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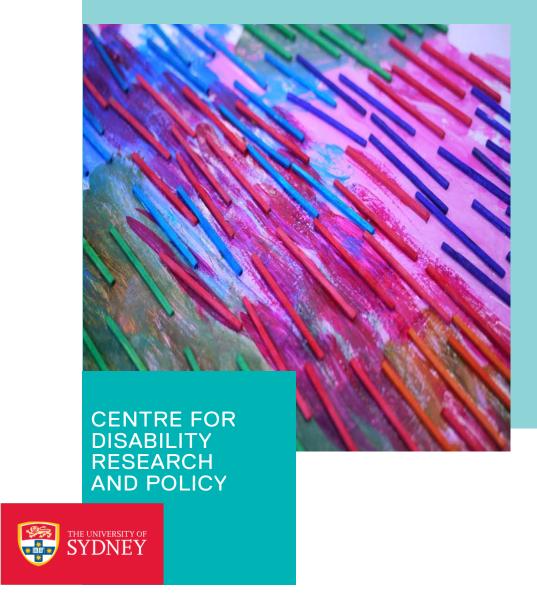
CROSS-SECTOR SERVICE COORDINATION FOR PEOPLE WITH HIGH AND COMPLEX NEEDS

HARNESSING EXISTING EVIDENCE AND KNOWLEDGE

A joint project of the Centre for Disability Research and Policy and the Young People in Nursing Homes National Alliance

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Cover Artwork: *Robbie S. is an artist supported by Sunshine's Community Access Program Art Studio*

INTRODUCTION

Australia's new National Disability Insurance Scheme (NDIS) is designed to 'support the independence and social and economic participation of people with disability' by the funding of 'reasonable and necessary supports' (NDIS Act 2013 (3)(1)(c) and (d)). It is aligned with the UN Convention on the Rights of Persons with Disabilities and the National Disability Strategy. The NDIS has been progressively introduced into trial sites around Australia from 1 July 2013.

People with high and complex needs generally require an array of supports to enable social and economic participation. As NDIS participants, funding will be available to purchase services and supports from disability sector providers to complement access to 'mainstream' services, including health, education, housing, justice and transport. The complexity of the specialist and mainstream services systems and the interfaces between sectors create barriers that make navigation challenging for participants and service providers, and create gaps in service provision. People with complex needs have historically been poorly served when their needs fall across or between different program areas (Commonwealth of Australia 2011:182-190).

The NDIS Act (2013) states that 'regard is to be had to...the provision of services by other agencies, Departments or organisations and the needs for interaction between mainstream services and the provision of supports' (S3(3)(d)). The NDIS is an entitlement program (needs based), while services in other sectors such as health are budget capped.

The transition to the NDIS offers a significant opportunity to learn from evidence and experience with coordinated services for people with high and complex needs, and to identify where there is scope to minimise the risk of people 'falling through the cracks'.

The Centre for Disability Research and Policy at the University of Sydney and the Young People in Nursing Homes National Alliance were partners in a project, supported by the NDIA, to produce a discussion paper to stimulate policy development and dialogue about the value of coordinated, cross-sectoral approaches in delivering supports and services to participants in the NDIS (CDRP & YPINHNA 2014). This paper is available for open access download at http://sydney.edu.au/health-sciences/cdrp/

RESEARCH METHODS

- Analysis and synthesis of reports on Australian pilots and programs and international literature on service coordination for people with high and complex needs.

- Stakeholder workshops with service providers and with consumers and advocates, and a 'policy workshop' including NDIA personnel, administrators from health and disability departments and agencies, and academics.

- Development of definitions of key terms and an organising matrix (see below) for analysis of the material reviewed (reports, literature and workshops).

ORGANISING MATRIX FOR STRUCTURING ANALYSIS

The framework used to organise and interrelate the evidence reviewed is depicted as a matrix (Figure 1). One axis reflects a 'system and stakeholder' perspective, recognising that service coordination 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)). The other axis represents a simple evaluation framework referring to goals, services and outcomes.

