and arrangements and processes in place that enable the necessary services to come together in a timely way. Funds are wasted when services are not properly coordinated.

3. What can we learn from academic literature?

3.1. Introduction

This section synthesises the findings of a review of international literature relevant to the topic of service coordination for people with high and complex needs. The first section outlines the methodology used to conduct the review. This is followed by a summary of the literature which presents evidence about models of service coordination, and goals and outcomes for clients, service providers and systems.

3.2. Search methods

An electronic database search was the primary search method used to identify papers from the academic literature which were relevant for inclusion in the review. Librarians from the Faculty of Health Science at the University of Sydney assisted in identifying relevant databases and search terms. Most research studies were identified through electronic databases and included the following databases: Cinahl, Embase, Informit, Medline, Proquest Central, Science Direct, Scopus, Web of Science. The search was undertaken in March 2014.

Search terms

A wide range of search terms were used to maximise the detection of relevant research. Key word searches combined "Care Coordination" OR "Continuity of patient care" OR "Continuity of Community care" OR "Integrative service provision*" OR "Tertiary case management*" OR "Interagency collaboration*" OR "Continuum care*" OR "Integrated Care*" OR "Packaged Care*" OR "Case Coordination*" OR "Self directed care*" OR "Service coordination" AND "Disabilit*" OR "Disabled" OR "Disabled Persons*" OR "Complex need*" OR "high complex need*" OR "Multiple disability*". All studies were stored using Endnote. The electronic database search resulted in the retrieval of 2586 potentially relevant references. These studies were filtered using the criteria outlined below.

Selection criteria

To determine whether to include or exclude a study from the review its relevance was assessed based on its title or abstract. All newspaper articles, commentary about disability-related topics and notes from conference proceedings were automatically excluded.

Studies that were included were:

- Published in English from the year 2000 onwards.
- About service coordination, coordinated care, integrated care or self-directed care.
- Targeted at adults aged 18-64 years with high and complex care needs.

Studies that were excluded were:

- Focused exclusively on children, adolescents or people aged over 65.
- Focused exclusively on mental illness.
- Focused exclusively on coordination in acute or residential settings.

This process yielded 78 studies, of which 10 were found to be duplicates and removed. In the second stage, the abstracts of all 68 studies were screened using the inclusion criteria to confirm their relevance to the review. Forty-three abstracts were found relevant and the full articles were analysed to verify that they met the inclusion criteria. At this stage, a further 12 studies were excluded when found to report findings solely about coordinated care for people aged over 65 (n=3) or with serious mental illness (n=1), were not focused on high and complex care needs (n=7) or where only the abstract had been translated into English (n=1). In total, 31 studies from the electronic database search were included in the review.

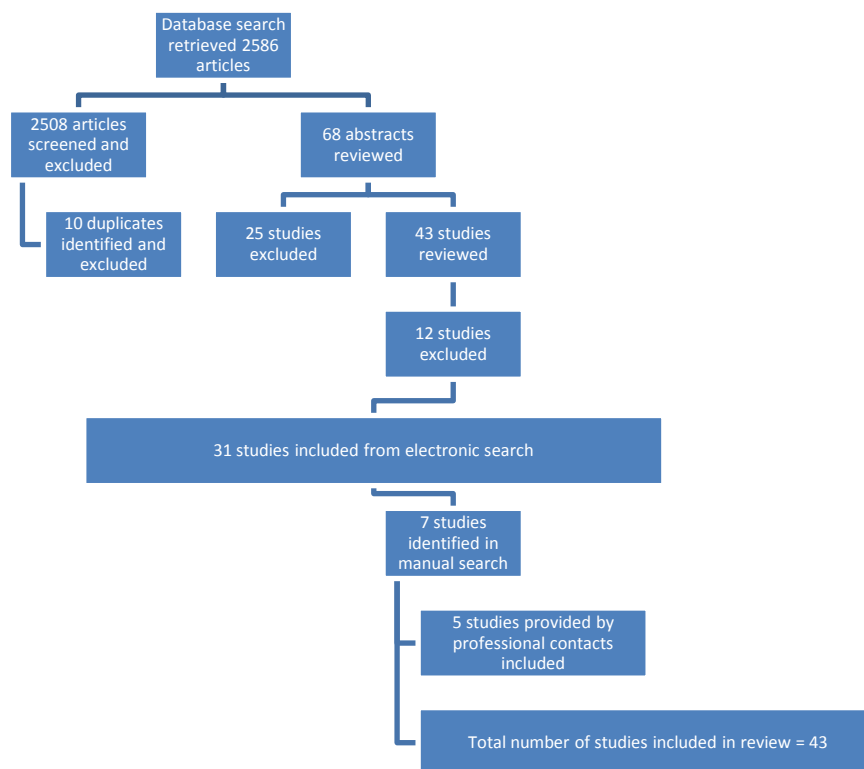
Secondary search strategy

A manual search of the references of these 31 reviewed studies was undertaken to identify additional studies that were potentially relevant to the review. The abstracts of studies identified in this manual search were reviewed and an additional 7 studies were included.

Tertiary search strategy

A final source of potentially relevant references came from professional contacts who attended workshops and from University of Sydney peer reviewers. Using this strategy, two pertinent reports from the 'grey' literature (Craig et al., 2011; Goodwin et al., 2013) were included. Two peer reviewed studies, while not directly about service coordination, were deemed to be highly relevant to a discussion of service coordination models in the Australian context. Dew and colleagues (2013) reported on barriers to therapy access for people with disability living in rural and remote areas and O'Flynn and colleagues (2011) reported on an experimental "joined-up government" approach to tackling indigenous disadvantage. Similarly, a community based case management taxonomy developed by Lukersmith (Lukersmith, Fernandez, Millington, & Salvador-Carulla, 2014.) was included. In total, 43 international studies were reviewed.

Figure 1: Selection process for review



The project was undertaken over a relatively short-timeframe and this necessitated careful decision-making about the scope of the research. With more time, a more extensive review of literature, based on a wider selection of search terms and inclusive of research in the paediatric and aged care literature, would have been possible.

3.3 Overview of the studies

Types of Studies

The majority of studies in the review were conducted to evaluate or describe innovative service models ('program evaluations', n=23) or to explore the experiences and views held by service users, staff or policymakers about coordinated or integrated care models ('exploratory studies', n=6). Seven conceptual discussions on the topic and seven literature reviews have also been included. Studies are grouped by type (see Appendix Table A2).

Country of Studies

Fourteen of the 23 program evaluations were conducted in the United States, with two studies from Australia and one each from the Netherlands, the United Kingdom, Sweden, Canada and Singapore. Four exploratory studies were conducted in the United States and one each in Japan and New Zealand. The findings from two Australian program evaluations found in the peer-reviewed literature (Patterson et al., 2007; Segal et al., 2004) have been examined in the previous chapter and will not be addressed here. Appendix Table A2 provides a brief summary of the 43 studies reviewed.

Terminology used

The term 'person' is used throughout this section to mean the person for whom the services were coordinated, although a variety of terms were used in individual studies, such as patient, consumer, client and service user.

The studies reviewed do not all use the term 'service coordination'. As noted in the previous section, a broad range of terms were used to identify studies that focused on the concept of coordination for people with high and complex needs. The terms used in the literature include integrated care, comprehensive care, case management, transmural care, coordinated care, and continuous care. The review was undertaken to understand approaches to coordinating services for people whose needs are complex due to the interaction of multiple health and social needs.

3.4 Goals of service coordination

Four main goals were identified in the literature about service coordination for people with high and complex needs. These are to reducing the incidence of preventable hospital admissions or institutional placement; improve health and wellbeing, improve the interface between hospital and community, and support informal caregivers. As these goals frequently overlapped in many studies, the primary goal identified has been highlighted for review purposes.

Reduce hospitalisation or institutional placement

The primary goal of service coordination that was stated in many studies was to avoid unnecessary and costly hospital admissions or premature residential care placement (Goodwin et al., 2013; Master & Eng, 2001; Master et al., 2003; Meyer, 2011; Surpin, 2007). In some studies this was explicitly linked to the financial imperative of replacing high-cost crisis care with lower cost-preventative care (Bachman et al., 2008; Craig et al., 2011; Dobell & Newcomer, 2008; Palsbo & Dejong, 2003; Palsbo & Diao, 2010; Palsbo & Ho, 2007; Mastal et al., 2007) and, in others, to the delivery of healthcare services to meet complex needs (de Bruin et al., 2012; Ehrlich et al., 2009; Fisher & Elnitsky, 2012; Kathol et al., 2011; Mur-Veerman et al., 2003; Oeseburg et al., 2004; Van Raak & Paulus, 2008; Van Wijngaarden, 2006).

Improve health and wellbeing

Associated with preventing hospitalisation or institutionalisation was the goal of enhancing health and wellbeing. Some studies focused on coordination to improve health or quality of life (Noël et al., 2005; Jansen et al., 2007; Kroll & Neril, 2003;) or to enable a person with high and complex needs to remain living safely in the community (McConnell, 2006; Palsbo & Kailes, 2006; Palsbo et al., 2006; Sang, 2007).

Improve hospital/community interface

Six studies focused on the role that coordination plays in the transition between hospital and community for people with ongoing health and social care needs. Three focused on hospital and health systems. Powell Davies and colleagues (2006) conducted a systematic review of studies about the interface between primary health care and other health services; Øvretveit and colleagues (2010) evaluated a Swedish model to improve the hospital discharge process; Sampalli and colleagues (2012) evaluated a Canadian model of integrated care that provided short-term support following hospital discharge; and Ansari and colleagues (2001) proposed a model whereby a coordinator mediates between hospital and community to improve service access for young people with cerebral palsy in the United Kingdom. Three studies explored continuity of care for patients being discharged from hospital. Corbett and colleagues (2009) identified strategies to improve the coordination of care for adults with physical disability in New Zealand, Venketasubramanian and colleagues (2008) described a care coordination approach to reduce adverse outcomes for stroke patients discharged from hospital, and Matsushige and colleagues (2012) explored a model of integrated care following hospital discharge in Japan.

Support informal caregivers

Three studies focused on the role of service coordination in meeting informal carer support needs. Abendroth and colleagues (2012) found that increased caregiver strain as Parkinson's disease progressed led to premature institutional placement and this could be reduced by timely support that anticipates disease progression. Cameron and Gignac (2008) found that effective support for carers of stroke patients was timely and appropriate to their changing support needs. Ruiz and colleagues (2012) described an evaluation of service needs of people with lifelong disability in the United States which identified informal caregiving as critical to preventing institutionalisation.

3.5 Approaches to service coordination for people with high and complex needs

This section presents evidence about, and describes different models of, service coordination for people with high and complex needs in the context of the NDIS. Therefore, only those studies that address key features, barriers/enablers and outcomes of service coordination for this group will be addressed. A summary of all studies reviewed is included in the appendix (see Appendix Table A2).

Literature reviews and conceptual discussions

Nine literature reviews or conceptual discussions describe approaches to service coordination for people with high and complex needs. Overall, the reviews include studies conducted with people aged over 65 and a focus on primary health or aged care settings. As such, there is minimal overlap between the studies included in these reviews and the current literature review however they present a useful background for the investigation of service coordination. A report about the housing and disability support sectors in Australia has been included because it highlights issues around service coordination that are pertinent in the NDIS context. A taxonomy that describes the components and activities of case management is included in recognition of the overlap in the literature between the terms 'case management' and 'service coordination' and because the taxonomy offers potential insights into the literature about case management which may be useful in the context of service coordination for the NDIS. First, the two systematic reviews, which offer a thorough investigation of the topic, are described. This is followed by the remaining studies, which are presented in alphabetical order.

De Bruin and colleagues (2012) conducted a systematic literature review of 33 studies evaluating 28 comprehensive care programs for patients with multiple chronic conditions conducted in the US, Canada, Australia, Netherlands, Italy, Norway, UK. Wagner's chronic care model was used to define comprehensive care as related to the delivery of care that provides: a) self-management and decision

support that enables patients and families to obtain skills and confidence to manage the chronic condition; b) delivery system design through case management and multidisciplinary; c) clinical information systems that enable proactive interactions between caregivers and patients, and d) a healthcare system that supports care for chronically ill patients by endorsing quality of care improvements. Programs that included interventions related to at least two components were included. These were variously called disease management, or integrated, guided, transitional or shared care programs. Programs varied in target population, implementation setting and the number of interventions included. Fifteen programs focused on frail aged people with multiple conditions, seven programs were for multi-morbid older people who were currently hospitalised and at risk of future hospital admission, five programs were for older people with a specific chronic condition, and one program was for people aged over fifty years at risk of functional decline. Programs were implemented in varied settings including home care organisations, community centres, primary care practices, hospitals, and specialised clinics. Most programs included interventions to support self-management (N=25) followed by clinical information systems (n=12) with only four program interventions to address the healthcare system. Substantial differences between the programs and the quality of program information available in the studies hampered the strength of evidence about program characteristics that may be related to positive outcomes or the groups most likely to benefit from a specific intervention. However, the following outcomes were identified:

- Moderate benefits were identified for inpatient health utilisation and cost based on 16 studies that compared inpatient hospital utilisation for patients receiving comprehensive care and patients receiving usual care. In three studies the number of hospital readmissions was significantly lower for the comprehensive care group, two studies showed significant differences that were not in favour of the comprehensive care group, and one found more emergency department visits for the comprehensive care group.
- No evidence was found of benefits for patient clinical outcomes (cognitive functioning, depression, functional status, and mortality) and quality of life in terms of physical functioning.

Insufficient evidence was available of benefits for outpatient health utilisation and costs based on eight studies that compared this outcome for comprehensive and usual care patients. Six studies measured utilisation of outpatient health care services and two studies did not specify costs for outpatient services. Four studies that observed differences between the groups differed widely in the measurement of utilisation.

Powell Davies and colleagues (2006) conducted a systematic literature review of 85 studies conducted in Australia and comparable countries (United Kingdom, United

States, Canada, Netherlands, and New Zealand) to understand strategies used to improve coordination of care within primary health care (PHC), and between PHC and health-related services. Most studies were focused on chronic disease, mental health management or aged care and it was noted that coordination was not the main study factor in all cases. Strategies were assessed in terms of outcomes relating to health and patient satisfaction and, while some information about costs was reported, few studies had undertaken robust economic evaluation. The most effective types of strategies for improving health outcomes were those which provided the structures to support coordination. The strategies that achieved this were: coordinating clinical activities, strengthening service provider relationships and providing tools or systems to support collaboration. Coordination of clinical activities is enhanced when service networks facilitate joint consultations between primary health providers, shared assessments and improved access to early intervention services. Relationships between providers are strengthened by co-location of general practice and other services, case management and use of multidisciplinary teams. Systems to support coordination include common assessment and care plan tools used by a range of service providers and communication systems that enable information sharing, including standardised referral systems.

- Sixty-five studies reported health benefits as a result of coordination strategies, measured by, for example, improved general health and functioning based on standardised measurements. The strategies that delivered the most positive health outcomes were systems for supporting coordination, such as use of proformas for communication and shared records, and coordinated clinical activities through multidisciplinary teams and case management.
- Thirty-one studies reported patient satisfaction outcomes, which were associated with improved relationships between providers through such strategies as co-location of primary health care and specialist staff.
- Economic outcomes were measured in 28 studies and fewer than 20% found significant positive economic outcomes, and these were most commonly in studies concerned with aged care. Economic benefits include reduced medical and drug treatment costs for patients associated with interventions compared to usual care. Most studies used a number of different strategies and outcomes could only be attributed to a combination of strategies. Therefore, the contribution of specific strategies could only be assessed in aggregate across studies.

Ansari and colleagues (2001) reviewed the literature on unmet service needs of young adults with cerebral palsy in the United Kingdom. The literature identified the lack of interagency coordination as a primary barrier to service access. The authors

note that several studies have proposed that multi-disciplinary, community based teams be established to improve the integration of care between hospital and community for adults with disabilities. A coordinator role would mediate between hospital and community as part of a community based rehabilitation service made up of clinical nurse specialists, allied health professionals and a range of service and voluntary organisations.

Bridge and colleagues (2002) examined the housing and service needs of older and younger people with disabilities in Australia, and issues associated with achieving linkages, cooperation and efficiencies across housing, disability and care sectors. The report describes the existing system for funding health and support services as lacking cross-sector coordination and an evidence-base about the relative effectiveness of different packages of support, accommodation and care services and argues that an integrated, flexible and whole of government approach is required. Housing and care services have traditionally been linked as they can be provided in any setting however the report underlines that in-home care depends on the security of accommodation and ongoing informal care or people are placed at risk of residential placement. Australian Bureau of Statistics data (Disability, Ageing and Care Survey, 1998) shows that two thirds of adults with a moderate disability reside in some form of care accommodation and, with most of this group over 65 years, mostly commonly in an aged care setting. Three quarters of those living in community with a significant disability receive informal support from carers and family, which reinforces need for policies to sustain these caring arrangements. Phone interviews were conducted with 24 informants from government and non-government sectors. Informants raised the issue of younger people who were living in aged care facilities due to lack of appropriate alternatives and argued for the urgent conversion of aged care beds into community-based care packages. The report concludes that resources need to be allocated to ensure that compatibility exists in Commonwealth and State policy and programs across the broad areas of urban planning, housing, social welfare, health and disability support. Further, there was felt to be urgent need for the expansion of social housing for adults with disabilities and the development of enabling community residential options.

Ehrlich and colleagues (2009) examined the concept of coordinated care in the context of chronic disease management. Coordinated includes coordinating and managing health care services, coordinating service providers to encourage teamwork, and coordinating service delivery organisations to create integrated entities. Coordination includes client, service and system levels (horizontal) and intersections between the three levels (vertical). Self-management is a crucial element as the person is the single constant feature across settings, but it is often overlooked. At the client level, person-centred care assumes that an individual has access to all the service types they need to meet their needs, through a single point

of entry, streamlined assessment process and individualised care plans that are communicated and agreed upon. At the service level, evidence supports case management as an effective approach to care delivery and a team approach based on the use of evidence-based guidelines and shared administrative and financial service as promoting cooperation, flexibility and sustainability. At the system level, coordination is facilitated by resource and information management, and organisational integration and collaboration. Cost-effectiveness can be achieved by leveraging resources and targeting to those with highest need to avoid escalation to more costly, acute care. However, cost savings may not be realised by coordination as it can reveal unmet needs by improving service access and utilisation.

