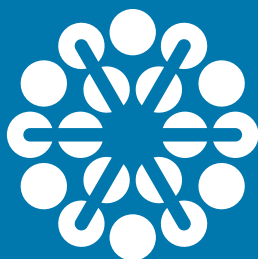


RESEARCH TO ACTION GUIDE

>> 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

Good Practice Summary





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.

ACKNOWLEDGMENTS

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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

WHAT IS THE PROBLEM?

The health and wellbeing of people with a disability are a national priority under the National Disability Strategy¹ but the National Disability Insurance Scheme (NDIS) separates disability from health with the NDIS covering only those disability services which are not covered by other systems such as ageing or health.

This may be a problem for workers for two reasons: 1) because these systems already have problems working together and 2) because people with a disability often experience poor health^{2,3} which makes cooperation very important.

Service coordination between health and disability is typically poor. People with disability often have needs that overlap between the disability and health sectors and coordinated care is critical for living a good life⁷.

The reasons for people with a disability having poor health are complex but include the following:

- People with a disability may take medications which improve their functioning in relation to their disability but may impact negatively on their physical health, for example medications for mental ill-health may lead to weight gain which may then cause diabetes or cardiovascular disease⁴.
- Health care workers may have trouble seeing the ‘person’ behind the disability and only treat their disability and not other things that make them unwell.
- Individuals with a disability may experience ‘fear and fatigue’ as a result of repeated failed attempts to access the health services that they need, meaning that they are less likely to then ask for that care in the future⁵.

The NDIS operating principles state that health and disability services must work together at local levels “to plan and coordinate streamlined care for individuals”⁸. These principles also state that the NDIS is able to fund work that assists NDIS planners to understand the health needs of clients and the coordination of cross-sector supports.

EXPERIENCE: POOR TRAINING AND COMMUNICATION

Jonas is a 45 year old man who is receiving support through the NDIS due to a long-term diagnosis of schizophrenia. He has also recently been diagnosed with Cardio Obstructive Pulmonary Disease (COPD). As part of his NDIS package his planner has organised for him to attend an exercise group for COPD run by a physiotherapist. The physiotherapist is concerned about his inclusion in the group as she thinks he may be “unpredictable”, she feels that she “knows nothing about people with mental illness” and does not know who to talk to about Jonas’s current mental health. Her reaction reflects her lack of training in mental health and accompanying stigmatised views about mental illness alongside poor information sharing between Jonas’ health care workers, the NDIS planner and the physiotherapist.

BARRIERS MAKING CURRENT WORK DIFFICULT

System barriers: Different levels of government (federal, state) and regulation make working together difficult and this can lead to poor information sharing between health and disability services⁶.

Professional barriers:

- Within different professions ways of working have developed which mean that different ways of thinking and doing make work in disability and health quite different⁶.
- People's work is becoming more specialised in both health and disability services which may mean that professionals may not feel able to assist people with a disability with health needs^{6,9}.
- Services may also be too rushed to take the time with people with complex needs and work out care plans through communicating across sectors¹⁰.

Organisational barriers: Barriers exist which mean that health services are not accessible to people with some forms of disability⁹, for example some health services are not available to people who have drug or alcohol addictions or particular types of physical disabilities.

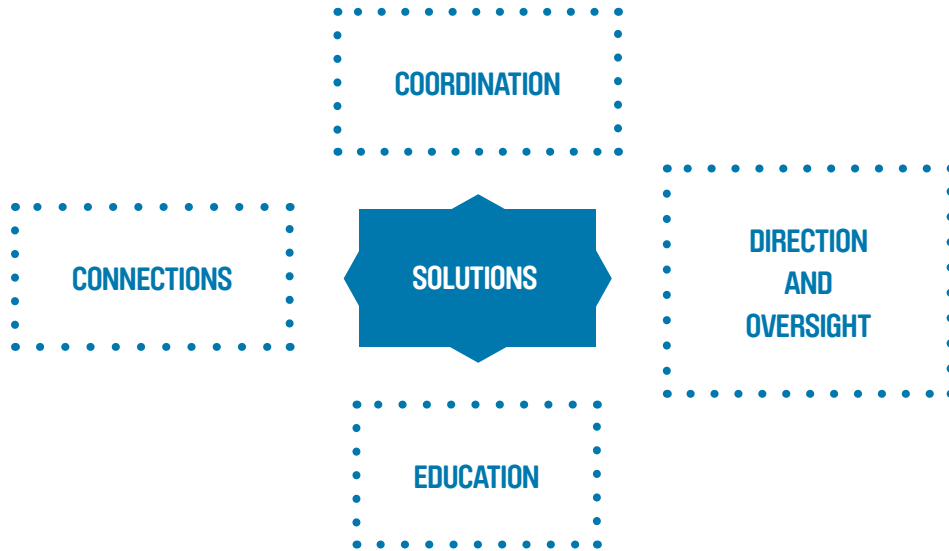


EXPERIENCE: ACCESSIBILITY PROBLEMS

Rosa is a 13 year old girl whose disability impacts on her speech and movement. She uses a wheelchair and communicates via an eye gaze communication system. She receives support from the NDIS. Recently her parents have become concerned about her vision which is crucial to her communication. She needs to see an Ophthalmologist but her parents have only been able to find one which could fit her wheelchair in the consulting rooms. Her parents were unhappy with that specialist who would not speak directly with Rosa and take the time to work with her parents to understand her communication. Her parents have now been referred to an Ophthalmologist at a major public hospital two hours from their home and have to wait more than 6 months for an appointment. These problems arise from a lack of basic services meeting the needs of people with a disability, poor information sharing between carers and health services and a lack of understanding about the involvement of people with a disability in their own health care.