Figure 1: Organising matrix for structuring analysis

		Evaluation focus		
		Goals	Services	Outcomes
System and stakeholder	**Micro**			
	Meso			
	Macro			

Definitions of key terms were developed and refined progressively in the course of the research (see Box 1).

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 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

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DOES CROSS-SECTOR SERVICE COORDINATION WORK – AND HOW?

There are two main areas of agreement derived from the literature, the Australian reports and the stakeholder workshops:

1. **Cross-sector service coordination (as defined) is of value. Indeed, it is required in the current Australian context.**

   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.**

OUTCOMES FROM CROSS-SECTOR SERVICE COORDINATION: OVERVIEW OF EVIDENCE

The body of evidence points to positive outcomes for people, service providers and systems, as summarised in Figure 2. It is clear that improvements, in terms of more effective provision of services as well as efficiencies and cost savings, could be made with the right cross-sector service coordination design.

Figure 2: Outcomes at different levels	
Micro (*person*)	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.
Meso (*service providers*)	Greater understanding of people's needs and improved linkage and communication with other services in order to meet these needs. Better understanding of local population. Overall enhancement of service quality.
Macro (*systems*)	Positive outcomes can include: streamlining and avoidance of duplication, reduced hospital stays and use of emergency services, and prevention of admissions to residential care—with corresponding cost savings.

Two examples of Australian service coordination programs are described briefly in Box 2. Despite promising pilots and a patchwork of positive experience, there is a need to design long term and sustainable service coordination options to realise the benefits evident in the research literature and previous Australian experience.

Box 2: Examples of recent Australian programs

Victorian Continuous Care Pilot

› Pilot conducted 2008–09, providing service coordination to 19 people aged 33–49 years with a progressive neurological condition.

› Key features: Holistic assessment; Risk identification and management (focused on enabling people to remain living in community); Coordinator with expertise in progressive neurological conditions facilitated communication between all parties; Expert Clinical Advisory Group (CAG) provided specialist clinical input and contributed to future-oriented planning for each participant; Ongoing monitoring and review of needs and supports; Training for service provider agencies; Limited brokerage fund for direct purchasing when no other response available.

› Outcomes: Participants able to access additional or more appropriate services; Equipment issues resolved; Respite arrangements established; Program prevented inappropriate admission to residential aged care for between 2 and 5 participants.

Spinal cord injuries response (SCIR), Queensland

› Program initiated 2005–06; ongoing. Provides service coordination for people with SCI transitioning from the Spinal Injuries Unit to the community.

› Key features: Formal partnership between health, housing and disability departments that assisted in securing access to necessary services and supports for participants; Multidisciplinary needs assessment, coordinated by the participant's 'Key worker' within the SIU; Resource and transition planning (involving all stakeholders); Implementation of services and supports in advance of transition back to the community.

› Outcomes: 21 SCIR participants compared with 15 'controls'— higher quality of life for SCIR clients immediately post-transition (less financial hardship, greater access to equipment and support, less frustration about unmet needs, greater choice about where to live and how to live, and increased levels of independence); Hospital length of stay reduced for SCIR clients with paraplegia (but not quadriplegia – additional time taken to ensure supports in place).

Victorian Continuous Care Pilot (Vic CCP). (MS Australia and Calvary Healthcare Bethlehem, 2009)

Spinal cord injuries response (SCIR), Qld. (Griffith University, 2008)

THE KEY COMPONENTS OF SERVICE COORDINATION

The key components of effective service coordination, derived from analysis and synthesis of the materials gathered for this project, are listed in Box 3.

A critical component is the 'single point of contact' — a skilled service coordinator, working across sectors, as an active negotiator, understanding the person and their needs, and familiar with and expert in the human services system more broadly. They would have a positive, problem-solving attitude enabling them to communicate and work effectively with relevant services and systems to negotiate supports to meet the person's needs. They would require high level support across sectors, and control of a small contingency fund to solve short-term problems, e.g., to buy equipment to enable the person to return home earlier from hospital.