Fisher and Elnitsky (2012) reviewed 76 recent articles about different approaches to service integration, most of which were focused solely on the elderly, and provided an overview of the diverse models and theoretical concepts that can be used to inform planning and evaluation. They argued that service integration is particularly relevant to groups whose needs span physical health, mental health, housing, and disability support. Challenges or facilitators of integration were related to a) level and scope; b) planning, implementation and management; and c) funding. Successful integration efforts were likely to focus on limited geographical areas where identification of need and client-driven responses could be most effective; however, increasing the role of local communities in administration and financing was also thought to exacerbate existing system fragmentation. Barriers to integration lay in the realm of leadership and management, including decision support, delivery system design and clinical information systems. Collaboration, through activities such as program planning, staff training, and service delivery, was identified as a facilitator to overcome these barriers. Funding based on discrete categories could reduce program responsiveness and blended funding was proposed as a more flexible alternative. This involved matching funds from different sources and allocating these funds in ways that accounted for individual diversity and changing service needs. The authors noted that only a small minority of the models reviewed included project evaluation results, and data was often lacking on patient perceptions and clinical outcomes.

Jansen and colleagues (2007) reviewed the literature on integrated care initiatives for patients with multiple sclerosis (MS) to improve quality of care and manage costs. Based on the limited available evidence about patient satisfaction, they suggest that patients were most satisfied when they had access to continuity of care by the same staff and least satisfied with the adequacy of staff training and their level of participation in care planning. The authors note that integrated care appears to offer potential advantages for continuity of care and efficient use of resources for patients with MS but the use of different concepts related to integrated care, such as transmurals care, creates ambiguity and reduces cross-program comparison. The

authors reported that the high cost of care for people with MS was often used to explain why integrated care was an effective approach, but detailed information on the healthcare demands of patients with multiple sclerosis is missing. In general, there is a lack of evaluation studies and inconsistent evidence about the impact of integrated care.

Lukersmith and colleagues (2014) developed a case management taxonomy, initially focusing on two complex health conditions – severe brain injury and spinal cord injury. The taxonomy is a framework which provides an understanding of community case management and an agreed language for the actions performed by a case manager. Understanding what is and what is not case management enhances quality analysis. The biopsychosocial perspective of functioning, disability and health (WHO 2001) and a person-centred approach to service delivery informs the taxonomy. The taxonomy development involved a mapping review of case management, a critical review of appropriate frameworks and then iterative refinement of the taxonomy using a nominal group technique with a group of case management experts. The taxonomy shows the relationship between the actions (activities), related actions and the definitions. The community case manager's focus is on the person's unmet needs for supports and services related to their health and goals for participation in life roles. Case management recognises the person's context including informal as well as formal (paid) supports. The actions promote the client's ownership (and their family or people close to them) in planning for community supports including setting their own goals, making choices, accepting responsibilities, and contributing to (the extent possible) their own case management and coordination. The taxonomy of case management includes the actions of engaging the client, (holistic) assessment, planning, training and skill development, education, emotional and motivational support, advising, coordination and monitoring.

Van Raak and Paulus (2008) reviewed literature about interagency service coordination in European countries for people with disability, chronic illness and the aged. The problem of system fragmentation was experienced in different ways depending on the level of decentralisation of health and social care systems and the financial arrangements for funding health services (e.g., taxation, social insurance). Vertical fragmentation refers to the transfer of decision-making power from national governments and horizontal fragmentation refers to the level of differentiation between government ministries for health and social care. Multidisciplinary teams have been developed as a solution to fragmentation. These multi-professional teams with integrated information technology systems are used to address fragmented service delivery in acute, long-term and primary care, including professional fragmentation which can occur as a result of professional specialisation. A multidisciplinary team approach can be fragile and face challenges from professional specialisation but can be fortified where sufficient management support exists and

roles and functions become more blurred and overlapping. Interdisciplinary education is a promising tool that has been used in the United Kingdom and Finland to increase knowledge of other professions, break down boundaries, and create an environment that fosters multidisciplinary cooperation.

Models of service coordination

This section presents knowledge about approaches to service coordination gained from program evaluations and exploratory studies. To date, evidence about service coordination models for people with high and complex needs, and not from literature about coordinating aged care, is largely based on integrated care program evaluations conducted in the United States. Fifteen studies examined integrated care provided through managed care entities in the United States. Managed care entities provide a range of pre-paid healthcare services to individuals through employer health insurance. Eligible unemployed people and people with disability receive health insurance through government-funded Medicare and Medicaid programs which entitles them to acute, primary and community based services provided by some managed care organisations (Dobell & Newcomer, 2008; Master et al., 2003). For patients identified as having special healthcare needs, the goal of managed care is to reduce costly and preventable hospitalisation and premature nursing home placement by providing community-based, coordinated, holistic health and social care services (Master & Eng 2001; Mastal et al., 2007; Meyer, 2011). This is achieved by reallocating the inpatient portion of funding to outpatient services using integrated care (Bachman et al., 2008).

Integration relies on multidisciplinary teams and a coordinator who acts as a single point of contact and facilitates access to the necessary range of supports to prevent deteriorating health conditions (Palsbo & Kailes, 2006). Palsbo and her colleagues (Palsbo & Kailes, 2006, Palsbo, Mastal & O'Donnell, 2006; Palsbo & Ho, 2007) have conducted studies of integrated care by managed care organisations called Disability Care Coordination Organisations (DCCOs) that contract with state Medicaid programs and managed care organisations to provide disability-competent health and social services (Palsbo & Diao, 2010). The model consists of comprehensive assessment, self-directed care and person-centred planning, support to attend health appointments, centralised record-keeping, community resource engagement and ongoing communication between providers and with the person (Palsbo et al., 2006). Self-directed care recognises the person receiving care, their family and carers as active partners in the planning process (Craig et al., 2011; Palsbo et al., 2006; Palsbo & Ho, 2007). A key aspect of the coordinator role is to support the person to develop the skills they need to manage their care proactively and effectively (Palsbo & Ho, 2007). For instance, by providing support to locate accessible websites or teaching goal-setting skills (Palsbo & Kailes, 2006). Palsbo and colleagues (2006)

conducted interviews with executives, managers and coordinators who were from six separate Disability Care Coordination Organisations (DCCOs). Program staff reported that their clients, often from severely disadvantaged backgrounds, frequently lacked the skills to set goals or make decisions. Coordinators focused on fostering positive health behaviour through education and coaching as a strategy to increase their skills in self-management of their health conditions. They routinely attended health visits with clients in order to interpret health information and reinforce clinical goals, especially for clients with cognitive impairments (Palsbo et al., 2006).

Surpin (2007) describes the Independence Care System (ICS), a DCCO which provides coordinated health and long-term care for adults with disability to prevent serious medical problems and reduce unnecessary hospitalisations. ICS is based on multi-disciplinary team approach and is underpinned by the principle that people with disability are experts about their needs and can often lead in the planning and management of their health and social supports, but need a service system that blends social and medical support. The program uses the flexibility of managed care funding to offer a range of health and support services, such as coordination, equipment maintenance and home-based services to support independence. Participants are supported through case management and individualised care planning. Organisational strategies have been used to promote continuity and quality of care. A partnership between ICS and a home care provider ensures that participants receive services from a single provider. Quality of care is facilitated by a partnership with a registered training organisation. No program outcomes were evaluated. Craig and colleagues (2011) present a white paper on coordinated care for people with multiple health and social needs in the United States who are likely to be failed by primary care resulting in costly hospitalisations. Known as IHI Triple Aim, the approach aims to improve individual health outcomes, and produce better experience of care at a lower overall per capita cost. The framework relies on person-centred and coordinated planning through a relationship focused on individual needs, strengths and barriers. Like DCCOs, Triple Aim provides a multidisciplinary approach in which a care coordinator is responsible for identifying the individual's health goals and most pressing needs, and coordinating services to meet them. This approach enables an individual's personal assets, strengths and gifts to be appraised and a care plan developed in partnership with that person that responds to their needs for enhanced self-management skills. The primary coordination role may be best met by a physician, specialist nurse, social worker or community health worker depending on the person's most prominent needs (e.g., mental health, medical complexity or social instability).

Another group of DCCO integrated care programs evaluations from the United States were conducted by Master and colleagues (Bachman et al., 2008; Master & Eng,

2001, Master et al., 2007). The Commonwealth Care Alliance (CCA) is a DCCO that redistributes health resources from hospitals and institutions to community-based services for high-risk patients with disabilities, chronic disease, and multiple co-morbidities. Clients have access to unlimited medical, health and psychosocial support from co-located teams of behavioural health workers (social workers and counsellors), a nursing care management team, and primary care provider. The model relies on effective communication systems and tools to build collaboration and uses co-location to facilitate communication among providers and foster a shared understanding of goals, roles and decision-making to permit comprehensive and continuous care. However, as the authors note, program implementation was compromised by delays in establishing the necessary information systems to support effective communication. Bachman and colleagues (2008) evaluated an integrated care program for Medicaid-eligible adults with complex health and social care needs also offered by a DCCO, the Neighbourhood Health Plan (NHP). The program provided a full spectrum of on-site primary and preventative care services including care coordination, enhanced primary care, and mental health, addiction and other support services. The program offered a multidisciplinary clinical team model with a primary care physician as a core team member, and integrated behavioural and physical health interventions. A stratified approach was used to identify participants who needed more intensive support and these individuals received case management, nurse home visits, accompaniment to primary and specialist care appointments and 24 on-call support. The study analysed 2 year claims history on inpatient and outpatient care and in-depth interviews with 18 participants. Participants reported that managing their health was burdensome before intervention. For example, they reported negative experiences with the healthcare system, difficulty accessing services and language barriers.

In the United Kingdom, Goodwin and colleagues (2013) report on the evaluations of five coordinated care programs for people with chronic or medically complex needs in primary care and community settings. The report identifies key elements, success factors and barriers to coordination. Each of the programs aimed to manage complex needs holistically, improve quality of life, reduce hospitalisation and promote home-based care as preferable to institutional care. The programs demonstrate that building effective care coordination programs takes simultaneous innovation at the organisational level and new approaches at the service level. Without alignment of political, regulatory and organisational commitment new programs rely on local leaders to make change happen. Innovation takes place at person, service and system levels.

- At the micro level, continuity of care is assured by having a single point of contact when problems or issues arise. Care coordinators take a holistic view of the person by including families and carers in the planning process and

focusing on carer and environmental needs by, for example, building carer resilience. Coordinators use explicit strategies to promote patient and carer engagement and self-management as well as functional independence. Comprehensive, holistic assessment upon which care plans based are flexible and changeable over time.

- At the meso level, a care coordinator is a single point of entry to ensure that referrals from various sources are managed effectively to maximise timeliness and that program objectives are met. The coordination role spans many activities (e.g., advocacy and communication with providers on behalf of the person, system navigation, and care plan implementation) and needs have organisational authority to influence decisions at the local health system level. Multidisciplinary teams bring together range of skills and team-building is important to ensure that team members have shared vision.
- At the macro level, an approach that builds understanding of local community health needs enables effective program targeting. Localised programs address the needs of specific communities and populations through local leadership and long-term commitment.

Service coordination by primary care providers

Five studies examined models of service coordination for which coordination was undertaken by a person's primary care provider. Three studies are described here. Noel and colleagues (2005) and Kroll and Neril (2003), are presented in the next section about personal experiences of coordination as they were conducted to gain understanding about this experience.

Segal and colleagues (2004) report on a randomised control trial of 2,742 participants in primary care based 'co-ordinated care' program in Australia, targeting patients with a history of high use of in-patient service use. Care coordinator by the patient's general practitioner involved the creation of a holistic care plan that incorporated service responses to the patient's needs, taking into account environmental supports and impediments. The trial demonstrated no significant differences between the intervention and usual care group for two quality of life measures, and no difference in mortality rates. Total resource usage in the intervention group was substantially higher, largely because of the extra costs for care planning and case management, and for administering the co-ordinated care model. The lack of measurable improvements to quality of life or health outcomes reported may suggest that the success of service coordination depends on 'getting it right', in terms of matching the model to the needs of the particular consumers and stakeholders involved, or that the scope for achieving measurable benefits is limited to particular groups.

In the Netherlands, Oeseburg and colleagues (2004) evaluated an approach to coordinated care for people with multiple sclerosis (MS). Transmural care involves the use of nurse specialists as case managers who coordinate comprehensive, multiple assessments from neurological, rehabilitation, nursing and healthcare professionals in order to develop an individualised care plan. Care plans are then used by all health professionals who are working with the individual to document their findings and actions. This facilitates communication between professionals. The nurse specialist works closely with the patient to plan and arrange support and monitors the care process. Interviews with nurses and twenty patients about their experiences with transmural care were analysed along with data about individual information, self-actualisation, equipment, service and financial needs. The evaluation analysed outcomes using validated assessment instruments and found that total expressed needs declined significantly over time as unmet service needs, particularly related to service provision and information, were met.

In Singapore, Venketasubramanian and colleagues (2008) proposed a model for integrated long term care of stroke patients based on Wagner's model of chronic care delivery. The aim was to improve the transition between hospital and community by developing a collaborative approach to care. After being discharged from hospital, the patient's physician supervised treatment and rehabilitation was while a specialist nurse coordinated home-based services. These nurse case managers provide a single point of contact, monitor the person's multiple medical conditions and take responsibility for coordinating referrals and follow-up with specialists and other health professionals. Self-management support is central to the approach and this involves collaboration between a motivated and informed patient and their primary care team. A program evaluation had not been conducted to measure clinical and financial efficacy.

The experience of service coordination for the person

Three US studies that explored the experiences of coordination for the person are described here.

Palsbo and Ho (2007) evaluated access to and quality of care for participants of a DCCO (described elsewhere in Section 3, see Palsbo & Kailes, 2006; Palsbo et al., 2006). This is the first evaluation of consumer-reported measures of access to care and quality for people with disability served by DCCOs. Sixty four people completed a survey and a follow up two years later about the health care they received, their primary care physician, and personal care assistance. A statistically significant improvement was recorded in individual responses about service coordination, comprehensive assessment, self-directed care and health support and education. Most people were more satisfied with provider interactions, timeliness of services and healthcare coordination. Access to primary care physicians, equipment and

rehabilitation also improved. Over time, more respondents identified a need for primary care services which was interpreted as resulting from education provided by coordinators about preventative care.

Noël and colleagues (2005) examined the use of collaborative care management for people with multiple chronic illnesses. Collaborative care management is a model of patient-centred chronic care management in which a patient and primary physician define the patient's medical problems, establish goals and create a care plan. As has been noted with other approaches, self-management by the person themselves is a key element of collaborative care management. The person is supported to develop self-management skills and support services during a period of active and sustained follow up. In focus groups, sixty veterans (aged 20 to 80 years) reported problems with collaborative care including long waits for referral, poor continuity of care, multiple appointments, and problems communicating with providers. Most patients expressed overall satisfaction with their care and appreciation of their primary care physician. Some patients felt their concerns were overlooked by physicians or that the physician disagreed with them about the most important illness to treat, but most felt their physicians shared their view and were attentive. Knowledge and skill deficits interfered with self-management however, most patients wanted to be active partners in their care. They blamed 'the system' rather than individual providers for a lack of continuity of care and communication problems that they experienced with service providers. Technology was used as a strategy to enhance collaboration and manage resources. Patients were willing to use technology for monitoring or education as long as it did not substitute for human contact.

Kroll & Neril (2003) explored the care coordination experiences of thirty adults with physical disabilities including cerebral palsy, multiple sclerosis and spinal cord injury. Care coordination was defined as a planned, interdisciplinary approach to organise continuous, timely and efficient healthcare and related support services. An annual survey examined health care access, utilisation and satisfaction and distinguished two types of health insurance plans: managed care and 'fee-for-service'. The former was characterised by a preferred list of providers and pre-paid access to limited specialist and care services. Fee-for-service plans allowed patients to choose providers and services without limitation. Regardless of health plan type, care coordination was mainly undertaken by the person's primary care physicians. Physicians were not perceived as well-equipped to coordinate care and viewed as insufficiently knowledgeable and lacking in the time needed for effective coordination.

Financial performance and modelling

Of the program evaluations reviewed in this section, only two evaluated financial outcomes. Palsbo & Diao (2010) analysed the financial performance of a DCCO by examining claims data over previous three years for 245 participants with paralytic syndromes. The model described by Palsbo and Diao (2010) has been described elsewhere in this section (Palsbo & Kailes, 2006, Palsbo, Mastal & O'Donnell, 2006; Palsbo & H, 2007) and evaluation findings are presented in the next section on outcomes. Bachman and colleagues (2008) compared expenditure under an integrated managed care program for 104 people with disability and chronic illness (described earlier) with fee-for-service expenditure for a comparable population over two years and found that there were consistently lower costs for the integrated care recipients. All reductions in expenditure were due to decreased inpatient and outpatient hospital costs. Other medical costs including physician, transport, pharmacy, and behavioural health increased under the intervention and this was explained as likely to be related to improved access to preventative and necessary care. Emergency department costs also increased, however, emergency department utilisation decreased. Qualitative data was also collected and the results indicate improvements in health and quality of life. Coordination reduced barriers that had prevented bilingual people, particularly those with mental illness, to seek healthcare services.

In a system improvement initiative, Kathol and colleagues (2001) discussed the development of a tool to improve integrated case management for patients with complex health needs. Integrated case management is based on patient complexity not disease. A template is used to target complex patients with multiple high-risk characteristics who are most likely to benefit from case management. The approach is based on developing a partnership between the person and case manager to work constructively toward addressing their health and social needs rather than focusing on their problems. The tool is designed to be used by case managers across health settings, including hospital, clinic and community. A collaborative care plan is created and there are specific actions, agreed goals and definable outcomes. The authors argued that the model will lead to significant cost savings to the health system for patients with health complexity however no data was presented to support the claim.

3.6 Evidence about outcomes

The findings from the literature present some evidence about the outcomes of service coordination for the person, service providers and — to a lesser extent—the system. This evidence is now presented.

Outcomes for the person

The evidence points to some positive outcomes for the person associated with service coordination. These are:

- Significant improvements in:
 - satisfaction with self-directed care and health support (Palsbo & Ho, 2007);
 - health system and physician (Noël et al., 2005; Palsbo & Ho, 2007)
 - health and wellbeing (Sampalli et al., 2012)
 - Quality of life (Palsbo et al., 2006).
- Improved clinical outcomes measured by decline in acute admissions (Palsbo et al., 2006)
- Reduced need for rehabilitation attributed to improved primary health care provision (Palsbo & Ho, 2007).
- Improved access to appropriate services (Palsbo & Diao., 2010).
- Increased consumer satisfaction linked to continuity of care and participation in care planning (Jansen et al., 2007; Noël et al., 2005).
- Informal support to prevent premature institutionalisation (Abendroth et al., 2012).
- Increased health-seeking behaviour (Bachman et al., 2008).

There is some evidence about less positive, or less conclusive, outcomes for the person. For example, an evaluation of a Dutch coordinated care program reported no change in health outcomes (Oeseburg et al., 2004) and a systematic review (de Bruin et al., 2012) reported mixed findings including:

- Moderate benefits of comprehensive care programs on inpatient healthcare use and costs, health behaviour, perceived quality of care and client satisfaction.
- Insufficient evidence of benefits on health-related quality of life and outpatient healthcare use and cost
- No benefits for cognitive functioning, mortality, depression, functional status, quality of life, and caregiver burden.

