CRE–DH

Centre of Research
Excellence in
Disability and Health

SYSTEM CHANGES TO ENABLE OPTIMAL HEALTH OUTCOMES FOR PEOPLE WITH DISABILITY

Discussion paper from the 2022 CRE-DH Policy Forum

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in partnership with

THE UNIVERSITY OF MELBOURNE

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UNSW CANBERRA

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MONASH University

About the CRE-DH

The Centre of Research Excellence in Disability and Health (CRE-DH) aims to identify cost-effective policies to improve the health of people with disability in Australia. There are four interconnected research areas the CRE-DH focuses on:

- mapping the health inequities between Australians with and without disabilities,
- analysing the social, economic and environmental factors that contribute to the poorer health of people with disability,
- modelling the cost-effectiveness of health policy interventions, and
- policy analysis and reform.

The CRE-DH is an interdisciplinary research group with Chief Investigators from the University of Melbourne, University of Sydney, Monash University, UNSW Canberra and RMIT with multidisciplinary skills in epidemiology, health economics, health and social policy, psychology and public health. We work closely with government and peak bodies in the disability advocacy and service. The CRE-DH Co-Directors are Professor Anne Kavanagh (University of Melbourne) and Professor Gwynnyth Llewellyn (University of Sydney). Several members of the CRE-DH research team have lived experience of disability.

Authors and acknowledgments
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Abbreviations

COVID-19	Coronavirus (SARS-CoV-2 virus)
CRE-DH	Centre of Research Excellence in Disability and Health
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DLO	Disability Liaison Officers
DRC	Disability Royal Commission (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability)
MBS	Medicare Benefits Schedule
NDIS	National Disability Insurance Scheme
NDDA	National Disability Data Asset

Executive summary and recommendations

Introduction

- Australians with disability have poorer health than their peers without disability across a range of health outcomes, despite Australia's obligation under the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (Article 25) that people with disability have the right to the highest attainable standard of health, without discrimination on the basis of disability. A significant proportion of the gap in health between people with disability and people without disability (disability-related health inequalities) are avoidable.
- The poorer health of Australians with disability is related to social and economic disadvantage (social determinants) as well as lack of access and inclusion in health promotion, preventative health care and health services. To address these multiple drivers of health, cross-sectoral collaboration is required, particularly between the health and disability sectors.
- The CRE-DH held a virtual policy forum[1] with Commonwealth government policy makers and Disability Representative Organisations. The forum was repeated the next day with different attendees. Participants in each forum were separated into groups and the groups discussed two questions:
    - How can health care systems be designed so that people with disability receive the support they need to achieve health on an equal basis to others?
    - How can health, disability and related service systems work together to help achieve optimal health outcomes for people with disability?
- As the discussions were focussed at a national level, recommendations primarily relate to health and disability reforms within the Commonwealth government however inevitably they did highlight the importance of whole-of-government responses. Further workshops could be held to better understand effective policy reforms across levels of government and sectors.

Although the discussions mainly focused on the disability and health systems, the social determinants of health such as housing, justice and employment were raised, however their interactions with the health and disability systems were not fully explored and could be the focus of future workshops.

What we found

- The working groups identified 12 issues and discussed several solutions which form the basis for the 12 recommendations for reform that should be considered. These are summarised in Table 1 and grouped under three categories: whole-of-government, health system, and across the disability and health systems.

Concluding remarks

- This report and its recommendations offer guidance for the Commonwealth government and agencies to move forward to improve health of people with disability. Of the 12 recommendations for action, two were identified as critically important and implementable:

  Recommendation 1: Develop a National Disability and Health Strategy which incorporates some of the recommendations made in this report. There should be meaningful inclusion and active involvement of people with disability in shaping the National Disability and Health Strategy.

  Recommendation 5: Conduct Disability Impact Assessment in the Department of Health and Aged Care. The assessments will enable the government to understand the potential impact of health policies on people with disability before their implementation. By doing so, any policy adjustments or major revisions can be made before policy rollout and prevent harm to people with disabilities.

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[1] See Appendix 1 for detailed information on the structure of the policy forum workshops.