'What we need is a kind of systems wrangler'

Participant in the service provider workshop

Structurally, the service coordinator would be the designated central 'linkage point' in the disability sector, able to identify and link with linkage points in other sectors (e.g., health, housing, education, justice), helping each other to navigate systems. Paramount would be their respect for the person and their autonomy, and a commitment to work in partnership to enable the individual to self-manage whenever possible Infrastructure and high level agreement at the 'macro' level are required to support this role, recognising the overriding purpose of delivering positive outcomes and experiences for people (the 'micro' level).

The evidence-based key components of cross-sector service coordination, summarised in Box 3 at the micro, meso and macro levels, provide a resource for NDIS design and policy development.

Box 3: Key components of effective cross-sector service coordination at each level

Micro: the person's experience of coordination	Meso: the coordination role and enabling mechanisms

➤ 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
	Elements of the service coordination role:
	
	➤ 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.
	➤ 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
	   a. facilitating choice of providers
	   b. monitoring and reviewing the person's needs
	➤ Advising on service provider education and training needs

Macro: High level commitment and agreed infrastructure ➤ Cross-sector formal commitment to service coordination ➤ Shared accountability supported by structures and mechanisms, e.g., 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)	**Skills and qualities needed to carry out role:** ➤ 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 **Structures, processes and mechanisms (endorsed and supported at macro level) to enable coordination:** ➤ 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)

MAIN THEMES IN THE EVIDENCE

The research

- demonstrated the value of cross-sector service coordination and
- identified the components of service coordination that can deliver positive outcomes for people and systems.

Cross-sector service coordination 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.

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). The absence of one key element can mean that the resources outlaid on other services are wasted, undermining the investment made across sectors.

High-level cross-sectoral commitment and agreement are essential. 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. Disability services reform is not enough on its own. Failure of other sectors to provide quality and accessible services will increase the costs of disability care. Coordinators need high level 'permission' to exercise some independent capacity to act to break down barriers, and a modest contingency fund to call on.

Designated coordination linkage points (e.g., in health, disability and housing) would facilitate cross-sector coordination.

Vertical as well as horizontal integration are required. As well as cross-sectoral commitment at a high level, and linkages at service level, a comprehensive approach involving action at all three levels is required. Lack of vertical integration was a design limitation commonly noted in the Australian and international literature.

> *'What's the point of having housing if you haven't got personal care?'*
>
> *Participant in the Spinal Cord Injuries Response (Queensland) evaluation*

Workforce development including skill development is crucial. National workforce strategy should include 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.

Language can be a barrier to cross-sector coordination, with different systems and disciplines using their own language to describe people's needs and service responses to those needs. Agreeing on key terminology is important, as are strategies to help build understanding and purposive communication across sectors.

Coordination options should allow some variation in where the cross-sector coordination function is 'anchored' and who provides the coordination — a new entity or existing individuals or bodies with a strong cross-sector coordination track record.

Experiment and ongoing review and adjustment should be encouraged, and built into trial sites as NDIS rollout continues. The key components of cross-sector service coordination (in Box 3) can inform the design of options for testing. 'One size' is very unlikely to fit all.

PROPOSALS

No single cross-sector service coordination model is proposed for the NDIS. Rather, the development and testing of possible models is proposed, each capable of providing the key components of cross-sector service coordination (as in Box 3). Locations and linkage points can be tailored to suit different NDIS trial sites (e.g., according to services or linkage structures already in place, or to particular participant groups such as Indigenous communities or groups based on a shared health condition). See Box 4 for a brief outline of proposals from the discussion paper (CDRP & YPINHNA 2014).

Box 4: Outline of proposals for the NDIA

1.   Include cross-sector service coordination (as defined) 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 of the discussion paper to specify and design these models

   b)   Involve skilled coordinators with the necessary capability to undertake the cross-sector coordination role.

   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 as outlined in Section 6 of the Discussion Paper (CDRP & YPINHNA 2014).

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.

REFERENCES

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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