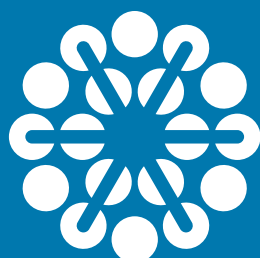


RESEARCH TO ACTION GUIDE

>> Bridging the
gap between
what we know
and what we do



Centre for
Applied Disability
Research

An Initiative of National Disability Services

Working collaboratively at the interface of disability and health services

Rapid Review





ABOUT THE CENTRE FOR APPLIED DISABILITY RESEARCH

The Centre for Applied Disability Research (CADR) is an initiative of NDS. CADR aims to improve the wellbeing of people living with disability by gathering insights, building understanding and sharing knowledge. CADR's applied research agenda is helping to build the evidence base and support stakeholders to better understand what works, for whom, under what circumstances and at what cost.

RESEARCH TO ACTION GUIDES

Bridging the gap between what we know and what we do.

Our objective is to build a comprehensive online collection of disability research and translational resources for the Australian context. Our Research to Action Guides are based on the best available local and international evidence and put together by subject matter experts to support research end users to engage with the evidence. We gather and analyse evidence about what works, and package that information into efficient and practical resources.

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SUGGESTED CITATIONS

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ABOUT THIS RESEARCH TO ACTION GUIDE: 'WORKING COLLABORATIVELY AT THE INTERFACE OF DISABILITY AND HEALTH SERVICES'

This Research to Action Guide Rapid Review reports on the existing literature that addresses the interface between health and disability. The Guide will be useful to all individuals who support the health of people with disability across both sectors by providing an increased understanding of the issues associated with this interface, from which positive action can be taken.

This Rapid Review forms part of a suite of resources produced by CADR on this topic. The suite also includes a Good Practice Summary, which contains 12 actions points for health and disability services. Both are available at the CADR Clearing House: www.cadr.org.au

FEEDBACK

Do you have feedback, or a suggestion for a Research to Action Guide? We welcome your thoughts and ideas. Please contact info@cadr.org.au

WORKING COLLABORATIVELY AT THE INTERFACE OF DISABILITY AND HEALTH SERVICES: A RAPID REVIEW OF THE LITERATURE

This paper reports on the literature which can be used to broaden our understanding of the interface between health and disability in the context of the NDIS. A systematic rapid review of academic literature and relevant 'grey' literature on the health and disability service interface was conducted and key themes identified from the literature. Key themes focused on practical strategies and frameworks which can be implemented in order to address the current disconnections between the sectors.

The report starts with a discussion of the context of health and disability before reflecting on current barriers towards collaborative working. The focus then turns to practical strategies for action. The methodology for the rapid review is included as Appendix one, positioned before the reference list.

RESEARCH QUESTIONS

- What are the barriers impacting on current service collaboration?
- What are the solutions and facilitators of action in this area?

1. BACKGROUND

The health and wellbeing of people with disability are a national priority under the National Disability Strategy¹. The health of those with disability is currently poor in comparison to those without disability². The Australian Institute of Health and Welfare (AIHW) reports that:

- 46% of people with disability self-rate their health as poor to fair, compared to 5% of the general population.
- 48% of people with disability had a coexisting disability and significant mental health problem. Only 6% of Australians without disability had significant mental health problems.
- 23% of people with disability had either diabetes or very high blood sugar before the age of 25 compared to just 7% of Australians without disability.

Health is even poorer for individuals with disability who also belong to ethnic and other minority groups³⁰.

The reasons for people with disability experiencing poor physical health are complex but include the following individual factors:

- People with disability may take medications which improve their functioning in relation to their disability but may impact negatively on their physical health. A good example of this is mental ill-health related medications which may lead to weight gain which may then cause diabetes or cardio-vascular disease³⁹.
- They access health care less frequently and miss out on screening programs and other preventative health care^{30,19,20,8}. People with disability are at greater risk of injury because they live in environments not set up for their disability or through care-related

accidents¹⁹.

- 43% of people with disability do little to no exercise weekly compared to 31% of people without disability¹. This may be due to physical problems related to their disability or a lack of resources to facilitate participation in exercise. Lack of exercise means that people with disability are more likely to contract diseases related to sedentary behaviour¹⁹. In 2010 69% of Australians with disability were likely to be overweight or obese compared to 58% or people without disability¹.