Table 1. Issues and recommendations from national workshops for whole-of-government, health systems, and reforms across the disability and health systems

ISSUES	RECOMMENDATIONS
Whole-of-government reforms	
1. Lack of overarching disability and health strategy to inform government action at a national level.	1. Develop a National Disability and Health Strategy.
2. Exclusion of people with disability from policy and decision-making processes at national level.	2. Include people with disability in the design and implementation of policy across all sectors.
3. Lack of coordination across government services and sectors to ensure the needs of people with disability are met.	3. Consider the establishment of a National Agency for Disability to coordinate disability-related policy and programs across government including health, possibly within the Department of the Prime Minister and Cabinet.
4. Absence of quality national data to monitor and evaluate the impact of health and related policies, for example, education, employment and housing on the health of people with disability	4. Improve the quality of national data through the development of disability identifiers and integration (linkage) of data across State and Territory service systems.
Health system reforms	
5. Policies and programs not being assessed prior to implementation in terms of the likely impacts on the health of people with disability.	5. Conduct Disability Impact Assessments to understand the potential impacts of policies on the health of people with disability.
6. Health services are often not accessible to people with disability and do not address their needs.	6. Health services should be high quality, person-centred, accessible and address the needs of all people with disability.
7. Particular groups of people with disability experience considerable barriers to access mainstream services and do not have their specific needs met in the health care system.	7. Tailored health care services where necessary and building the capacity of mainstream services for all people with disability.
8. Health care systems do not adequately incentivise the promotion of health.	8. Health care systems should incentivise the promotion of health and equity outcomes, including for people disability, rather than simply fund activity (i.e., delivery of a service).
9. While responsibilities for health are the responsibility of Commonwealth and State and Territory governments, actions are often uncoordinated and boundaries unclear.	9. Commonwealth, State and Territory governments work together to achieve optimal health outcomes for people with disability through a National Disability and Health Strategy and a specific action plan through the Australian Disability Strategy.
Cross-sectoral disability and health system reforms	
10. People with disability experience difficulties understanding and navigating complex and poorly connected disability and health service systems.	10. The health system should proactively collaborate with other organisations to guarantee accessible and timely availability of information and services catering to the broader health and wellbeing needs of people with disability.
11. Lack of incentives, structures and processes that enable sharing of knowledge and collaboration within government.	11. Provide funding and opportunities for Commonwealth departments and agencies to work together.
12. Lack of accountability within each system for the health of people with disability.	12. Build on current cross-sectoral forums and committees that include people with disability and other stakeholders to identify opportunities for reforms across the sectors.

Introduction

The COVID-19 pandemic has been an unprecedented public health emergency and its onset required prompt and effective action across all levels of government and multiple sectors. While the pandemic presented many challenges for people with disability, it also led to significant changes to the delivery of health and other services that potentially improved outcomes for people with disability.

In September 2022, the Centre of Research Excellence in Disability and Health (CRE-DH) facilitated policy forums that enabled discussion between the health and disability sectors. The forums aimed to understand the challenges and opportunities for cross-sectoral collaboration presented by the pandemic and in 'business as usual' for people with disability. The CRE-DH brought together senior government policy makers and key individuals and organisations in health and disability that interact at the Commonwealth level. The virtual policy forums held over two half-days[2] were attended by senior personnel from Commonwealth Government departments, Disability Representative Organisations, Australian Institute of Health and Welfare, and the Australian Bureau of Statistics.[3]

Prior to attending the Policy Forum, participants were provided with a Background Paper outlining the following issues:

- Australians with disability have poorer health than their peers without disability across a range of health conditions[1, 2]
- As a signatory to the United Nations Convention on the Rights of People with Disability (CRPD), Australian governments are required to ensure that Australians with disability have the highest attainable standard of health without discrimination on the basis of disability (Article 25)[3]
- Much of the poorer health of people with disability is avoidable and relates to systemic issues including socio-economic disadvantage and lack of access to quality and affordable health care, health promotion and prevention[4-9]
- Health and wellbeing is one of seven outcome areas in the Australian Disability Strategy
- The health of people with disability is shaped by policies across health and other service systems such as disability and education

Workshop questions

Discussions were structured around the two following questions:

1. *How can health care systems be designed so that people with disability receive the support they need to achieve health on an equal basis to others?*
2. *How can health, disability and related service systems work together to help achieve optimal health outcomes for people with disability?*

This paper

This paper summarises opportunities for disability reforms in three categories: whole-of-government, health system, and cross-sectoral disability and health systems. In each category we summarise the major issues and recommendations identified in the workshops and describe the rationale for each recommendation.

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[2] The two days were identical in structure and participant composition, with the exception of attendees. Details in Appendices 1-3.

[3] Appendix 4 contains the complete list of departments and organisations in attendance.