Lack of knowledge has been identified as a barrier to effective service coordination. For example:

- A lack of disability-specific knowledge by care coordinators, usually physicians, was perceived to hamper effective coordination (Kroll & Neril, 2003).
- Knowledge and skill deficits for the person with complex care needs can interfere with their self-management (Noël et al., 2008).

- Lack of place-based approaches (e.g., collaboration between outreach and community-based therapists, support for use of technology, training local therapy assistants) to facilitate service access for people from rural and remote areas (Dew et al., 2013)

Outcomes for service providers

The literature presents evidence of enablers and barriers to service coordination for service providers.

Enablers to service coordination are:

- Multidisciplinary teams to:
 - Reduce system fragmentation (Van Raak & Paulus, 2008).
 - Build expertise, trust and reciprocity (Van Wijngaarden, 2006).
 - Standardise communication for sharing resources, information and skills (Goodwin et al., 2013; McConnell, 2006).
 - Create shared understanding of goals, roles, decision-making (Mastal et al., 2007).
 - Establish close working relationships with other service providers, community members, patients and carers (Dobell & Newcomer., 2008; Goodwin et al., 2013).
- Co-location of multidisciplinary teams promotes linkages between providers (Mastal et al., 2007).
- Common information systems (Meyer, 2011), shared patient information and integrated care plans (Mastal et al., 2007; Palsbo & Kailes., 2006; Palsbo et al., 2006).
- Cross-sector innovations such as pocket cards designed by care coordinators that prompts clinicians to ask appropriate questions of patients with complex needs during medical appointments (Palsbo & Kailes, 2006).
- Use of technology to enhance communication and support distance therapy interventions (e.g., therapeutic software applications) for people in rural and remote areas (Dew et al., 2013).
 - Multidisciplinary education has been used in the United Kingdom and Finland to increase professional collaboration (Van Raak & Paulus, 2008).
- Training community-based therapy assistants to implement therapy interventions in rural and remote areas (Dew et al., 2013).

Barriers to service coordination for service providers include:

- Cultural differences between health professions (Øvretveit et al., 2010).
- Lack of access to shared E-health records (Goodwin et al., 2013).
- Lack of investment in the IT infrastructure needed to support financial management systems (Master & Eng, 2001).

- The disengagement of general practitioners in care coordination can prevent effective information exchange and loss of knowledge about patient care (Goodwin et al., 2013).
- Shared care planning by all service providers can be perceived as time-consuming (Oeseburg et al., 2004).
- Communication fragmentation between providers increases with complexity of needs (Kroll & Neril, 2003).
- Multidisciplinary teams are fragile without management support to break down barriers, span boundaries and enable professionals to work in parallel, and transfer knowledge (O'Flynn et al., 2011; Van Raak & Paulus., 2008).
- Co-location is not a standalone solution and needs to be backed up by skill development to foster collaboration (O'Flynn et al., 2011)

Outcomes for systems

At the system level, the outcomes measured were financial performance and cost effectiveness. Several authors noted that it was essential to invest in the development of tools and systems to evaluate program effectiveness. For example, care planning tools to measure patient healthcare costs and outcomes (Kathol et al., 2011), and performance review systems to measure/compare hospital readmission rates and service costs (Meyer, 2011) and financial accounting systems that permit large-scale cost tracking and cost-shifting over time (Palsbo & Diao, 2010). An evaluation of coordinated care programs in the UK (Goodwin et al., 2013) found that none set specific cost-reduction targets and had only a marginal impact on the costs of care. However, all were able to demonstrate improvements in the care experience and outcomes. The authors conclude that care coordination needs to be adopted as a quality improvement rather than cost effectiveness strategy.

Findings about the financial outcomes of service coordination are:

- High-level measures to track improvements in population health, individual experience of care and cost provide evidence of cost savings and statistically significant reduction in median hospitalisation rates (Craig et al., 2011).
- Over 3 years, annual reductions in medical costs through integrated care paid for the additional costs of coordination (Palsbo & Diao, 2010).
- Palsbo and Diao (2010) found that:
 - Expenditure increased initially (1.75 higher than usual care) as unmet needs were addressed and then reduced over 12-18 months.
 - Expenditure increases were attributed to the additional cost of care coordination as well as previously unmet equipment needs.
 - Hospitalisation rates were unchanged but length of stay and cost per admission dropped significantly.

- Integrated care reduced overall expenditure due to decreased inpatient and outpatient hospital costs even when additional cost for enhanced care was included. The cost reduction was dramatic for higher cost patients (Bachman et al., 2008).
- Hospital stays and home nursing use was lower for people with complex care needs accessing an integrated care program than comparable populations (Dobell et al., 2008).
- Computerised performance systems are needed to measure/compare hospital readmission rates and service costs (Meyer, 2011), healthcare costs and outcomes (Kathol et al., 2011), and cost effectiveness (Mastal et al., 2007).

Other suggestions for improved coordination at the system level include:

- Formal authority and high-level support for collaborative activity (O’Flynn et al., 2011)
- A whole of government approach for housing, health and disability care (Bridge et al., 2002) and to embed a more collaborative work culture across multiple arms of the public service (O’Flynn et al., 2011)
- Local leadership and long-term commitment to address the needs of specific communities and populations and ensure effective program targeting (Goodwin et al., 2013; O’Flynn et al., 2011)
- Tools to track equitable access to programs across age groups and disability types (Ruiz et al., 2012).
- Integrated purchasing, planning, organisation and governance systems (Goodwin et al., 2013).
- Structural incentives to reward collaborative behaviour and formal authority to build trusting relationships across sectors, government departments and with community (O’Flynn et al., 2011)

Conclusion

The academic literature is heterogeneous and includes studies that were conducting using different terminology to describe and operationalise service coordination. Studies were conducted across multiple healthcare settings and in countries whose funding, policy and historical contexts differ substantially to Australia. Even an Australian randomised trial (Segal et al, 2004) was not conducted to examine cross-sector service coordination but solely in the context of primary health. As de Bruin and colleagues (2012) point out, research heterogeneity makes direct comparisons impossible however, as the previous section on outcomes demonstrated, aggregating consistent findings across different studies can be used to reach a number of conclusions about the benefits and barriers to effective service coordination. There is a clear case that coordination leads to improved quality of life

and clinical benefits, and, possibly, cost effectiveness. There was also persuasive evidence of positive outcomes at the system level.

There has been insufficient focus on outcome-based assessment of program efficacy and efficiency. Much of the evidence is based on small-scale evaluations of pilot programs and, in some cases, lacks methodological rigour. Goodwin and colleagues (2013) point out that this makes it impossible to ascribe improved outcomes to the program intervention and the perception that pilot programs are 'outside' the system increases their vulnerability to being axed. Program evaluations have tended to lack specific cost-reduction targets and assumed that care coordination and case management can reduce hospital admissions for populations with complex care needs. Analysis of five program evaluations from the United Kingdom did not support this conclusion (Goodwin et al., 2013). Only one in three studies in a systematic review of care coordination measured economic outcomes and fewer than 25% of these found significant positive results (Powell Davies et al., 2006). Another systematic review found only moderate support for a reduction of healthcare utilisation and cost (de Bruin et al., 2012). In contrast, emerging evidence from the United States (Bachman et al., 2008; Palsbo & Diao, 2010) suggests that service coordination for people with complex care needs can lead to substantial cost savings through reduced hospital admission and institutional placement. While Palsbo and Diao (2010) found a short-term increase in healthcare costs with the introduction of service coordination, it has been suggested by these authors and others (e.g., Ehrlich et al., 2009) that this may be due to the identification of (and response to) unmet service needs by coordinators. It has been proposed that coordination may be more appropriately viewed as a quality improvement (Goodwin et al., 2013). This is an important point in the context of the NDIS, in recognition that increasing economic and social participation for people with disabilities is a primary goal of the Scheme.

4. Input from stakeholder workshops

This section reports on workshops with consumers, service providers and policy makers. The policy workshop was held late in the project's life to enable discussion of draft findings.

4.1 Consumer and provider workshops

Input from consumers and service providers was gathered through three workshops conducted for the project:

- A workshop convened in Melbourne involving service providers, many of whom had direct experience working with service coordination programs (including some of the pilots/programs reviewed in Section 2).
- Two small workshops involving consumers and consumer advocates, some with experience of service coordination, and one from an NDIS pilot site.

These three workshops have provided valuable material to augment the review of literature presented in sections 2 and 3, and to strengthen the project findings. A summary of key messages and themes from the workshops is presented.

Goals

Key goals for consumers and families that were discussed in all the workshops were:

- Being able to access necessary services and supports, and
- Having a say in determining the content of a service plan, and choosing the providers to deliver those services.

Participants at the provider workshop identified problems with access to community-based rehabilitation as a particular issue, especially for people with acquired brain injury or spinal cord injury who often need rehabilitation over extended periods. A goal for this group would therefore be to facilitate better access to rehabilitation and other health services. Providers familiar with the needs of people with progressive neurological disease talked about the types of support people need when they have recently received their diagnosis. There is a need for counselling and information, and a need to be linked with relevant mainstream services. People need a point of contact—someone they can come back to with questions and when physical symptoms start to manifest.

The importance of equitable access was discussed. Providers noted that, currently, people with self-advocacy skills (or a devoted advocate) often get substantially better access to services and supports. A goal of coordination support would be to ensure that people who are less able to advocate for themselves can get equally good outcomes.

One workshop invitee made the point that the NDIS is 'not just a funding system'—we need to 'look at people's lives'. That is, a key goal is the effective provision of the full spectrum of services and supports people need to live their lives, not just disability services and supports.

Features of service coordination

Micro: what coordination looks like for the person

From the consumer workshops, key features of service coordination identified were:

- Provision of **accurate information**, including ‘what the limits are’, in terms of the supports a person can realistically expect to get through the NDIS and other mainstream programs.
- **Individual advocacy** to help access services.
- Facilitation of cross-sector **communication between service providers**, so they are better able to provide joined-up services for the individual.

The coordinator should be **someone the person is able to contact** when issues arise, and should **help the person ‘find their way around the system’**. It was seen as important that the coordinator should know the person well and be able to **anticipate their future needs**; there should be a **relationship of trust**.

Participants at the provider workshop stressed that service coordination is not the same as care plan implementation; it includes **system navigation**, and **linking the person with relevant services in their community**. There should be a focus on transition times, when the person’s needs or circumstances change.

Meso: aspects of cross-sector service coordination

System navigation

A service coordinator would assist the person to find their way around the system, and would help ‘make the system work for them’. Cross sector service coordination for people with chronic disease needs to cover a wide range of life areas—not just health or disability services, but also employment, education, children’s services. These aspects of life are centrally important to people, but are sometimes neglected because workers in health, disability and other sectors stick to what they know and do not link to other service areas.

Continuity of relationships—with the coordinator and with service providers

Ideally, the service coordinator should have an enduring relationship with the person. Coordinators would also have a role in ensuring that there is continuity in the services the person receives—the point was made in the provider workshop that individual plans should be developed in the context of current services and supports for a person.

Goal setting and providing information

Often people need support to establish achievable goals and realistic options. Questions were raised in the workshops about the appropriateness of some plans in NDIS trial sites; in some instances planners may not have the skills needed to work with people with specific disabilities and conditions (e.g., intellectual disabilities, ABI

or progressive neurological diseases). Coordinators would have a role in ensuring people are given good advice and information that is accurate, practical and honest. A coordinator with expertise relevant to a person's condition should be able to anticipate emerging care needs and educate the person about their options; as well as educate disability and mainstream service providers about the individual's changing needs.

Advocating for the person during service planning

Workshop participants saw a potential advocacy role for the coordinator during the NDIS planning process, as someone who knows the person and has a good understanding of their circumstances, current needs, likely future needs, and relevant aspects of the service system. The coordinator should be able to go back to the planner later to negotiate changes to the plan, where needed. Both short and long term planning are needed, especially for people with progressive conditions whose needs may change rapidly.

There was a view that, currently, there is not enough time for the planner to get to know the person or understand their needs well enough.

Participants in the provider workshop said that the planning process should:

- be future-orientated with an emphasis on anticipating needs, not reactive or crisis-driven;
- be dynamic and include opportunities for review, so that the service plan can respond to the person's evolving needs;
- be owned by the person and informed by the person's own goals;
- recognise the person's broader life situation, and the range of factors that influence a person's needs; and
- focus on what will work best for the person in the context of all relevant circumstances.

Advocating for the person during implementation of the service plan

Where needed, a service coordinator could advocate for the person to ensure they are able to access the services and supports identified in the plan, including helping to sort things out if the services accessed do not properly meet the person's needs. 'Systems wrangling' was a term used in the provider workshop—finding creative solutions to deliver good outcomes for the person despite the obstacles that can exist within and between service systems.

A specific issue identified during one consumer workshop was long delays in receiving home modifications because younger people who receive HACC services are not prioritised by providers. In such instances a service coordinator can help negotiate access to services in other sectors. The provider workshop emphasised the importance of service coordination in ensuring adequate access to health services

for people with disabilities, particularly extended community-based rehabilitation for people with acquired disabilities. Participants thought that coordination will be needed among NDIS and 'outside' services, since the sectors and programs that are relevant will be determined by the circumstances and goals of the individual and their family rather than by current service structures.

Participants in both the provider and consumer workshops talked about experiencing problems with plan implementation in NDIS trial sites. In some cases the funding and supports allocated in a plan are inadequate to effectively meet an identified need (e.g., a plan that included a behavioural assessment but no funds for follow-up). There was a view that some people need support with plan implementation to ensure that they can actually access the services identified. It was suggested that a coordinator could take lead responsibility for ensuring the plan is implemented, and monitor implementation within the 12 month life of the plan.

At the provider workshop, an example of informal coordination support in the Victorian NDIS trial site was given. The Linkages program, funded to provide case management, has enlisted specialist tertiary case management support from MS Australia where this expertise was necessary. These informal arrangements can mask the fact that this need for specialist coordination is not currently recognised or funded in plans.

Service coordinators could also have a role in facilitating the training and education of service providers across sectors, for example in relation to clients who have particular characteristics and care needs associated with less common health conditions. This would be to help ensure that providers are adequately skilled and informed to properly meet people's needs.

Self-management support and budget monitoring

In all three workshops the role of a coordinator in supporting self-management and the exercise of choice and control in pursuing individual and family goals was discussed. Some participants expressed the view that, in their experience, the planner often decides the package a participant receives. In one of the consumer workshops it was suggested that, once an individualised budget has been agreed upon, the person should be given a list of suggested resources to indicate what the money can be used for. An electronic record card could be used to help people to manage their funding without them having possession of the funds. Consumers also suggested the role of a coordinator could include helping people locate cheaper services and equipment (e.g., home modifications, which can currently be very expensive when accessed through approved providers).

There was also discussion of the need for a clear approach to assessing risks associated with the exercise of choice and control, including the decision to self-manage funds. Some people may not have the personal resources (including the

cognitive skills) to assess risk adequately, and may need assistance to manage their budget. A service coordinator could provide this kind of support, where needed, including monitoring expenditure to ensure funding is spent on the 'right things'.

Communication

There was general recognition across all the workshops that good communication is critical to effective cross-sector service coordination. Participants saw a role for service coordinators in facilitating communication between different service providers so as to deliver a more 'joined up' package of services for the person, and drawing in professionals with the relevant skills and expertise at times when they are needed. Coordinators should also liaise among themselves to share knowledge.

Location of the cross-sector service coordinator role

Participants in the consumer workshops expressed the view that coordinators should be located in the same geographic area as the person, and should be distinct from planners, funders and disability service providers. They thought that a coordinator may be someone already in the person's life, such as a carer, advocate or existing service provider.

During the provider workshop there was discussion about where in the system the coordinator role should be located. The following points were made:

- Coordinator and funder roles should be separated. The cross-sector coordinator role should be uncompromised, independent and focused on achieving goals and outcomes for the person across all relevant program areas.
- The NDIA should manage the eligibility process, then 'direct traffic' to appropriate meso-level agencies to provide cross-sector coordination.
- For people with an acquired disability (e.g., MND, ABI, SCI), cross-sector coordination should start from the health sector.
- There could be conflicts of interest if agencies have dual roles, i.e., both coordination and service provision.

Both provider and consumer workshops emphasised that there should be a continued role under the NDIS for specialist agencies that have a history in serving specific groups—providing support for individuals and families, and as a source of expertise for service providers. These agencies are an obvious source of expertise in cross-sector service coordination for the client groups to which they cater.

Qualities of the service coordinator

Based on participants' experience of professionals who achieve good outcomes for people and their families, often amid challenging circumstances, it was felt that a coordinator should be someone who has a focus on quality outcomes for the person and a 'can do' mentality, who is able to 'work around system blockages' to find a

solution. One workshop participant expressed the view that coordinators need to be good leaders, and to have ‘great expectations’ and faith in people’s competence.

The importance of employing coordinators with the right skills and expertise was emphasised. Service coordinators need to have good cross-sectoral system knowledge and established links in the community, practical problem solving skills, and should prioritise spending time building rapport and trust with the person. Different groups have distinctly different needs, and different expertise may be required in the coordinator role. In choosing a coordinator the focus should be on someone who can achieve the best outcomes for the person.

Enabling service coordination

Participants at the provider workshop talked of the need for coordination to be both multidisciplinary (team based) and interdisciplinary (about communicating effectively across services and sectors); it is about lasting partnerships, not just ‘handovers’. Establishment and maintenance of relationships between providers is key to meeting needs effectively.

To make cross-sector coordination work, it is necessary to foster a willingness by all parties to work together across disability, health, aged care, and other relevant sectors, not just enthusiasm for this from the coordinator or the individual. There needs to be **‘buy in’ to collaborative relationships at the decision-making level** in organisations. To the extent that coordinators have a role in building cross-sectoral service networks at a local level, those individuals will need to have a **mandate** that is recognised by the relevant organisations.

There was some discussion of the idea of **‘nodes’ of communication within health and other relevant systems**—individuals who are points of contact in relevant sectors that coordinators in the disability sector can link with. It was felt that, in the current system, so-called ‘system wranglers’ seek others with similar skills to connect with informally to ‘get things done’, but that this needs to be more systematic. There was also discussion about establishing **‘hubs of expertise’** including specialists from different sectors as a resource for coordinators (BrainLink Services in Victoria was cited as an example).

Effective cross-sector service coordination is not just a matter of installing coordinators, but recognising that there is a ‘network’ of service providers who will all contribute time to working with the coordinator and others in the network. The time required for this should be factored into funding, and recognised and supported by agencies across sectors. For instance, the health system needs to recognise that extra staff time commitment is part of the equation. Thus there should be **provision for the cost of cross-sector coordination**, both within individual service plans and at a broader, system level.