The AIHW reports a smoking rate amongst adults with disability at 31% compared to 18% of Australians who do not have disability¹. People with disability are also less likely to receive help for their physical health³⁴. Legislation for the National Disability Insurance Scheme (NDIS) separates disability from health with the NDIS covering only those disability related services which do not fall under other legislation such as health, education and aged care. This separation between disability and health occurs against a background of systems that already have a history of poor coordination and if not dealt with proactively this separation may therefore lead to further fragmentation¹².

Coordination improves health^{32,33,17} but service coordination between health and disability is poor. People with disability often have needs that overlap between the disability and health sectors and continuity of care is critical for living a good life²⁶. A lack of a clear boundary around who takes responsibility for client needs means that 'boundary disputes' may occur where services attempt to either take responsibility for all or nothing, with both approaches limiting effective collaboration¹².

COAG principles for the operation of the NDIS state that health and disability services must work together at local levels "to plan and coordinate streamlined care for individuals requiring both health and disability services"¹⁰. The NDIS will also fund work that assists NDIS planners to understand the health needs of clients for planning purposes and the coordination of supports which must be delivered cross-sector.

2. FINDINGS

2.1 General description of studies

The studies were generally reviews of existing practice, discussions of current barriers to practice in the area or descriptions of small-scale studies. Particular forms of functional disability were more frequently discussed in the literature than others. Mental health disabilities, intellectual disability and brain injury were more discussed, likely reflecting a history of practice difficulties in these areas.

2.2 Barriers impacting on current practice.

Systemic and legislative barriers: Different levels of government (federal, state), government departments and regulators, reporting requirements, funding and legislative and regulatory frameworks make collaboration difficult. These factors have meant that there has been a systemic separation of one person's, often overlapping, needs into different fields of action with different associated actors and responsibilities¹⁵. The systems have grown so separate

that those in other systems may have minimal understanding about how other areas function¹⁵ including who to speak to and who has responsibility to act. All of these factors are responsible for current poor information sharing between the two sectors²⁸.

There has been little research on the impact of this separation from a consumer and carer perspective but the research that has been conducted shows that this separation leads to significant continuity of care problems⁵. Consumers and carers have pointed to the negative impact of poor information sharing and complicated and changing care coalitions and responsibilities on their care⁵. Carers are also being left out of the loop with carer involvement left up to individual organisations meaning that they are included in some conversations and not others¹⁵. These systemic problems are compounded in rural and regional areas where distance adds another level of complexity¹³.

Professional barriers: Within the different professions ‘silos’ of working have developed which mean that different practices and forms of knowledge tend to dominate work in disability and health and other types of knowledge are not accepted as valid in comparison^{7,29}. While not all practitioners work with the models which characterise their fields, practitioners are generally trained and retrained within a bio-medical model, whereas a psycho-social model dominates disability related practice²⁸. The opposing knowledge and training systems are sometimes actively disparaged in one or the other systems, which limits joint working³⁸.

Health and medical care tends to operate within an ‘acute mindset’ and is unfamiliar with the timelines, processes and interactions involved in long-term care¹⁹. With increasing specialisation there has also been a reduction to work within particular ‘disease boundaries’ even within healthcare, so specialists feel unprepared to assist those whose needs lay outside of their direct speciality²⁰. These barriers mean that physicians may sometimes fail to see the ‘person’ behind the disability and only treat them in relation to their disability or health problem, rather than in an holistic manner.

Increasing specialisation of both health and disability services may mean that professionals within services may not feel equipped or competent in assisting people with disability with health needs^{28,4, 30,19}. Services may also be too rushed to take the time with people with complex needs and work out appropriate care plans through communicating across sectors^{40,19}. These factors stop consumer goals and individualised plans being developed or shared across systems^{21,13}.

The AIHW reports that 22% of people with disability living in rural or remote regions, and 15% in major cities reported communication problems with health care providers impacting on their care³. This was highest for individuals experiencing the highest levels of functional disability. Physicians lack confidence in their ability to work with people with disability and feel that they are not able to meet their needs effectively²⁸. Practitioners with limited understanding of cognitive and psychiatric disabilities may find it difficult to know how to communicate and understand the wishes of these individuals, assuming that they lack any ability to understand or direct treatment or interventions¹⁹. Health practitioners often feel that they lack skills in this area and have reported feeling difficulty in answering questions posed by people with disability about their care^{30,19}. The impact of stigma needs to be considered as this can also lead to poor communication and understanding³⁰. Disability workers likewise feel that they lack skills in

speaking about physical health problems³⁰.