SOLUTIONS

Action on better coordination, connections, direction and education is needed by both the health and disability sectors. Consumers and carers are also important and they should be included as partners in this process.



Health and disability systems are at their heart systems of people. This means that “human connections matter”⁶ and solutions must focus on the people involved in health and disability as workers, carers and consumers.

HEALTH WORKERS	Education on the NDIS Education on disability-focused practice Positioning of NDIS champions within key health services Participation in shared working groups and interagency forums	Education on avenues for accessing accessible health care Education on the boundaries of NDIS Employment of consumer peer workers and champions Consumer ‘enabling’ and valuing	CONSUMERS
DISABILITY WORKERS	Time within work roles to ‘build bridges’ with key individuals through working groups, interagency forums Employment of individuals with experiences in both sectors into key roles	Education on how to access accessible health care Education on the NDIS separation between disability and health Employment and involvement of carer advocates in key organisations	CARERS



EXPERIENCE: EFFECTIVE COMMUNICATION

A small disability service provider in a regional centre in NSW has taken a proactive approach to educating staff in their local hospital. The client group have profound disability and are medically frail.

As a result, they have a lot of contact with health services, including the local hospital via planned and emergency admissions. Disability service staff regularly make educational presentations and provide resources to the hospital social work department. The social workers practice throughout the hospital, and are expected to educate others in turn.

When it comes to hospital admissions, the disability service provider and local hospital have made an agreement, providing a uniform system of resourcing and role division that is consistently implemented. At the commencement of any hospital admission, the disability worker presents a letter to the hospital describing who they are and why there is a support person at the hospital. The document details what support the disability practitioners will provide for the individual and why, and what the hospital needs to do. The consistency of the application of this policy means that the hospital is well versed in the value of the support of the disability service provider¹.

THE EXISTING RESEARCH SHOWS TWELVE POINTS OF ACTION THAT YOU CAN INFLUENCE TO MAKE A DIFFERENCE

DISABILITY WORKFORCE ACTION

1

Get educated about the principles of the NDIS and its expectations for working together with health services.

2

Grow connections with key people in the health system, and learn about the context of their work. Develop inter-agency forums on health or disability-focused issues and working groups which undertake shared action projects^{11,12}.

EXAMPLE: In the Hunter NDIS trial site connections with General Practitioners and Practice Nurses were made in order to engage these professionals (who are sometimes isolated in communities) and this was successful in increasing conversations and understanding.

3

Appoint people who have knowledge about the health sector to key roles within disability service organisations. This makes connections and access easier through providing a starting point for communication¹².

4

NDIS Planners and Local Area Coordinators or Community Connectors must dedicate significant time to 'build bridges' included in their roles rather than as an incidental part of their work^{6,12}.

5

Use flexible funding pools to promote shared projects across health and disability.

EXAMPLE: A shared project funded by Inner Western Sydney Partners in Recovery which brings together Partners in Recovery, Sydney Local Health District and Justice Health to create a transition support program for people with mental health related disabilities leaving custody¹².

HEALTH WORKFORCE ACTION

6

Get educated about the NDIS and disability more generally to feel both comfortable and knowledgeable in working with people with disability and in disability-oriented practice (working in an individualised, person-centred way, drawing on an individual's capacities)². Health services should develop and implement a set of competencies in NDIS and disability-oriented practice for workers which can be offered through existing professional development programs.

7

Respect disability worker and carer competency and the importance of non-clinical knowledge. Create of community alliances through worker and administrator involvement in cross-sector working through key roles, forums and working groups⁶.

8

Appoint NDIS 'Champions' within health services.

EXAMPLE: 'Champions' were used at the Hunter trial site in order to spread understanding about NDIS in mental health services.

CONSUMER AND CARER ACTION

9

Become a carer and consumer representative through involvement in consumer, carer and practitioner forums. Sharing stories about disability to spread understanding of the experience of disability and how services can be better designed will have an impact.

10

Disability and health services should engage with or employ consumer 'peer workers' (people with a lived experience of disability) and carer advocates¹³.

11

Disability and health practitioners must involve self-managers in decision making, working groups, forums and organisational development and planning¹¹. Inclusion of carer and consumer self-managers in both the health and disability systems will make the system more responsible to their needs.

12

All workers need to 'enable' consumers and carers through placing a value on their experiences and meaningfully explaining how they can contribute¹⁴. When individuals are used to having their needs and experiences ignored it is difficult for them to speak up.

Administration: For any of these strategies to be successful both local organisations and central policy makers must push and prioritise a shared vision and "mutual respect"^{15,16}. Involvement of consumers, carers and practitioners in 'on-the-ground' in decision making and at high levels is essential so that administration is grounded in the experience of those actually involved in the frontline provision of support and services.

Action is most likely to work if there are individuals with a named responsibility, targets for action made and specific funding given¹⁴.

The definition of disability which underpins this document is the UN 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).

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