Resourcing the **education and skilling of service providers** was identified as an important enabler of cross-sector service coordination. The outreach component of the SCIR model involves the use of telehealth options, providing locally-based education and training for regional service providers, and linking with local services—that is, building capacity in the system. An example was given of a worker in an NDIS pilot site who was completely unprepared for the emotional state of a family coming to terms with a recent diagnosis of MND—appropriate prior education about MND would have been valuable, both for the worker and the family.

Workforce development more broadly was also seen as important, in particular to develop the skill set for working cross-sectorally. It was suggested that a national strategy may be needed, including accreditation standards with an emphasis on cross-sector competencies, and possibly the development and promotion of cross-sector career paths.

The development of mechanisms and protocols for **information sharing** was also seen as important—e.g., regular meetings of stakeholders (at micro, meso or macro levels), or agreed approaches to sharing written records. An electronic record system for NDIS participants was suggested by a consumer as a way of keeping track of and sharing information between providers. Information and data was also acknowledged as a foundational element of cross-sector coordination in both the provider and policy workshops.

‘Practice-based evidence’ about cross-sector service coordination was seen as lacking. A well designed cross-sector service coordination model should include **data collection mechanisms** from the outset, to help build an evidence base to support better practice and allow cost-benefit analyses (including on outcomes for people).

Macro: requirements for coordination across different service sectors

It was considered by some that a ‘silo’ mentality is entrenched within and across sectors; for instance, there are barriers within the health sector between mental health and neurological conditions (including ABI), which can be a problem for people with a neurological disease that has psychiatric manifestations. Workshop participants agreed that macro level efforts are needed to break down these silos. Those with decision making power within organisations must come together to foster **improved mutual understanding** of what other services/sectors do, and a **commitment to collaborative approaches to cross-sector coordination**.

In order to get real commitment to **shared goals** it was considered necessary to look at which sector owns the outcomes/benefits and which sector bears the costs and responsibilities for providing the services—it is important to get ‘buy-in’ from all players. A **dedicated budget to fund cross-sectoral efforts** to improve service coordination can work well (the SCIR model was cited as an example).

Participants at the provider workshop emphasised the importance of rehabilitation services for people with disabilities, and the difficulty of accessing services. Community health providers may be constrained by requirements associated with their block funding, and can be reluctant to take on more costly individuals; service managers sometimes use restrictions that limit access for people with disabilities as a means of demand management. This gap has been hidden somewhat by programs like 'Slow to Recover' (see Appendix Table A1), which funds rehabilitation services for people with ABI by taking the responsibility for meeting demand away from health service programs.

It is essential for the NDIS to lead cross-sector efforts with health to **facilitate better access to rehabilitation and other community health services for people with disabilities**. Outside hospital-based rehabilitation options, slow stream rehabilitation services are not widely available in Australia and the types of community health responses individuals with disability need to access to maintain health and well-being in community settings may be non-existent. Working collaboratively with the health system to develop and deliver these resources is beneficial to all stakeholders and will help the NDIS deliver on its social and economic objectives. Measures to promote better linkages with health services and **possible joint (health–disability) funding of cross-sector coordination** should be considered.

Outcomes

Participants at the service provider workshop believed that an important outcome of effective service coordination would be reduced duplication and over-servicing through better cross-sectoral communication. Cross-sector coordination would enable streamlining and more effective use of existing services, including services available in the community, to reduce pressure on NDIS funds.

There is a risk of over-servicing where generalist disability services are not best placed to offer specialist cross-sector coordination but are funded for this, and the role is then supported or duplicated by specialist organisations (e.g., Motor Neurone Diseases Association, MS Australia). This can be avoided where there is both a designated coordinator role and specialists are engaged at times of transition where the individual's needs change.

Participants at all workshops saw service coordination as a means of delivering better outcomes for people: a more streamlined journey, and more control over the services they receive. It was emphasised that qualitative outcomes are important to value and document. Rather than a narrow focus on economic costs/benefits, there should be recognition and measurement of social return on investment, such as keeping families together and enabling people to return to work. There was also a strong view that early coordination is cost effective; there is a need to more fully explore and expand the role of early intervention for adults.

4.2 The policy workshop

A fourth workshop involving a range of participants (including NDIA personnel, administrators from health and disability departments and agencies, and academics) was held towards the end of the project.

Participants had the opportunity to comment on the draft discussion paper. During the workshop there was some discussion about areas of research relating to cross-sector coordination that may not have been captured by the literature search terms used, but it was not suggested that evidence on service coordination in the literature from those areas was inconsistent with that presented in the draft discussion paper. Some participants talked about other programs that have implemented models of service coordination that would be relevant to the project. Where materials were available these were reviewed and, where found to be relevant, incorporated into the final discussion paper. The project team is grateful to those participants who provided follow-up information on these programs.

The workshop focused particularly on issues relating to implementing cross-sector service coordination. Key messages and themes from the workshop are outlined here. Much of the discussion was framed in terms of identifying barriers to cross-sector coordination and potential solutions.

Barriers to cross sector coordination

Workshop participants agreed that, while the need to ‘break down the silos’ and work collaboratively across sectors to deliver better outcomes for people has been long acknowledged, structured attempts at cross-sector service coordination have tended to be short lived (e.g., pilots that are not continued) or limited in scope (e.g., focused on a tightly defined group). A number of persistent barriers to cross-sectoral coordination were discussed.

‘Gate keeping’

Some participants made the point that often the barriers to accessing services in other sectors for people with disabilities are created at program or service level as a means of managing demand in the context of limited resources. There is an entrenched ‘gate keeping’ culture. In some instances barriers are perceived rather than real, in that people working in a system accept the ‘myths’ or conventional wisdom that certain things are not possible. A comment was made that ‘you need to keep going until you hit a real road block’.

At the macro level, lack of expertise or the pressure of competing demands can result in administrators putting up ‘road blocks’ (e.g., regulatory restrictions) to manage workload or budgetary constraints, rather than because there are real limits to flexibility in the provision of, or access to, services. An example given was denial of access to health care, whereby health service managers block care provision to people with disabilities by defining them as not being ‘core business’. Lack of clarity

as to where responsibility lies is a related problem. For example, in mental health it is often unclear which sector has responsibility for meeting needs, particularly as it can be difficult to delineate clinical from functioning support needs, and this can result in unmet needs.

Commonwealth–State/Territory divisions

Divisions between Commonwealth and state/territory responsibilities are seen as problematic. In the context of the NDIS, the Commonwealth has responsibility for managing a needs-based scheme that operates on insurance principles, and assumes the risks associated with such a scheme. The states, responsible for some key mainstream service sectors, continue to provide budget limited services. This creates a risk of cost-shifting from service areas of state responsibility onto the NDIS. The need to develop ways to make these current barriers more porous exists both inside and outside the NDIS trial sites. The responsibility to resolve them does not lie solely with the NDIS, but with mainstream programs at both levels also. As co-funders of the scheme, the States and Territories thus have interests in the development of collaborative working arrangements between the NDIS and mainstream programs.

Lack of understanding of different service systems

The view was expressed that people working in the health system, including some in senior administrative positions, often do not fully understand the disability sector—for instance, there is a common misapprehension that health services for people with disabilities are provided within the disability sector. There can be similar lack of understanding in education and employment. Promoting understanding of other sectors can help break down the barriers—e.g., by creating positions in which professionals work across multiple sectors, or by creating opportunities for people working in different sectors to talk face-to-face.

For people and families, trying to gain an understanding of different service systems can be confusing and overwhelming; often people do not know what services are available or how to access them. With no single point of contact and no assistance with system navigation people may be unable to access the services they need. Sometimes an individual receives ‘case management’ from multiple sectors, which can result in redundancy, duplication of effort and over-servicing, and can be overwhelming for people and families. Cross-sectoral collaborative effort is required to ensure that this is avoided.

Lack of cross-sectoral expertise

Health professionals are not trained to work with people with disabilities, and often lack the appropriate skills and expertise (especially in relation to people with challenging behaviours and communication difficulties). Likewise, professionals in the disability sector often lack expertise and understanding relating to the health needs of people with disabilities and the health system. This problem clearly

illustrates the need for better communication, education and knowledge sharing across sectors.

Language and terminology

Language can be a barrier to communication between sectors. Lack of a common understanding of key terms can make it difficult to compare existing evidence about service coordination.

For example, the term ‘case manager’ is used and understood differently in different program contexts. In some contexts case management is seen as a more limited role, not encompassing the range of activities involved in cross sector coordination, while in other contexts case management is understood more broadly, with coordination as one of its elements. To some, ‘case management’ suggests a view of the person as a ‘case’ to be ‘managed’, rather than someone for whom coordination assistance can help deliver better outcomes.

Language can also be a barrier for individuals. Access to services can be hampered by not knowing the right language to use to get what you need.

There was general acknowledgement of the need to define the terms used in the context of this project and clearly specify what is meant by ‘service coordination’. More broadly, efforts to work cross-sectorally to improve service coordination should be mindful of this issue, and should ensure that all stakeholders have a common understanding of key terminology.

Local and personal factors

The success or failure of service coordination can depend on local factors—individual people and personalities, and the politics around a program. One participant talked about the GP coordinated care trials as an example: the initiative worked very well in some sites, due to the individuals involved finding good solutions appropriate to the local community (e.g., in some Indigenous communities).

Overcoming the barriers

The cross-sector coordinator as a single point of contact for the person

A cross-sector coordinator would provide a **single point of contact for the person**, and also a single point of accountability, taking responsibility for ensuring a joined-up service response to meet the person’s needs. The coordinator would **support the person in exercising choice and control**, for example, exercising control over the information about them that is shared between service providers.

The point was made that individuals, families and their community supports need to be seen as partners in service coordination. There should be a focus on **facilitating progress towards self-management** for people for whom this is possible, rather than creating a relationship of dependency.

The need for ‘systems wranglers’

While some systematic barriers can be identified, there is no ‘magic bullet’ to break down program silos and enable effective cross-sector collaboration and coordination. Individual system blockages must be dealt with when they are identified. An example given was an effort to reduce hospital ‘bed blocking’: hospital discharge was often unnecessarily delayed because the home modifications committee only met quarterly, and individuals could not be discharged without the necessary home modifications in place.

There was general acknowledgement of **the value of cross-sector coordinators, or ‘systems wranglers’**—people who have the knowledge and skills necessary to ‘work the system’. The point was made that **this is a specialised role**, as staff within systems often do not understand how those systems work.

There was discussion of the idea of coordinators having **access to brokerage funds**, which they would use strategically to broker timely solutions in instances where a person’s needs cannot otherwise be met. One participant expressed the view that ‘you can’t do deals to find solutions across sectors if you have no money’. Local Area Coordination in Queensland was given as an example, where access to limited brokerage funds was effective in enabling coordinators to broker creative solutions.

Facilitating cross-sector coordination and collaboration

The ‘gate keeping’ culture outlined above creates inefficiencies in the system and places unnecessary burden on coordinators and ‘system wranglers’ trying to negotiate access to services. ‘Enabling mechanisms’ are needed to make this job easier. Importantly, there should be **shared accountability for micro level outcomes at the meso and macro levels**—cross-sector service coordination cannot be achieved by super-human ‘system wranglers’ alone. Participants discussed the need for **formalising links, horizontally between sectors and vertically within sectors, and defining pathways of accountability**.

On the topic of language and different cultural paradigms as barriers to cross-sector collaboration, solutions suggested included the use of shared tools for training and education, data sharing, and the articulation of shared values. One participant made the point that ‘sharing tools and resources is a good strategy in a budget-limited environment’.

High level cross-sectoral agreement and leadership

Effective cross-sector service coordination requires **high level political will and commitment**. Ministers of relevant portfolios should be mandated to work together and find ways to prevent ‘buck passing’ or cost shifting from one sector to another (not only health and disability, but also aged care, youth justice, education, employment and housing). There needs to be shared accountability and ownership. Such high-level commitment can be expressed horizontally in memoranda of

understanding or bilateral cross-sector service agreements. It was suggested that nominating high level ‘champions’ (along the lines of State Ministers for the National Disability Strategy) could be effective—that is, individuals who would take a lead role in making cross-sectoral collaboration happen at the macro and policy levels.

Cross-sectoral funding approaches can be effective in breaking down silos—when money follows the person and is not limited to one sector there is an incentive to work with that person across sectors. Cross-sector funding of the coordinator role was also suggested.

Explicit high level ‘permission’ is important in enabling people and programs to be innovative and to act across sectors. At a meso level, **cross-disciplinary team-based approaches** can be effective in breaking down silos, promoting communication, and building understanding. Multi-disciplinary ‘case conferencing’ can produce a more comprehensive and integrated response to meeting a person’s needs. There was some discussion of the desirability of **organisational restructuring** to break down ‘silos’ and facilitate ‘inter-professional’ education and the formation of interdisciplinary teams.

One participant talked about the effectiveness of cross-disciplinary teams in improving coordination between primary, secondary and tertiary services in mental health. Closing the Gap initiatives were cited as another example where high level policy commitment has enabled valuable cross-cutting work spanning different portfolio areas.

In relation to the barriers to people with disabilities accessing appropriate health services, the use of Key Performance Indicators, linked to pay, for doctors and senior health professionals was suggested. Performance indicators could be used as a means of applying incentives to work cross-sectorally, and making it clear that provision of services for people with disabilities is a core responsibility of administrators in health and other sectors. However, it was noted that performance indicators would need to leave room for discretion within broad parameters, to encourage innovation and creativity in finding cross-sector solutions.

Building an evidence base

There was discussion of the importance of **building in an evaluation framework** up front when a new program is designed, to enable collection of data that can be used to answer questions about costs, effectiveness and outcomes across sectors. There should be a **shared commitment to data collection, using national standards** where available, to enable consistency, comparability and collation at national level and across sectors. Data collected should inform evaluation and adaptation of the model at the macro and meso levels. Pathways analysis was also suggested as a valuable tool for understanding what happens to people on their ‘journey’ across multiple sectors (this is done in Queensland).

It was suggested that a set of **'headline indicators'** (similar to the Closing the Gap indicators) could be used to keep agencies and administrators focused on the goals of cross-sector coordination, and as a way of communicating with the community at large.

The NDIS is not yet collecting information on what mainstream services people with high and complex needs are accessing. **Inclusion of a 'disability flag' in administrative data** collections across sectors (e.g., health, education, housing) would be one means of gathering this kind of information; there is a national data standard for such a flag.

Moving towards implementation of cross-sector service coordination for the NDIS

The point was made that cost quantification is needed for investment in cross-sector service coordination to go forward. For the NDIS, being able to see the cost-benefit is important; service quality is also key. There needs to be a focus on evaluating costs and demonstrating benefits (including savings), improved whole of life outcomes for scheme participants and achievement of the scheme's social and economic goals for participants.

In the context of the NDIS roll-out there is an opportunity to trial and evaluate different models of cross-sector service coordination in different sites, varying model components and comparing measures of effectiveness, cost-benefits and outcomes for people. This would help to strengthen the evidence base for service coordination, including cost quantification.

It was suggested that Medicare Locals, soon to become 'primary health care networks', could be explored as a first point of cross-sector coordination for the NDIS. The Partners in Recovery program (which provides coordinated support and flexible funding for people with severe and persistent mental illness and complex needs) is provided through Medicare Locals in NSW; this model may provide some relevant learnings.

One participant noted that there are models of cross-sector collaboration operating in other countries that would be useful to look at in developing a model for Australia. For example, Germany and Austria have systems that are somewhat similar to Australia's—they have insurance-based models in place, and approaches to delivering integrated care are developed at local level.

The NDIA is currently looking at purchasing case management, or 'complex care management', for clients with complex needs in trial sites. As a first step it is necessary to describe the activities that these managers would undertake and the parameters within which they would operate, so as to be clear about what is being purchased and how performance should be measured.

Whatever model of cross-sector service coordination is adopted, the point was made that it must be embedded in systems and not just around the individual, and have the flexibility to evolve and adapt to accommodate change in neighbouring systems. There should also be scope for the model to be tailored to needs and circumstances at a local level—providing mechanisms that facilitate local communities to develop their own solutions.

5. Synthesis of the evidence

In this section we draw together the evidence from the previous two sections, and outline key findings which signal the way forward for cross-sector service coordination for people with high and complex needs in the context of the NDIS. Our focus in this section is on the findings for which there is adequate evidence to inform action. The consistent use of our 'organising matrix' (Figure 1) throughout Sections 2, 3 and 4 is designed to enable readers to look back and find the relevant evidence on which this section relies. For convenience, the abbreviations for the Australian programs reviewed in section 2 are used again here.⁴

The evidence on outcomes is our starting point (Section 5.1), as this provides the rationale for recommending cross-sector service coordination for people with high and complex needs within the NDIS.

An overview of goals is then presented (Section 5.2). Goals at micro, meso and macro levels inform choices about operationalising the various components of cross-sector service coordination, and provide a basis for specifying outcomes against which cross-sector coordination efforts can be judged.

Finally (Section 5.3), we come to the central column of the matrix—essential components of cross sector service coordination at micro (person), meso (service) and macro (system) levels.

The key suggested directions which flow from these findings are discussed in the concluding Section 5.4.

5.1 Outcomes of service coordination

What evidence do we have about outcomes from service coordination, and how they play out for the person, for service providers and for systems?

While the evidence presented in sections 2 and 3 is of varying strength, and relates to a variety of different target groups and service models, there is nevertheless a

⁴ Victorian Continuous Care Pilot (Vic CCP). (MS Australia and Calvary Healthcare Bethlehem, 2009)
NSW Continuous Care Pilot (NSW CCP). (MS Australia, 2010)
Spinal cord injuries response (SCIR), Qld. (Griffith University, 2008)
Spinal Cord Injury Community Participation Project (SCI CPP), NSW. (Motor Accidents Authority of New South Wales, 2007)
Collaborative Care in Motor Neurone Disease in Victoria (CC MND). (Calvary Health Care Bethlehem, 2009)
ABI Slow to Recover Program, Victoria (ABI STR). (Victorian Department of Human Services, 2004)
Neurodegenerative Conditions Coordinated Care Program, WA (NCCCP). (Bahn & Giles 2012)
Better Pathways Pilot Project, SA (BP). (Warren, 2012)
Multiple and Complex Needs Initiative, Victoria (MACNI). (KPMG, 2007)
Economic benefits of coordinated service delivery for YPINH. (ACIL Tasman, 2013)
Disability care at Western Health, Victoria. (Thompson, 2011)
Hospital Admission Risk Program (HARP). (Victorian Government Department of Human Services, 2006).

weight of evidence that points to the value of cross-sector service coordination for people and for systems.

Micro

Evidence from Australian experience indicates that, for the person, coordination can promote better access to appropriate services (e.g., Vic CCP, NSW CPP, SCIR, SCI CPP, ABI STR, NCCCP, BP, MACNI). It can enable previously unmet needs to be met (including supports for family and carers, thus potentially contributing to the sustainability of informal caring arrangements), better continuity of service provision and increased certainty about accessing services and supports into the future (e.g., BP, Vic CCP and NSW CCP). Other reported benefits include: reduced waiting times, giving the person a better understanding of services available, and increasing choice of services accessed (e.g., SCIR, Vic CCP and NSW CCP). People's communications and relationships with service providers can be improved (e.g., NCCCP, NSW CCP). People can also be empowered to be more 'in control' and have their views heard (NSW CCP).