Organisational and inter-organisational barriers: Physical or organisational barriers, including operational policies, may mean that health services are not accessible to people with some forms of disability^{4,16}. Physical barriers regularly limit access to services by people with disability including a lack of accessible transportation and inaccessibility of buildings, rooms or equipment^{19,25}. Some services also actively exclude people with particular needs, for example some health services are not available to people who experience drug and alcohol addictions²⁹. Individuals with a mental health-related disability have also been excluded from disability organisations with mental health not seen as a disability by some⁴². Organisational barriers often result from poor communication¹⁵, including:

- Poor cross-service working because of a lack of understanding about who to make contact with¹⁹.
- Incorrect 'assumptions' about other sectors and organisations and what they do²³.
- Competitive funding arrangements which have led to increases in organisational privacy concerns³⁷.

While annual levels of GP contact amongst Australians with disability are generally high (94.9%)³ people with disability and their carers often report low satisfaction levels with health care generally^{20,15,30}. Key areas in which they report low satisfaction include high waiting times for service access and poor communication³¹. Individuals with disability may also experience 'fear and fatigue' as a result of repeated failed attempts in the past to access the health services that they need, meaning that they are less likely to then ask for that care in the future³².

3. SOLUTIONS TO CURRENT PRACTICE PROBLEMS

Policy change alone will not change practice, so while commitments made and expressed at a government level are important, specific strategies for implementation need to be devised for the health and disability systems⁴². Health and disability systems are at their heart systems of people. This means that "human connections matter"²⁸ and solutions must focus primarily on the people involved in health and disability as practitioners, planners, connectors, administrators, carers and consumers. In doing so, human qualities are important, and the creation of circumstances where individuals are encouraged to reorient their individual practice and are valued for their dedication to shared working will help^{23,30}. Both health and disability sectors need to be involved in strategies for work to progress²⁰.

The workforce for disability is a core mechanism for connecting the health and disability sectors. The literature tells us that specific mechanisms to create connections are:

- A core focus in key roles on making connections through involvement in cross-sector collaboration and discussion. Key vehicles for this are inter-agency forums on particular health or disability-focused issues and working groups which develop shared action projects^{6,38}.
- A stated orientation within organisations towards all forms of disability, to include mental health⁴². Linked to this should be work on stigma in order to educate practitioners about the reality of mental health and illness.

- Active development of connections with key individuals. In the Hunter NDIS trial site connections with General Practitioners and Practice Nurses were actively made in order to engage these professionals (who are sometimes isolated in communities) in order to increase connections.
- Key roles within NDIS service organisations need to have pre-existing knowledge (not necessarily clinical) of the health sector. Pre-existing connections held by key roles within organisations facilitate connections and access through providing a starting point for communication³⁸.
- The literature emphasises that core workers must have time within their roles to actively make connections^{28,38}. NDIS Planners and Local Area Coordinators or Community Connectors therefore need to have significant time to ‘build bridges’ included in their roles rather than as an incidental part of their work. Case load needs to be low enough for communication to be built in so that shared planning can be completed for each client where necessary^{23,31}.
- The use of flexible funding pools to promote shared projects which build cross-sector capacity¹³. This has been used effectively in this way in the Partners in Recovery mental health program³⁸.
- While a focus on cooperation and collaboration needs to be built into each role in the system there should be primary roles with a responsibility to make sure that this is happening^{7,18}.
- Many of these innovations are already being practiced extensively in mental health because they have been forced to work in a cross-sectoral way due to the complexity of need in relation to mental ill-health and the emphasis placed on cooperation in previous programs such as Partners in Recovery^{7,38}. The disability sector therefore has much to learn from mental health with regards to the successes and failures of previous work.

Action will not take place if it is only left to one sector to do all of the work. Therefore **the health workforce** is also a key area for action. The literature tells us that this should happen through:

- Education and training about the NDIS so that those working in the health sector understand eligibilities and cross-overs⁷.
- Education about disability more generally so that health workers feel both comfortable and knowledgeable in working with people with disability and in disability-oriented practice^{12,19,43}.
- Building community alliances through practitioner and administrative involvement in cross-sector collaboration through key roles, forums and working groups²⁸.
- Appointment of NDIS ‘Champions’ and named individuals with primary responsibilities in intersectoral collaboration^{7,18}. Champions were used at the Hunter NDIS trial site in order to spread understanding about NDIS in mental health services. This practice is highly effective and will be important in spreading understanding of the NDIS in key professions and health services.