Individual advocacy provided by a cross-sector coordinator to assist people to access services can be very beneficial in reducing the burden on individuals and families 'fighting to fill the gaps', and can improve equitability of outcomes for people who are less able to self-advocate (SCIR). This was a point emphasised by participants at the provider workshop—under current arrangements, outcomes are often notably better for people who have self-advocacy skills or a devoted advocate; cross-sector service coordination can assist in ensuring equally good outcomes for those less able to advocate for themselves.

Health and wellbeing outcomes can include higher measured quality of life, life satisfaction, and self-efficacy (e.g., SCIR, NSW CCP, SCI CPP); reduced stress and fatigue (NSW CCP), higher levels of community participation (including workforce participation) (e.g., SCIR, SCI CPP), better social outcomes (e.g., families remaining intact—SCIR), reduced time in hospital (declines in readmission rates and/or length of stay) (e.g., SCI CPP, SCIR, MACNI), and ability to remain living in the community (Vic CCP, NSW CCP, ABI STR).

A recent international systematic review of comprehensive care programs for people with multiple chronic conditions (all but one program being for 'frail aged' people) found mixed results (De Bruin et al., 2012). Program heterogeneity and a lack of methodological rigour made firm conclusions about the benefits of these programs difficult to reach. However, other evidence from the international literature indicates that coordinated services can lead to significant improvements in satisfaction with: self-directed care and health support (Palsbo & Ho, 2007); health system and physician (Noel et al., 2005; Palsbo & Ho, 2007); health and wellbeing (Sampalli et al., 2012); and quality of life (Palsbo et al., 2006). Palsbo and Ho (2007)

argued that a reduced need for rehabilitation was attributable to the improved primary health care provision that service coordination facilitated.

Meso

Service providers involved in cross-sector service coordination programs considered that they were better able to meet people's needs, and that this was facilitated by a better understanding of needs and of the local service system (including across sectors such as health and disability), and a better ability to link with services that could meet these needs (e.g., Vic CCP, NSW CCP, BP, SCIR, MACNI).

Information sharing and appropriate training or skilling enabled this more informed approach. Several of the Australian programs reviewed reported improvements in communication and information sharing between professionals, but also suggested the need for further strengthening communication structures and processes—both horizontally between services and sectors, and vertically between strategic and operational levels in service systems (e.g., Disability Care at Western Health, SCIR, MACNI). Improved communication processes that fostered resource, information and skills sharing among service providers were key to creating a common understanding of goals, roles and decision-making (Dobell & Newcomer, 2008; Goodwin et al., 2013; Mastal et al., 2007; McConnell, 2006; Van Raak & Paulus, 2008). Mechanisms that optimise communication include common information systems to enable assessment and care planning data to be shared (Mastal et al., 2007; Meyer, 2011; Palsbo & Kailes., 2006; Palsbo et al., 2006), designated points of contact within different organisations (e.g., BP, Disability Care at Western Health), and co-located, multidisciplinary teams (Dobell & Newcomer, 2008; Master & Eng, 2001, Master et al., 2007; Surpin, 2007; NSW CCP, SCIR). However, other evidence suggests that co-location as a strategy to achieve collaboration is insufficient without the necessary management imprimatur and skill development (O'Flynn et al., 2011). Some evidence suggests that multidisciplinary education can increase professional collaboration (Van Raak & Paulus, 2008).

Cross-sector coordination can achieve a better understanding of the needs of a local population or specific client group, potentially leading to better resource allocation (Goodwin et al., 2013; O'Flynn et al., 2011). 'Place-based' approaches are needed in rural and remote areas to address access barriers such as the lack of timely and appropriate therapy services. Local solutions include coordination of outreach and therapy services, fostering use of emerging technology and training locally-based therapy assistants to deliver therapy interventions (Dew et al., 2013). Nevertheless it was recognised that coordination models, once established, require ongoing review and adjustment to better align need and outcome (Bachman et al., 2008; Goodwin et al., 2013; Master et al, 2007; BP, SCIR, MACNI, NCCCP). According to some authors this included investment in the development of financial accounting to permit large-

scale cost tracking over time (including of cost-shifting) (Bachman et al., 2008; Palsbo & Diao, 2010) and improved monitoring of intervention efficacy (Goodwin et al., 2013; MACNI). Management styles that actively encouraged shared responsibility and high-quality communication could create permission for 'rule-breaking' to overcome perceived program barriers (O'Flynn et al., 2011).

Participants at the provider workshop suggested that an important outcome of effective cross-sector service coordination would be reduced duplication and over-servicing because of better communications between service providers and between sectors. Cross-sector coordination would enable streamlining and more effective use of existing services, including services available in the community. Currently, there is a risk of over-servicing, if generalist disability services are funded for cross-sector coordination but are not best placed to provide it, so that the role is then informally supported or duplicated by specialist organisations. Clarity about the mandate of cross-sector service coordination and location of key functions is required to avoid this risk.

Macro

The positive outcomes identified above for individuals and families translate into outcomes at system level, because a primary goal for service systems is to meet the needs of people. Good outcomes for service users indicate service quality and thus contribute to value for money.

There is evidence that a coordinated cross-sector service response can keep people out of hospital beds (including long-stay) and residential accommodation (e.g., Vic CCP, NSW CCP, SCIR, MACNI, ABI STR, SCI CPP). Dobell and colleagues (2008) found that hospital stays were shorter and that home nursing use was lower for those receiving coordinated support from an integrated care program than for a comparable Medicare managed care or fee-for-service population. Palsbo & Diao (2010) analysed claims data for 245 integrated care program participants with physical disability in the USA and found that, while coordination did not initially change hospital admission rates for high-cost patients, over time it led to a reduction in medical costs associated with reduced length of stay and admission complexity. Annual reductions in medical costs over three years exceeded the additional costs of cross-sectoral coordination. Bachman et al. (2008) found that overall health expenditure was reduced due to decreased hospital inpatient and outpatient costs and that these reductions were most dramatic for high-cost patients. In contrast, de Bruin and colleagues (2012) argue that there is only moderate support for the benefits of comprehensive care programs on inpatient hospital utilisation and healthcare costs. However this systematic review was restricted to studies which employed methods designed to measure statistically valid outcomes and, as such, excluded many studies for which results may have been persuasive, albeit less robust.

In the Australian context, reductions in hospital bed days were reported for participants in the SCIR, NSW CCP, MACNI, and HARP. Evaluations of the Victorian and NSW CCPs and the ABI STR concluded that some participants would have been admitted to residential aged care in the absence of the respective programs. The NSW CCP evaluation estimated that the total cost of the pilot was roughly offset by a reduction in hospitalisation. The SCIR cost analysis also suggested that reduced length of hospitalisation due to the transition support provided by the program could deliver substantial savings.

Cost savings resulting from effective cross-sector coordination often accrue to sectors other than the disability sector (e.g., health, aged care), underlining the need for cross-sectoral or whole-of-government commitment to and investment in service coordination.

The ACIL Tasman cost modelling analysis placed an economic value on additional years lived, and improvements in health and wellbeing with a case study approach comparing coordinated service scenarios with business as usual scenarios. Results indicated that, in 5 of the 8 case studies, cross-sector service coordination would result in net savings to society over the lifetime of the individuals, with an average saving of \$1.36 million per case. While the cost of community-based care was higher than in the business-as-usual scenarios, service coordination resulted in much reduced suffering (an average lifetime disability burden reduction valued at \$0.46 million) and longer lifespan (valued on average at \$1.61 million).

As noted in Section 2, many of the Australian programs emphasised linking people with relevant services in the community and making better use of these existing community services to meet people's needs. In the context of the NDIS, cross-sector service coordination that could achieve this for participants with high and complex needs would reduce the risk that the NDIS will be required to duplicate these services and should logically assist in reducing costs for the scheme.

Recognising that the effectiveness of one service or support is dependent on the other necessary services and supports being in place, attention needs to be given to building a culture of collaboration across sectors for cross sector coordination to work. Any failure of other sectors to provide quality and accessible services risks increasing the costs of disability care, as individuals who fail to have their needs met in other areas are likely to manifest greater needs for disability support. Cross-sector coordination can thus be seen as a way of mitigating this fundamental risk facing the NDIS and as a core element in NDIS design.

5.2 Goals of service coordination

Goals provide guidance to inform the design and delivery of programs and services, and key markers against which outcomes can be evaluated. What statements about the goals of service coordination are made in the literature and reports examined?

To what extent are clear goal statements made, against which services and program outcomes can be evaluated?

Micro

Goals for people and families identified in the Australian programs reviewed included being able to remain living at home and having access to services and supports locally, through providers who have the necessary knowledge and skills. The Victorian CCP evaluation lists the following issues identified as of greatest importance to participants and families:

- Reliability, regularity and dependability of carers and service providers
- Service providers who understand the person's condition
- Housing alterations, and adequate facilities and equipment at home
- A central source of information about what assistance is available (including eligibility) and help with paperwork
- Consistent response to urgent needs
- Communication equipment and support for communication needs
- Confidential psychological support for carers
- Services that can adapt to rapidly changing needs

Key goals for people and families discussed in the consumer and provider workshops were:

- Being able to access necessary services and supports, and
- Having a say in determining the content of a service plan, and choosing the providers to deliver those services

Better access to rehabilitation and other health services was identified as a goal of particular importance for people with acquired disabilities (e.g., ABI, spinal cord injury). More equitable access to services (less dependent on an individual's self-advocacy skills) was also identified as important.

The burden of identifying and gaining access to relevant services was a recurring theme in the Australian reports. Reducing this burden is a major goal for individuals and families. Participants at the provider workshop made the point that people with disabilities do not want to be over-serviced; they just want help to access the services they need to live their lives. International literature also highlights the importance of self-management support to enable people with high and complex needs to gain the skills needed to overcome barriers, set achievable goals and consult with a range of providers on their own behalf (Craig et al 2011; Palsbo & Kailes, 2006).

Meso

At the meso level goals centre on resources, systems and mechanisms that enable service providers to better meet the needs of people with disability. To a large extent, the Australian programs and pilots reviewed aimed to find ways of overcoming or circumventing barriers in the current service system in order to more fully meet people's needs. Specific barriers and service gaps discussed in the reports are listed in section 2.2 and include a 'silo' mentality and fragmentation of the service system, inadequate management of health issues for people with disability (e.g., due to limited knowledge and understanding on the part of providers in the disability system and no clear pathways to enable service integration across the disability and health sectors), service rationing, long waiting times for services and equipment, poor communication between providers, and lack of forward planning and anticipation of future support needs.

Equipping service providers with the resources (e.g., information systems to share data, training) and management imprimatur to effectively target individuals at risk of health deterioration and preventable hospital or institutional care, and then to respond appropriately to their needs were key meso level goals apparent in some of the international literature reviewed (Craig et al., 2011; Master et al. 2003; Meyer, 2011; Palsbo & Kailes, 2006).

Macro

Macro or system-level goals of cross-sector service coordination did not tend to be articulated in the international literature reviewed—most goals related to the person (micro) or were pitched at the service or program level (meso).

This was also true to a large extent for the Australian programs reviewed. However, the following broad macro level goals for cross-sector service coordination can confidently be inferred from the reports:

- Provision of quality services to meet the needs of people with disabilities (being a primary objective of disability service systems).
- Efficient use of resources – reduced duplication and over-servicing, and 'joined up' services across sectors
- Enabling people to remain living in the community for as long as possible, and thus reducing demand for more expensive service responses in the acute care and residential aged care sectors.

The MACNI Initiative identified the development of a regional service framework that ensures a coordinated and collaborative response to individuals with multiple and complex needs as a key objective.

Any future consideration of 'macro' goals should clearly be linked with cross-jurisdictional work being undertaken under the National Disability Strategy, the NDIS

bilateral agreements with the States and Territories and the *National Disability Insurance Scheme Act* (2013). For instance Section 3 (Objects of the Act) and Section 4 (General principles guiding actions under this Act) of the *NDIS Act* set out goals relating to the person, mechanisms such as the provision of ‘reasonable and necessary supports’, and essential ‘macro’ principles such as ensuring ‘the financial sustainability’ of the NDIS and that the appropriate sectors should deliver the services for which they are responsible. Section 3(3)(d) recognises the ‘need for interaction between the provision of mainstream services and the provision of supports under the’ NDIS.

5.3 Key components of a cross-sector service coordination model

Here we set out the key components of cross-sector service coordination at the micro, meso and macro levels, as evidenced in the previous sections of this paper (i.e. the middle column of the organising matrix at Figure 1). We do not describe a single model of service coordination for the NDIS, as there are different ways of operationalising the proposed components.

Micro: cross-sector service coordination support as experienced by the person

Here we outline the key components of cross sector coordination support in terms of the person’s experience, that is, what good coordination support looks and feels like from their perspective.

A single point of contact—a person who provides assistance with navigating the complexities of the service system and who is a source of relevant information (e.g., Vic CCP, NSW CCP, BP, SCI CPP; Palsbo & Kailes 2006; Palsbo et al., 2006). Consumer workshop participants referred to their need for help finding their way around the system and making the system work for them. **Being properly informed** is important for individuals and families, that is, having access to **information that is accurate, practical and honest** (e.g., in relation to what can and cannot be provided).

A relationship of understanding and trust with the coordinator: This includes understanding of the person’s goals and needs, their disability, health condition as well as their environments (e.g., home and work) and responsibilities (e.g., families)—a point emphasised in the provider and policy workshops and in many studies found in the international literature (e.g., Bachman et al., 2008; Master & Eng, 2001, Master et al., 2007; Palsbo et al., 2006; Palsbo & Ho, 2007). Understanding should also relate to people’s individual assets, strengths and gifts (Craig et al., 2011). Empathy is what is needed, as well as respect for the person’s right to set their own priorities (according to the consumer workshops).

Support to exercise choice and control—enabling and empowering the person to play a maximum role in choosing and controlling their supports, **in line with their**

own goals and priorities; this may include capacity building and skill development for the person and their family/carers (Craig et al., 2011; Palsbo et al., 2006). In line with the person-centred planning philosophy, and the philosophy of the *NDIS Act*, the person should be able to exercise choice in terms of engagement with coordination support—that is, whether or not to receive individualised cross-sector service coordination support, and the timing and intensity of support received. As discussed in the previous sections, the need for coordination support and the nature of support needed can vary over time. More support, or support that is more specialised, may be needed at times of transition such as hospital admission or discharge, when needs increase, or when accommodation or service provider changes (Abendroth et al., 2012; Cameron & Gignac, 2008).

Timely access to services and confidence that future needs will be met— anticipating and planning for future needs is essential, so that necessary services and supports are in place when they are required and risks are avoided. This requires regular review of support plans, and timely response at critical transitions (e.g., CCP Vic, CCP NSW, SCIR, CC MND; Surpin, 2007). Plans need to evolve over time and require both short- and long-term planning (as emphasised in consumer and provider workshops).

Service providers with the necessary knowledge and expertise relevant to the person's particular disability and health condition, and the context around their goals, on the part of both the cross-sector coordinator and other service providers, so that the person's needs can be appropriately met. Consumer feedback suggested that there needs to be a recognition that a person's needs do not relate to only disability but can be affected by age, culture, and family situation. Behaviour can affect access to and costs of services (e.g., for people with brain injury: NSW report on accommodation needs after TBI). An experienced consumer advocate suggested that behaviour was a form of communication in response to a situation, and that analysis by an experienced provider is required to avoid escalating distress and putting people in 'awful situations'. Giving people freedoms to choose in their everyday lives and enabling them to be heard effectively can have a significant effect on outcomes (including behaviours).

Consistent information provided to service providers—that is, service providers having the information they need, including relevant information about other services the person is receiving, and the person does not have to provide the same information repeatedly to different service providers (suggested in the workshops and also reflected in research findings about the value of shared information at meso level (e.g., NSW CCP, MACNI; Mastal et al., 2007; Meyer, 2011; Palsbo & Kailes., 2006; Palsbo et al., 2006). Choice is needed; people need control over the 'story' told about them when service providers share information and may prefer to

explain their situation themselves to a new service provider. Ethical and privacy guidelines are required to enable information sharing across services.

Meso: the cross-sector service coordination function

The key components of service coordination are embodied in the ***cross sector service coordination role*** at the meso level, and include:

- **Advocating to enable a person to access services and supports**, to meet their needs and achieve their goals, including access to mainstream services (e.g., BP, MACNI, Vic CCP, NSW CCP, SCI CPP) across systems. This may require the cross-sector coordinator to take on the role of **'systems wrangler'**, to **overcome system blockages and negotiate access**. This role is ongoing, and distinct from planning (either in a general sense or in reference to the process by which NDIA decides on a package of supports for a person). The coordinator (or 'wrangler') must have a 'can do' approach and seek to make the system work as it is, despite apparent barriers; they should also be ready to devise innovative ways of making the system work more effectively to benefit the individual.
- **Using and having access to a 'contingency fund' to use strategically to broker solutions where a person's needs cannot otherwise be met**. Sometimes bridging or temporary funding may be needed to extricate the person from a negative situation. Several of the Australian programs reviewed used a brokerage funds to help achieve better outcomes, as an 'interim' means of accessing items and services not funded by other agencies (SCI CPP), enabling coordinators to try creative and innovative approaches (MACNI), or responding to urgent needs that could not otherwise be met (Vic and NSW CCP). There is no 'magic bullet' to solve all issues of program silos (according to the policy workshop); individual systems blockages need to be dealt with as they arise, e.g., hospital bed blocking was reported in workshops to be affected in one state by the decisions of a home modifications committee in the disability portfolio that meets quarterly.
- **Providing a single point of linkage—liaising within and across systems** to establish links and facilitate collaboration, communication and **information sharing** between different service providers (e.g., NSW CCP, Vic CCP, SCIR, SCI CPP, BP, MACNI). The coordinator should have an active role in **developing and maintaining cross sector networks** (e.g., MACNI). This is a system capacity building function: bringing services and systems into more effective working relationships with each other, ensuring ongoing access to and links between skilled professionals, overcoming barriers, and promoting shared information (Dobell & Newcomer, 2008; Powell Davies et al., 2006). Consumer workshop participants believed that cross-sector coordinators need to have a mandate to coordinate across different sectors.
- **Respecting and enabling the person** and their family, including coaching and education (Palsbo & Kailes, 2006); encouraging 'high expectations' of people's

possibilities and competence; and, from consumer workshops, an ability to listen, analyse a situation and respond to people's needs (e.g., Vic CCP, NSW CCP, BP). As discussed in the consumer and provider workshops, this function should include supporting the person in system navigation and in self advocacy, and in discussion and preparation for planning with the NDIA. **People, families and their community supports should be seen as partners** (Dobell & Newcomer, 2008; Goodwin et al., 2013). Cross sector coordination needs to be capable of moving toward self-management for people for whom this is possible (rather than creating dependency) (Palsbo et al., 2006).