Organisational oversight: For any of these strategies to be successful there needs to be strong oversight within both local organisations and central policy organisations which actively pushes and prioritises a shared vision and “mutual respect”⁴¹ which moves beyond rhetoric and into action³⁶. Involvement of consumers, carers and practitioners ‘on-the-ground’ in decision making at high levels is essential so that oversight is grounded in the experience of

those involved in program implementation. High level leadership is also essential to successful implementation. Action will be most effective if it is tied to targets and with dedicated funding attached^{23,27}. New systems of shared record keeping and information management should be prioritised as an administrative support to foster ease of cross-sector working^{15,25}.

The literature tells us that an overarching effective principle which orients services towards collaborative working is **individualisation or personalisation**⁷. This concept is core to recovery-oriented practice in mental health, person-centred care in disability and re-enablement philosophies in aged care. This is thus an ethic that should already be operating in both health and disability services, and indeed structures the operation of the NDIS, but it is rarely considered and operationalised in a cross-sectoral manner. A focus on individualisation at a cross-sectoral level would allow processes to become more 'human'⁵ and meet needs from the individual's perspective rather than the conflicting structures of the different systems³⁰. If this is used as a starting point for cooperation, consumer involvement in cross-sectoral work is prioritised because of the necessity for following consumer needs. An organisational orientation towards individualisation means that organisations must set up the circumstances which facilitate this process through prioritising consumer oriented, collaborative processes. When cross-sectoral conversations and action around individuals' needs occurs repeatedly then natural connections start to evolve which bring the system together³⁸. Individual NDIS plans can therefore be a key strategy for connecting the system as a whole and this opportunity needs to be grasped and facilitated through the other strategies identified here in this review.

INDIVIDUALISATION NECESSITATES

- >> consumer focus
- >> carer or support staff involvement
- >> collaboration as needed to fulfil consumer's needs.

The literature focuses very strongly on the need for **health and disability workers and organisations** to work with **consumers, carers and support workers** as they also have a strong role in facilitating these connections. The main strategies identified are:

- Employment of consumer peer workers and carer advocates within health and disability services¹⁴.
- Encouragement of consumer 'self-efficacy' is key to successful collaborative care by supporting consumer decision making and involvement in their own case management^{7,18,19}. Consumer empowerment will enable individuals to advocate to health services on their own behalf and know that they can ask for help when they need it^{30,11}.
- Recognition of the importance of carers who are important for progressing care alongside formal care programs^{7,18}.
- Carer mentoring programs where carers can be mentored to take on carer case management roles¹⁵.
- Sharing stories through paid positions and involvement in consumer, carer and practitioner forums. Within health services they are able to spread understanding and 'humanise' disability. Within disability services they may draw attention to difficulties involved in health

service interaction.

- Co-production of the system with carers and consumers through the creation of 'learning networks' or 'local coalitions' involving consumers, carers, practitioners and administrators³⁷.
- The validation of carer case-managers and consumer self-managers through their involvement in decision making, working groups, forums and organisational development and planning exercises⁶.
- Key to consumer and carer involvement in these ways is a focus within the health and disability workforce on enabling this action through education and validation of the consumer experience²⁷.
- Involvement of consumer, carers and support staff in system evaluation going beyond basic satisfaction surveys¹⁹.

4. CONCLUSIONS

For health and disability services to effectively work together to meet complex care needs in the context of the NDIS there needs to be action and ownership from both the health and disability sectors. This action is best focused around an ethic of individualisation, an opportunity offered by the NDIS, which should also highlight the importance of consumer and carer involvement.

Organisations must see cooperation and connections as a core part of each role by making time within positions, identifying key roles that can help others to understand the NDIS-Health interface and validating and including consumer, carer and support worker knowledge in organisational decision making. Organisations must also look externally and open themselves up to cooperation through involvement in jointly managed working groups, interagency forums and projects funded by the flexible funding pools available through the NDIS. This will develop a shared community of practice where each 'system' understands themselves as part of the other and cooperation becomes a natural part of work.

APPENDIX A: METHOD

Relevant research and other useful documents were identified through structured journal database searching and a search of relevant ‘grey’ literature such as policy and practice guidelines and associated documents. The aim was to create a rapid review which would allow those working in NDIS related policy and practice to understand the barriers to effective practice at the interface between health and disability and to propose solutions which would address these barriers.