- **Supporting the implementation and monitoring of a support plan** (e.g., Vic and NSW CPP, BP, SCI CPP, ABI STR, SCIR, CC MND, MACNI), including
 - a. **Facilitating choice of providers**, disability and mainstream (emphasised in the consumer and provider workshops). (Including choice of the organisation assisting with budget/financial management or employment of personal care assistance)
 - b. **Contingency and forward thinking**, anticipating future needs, and timely responses to transitions. This would include an active role in **monitoring and reviewing the person's needs** (including anticipating future needs) and facilitating necessary adjustments to services and supports.
- **Advising on service provider education and training needs**, to ensure that providers are able to adequately meet the needs of the person (e.g., Vic CCP, ABI STR, MACNI). The cross-sector coordinator may work directly with the service provider and the individual with disability, their families and carers to ensure education and training happens in situ and as needed. Cross sector coordinators can also play a role in ensuring service providers understand the need for ongoing training.

The **skills and qualities** necessary in order to carry out the coordinator role include:

- **Knowledge and understanding of the person** with high and complex needs, including their disability, health condition, their goal, needs, and rights (e.g., Vic CCP, NSW CCP, BP; Kroll & Neril, 2003; Palsbo & Ho; Palsbo & Kailes, 2006, Palsbo et al., 2006 ; Sampalli et al., 2012).
- A focus on quality outcomes for the person; the coordinator should be someone with a **'can do' mentality** (O'Flynn et al., 2011), who is able to 'work around system blockages' to find a solution for the person.
- **Able to build trust and relationships with people** with disability and their families and carers (e.g., Vic and NSW CCP). Coordinators need empathy to reassure the person that they understand their goals and needs (as emphasised in the consumer workshops).
- **A thorough working knowledge and understanding of relevant service systems**, including an ability to distinguish 'real' and 'perceived' system blockages (as

discussed in the policy workshop). Sometimes there are in fact no barriers at macro level; rather, blocks may be created at meso level to manage demand. Limited resources and ‘gate keeping’ practices contribute to perpetuating these barriers (according to policy workshop discussions). There may be myths about what is and is not possible; there are both real and perceived resource issues. Cross sector coordinators need to be able to communicate what policies, programs and resources are actually really are in place - for instance, to correct a reported misapprehension in the health sector that health services for people with disabilities are provided within the disability sector (workshop participants).

- **Liaison skills.** Being able to **build collaboration** and foster partnerships, engage services through developing relationships in and across programs and sectors, and resolve issues through discussion and negotiation (MACNI; O’Flynn et al., 2011; also emphasised in provider and policy workshops).

Structures, processes and mechanisms that may facilitate and enable this role and promote integration of services within and across sectors include:

- **Communication and information sharing mechanisms** (Goodwin et al., 2013; Mastal et al., 2007; Meyer, 2011; McConnell, 2006; Palsbo & Kailles., 2006; Palsbo et al., 2006). The Clinical Advisory Groups (Vic and NSW CCPs), Better Pathways Interagency Panel, and the MACNI Regional Panels are examples of structures that facilitate communication and information sharing among stakeholders across sectors, concerning the service needs of individuals and cross-sector coordination issues more generally.
- **Formal cross-sector arrangements that enable the coordinator to secure access to services for the person** (Goodwin et al., 2013; O’Flynn et al., 2011). The SCIR program is a good example of this, based on a formal partnership between health, housing and disability departments that assisted in securing access to necessary services and supports for program participants; Better Pathways and the MACNI are also examples of programs underpinned by formal, higher level cross-sector arrangements.
- **Points of contact in relevant sectors**—cross sector coordinators need to be established in all sectors to **facilitate linkage between disability and mainstream services** (Bridge et al., 2002; Ehrlich et al., 2009). The school key contacts in the Better Pathways program illustrate how this could work; ‘key contacts’ to link between disability and health sectors were also a feature of the model proposed in Disability Care at Western Health. In the policy workshop it was suggested that Medicare Locals, soon to become ‘primary health care networks’, could provide a good linkage point for the NDIS, as could NDIA Local Area Coordinators (LACs). Partners in Recovery (from mental health) may provide a useful model.
- **Mechanisms for training and skilling service providers in different organisations and sectors** (e.g., peer education; in-reach and out-reach tools) (Oeseburg et al.,

2004; Van Raak & Paulus, 2008). The importance of the coordinator's role in providing specialist peer support and secondary consultation advice for health and community care service providers was emphasised in the Victorian CCP. Peer education was suggested in the ABI STR evaluation as a means of increasing skill levels of therapists in rural areas. In-reach and outreach strategies across services and sectors can also be valuable (e.g., SCIR and Disability Care at Western Health). Strategies to support ongoing training for professionals involved in cross-sector service coordination are likely to be needed, in the context both of staff turnover within agencies and the changing needs of individuals with disability.

- **Mechanisms to ensure access to expertise.** Advisory groups and panels with specialist membership from relevant services and sectors can provide a central and 'joined up' source of expertise to support cross-sectoral service coordination (e.g., Vic CCP, NSW CCP, CC MND, BP). Interdisciplinary teams are another effective mechanism (e.g., SCIR). Support for the development of cross-disciplinary professional networks can also facilitate this (e.g., MACNI).

Macro: service coordination at system level

High level commitment and agreed infrastructure are vital to success, particularly according to policy workshop participants. The key macro components of cross-sector service coordination at the system level (macro) include:

- a) **Cross-sectoral formal commitment to service coordination.** High level leadership and support within relevant sectors is important—mandates and formalised processes can provide impetus for the necessary communications and collaborative processes at lower organizational levels (e.g., SCIR, MACNI, BP; Goodwin et al., 2011; Mur-Veerman et al., 2003; Powell Davies et al., 2006; this point was also emphasised at the policy workshop. Cross-sectoral collaboration is essential to person-centred human services delivery. In Australia there are already solid agreements and legislation (e.g., National Disability Strategy, *NDIS Act*, UN Convention on the Rights of Persons with Disabilities), with supporting committee structures, to provide the core reference points and standards, as a high-level basis for communication and coordination. Cross-sectoral funding arrangements can be a powerful means of getting all players 'on board' (e.g., SCIR, ACIL Tasman model; Ehrlich et al., 2009; Goodwin et al., 2013; Mur-Veerman et al., 2003; O'Flynn et al., 2011; Powell Davis et al., 2006).
- b) Cross-sectoral commitment should be accompanied by **shared accountability supported by structures and mechanisms** both macro and meso levels. As discussed in the policy workshop, shared vision and accountability have been an effective mechanism for Indigenous programs established under the Closing the Gap initiatives, where, for instance, high level and agreed indicators are used to gauge progress and performance, and to communicate outcomes to the

community at large (see also research evidence, O’Flynn et al., 2011).). The draft baseline outcome indicators for the National Disability Strategy implementation in NSW provide another interesting example of cross-sectoral responsibility and accountability (NSW Government, 2014). Key Performance Indicators (KPIs) for professionals and administrators in other sectors can be used as a means of supplying incentives to work cross-sectorally, and making it clear that provision of services for people with disabilities is a core responsibility. Clarity is needed, with respect to where responsibility lies, channels of accountability, and the roles of different stakeholders and structures (e.g., NSW CCP, ABI STR, MACNI).

- c) As well as accountability, the point was made in several of the program reports and at the provider and policy workshops that flexibility is also critical. As emphasised at the policy workshop, there needs to be **high level ‘permission’ to encourage flexibility at meso level to overcome system blockages**. Any model of cross-sector service coordination must itself have the flexibility to evolve and adapt to accommodate system change (e.g., MACNI), and to be tailored to needs and circumstances at a local level. This is also supported by research evidence about the need for organisations to be given the authority to develop localised solutions (Goodwin et al., 2013; O’Flynn et al., 2011).
- d) **Funding coordination across systems**. There needs to be funding of cross-sectoral coordination at meso and macro levels. As discussed at the provider and policy workshops, cross-sectoral funding approaches can be effective in breaking down silos, and a dedicated budget to fund cross-sectoral efforts to improve service coordination can work well (e.g., SCIR). The business case to support funding of cross-sector coordination would include likely cost savings at whole-of-government level (as discussed above), but must also include outcomes for the individuals the systems are intended to serve and broader social investment returns (ACIL Tasman, 2013; Bachman et al., 2008; Palsbo & Diao, 2010). Resourcing should include provision of **linking or focal points in sectors such as health, housing and education** (as described in ‘meso’, above) to facilitate linkage between disability and mainstream services. Regional differences would require consideration; for instance, locally based solutions, such as the use of tele-health methods and intervention software applications, can make more supports and services available to people in rural or remote areas.
- e) **Building cross-sectoral understanding**. As discussed at the policy workshop, language can be a barrier to communication between sectors (Ovretveit et al., 2010; van Raak & Paulus, 2008). Language may be a barrier in terms of comparing existing evidence about cross-sector coordination (as noted in section 3, literature search terms used can affect what evidence is captured). Terms such as ‘coordination’ and ‘case management’ can be ‘read’ differently by different groups and in different settings; definitions of disability may influence how service providers respond to individuals. The importance of communication,

building understanding and common language is recognised in the literature (Mastal et al., 2007; Master & Eng, 2001; Meyer, 2011; Oeseburg et al., 2004). Agreeing on key terminology is important, as are strategies to help build understanding across sectors, and purposive communication between key stakeholders (e.g., regular face-to-face meetings). At the policy workshop cross-sector coordination teams which can move between sectors were suggested as a possible means of promoting communication and understanding across sectors; this approach has been used successfully to improve coordination between primary, secondary and tertiary services in mental health.

- f) **Workforce training and skilling to work collaboratively across sectors** and develop coordination expertise (O’Flynn et al., 2011; Van Raak & Paulus, 2008). Specific training needs may be identified for professionals working in different sectors. For example, as discussed in the policy workshop, professionals in the health sector may lack the skills to understand the needs of people with disabilities. Likewise people in the disability sector may lack expertise about the health-related needs of people with disabilities and the workings of the health system (CC MND, Disability Care at Western Health).
- g) **Systems for shared data and information** are needed to **build an evidence base** for cross-sector service coordination and to underpin quality improvement. Sharing and use of information and data across systems can streamline action and improve continuity of care (Palsbo & Diao, 2010; Palsbo & Kailes., 2006; Palsbo & Ho, 2007; Palsbo et al., 2006). The policy workshop discussed the importance of building in an evaluation framework up front, to enable collection of data that can be used to answer questions about costs, effectiveness and beneficial outcomes for people across sectors. There should be a shared commitment to data collection, using national standards where available, to enable consistency and collation. The use of a ‘disability flag’ (a national standard for which is available) in data collections across sectors (e.g., health, education, housing) would enable monitoring of access to mainstream services by people with disability. Shared tools and IT solutions were suggested by workshops as a cost effective strategy and one which could also promote shared language.

5.4 Conclusion and defining ‘cross-sector service coordination’

The findings from the literature (Australian and international) and the workshops have combined to build a strong and consistent picture of a desirable design element for the NDIS and for the human services system more broadly.

The evidence-based key components of cross-sector service coordination, described in this section at micro, meso and macro levels, provide a resource and reference points for NDIS design and policy development.

The research in total enables us to put forward a definition of service coordination reflecting this assembled evidence:

Cross-sector service coordination is a key element of NDIS design, requiring funding, and involving:

- high level inter-sectoral collaborative agreements and related infrastructure (macro level) so that system barriers do not undermine NDIS aims
- coordinators actively negotiating between sectors and services to ensure people obtain the necessary supports: a range of local and cross-sectoral mechanisms enable coordination activities
- agreed goals focussed on outcomes for people, including social and economic participation.

6. Discussion and key directions

The preceding sections of this paper demonstrate agreement in the literature and in expert experience in Australia, that:

1. Cross-sector service coordination is of value. Indeed, in the current Australian context, cross-sector service coordination is needed. Personal outcomes are positively influenced and system efficiencies can be gained.
2. The key components of effective service coordination can be identified at macro, meso and micro levels; vertical and horizontal integration are required. Models of effective cross-sector service coordination can be built based on these components.

What is also apparent is that, despite promising pilots and a patchwork of positive experience, no long-term service coordination model has been adequately designed and sustained to realise the long term benefits to people and systems that appear possible from this research.

Participants in the NDIS will purchase services and supports from a range of different providers, while also having the right to all 'mainstream' services including health, education, housing, employment and transport. The complexity of service systems, and the interfaces between major systems, can create gaps that are complex for participants and providers alike to navigate. People with high and complex needs and requiring a complex array of supports may experience particular difficulty and vulnerability in the presence of gaps and barriers in service systems.

Cross-sector coordination to overcome potential problems is critical to ensuring that NDIS participants get the range of services and supports they need to participate in society and the economy, and that the NDIS remains sustainable. Moreover some of the benefits from coordinated service responses accrue to other programs (e.g., health) and not necessarily to the NDIS in a financial sense. Benefits to the NDIS may however accrue in terms of helping the scheme deliver on its economic and social objectives to offer improved health, wellbeing and social outcomes to scheme participants.

This section builds on the evidence drawn together in Section 5, by drawing out some major themes and concluding with five proposals to take this work forward.

6.1 The main themes emerging

High-level cross-sectoral commitment and agreement are essential. This is in line with Section 3(3)(d) of the NDIS Act, which stipulates that regard is to be had to:

‘the provision of services by other agencies, Departments or organisations and the need for interaction between the provision of mainstream services and the provision of supports under the National Disability Insurance Scheme’.

Ensuring people have access to the services they are entitled to in (say) the health sector ensures that costs are met by the right sector, avoids cost shifting or perverse incentives, and, according to the literature, can save costs across government including within the health sector (e.g., by avoiding readmissions and getting people out of hospital sooner). Disability services reform is not enough on its own. The National Disability Strategy recognises this by having six areas for policy action, of which ‘personal and community support’ (now the NDIS) represents just one. Any failure of other sectors to provide quality and accessible services will increase the costs of disability care. Cross-sector coordination can thus be seen as a way of addressing this fundamental risk facing the NDIS and as a core element in NDIS design.

Designated linkage points would streamline cross-sector coordination across systems e.g., health and disability. These could be the equivalent of Local Area Coordinators in the disability system including those now in the NDIA—they could be existing staff with extensive regional knowledge. If the DSO model (of the Productivity Commission—see Section 1) is used as a model, agencies undertaking cross-sector coordination would need to separate this role clearly from any other roles they may have e.g., relating to service provision.

Vertical as well as horizontal integration are required—as well as cross-sectoral commitment at a high level, and linkages at service level, consistency of approach at macro, meso and micro levels is required. Enabling infrastructure, as outlined in Section 5, is needed to make this happen. To reap the full potential benefits of cross-sector coordination a comprehensive approach involving action at all 3 levels is required. A common design limitation identified in the Australian and international literature is that the projects were not vertically integrated.

For people with high and complex needs, there is typically **interdependency between the necessary services and supports** (e.g., disability supports, specialist rehabilitation, equipment, accommodation, health and education). All must come together in order for people’s goals to be realised, outcomes enhanced and for the overall return on investment to be maximised. The absence of one key element can mean that the resources outlaid on other services are wasted, undermining the investment made across sectors. As stated succinctly by a participant in the SCIR evaluation: ‘what’s the point of having housing if you haven’t got personal care?’

Workforce development including skill development is crucial. Both the literature and workshop participants emphasised that employing the ‘right people’ and skilling up all people involved in coordination are both essential. These are the key means to ensure that the cross-sector service coordination role can be carried out fully and effectively. Any national workforce strategy should include the need for

development of the workforce to undertake or collaborate with cross-sector coordination efforts.

The workforce in related sectors (e.g., health) needs to be more literate about disability and the disability sector, and about their responsibilities to people with disability.

A decision would be needed about the **key terminology of cross-sector coordination** and who **coordination is for**. Cross-sector service coordination, case management and a host of other related terms appear in the literature and the Australian services system. They are ‘read’ differently by different groups and in different settings; for instance, to some ‘case management’ may sound as if the person is a ‘case’ to be ‘managed’ rather than a person for whom services and systems need better coordination. These terms nevertheless have many of the same features and components and represent services and professionals with similar goals and the same respect for people with disability. Equally there is the question of who are the people with ‘high and complex needs’ for whom services need to be coordinated? There is some discussion of what is meant by ‘high and complex needs’ in Section 1, and decisions on these terms could affect the numbers significantly. Is this a service for a relatively small group of people with unusually high and complex needs—at risk (say) of ongoing institutionalisation, or of being left ‘stranded’ in unacceptable conditions and without access to essential services from another sector (e.g., health, justice). The group defined in Section 1 are a minority of people, whose life situations would be unacceptable without suitable (even if high cost) supports, careful integration and cross-sector collaboration. More generally it is important to recognise the potential for **language to be a barrier to cross-sector coordination** – certainly the view of the policy workshop. Discussions of this broad subject and the relevant literature are themselves complex. There are varying terms for service coordination, sometimes with only subtle differences in meaning. Different systems and disciplines use their own language to describe people’s needs.

The **key components of service cross-sector coordination outlined in this section can inform the design of coordination options for testing and evaluation**. Specific funding would be needed to support the ‘meso’ coordination role(s) outlined here. There is a range of different models which the literature describes and evaluates. Workshop participants considered that selecting just one—a ‘one-size fits all’ service coordination model—will not be adequate. What is required is not a single model but an understanding of the key reasons for and components of service coordination, and the ability to design and refine purpose-built cross-sector coordination options, relevant to location, current structures, and needs.

Coordination options should allow choice about the ‘home’ of cross-sector coordination (e.g., related to health condition, or geographic area etc.) and who

provides the coordination (e.g., a DSO-like organisation—see Section 1) or an existing body with a strong cross-sector coordination track record. Diversity needs to be considered here—e.g., existing organisations might have specific expertise in intersectoral coordination relating to: Indigenous disability, cultural diversity; specific health conditions, e.g., Motor Neurone Disease or Spinal Cord Injury.

Commitment to cross-sector coordination is especially important while the NDIS evolves, so that coordination design responds to the imperatives of interface development, service sector development and the goals of participants.

Implementation of cross-sector service coordination in this context may take time or, rather, require **experiment and ongoing review and adjustment**. In the launch or trial sites for the NDIS different options could be developed, offered and evaluated.

Evaluation of service coordination options should be built in to the trialling of new models. Too often the literature reviewed was inconclusive, in terms of inadequate service specification, absence of goals or poor research design including inadequate measurement of outcomes related to goals. In the following section we propose the design and trialling of three different service coordination models (designed to suit particular locations, or populations or current service structures). These are not the only models that could be trialled but are suggested as a starting point. We suggest a quasi-experimental design enabling comparisons and evaluation of the models and involving before- and after-coordination comparisons, and comparisons of experience in NDIS trial sites with that in comparable locations outside trial sites.

6.2 Conclusion and proposed next steps

This paper is about the needs of some people to access supports and services from multiple programs in the human services system, and the benefits that can be achieved by a connecting and problem-solving cross-sector coordinated service response:

- Improving quality of life across a range of parameters , focused directly on the individual's goals
- Assisting individuals to build and maintain family, community and employment connections
- Ensuring the NDIS' fiscal viability and sustainability by collaborating with other programs (health, aged care, education, employment, housing, justice etc.) to deliver the various supports and services they separately and collectively offer and for which they are responsible.
- Supporting the needed evolution and the building of capacity of relevant human services away from their present siloed configuration.

Based on this research, no single cross-sector service coordination model is proposed for the NDIS, but rather, the development and testing of possible models,

each capable of providing the key components of cross-sector service coordination, but with varying locations and anchor points which may suit different NDIS trial sites, or as part of jurisdictional preparation for the NDIS (e.g., according to services or linkage structures already there) or participant groups (e.g., in a local area, an Indigenous community, or a group based on a shared health condition).

This paper proposes that NDIA:

1. Include **cross-sector service coordination** as defined in this paper as an element of NDIS design.
2. Seek high level agreement with other sectors to work in partnership to design, trial and evaluate models of service coordination to improve outcomes for people and systems.
3. Work with other sectors to **design and fund three potential models of cross-sector coordination and a method of trialling and evaluating them during NDIS rollout.**
 - a. Use the information summarised in Section 5 (and the study's matrix framework) to specify and design models in terms of *goals* and *service coordination components* at each of *micro, meso and macro levels*; this should include a trial in an Indigenous community. In particular, draw on this discussion paper to ensure the inclusion of evidence-based components for these models.
 - b. Involve skilled coordinators with the necessary capability to undertake the cross-sector coordination roles as defined and outlined in this paper.
 - c. Include strong participation of consumers and families in the design of the models to be trialled.
4. **Test the achievement of the specified goals at each level** (micro, meso, macro) using the suggested design for the evaluation of these models (in Section 6), examining before/after effects, as well as comparisons among different models and between NDIS trial sites and other locations.
5. In the event of positive evaluation findings, **work to achieve long-term intersectoral agreement and funding of ongoing cross-sector service coordination for people with high and complex needs.**

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Appendix Table A1. Brief summary of reports reviewed in Section 2, Australian experience

Report	Target group	Model	Outcomes and costs
<p>Victorian Continuous Care Pilot (Vic CCP) Final report and evaluation report, 2009 (MS Australia and Calvary Healthcare Bethlehem, 2009)</p>	<p>People aged under 50 with a progressive neurological condition. Pilot conducted from 2008–2009 as part of the Victorian Young People in Residential Aged Care initiative (2006-11). Service coordination was provided to 19 people aged from 33 to 49 years.</p>	<p><u>Key features:</u> Holistic assessment using ‘biographical’ approach; Risk identification and management; CCP coordinator with expertise in progressive neurological conditions; Expert Clinical Advisory Group (CAG); Service Continuity Protocols (agreements with service provider agencies); Training for service provider agencies; Limited brokerage fund to directly purchase non-recurrent services or resources when no other response was available to meet an urgent, identified risk.</p>	<p>Descriptive information from interviews on outcomes for participants and program design and implementation outcomes.</p> <p>Beneficial outcomes for participants included accessing additional or more appropriate services, resolving equipment issues, establishing respite arrangements.</p> <p>CCP assessed to have prevented inappropriate admission to RAC for between 2 and 5 participants.</p>

Report	Target group	Model	Outcomes and costs
<p>NSW Continuous Care Pilot (NSW CCP)</p> <p>Evaluation report 2010 (MS Australia, 2010)</p>	<p>People aged under 50 with a progressive neurological condition at risk of inappropriate entry into residential aged care.</p> <p>Pilot conducted from 2008–2009 as part of the NSW Young People in Residential Aged Care initiative (2006-11). Service coordination was provided to 20 people.</p>	<p>CCP aimed to provide: pro-active disease management and clinical support; referral to services; and provision of equipment and non-recurrent services through brokerage.</p> <p><u>Key features:</u> Coordinator to work with case managers to ensure continuity of care; Expert Clinical Advisory Group (CAG); Brokerage fund to purchase non-recurrent services and/or equipment to mitigate a present risk of disability exacerbation where no other service response available.</p>	<p>Descriptive outcome data (from surveys and interviews with participants and stakeholders)</p> <p>Positive outcomes for clients: reduced hospital admissions; no admissions to RAC; better access to health and disability services.</p> <p>Cost of the pilot was \$160,740, which was roughly offset by a reduction in hospitalisation (\$158,850) when the equivalised annual number of hospital days was compared before and during the pilot.</p>

Report	Target group	Model	Outcomes and costs
<p>Spinal cord injuries response (SCIR), Qld. Evaluation report 2008. (Griffith University, 2008)</p>	<p>People with SCI transitioning from the Spinal Injuries Unit (SIU) to the community Program initiated 2005–06; ongoing. 80 clients had been assisted at time of review.</p>	<p><u>Key features:</u> Spinal Injuries Unit referral to Disability Services Queensland; Needs assessment (in collaboration with other service providers); ‘Key worker’ who is part of the person’s multi-disciplinary team; Resource and transition planning (involving individual /family, multi-disciplinary team, any advocates, community agencies and informal networks and service providers); Implementation of services and supports and review (again involving multiple parties).</p>	<p>Structured participant interviews (including validated outcome measures); interviews with key informants; focus groups for staff members; network analysis to investigate linkages and collaboration between partner organisations.</p> <p>21 SCIR participants compared with 15 ‘controls’— higher quality of life for SCIR clients immediately post-transition. Hospital length of stay reduced for SCIR clients with paraplegia but not quadriplegia</p> <p>Cost analysis suggested SCIR had the potential to deliver cost savings due to shorter hospital stays for people with paraplegia</p>

Report	Target group	Model	Outcomes and costs
<p>Spinal Cord Injury Community Participation Project (SCI CPP), NSW.</p> <p>Two year (2007) and five year (2010) evaluation reports.</p> <p>(Motor Accidents Authority of New South Wales, 2007)</p>	<p>people with traumatic spinal cord injury aged 16–65</p> <p>Pilot initiated 2004/05</p>	<p><u>Key features:</u> Development of community participation plan; Assistance with accessing and coordinating service and equipment to achieve the plan; Coordinator who provided client and family support, systemic liaison and advocacy, and goal development and lifetime planning; Access to funds for purchase of interim services and/or equipment.</p>	<p>Outcomes for participants (n=31) compared with control group (n=27); range of outcome measurement tools used and data statistically analysed; hospital readmission rates.</p> <p>Results suggested better community participation and self efficacy and lower rates of hospitalisation for CPP clients. At least one client would likely not have been able to return to community living in absence of the program.</p>

Report	Target group	Model	Outcomes and costs
<p>Collaborative Care in Motor Neurone Disease in Victoria (CC MND)</p> <p>2009 report reviewing evidence and proposing an improved collaborative care model for people with MND</p> <p>(Calvary Health Care Bethlehem, 2009)</p>	<p>People with motor neurone disease</p> <p>Proposed model has been implemented by MND Victoria as the Regional Advisor Service</p>	<p><u>Key features:</u> Single point of access for referrals (provided by MND Vic); Choice whether to join the program; Key care coordinator in the person's region (help with completion of applications for care packages, coordination of services, anticipation of future needs, etc.); Regional MND service team (specialist clinic, partnerships with local providers); 'The Hub' (specialist services, develop evidence-based protocols, etc.); Outreach tools (telehealth service, e-health record, teleconferencing, communication/coordination strategy, education for staff/carers, neuro-consultancy).</p>	<p>N.A.</p>

Report	Target group	Model	Outcomes and costs
<p>ABI Slow to Recover Program, Victoria (ABI STR) Program review report 2004 (Victorian Department of Human Services, 2004)</p>	<p>Non-compensable Victorians under 65 years with acquired brain injuries who require residential aged care facility level of care with long term support.</p> <p>Program established in 1996; ongoing</p> <p>181 participants over life of program; 124 receiving services at mid-2003</p>	<p>Aim to provide slow stream rehabilitation for people who have experienced catastrophic brain injury within previous 2 years.</p> <p><u>Key features:</u> Participant allocated to external case manager; Development of care plan; Contract purchasing of core services, including inpatient slow-stream rehabilitation, case management, equipment and home modifications; Subcontracting of external therapy providers and attendant carers to deliver specified services; Links with equipment services, accommodation and rehabilitation providers; Coordination of services funded by ABI STR and advocacy for access to mainstream services.</p>	<p>Feedback on program from various stakeholders on effectiveness and potential improvements.</p> <p>Evaluation suggested that without the program a significant proportion of participants would be inappropriately residing in residential aged care or acute care.</p> <p>Detailed program cost data provided</p>

Report	Target group	Model	Outcomes and costs
<p>Neurodegenerative Conditions Coordinated Care Program, WA (NCCCP)</p> <p>Evaluation conducted in 2010</p> <p>(Bahn & Giles 2012)</p>	<p>People aged under 65 with a rapidly degenerative neurological condition</p> <p>Pilot began in 2008</p> <p>215 participants</p>	<p><u>Key features:</u> Provision of in-home care and supports and respite to program participants; Multiple Sclerosis Society (WA) delivered services to participants in metropolitan and regional areas and acted as broker for clients in rural areas; Expenditure per individual capped at \$80,000 per year or \$10,000 per month for two consecutive months.</p>	<p>Qualitative data collected through semi-structured face-to-face interviews, and telephone interviews. Overall client satisfaction with the service. Some areas for improvement identified.</p> <p>Average cost per client was \$10,205; data on client costs by type of service given over 2 year period.</p>

Report	Target group	Model	Outcomes and costs
<p>Better Pathways Pilot Project, SA (BP)</p> <p>Process and interim outcomes evaluation report 2012</p> <p>(Warren, 2012)</p>	<p>Young people with disabilities and mental health issues 'at risk' of not making a successful transition to the post-school environment</p> <p>Program initiated in 2009; due to conclude later in 2014</p> <p>316 students were registered with the program at June 2012</p>	<p>Aim to improve engagement, transition, and post-school outcomes</p> <p><u>Key features:</u> Assessment and referral using specially developed tool (START); Interagency panels in each council area; Better Pathways Worker for each participant, providing advocacy, coaching and mentoring from year 9 to one year post school; Transition plans developed and monitored; Person Centred Thinking tools used in developing transition plan; Key contact person in each participating school; Central office team provides support to schools, service providers and agencies to work in partnership; Information resources (website, newsletter); communication strategies (meetings).</p>	<p>Qualitative outcome data gathered through: Student interview/surveys; 12 themed case studies; 4 parent focus groups; Project stakeholder surveys (Pathways workers, School key contacts, Interagency team representatives and key contacts).</p> <p>Few participants had achieved 'post school status' at the time of the evaluation, but many had improved their 'learning or earning' status, and almost all said they believed they are being supported to stay on track to achieve their goals and will have improved future opportunities.</p>

Report	Target group	Model	Outcomes and costs
<p>Multiple and Complex Needs Initiative, Victoria (MACNI)</p> <p>Evaluation report 2007</p> <p>56 participants accepted into the care planning and care coordination component of the Initiative.</p> <p>(KPMG, 2007)</p>	<p>People with multiple and complex needs related to combinations of mental illness, intellectual or physical disability, ABI, behavioural difficulties, family dysfunction or substance misuse</p> <p>Program initiated in 2004; ongoing</p> <p>56 individuals accepted into initiative as at October 2007</p>	<p>Provision of intensive, time limited (up to two years), care planning and service coordination intervention</p> <p><u>Key features:</u> Comprehensive needs assessment; Coordinated care planning; Intensive case management; Care plan coordinator (monitors implementation of a care plan and coordinates services); Brokerage funds to directly purchase services; Statewide Panel (statutory body, determines eligibility and care plans); Regional Gateway (manages consultation and referral processes).</p>	<p>Administrative data on program activities; Interviews and surveys of key stakeholders; 16 case studies based on detailed file and document review and consultation with relevant stakeholders.</p> <p>Half of the participants showed behavioural improvements; one-quarter showed a greater level of engagement with care managers and other supports in the community; reduced emergency department presentations, hospital admissions and bed days for participants.</p> <p>Initiative contributed to capacity within the sector, including workforce skills development and supporting the development of professional networks.</p> <p>Cost data presented, including a preliminary assessment of cost effectiveness.</p>

Report	Target group	Model	Outcomes and costs
<p>Economic benefits of coordinated service delivery for YPINH (ACIL Tasman, 2013)</p>	<p>People aged under 65 with a variety of acquired disabilities and complex health and other support needs</p>	<p>Cost modelling to examine the economic implications of moving towards a more coordinated approach to service provision across disability, health and aged care services (eight case studies based on the experiences of real life individuals).</p> <p><u>Key features:</u> Active partnership and collaboration between programs at (i) participant level, and (ii) systems level; Development of integrated care pathways; Risk management methodology; Specialist tertiary case coordinators linked to specialist health resources; Residential aged care used as a transitional service, with disability and health funding accompanying the person to deliver rehabilitation services and augmented personal support.</p>	<p>Coordinated services delivery results in reduced suffering (average lifetime disability burden reduction valued at \$0.46 million) and longer lifespan (valued on average at \$1.61 million).</p> <p>In 5 of the 8 cases, coordinated services delivery results in net savings to society—average saving approx. \$1.36 million (ranging from -\$0.18 million to \$8.40 million). Notable savings in medical treatment costs and in the costs incurred by family members. The cost of external care is much higher because of the greatly improved levels of care; home modification and other equipment costs are also slightly higher.</p>

Report	Target group	Model	Outcomes and costs
<p>Disability care at Western Health, Victoria. (Thompson, 2011)</p>	<p>Focus on people with Down’s syndrome and Autism Spectrum Disorder (some with Alzheimer’s)</p>	<p>Review of literature and case studies to suggest ways to improve the interface between health and disability services. <u>Key features:</u> Joint health–disability strategies for relationship development; Disability care liaison service; Geriatrician outreach consultation and outpatient service; Disability consultation liaison role; Education and training program for health staff; Medical advocate/advisor; Rehabilitation stream for people with intellectual disabilities.</p>	<p>N.A.</p>

Appendix Table A2. Description of studies reviewed in Section 3, by study type

Author	Target group, focus	Service model	Outcomes
Study Type: Literature review:7			
Ansari et al 2001	Unmet service needs of young adults with CP (UK)	Literature identifies lack of interagency coordination. Need for multi-disciplinary, community based teams. Coordinator mediates between hospital & community	N/A
De Bruin et al 2012	Comprehensive care programs for multi-morbid patients	Systematic lit review of 33 studies, most with older people (over 65). Mixed care types including interventions related to self-management, decision support, community resources, clinical information and health system innovation. Heterogeneous programs made comparison difficult.	Moderate support for benefits of CCP on: inpatient hospital utilisation, healthcare costs, health behaviour, perceived quality of care, satisfaction of patients/carers. Insufficient evidence of benefits on: health-related Quality of Life (QoL, outpatient healthcare use cost. No evidence of benefits on: cognitive functioning, mortality, depression, functional status, QoL and caregiver burden.
Fisher & Elnitsky 2012	Diverse approaches to service integration	Service integration is important for populations whose needs span multiple areas (physical, mental health, housing, disability) that increase risk of fragmentation e.g., veterans. Small minority of projects reviewed included evaluation results; data lacking on clinical outcomes, patient perceptions.	N/A
Jansen et al	Integrated care for MS	Few studies examined continuity of care	N/A

2007	patients (The Netherlands)	for people with MS but 4 showed inadequacies of care and limited findings about patient satisfaction suggest continuity of care and participation in care planning important. 2 studies described IC for MS patients across healthcare settings but lacked outcome data.	
Lukersmith et al 2014	Community based case management taxonomy	The taxonomy was developed using a mapping review of case management, a critical review of frameworks and expert consultation. 12 main (sequential and overlapping) actions were identified to describe the process of case management: engage with client, conduct assessment, preparation, manage risks, education, training/skills, emotional/motivation support, advice, coordination, monitoring, long-term planning, client support.	N/A
Powell Davies et al 2006	Coordinated care within primary health care (PHC) and between PHC & health-related services (Australia)	Systematic review of 85 primary studies & 21 prior reviews. Reported strategies were= micro level: communication between providers, system support. Meso level: joint planning, funding, management & agreements. Macro level: health service organisation support.	65 studies reported health outcomes and there were benefits for all except patient satisfaction. Combination of strategies more effective than single. Most important strategies= relationships between clinicians, system support (improve service networks, access to early intervention; relationship strengthening - co-location, tools/instruments/systems to support CC). Economic outcomes were measured in 28 studies and fewer than 1:4 found significant positive result (most common in aged care).