Rapid Reviews are ‘evidence summaries’ which aim to ‘rapidly’ provide end users with a summary of relevant research which will inform their practice²². Rapid reviews are designed to be a much faster review process than systematic reviews but are similar in process. While retaining the ‘systematised’ searching of systematic reviews, rapid reviews differ in that they do not offer a meta-synthesis of the data from papers identified, replacing this with a narrative summary of relevant findings²².

The following databases were accessed (in May 2016) in order to find relevant academic journal articles: Cochrane Collection, Cinahl, Medline, Social Science Citation index and the Web of Science.

The definition of disability used to frame the rapid review is the United Nations definition: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, hinders their full and effective participation in society on an equal basis with others” (Article 1, UN, 2006).

Search terms and method:

Search terms were expanded out from the basic research question which sought literature on the interface between health and disability.

Search terms were tested to determine those terms which would be most likely to return effective responses. Previous reviews on similar topics were also referred to in order to determine which terms had been effective in those studies^{e.g.27,35}.

SEARCH SET 1: TERMS FOCUSED ON HEALTH AND DISABILITY:

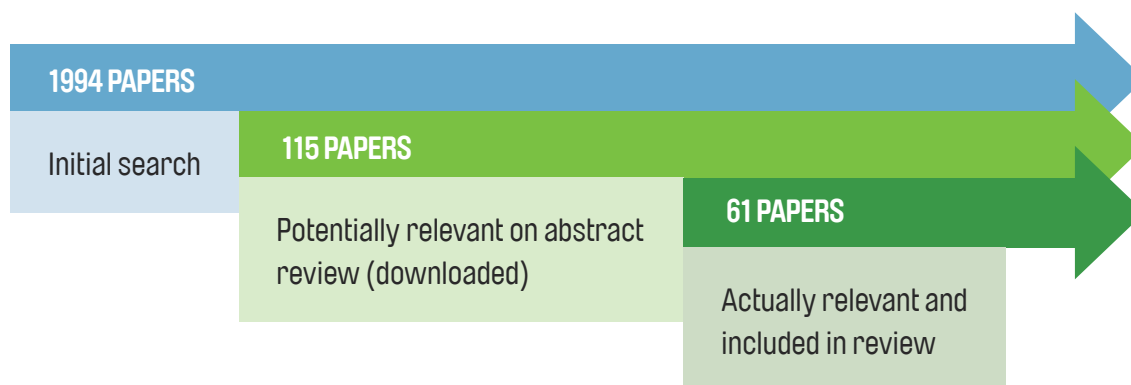
“complex needs” OR (Disab* AND health OR healthcare OR complex*) OR (Disab* AND health AND service*)

SEARCH SET 2: TERMS FOCUSED ON ‘INTERFACE’:

“care coordin*” OR “coordinated care” OR workforce OR workers OR “integrated care” OR complex* OR “case manag*”

Each database search brought together a term or string from Search Set 1 with Search Set 2. Duplicates were removed and the abstracts of remaining papers hand searched for relevance to the review. Potentially relevant papers were downloaded where possible and read. Those full papers relevant to review were included in the final article count. Additional papers were included where relevant papers not already included in the review were found through searching citations of included papers. A total of 61 relevant papers were included in the final review (see Figure 1).

FIGURE 1: NUMBERS OF PAPERS AT EACH STAGE OF REVIEW METHODOLOGY



Inclusion criteria for journal database search

- All long-term physical, mental, intellectual or sensory impairments were included as disability, as per the United Nations definition, above.
- Only papers published in the last 10 years were included as this gives a better understanding of current practice.
- Published in English.
- Dealt with both children and adults, but not those primarily focused on populations aged over 65. This criteria was chosen because of the inclusion criteria for NDIS which extends to children, but not into aged care.
- Did not deal with acute settings and immediate rehabilitation from episodes of acute care. This is an exclusion criteria for the NDIS.
- Excluded papers focusing on developing countries as those systems very different to those operating in Australia.

Search of 'grey literature'

The search of grey literature took the NDIS as its starting point and looked for all legislation, guidelines and other literature which spoke about the interface between health and disability services in that context. Searching was conducted via google search which prioritises

AS THE NDIS WAS CORE TO THIS SEARCH EACH SEARCH INCLUDED:

NDIS OR NDIA OR "national disability insurance"

OTHER SEARCH TERMS USED WERE:


health AND "care coordin*" OR "coordinated care" OR workforce OR workers OR "integrated care" OR complex* OR "case manag*"

Numbers of search terms were not mapped for the grey literature search because of the large numbers of irrelevant search results and duplicates. Any relevant papers were downloaded and added to the review and used as background information or included in the review results.

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