Van Raak & Paulus 2008	Comparison of interagency service coordination for people with disability, chronic conditions, the aged in European countries	Multidisciplinary teams solve problem of fragmented systems for service delivery in acute, long-term and primary care. Fragmentation differs depending on decentralisation of healthcare (social care often less centralised than acute) and financing arrangements (tax, insurance). Vertical = transfer of decision-making power from national level. Horizontal = differentiation between governments responsible/silos. Professional fragmentation = barrier to cooperation can be overcome by working in parallel. M/D teams are fragile without management support to blur functions, boundaries.	N/A
Study Type: Exploratory study: 6			
Abendroth et al 2012	Carers of people with Parkinson's disease (US).	Investigates carer decision-making about timing of institutionalisation. Method: interviews with 20 carers. Increased caregiver load and disease progress creates strain. In/formal support helps mitigate strain and prevent premature institutionalisation.	Suggests episodic caregiver assessment to anticipate changing needs; importance of respite care
Corbett et al 2009	Continuity of care for adults with long-term physical disability (NZ)	To identify strategies for continuity of coordinated care. Method: participatory action research in a small rural community. Identified need to collaborate with targeted health services to explore service delivery models; barriers/facilitators to continuity of care.	No outcomes reported

		Recommended development of clinical care pathway with a clinical care coordinator role to monitor patient care and transition from acute to primary care services	
Kroll & Neril 2003	Perceptions of care coordination by adults with severe physical disability on managed care or health plans (US)	Investigation of differences in coordination experiences. Managed care: all services covered but restricted to contracted providers. Fee-for-service plans: patient choice but onus on them to coordinate care, higher out-of-pocket expenses. Method: interviews with 30 adults with CP, MS and SCI. Barriers identified: Lack of disability-specific knowledge of coordinator (usually GP), high patient: provider ratio barrier to quality of coordination. Communication fragmentation between providers increased with complexity of needs.	No significant difference between perceptions of barriers by funding type. All reported lack of disability-specific knowledge by coordinators as barrier and this is promised by managed care industry.
Matsushige et al 2012	Integrated care in the community post hospital discharge (Japan)	Multidisciplinary care delivery during the post- discharge 'stabilisation' process. Method: in-depth interviews with 21 people (patients, carers, health professionals). Home viewed more positively than hospital by patients and carers resources but resources not allocated systematically and professionals expected to work outside their expertise in the home environment. Health professionals provide mutual aid (along	No outcomes reported

		with informal supports) to fill gaps in system but this is precarious.	
Noel et al 2005	Collaborative management by primary care physician (PCP) for veterans with chronic illnesses (US)	Community-based care management by primary care physician. Method: focus groups with 60 veterans 20-80 years. Patients reported problems with care- long wait for referral, lack of continuity, communication difficulties but blamed 'the system' not individual clinicians. Aware of self-management strategies but not always suited to their circumstances. Willing to use technology but wanted continued personal contact.	Medication dependence most common adverse life impact reported. Most wanted to be active partners in care Most were satisfied with overall health care and PCP
Palsbo & Dejong 2003	Drivers of private health plan providers managing coverage for people with disability/complex care needs (US)	Most prior research = billing and claims not performance measurement. Fiscal conservatism about 'high cost' members driving up costs and need to manage proportion of such members. Method: Convened panel of experts (n=24) about health insurance finance to explore contract models. Panel proposed risk-adjustment method. Responsive health care for this group: 1) benefit & care substitution (i.e. transfer costs from acute to community care), 2) self-directed 3) care coordination and 4) unlimited therapy.	Confirms that insurance companies make decisions based on medical business model
Study Type: Program evaluation or description: 23			
Bachman et al 2008	Evaluates program of coordinated care for low-	Pre-paid, capitation payment with inpatient portion reallocated to outpatient services for identified patients	Improved targeting of high needs; reduced expenditure

	income Latino people with chronic illness/disability (US)	with special healthcare needs using care coordination. Method: analysis of claims history data over 2 years; semi-structured interviews with 18 participants.	due to decrease in hospital costs, especially for highest-cost patients; reduced barriers to service access (e.g., language)
Craig et al 2011	Evaluates model for enhanced care coordination for people with multiple, overlapping health and social needs (US)	To replace high-cost crisis care with lower-cost preventive and primary care. Model elements are 1) identify individual/family assets (they overlay the CC process and can be leveraged to improve health), 2) identify patients who are likely to be failed by primary care (resulting in costly hospitalisations), provide a care coordinator who is responsible for identifying individual's health goals & most pressing needs and coordinating services to meet them (understanding individual assets-strengths and gifts -of individual/family) and care plan carried out in partnership with person so they develop self-care skills	No outcomes reported
Dew et al 2013	Describes a framework to access barriers for people from rural and remote areas (Australia)	Therapy barriers identified are: 1) travelling to access therapy, 2) waiting time, and 3) limited access past childhood. The study used qualitative methods to identify common themes and develop a person-centred, place-based framework to build capacity (individual, carer, community) including: active mentoring to utilise local resources (e.g., pool, gym) and training community-based therapy assistants to implement therapeutic plans; improved coordination of outreach services with local therapists/therapy assistants; enhanced use of audio/visual technologies and therapy software applications.	No outcomes reported

Dobell & Newcomer 2008	Describes program for integrated healthcare for vulnerable populations (US)	Integration requires: gatekeeper (manage eligibility), communication between providers, client education and facilitate and monitor care (e.g., refer, broker). Example= PACE (over 55s) has capitated payment model, multidisciplinary teams, discretionary resource allocation. Does not use case management but cross-reporting by team. Proposes that PACE sites be used as 'labs' for R&D of new approaches	PACE: delivers cost savings from higher cost care by delivering less expensive services. Evidence that hospital and nursing home use lower than in comparable populations.
Goodwin et al 2013	Evaluates coordinated care programs to manage complex chronic or medically complex needs holistically, improve quality of life, reduce hospitalisation and promote home-based care as preferable to institutional care (UK).	Case studies of five programs. Success in care coordination appears to be the result of a long-term process facilitated by local leaders during which capability and legitimacy of a new way of working are built up over Understanding the local context is key to transferring the lessons from other programs into a new setting. Care coordination needs to be adopted as a quality improvement rather than cost effectiveness strategy.	None of the programs set specific cost-reduction targets and the programs had only a marginal impact on the costs of care but all demonstrated improvements in the care experience and outcomes.
Kathol et al 2011	Describes a planning tool for integrated case management for patients with health complexity (US)	Describes adult complexity measurement tool (IM-CAG) used by case managers to create care plan (specific actions, agreed goals, definable outcomes) that can be used to measure patient healthcare costs and outcomes.	Cites (unpublished) data that supports financial and patient outcome effectiveness
Mastal et al 2007	Describes model of care coordination for high-risk patients with disability, chronic disease, multiple morbidity (US)	Community Healthcare Group (CHG) and Commonwealth Care Alliance (CCA). Promotion of shared understanding of goals, roles, decision-making relies on good systems: e.g., effective organisational communication (shared patient information, integrated care plans), tools to foster collaboration (co-location used to promote linkages between providers but relies on appropriate staffing, space)	No evidence of financial benefits IT integration not established and this hampered maximising cost effectiveness

Master & Eng 2001	Describes model of care coordination for high and complex older and younger people with disability who are Medicare-eligible (US)	Community Medical Alliance (CMA) and Program for all inclusive care for the elderly (PACE) aim to reduce hospitalisation. Flexible funding model: risk-adjusted payment– redistributive resources from hospital/institution to community. Team model of care to cover totality of needs. Most Medicare programs have not invested in IT infrastructure needed to support this funding system.	Integration between acute and long-term care services cannot occur until financing systems are integrated for higher cost target populations. Inflexibility in pricing of long-term care benefits is a barrier to innovation (non-eligible populations should be able to 'buy in' to scheme)
Master et al 2003	Describes model of coordinated care to Medicare-eligible high-risk populations (US)	Commonwealth Care Alliance (CCA) developed model to respond to need for early intervention to prevent complications (and hospitalisation). Pre-paid financing model (not fee for service) promotes flexibility to respond to complex needs but relies on risk-adjusted, integrated acute and long-term care funding	No outcomes reported
Meyer 2011	Evaluates program of coordinated care for 1) adults with complex medical needs 2) children and adults with multiple chronic conditions (US)	Commonwealth Care Alliance (CCA) launched disability care and complex care needs programs to reduce hospitalisation and premature nursing home placement. Features: common IT system, multidisciplinary team providing comprehensive assessment and care plan. Method: Outcomes assessed using computerised comparative performance system to measure 30 day hospital readmission rates; service costs.	Cites data that suggests monthly costs for DCP are lower than comparable Medicare fee-for-service patients
Oeseburg et al 2004	Evaluates coordinated care program for people with MS (The Netherlands).	Model includes multiple assessments to develop care plan (neurological, rehabilitation, nursing, care). Case manager – nurse specialist. Care plan used by all services who report actions. Use standardised instrument to measure outcomes: neurological, physical, incapacity, environmental.	Total expressed needs declined significantly over time but no change in 4 patient health outcomes measured – possible that the scale not suited for use

		Method: Interviews with nurses and patients; empirical data	with chronic, progressive disease. Health profs were positive about using the model but sharing info was time-consuming.
O'Flynn et al 2011	Describes "joined-up government" (JUG) case study implemented to address the persistent disadvantage of indigenous Australians (Australia)	JUG is a mechanism used to coordinate activities of government departments, non-government organisations and communities. ICCs (hubs for policy coordination, service delivery) were established. The model was to provide a one-stop access point into government for community and used co-location of government departments to improve coordination. Not evaluated but a document and thematic analysis undertaken from interviews with 45 staff.	Inhibitors: lack of structural incentives and formal authority to build trust with community; lack of investment in skill development (co-location not enough) and program focus reinforced 'silos'. Facilitators: craftsmanship leadership style (broad thinking, ability to marshal resources), cultivating networks required expertise gained over long-term.
Øvretveit et al 2010	Evaluates model of care integration for patients being discharged from acute setting to home (Sweden)	Integration of financial administrative and service provision to improve hospital discharge processes. Method: Interviewed 17 health professionals, government and service personnel about organisational change to integrate patient acute and community care services. Perception that coordination was hampered by: occupational cultural barriers, communication and record-keeping systems, lack of financial & discharge incentives	No outcomes reported
Palsbo & Diao 2010	Evaluates coordinated care program for people with	Self-directed care comprising comprehensive assessment, care planning, multiple services. Established	Investment in CC is cost effective over time. Over 3

	paralysis (US)	financial accounting system that permitted large-scale cost tracking (including cost-shifting) over time. Method: Undertook retrospective (3 years) analysis of claims data to assess financial performance. Monthly expenditure increased by 1.75, hospitalisation rates unchanged but significant decline in length of stay, costs per admission	years reductions in medical costs paid for additional CC costs. Notes that there was a high proportion (16%) of exceptionally high expenditure clients enrolled and this is likely to have under-stated cost reductions.
Palsbo & Kailes 2006	“Disability-competent health systems” for people with disability (US)	System redesign undertaken by Centres for Independent Living -adapt evidence-based Chronic Care Model (Wagner, 1998) to support people with disabilities. Based on belief that support needs to take place across 4 elements of healthcare organisations: 1) Delivery system (‘gate openers’ who expedite referral, holistic approach), 2) decision support (innovations to promote improvements across settings e.g., develop pocket cards for clinicians to prompt appropriate questions), 3) self-management (accessible websites, goal setting skills, ongoing contact), 4) clinical information systems (gather comprehensive information & use to integrate services – shared database, linked data across settings).	Cites preliminary evaluations of two programs that show significant client improvements in access, quality and reduced acute care expenses & premature placement in nursing homes.
Palsbo, Mastal & O’Donnell 2006	Evaluates program model for people with disability (US)	Review of 6 Disability Care Coordination Organisations (DCCOs) which share 6 universal activities: comprehensive assessment, self-directed care, person-centred planning, health visit support, centralised records, community resource engagement, constant communication. Method: interviews with staff in 6 DCCOs across 5 states about financing, governance, IT systems, quality programs, challenges. Coordination focus= coaching and	Preliminary data suggests expenditure increases initially (as unmet needs addressed) and reduces over 12-18 months. Program sites report improved clinical outcomes (decline in acute admissions) and clients

		education to change health behaviour, support with health visits (and interpret clinical info).	report improved quality of life.
Palsbo & Ho 2007	Evaluates Disability Care Coordination Organisations (DCCO) contracted for care coordination for Medicare/Medicaid eligible adults with disability (US)	Person-centred & directed services Person supported to gain skills to manage their care proactively and effectively. Method: Surveyed 150 clients; 2 year follow up with 64 clients.	Statistically significant improvements reported in coordination, education, competency, assessment, health support, self-directed care, satisfaction with health system & physician. Reduced need for rehabilitation attributed to primary health care, improved wellbeing.
Patterson et al 2007	Evaluates model of coordinated care for people with complex and chronic conditions (Australia)	GP practices funded to coordinate care to enhance collaborative partnerships between them, primary care and community services. Role of practice nurses as service coordinators = develop care plans following GP health assessment. Method: focus group with 7 practice nurses across 7 GP practices. Some believed they had influenced GPs to implement CC, took more active role in health assessments (more time & skill than GP).	Practice nurse are under-utilised resource at present. Potential for facilitation between different health professionals. Need for greater education around CC and care plan billing methods, clarify roles of service coordinator & communication between them and community nurses.
Ruiz et al 2012	Describes tool to measure Long-term support services (LTSS) for people with lifelong disability (US)	Developed indicators to measure national programs & policies for person-driven LTSS: sustainability, self-determination, person-centeredness, community integration, prevention, shared accountability, coordination. For ageing people with lifelong disability two indicators were: in/formal caregiving (loss increases	Most states provide support and prevention programs for people ageing with lifelong disability but do not target all age and disability populations

		risk of institutionalisation), health promotion and coordination of care (seamless transitions).	equally. System change needed to improve feedback loop between disability, community, scholarship, policy and practice. State government changes can destabilise new programs & infrastructure needed to resist this.
Sampalli et al 2012	Evaluates model of integrated care for adults with multiple chronic conditions (Canada)	Program to address multi-morbidity. Method: small pilot (n = 20) analysis of patient clinical and wellbeing outcomes Phases in care= 1) intake, 2) integrated care, 3) transition, 4) discharge. 1) Multidisciplinary assessment 2) active patient engagement, coaching, counselling & education strategies to build coping skills, ongoing medical support, care coordination. 3) Reassess for discharge readiness, identify community support. 4) Transfer to primary care provider or GP.	Average duration 6 months. Satisfaction and perceptions of health increased pre-post intervention
Segal et al 2004	Evaluates program of care coordination for patients with multiple chronic illnesses and complex needs (Australia)	Southern Health Care Network Coordinated Care Trial (CCT) targeting patients with a history of high use of in-patient service use. Care coordination provided by the general practitioner (GP) who coordinated a holistic care plan that incorporated service responses to the patient's needs, taking into account environmental supports and impediments. Method: 2,742 participants recruited to the trial or usual care and baseline and follow up measurement of clinical outcomes and quality of life were undertaken as was	Total resource use for CC group was higher due to extra \$ of care planning and case management and administration. No difference in mortality rates, no sign difference in QoL for CC group. However 25% vs 16% of CC clients reported the trial had

		financial data on healthcare costs.	improved QoL. Care coordination cost 8.2% more and admin added 12.5%. this effect noted elsewhere- with improved client satisfaction but not QoL
Surpin 2007	Describes model of coordinated care for adults with physical disability (US)	Independence Care System (ICS) supports 1000 people through managed care entities (state funded). Flexibility of managed care plus services (coordination, equipment maintenance, independent living support) based on individualised care plans and case management for service-related problems, critical transitions (e.g., hospital discharge, loss of housing) or mental health/substance issues.	No outcomes reported
Venkatasubramanian et al 2008	Describes approach to long-term care for stroke patients (Singapore)	Based on Wagner's chronic disease management model (informed, motivated patient working with team of health pros across acute, rehab, primary, community care) to reduce post-discharge adverse outcomes. Stroke nurses as single point of contact, case manager to monitor medical situation.	No outcomes reported
Study Type: Conceptual/Discussion: 7			
Bridge et al 2002	Discusses unmet needs of older/younger people with disabilities for housing and social services (Australia)	Barriers/facilitators to creating coordinated, flexible delivery of housing and social services- lack of whole of government approach, funding silos, cost-shifting. Recommends review of commonwealth/state agreements. Urgent need to create new models of housing within mainstream markets	N/A
Cameron &	To understand changing	Reviewed quantitative and qualitative studies and	N/A

Gignic 2008	needs of stroke caregivers across care environments (US)	identified 5 phases and different carer needs as they progress through diagnosis, stabilisation, preparation, implementation and adaptation. Caregivers benefit when they receive support appropriate to the stage they are at. Program can be generalised to other conditions with sudden onset, hospitalisation e.g., SCI, TBI	
Ehrlich et al 2009	Coordinated care in context of chronic disease management	Coordination involves horizontal and vertical integration. Self-management is central as the person is the one constant in the system. Client level: person-centred care. System level: resource/info management, integration. Service level: learning communities, guidelines, collaboration. Cost savings may not be realised because unmet needs are addressed. Need: single point of entry, streamlined assessment, agreed care plan goals. Team approach, flexibility and sustainability (at org level).	N/A
McConnell 2006	Coordinated care models	Integrated care models successfully implemented in Europe and US with elderly, mental health, at-risk populations. Key features: target services to greatest need, identify appropriate resources, share cross-sector information, standardise communication (single assessment process, multidisciplinary team). Case manager ensures right person delivers the right care, follow-up and coordination of effort.	N/A
Mur-Veerman et al 2003	Comparison of integrated care (IC) for high/complex needs (The Netherlands and UK)	Britain- public funded through taxation (more complex, mix of NHS & local social care providers), The Netherlands- private insurance model (less hierarchical, more discretionary). IC relies on new organisational arrangements (e.g., interdisciplinary teams, shared ICT facilities, special financing) and attitude/culture change. Health systems can impede development. Difficult to determine effectiveness given differences in policy	N/A

		approaches. Need to map network to determine (players, resources, interests)	
Sang 2007	Self-managed care for people with long-term disability (UK)	Integrated care promotes personalised, co-produced, enabling and adaptive service responses. People with disability want to live independently, active role in decision-making.	N/A
Van Wijngaaden 2006	Theoretical discussion of integrated care (IC) (The Netherlands)	IC- organisational process of coordination that seeks seamless, continuous, individualised care. The Netherlands= fragmented healthcare system (specialised institutions, compulsory and private insurance financing). Uses network learning theory to analyse IC as it occurs at operational, tactical and strategic levels. Build trust, mutual benefit, and reciprocity. Helps health professionals to collaborate and implement innovative IC mechanisms.	N/A

Appendix Table A3. List of workshop participants and reviewers

Name	Organisation and program
Christina Bolger	Scheme Design, Comcare
Branka Carter	National Disability Insurance Agency
Jodie Cook	Public Advocates Office, Queensland
Dianne Croker	Lifetime Care and Support Scheme, NSW
Dr Angela Dew	Faculty of Health Sciences, University of Sydney
Gordon Duff	National Disability Services, Sydney
Deborah Farrell	MS Australia
Greg Featherstone	National Disability Insurance Agency
Keryn Fox	National Disability Insurance Agency
Dr Sally Galbraith	Actuary, National Disability Insurance Agency
Denis Ginivan	South West Brain Injury Rehabilitation Service, Albury
Bronwyn Harding	Acquired Brain Injury Slow to Recover Program, Southern Health, Victoria
Dr Kirsten Harley	Faculty of Health Sciences, University of Sydney
Rod Harris	Motor Neurone Diseases Association, Victoria
Deb Hoffman	National Disability Services, National NDIS Trial Site Co-ordinator
Rebecca Jackson	Lifetime Care and Support Scheme, NSW
Professor Gwynnyth Llewellyn	Centre for Disability Research and Policy, University of Sydney

Suzanne Lulham	Lifetime Care NSW
Professor Richard Madden	Centre for Disability Research and Policy, University of Sydney
Dr Clarissa Martin	Institute for Safety, Compensation and Recovery Research, Victoria
Dr Susan Mathers	Calvary Healthcare Bethlehem, Victoria
Professor Harry McConnell	School of Medicine, Griffith University, Queensland
Julie McConnell	Motor Neurone Diseases Association, Victoria
Dr Michael Millington	Faculty of Health Sciences, University of Sydney
Chris Moretti	Behaviour Support and Complex Clients Team, Department of Communities, Queensland
Brett Morris	Department of Human Services Aged Care Division, Victoria
Professor Karen Nankervis	Department of Communities, Queensland
Mark Pattison	National Council on Intellectual Disability
Sue Race	Divisional Director, Sub Acute and Aged Care Services, Western Health, Victoria
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