Section 1 – Whole-of-government reforms

Participants recognised that the health of people with disability is influenced by the actions of several government departments. In particular, while health policy and access to quality health services were seen as important, so were social determinants of health, such as employment and housing.

Major problems impeding whole of government response:

1. Lack of overarching disability and health strategy to inform government action at a national level.
2. Exclusion of people with disability from policy and decision-making processes at national level.
3. Lack of coordination across government services and sectors to ensure the needs of people with disability are met.
4. Absence of quality national data to monitor and evaluate the impact of health and related policies, for example, education, employment and housing on the health of people with disability.

Recommendations to enable effective whole-of-government responses to improve the health of people with disability

Recommendation 1: Develop a National Disability and Health Strategy.

Recommendation 2: Include people with disability in the design and implementation of policy across all sectors.

Recommendation 3: Consider the establishment of a National Agency for Disability to coordinate disability-related policy and programs across government including health, possibly within the Department of the Prime Minister and Cabinet.

Recommendation 4: Improve the quality of national data through the development of disability identifiers and integration (linkage) of data across State and Territory service systems.

Recommendation 1: Develop of a National Disability and Health Strategy.

Government strategies do not comprehensively cover the health of all people with disability. Therefore, an overarching disability and health strategy is needed to guide policy.

The Australian Disability Strategy identifies health and wellbeing as an outcome area and has policy priorities that focus on improving capability of health services; provision of timely, effective, and accessible prevention and early intervention services; accessible mental health supports; and disaster preparedness. While government flagged that each outcome area in the Australian Disability Strategy will have a Targeted Action Plan, this is not yet available for health and wellbeing[10].

We note that the Commonwealth Department of Health and Aged Care has developed a 'National Roadmap for Improving the health of people with Intellectual Disability' which includes a $43 million investment to fund a Primary Care Enhancement Plan for People with Intellectual Disability; improving health assessment for people with intellectual disability; curriculum development; and the establishment of a National Centre in Intellectual Disability Health. In addition, the Department of Health and Aged Care is developing a National Roadmap to Improve the Health and Mental Health of Autistic People. The Roadmap will be associated with the National Autism Strategy, which is being developed by the Department of Social Services.

While these strategies are important, they do not systematically address the health issues for all people with disability, instead taking a diagnosis-specific approach. While diagnoses may guide health care, these do not include an understanding of functioning (e.g., self-care, mobility, communication) which impacts how well people can access quality health care and the barriers they experience accessing quality health care, social inclusion and community participation.

Without an overarching Disability and Health strategy covering all people with disability, Australia lacks a framework to guide action to improve the health of all people with disability in line with our obligations under the CRPD. A National Disability and Health strategy could consider the findings and recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and outcomes from the NDIS review, as well as consider the roles and responsibilities of all levels of government in relation to health and also in relation to disability.

Recommendation 2: Include people with disability in the design and implementation of policy across all sectors.

There was strong endorsement for the importance of centring the voices and interests of people with disability in in all policies that affect their lives.

Participants acknowledged that policies had often been developed for rather than with people with disability. They noted that without effective co-design of policy and programs there was the potential for policy to have detrimental impacts for people with disability because of misunderstanding of their needs and/or having decisions made on the basis of outdated attitudes about disability which are detrimental.

Recommendation 3: Consider the establishment of a National Agency for Disability to coordinate disability-related policy and programs across government including health, possibly within the Department of the Prime Minister and Cabinet.

A central agency tasked with leading and coordinating activities across government departments as a mechanism to foster collaboration across sectors, facilitating higher quality policy and program design.

Participants recognised the importance of disability being considered across all Commonwealth Departments. They argued that each Department had dedicated staff that had responsibility for ensuring the interests and needs of people with disability were considered in Departmental policies and programs and identifying whether specific policies were needed for people with disability. Some workshop participants strongly supported the establishment of a central agency responsible for coordinating policy responses across sectors, potentially located within the Department of the Prime Minister and Cabinet. A centralised agency will enable integration of policies across different departments. Participants proposed that all policies consider the impact on the health people with disability, although in practice it may be more practicable to do this in health policy first.

Recommendation 4: Improve the quality of national data through the development of disability identifiers and integration (linkage) of data across State and Territory service systems.

There was widespread endorsement of the need to improve data systems in line with what has been proposed for the National Disability Data Asset (NDDA).

The dearth of information on the health of people with disability and lack of dissemination of this information were seen as impediments to action. Without this information governments do not know the extent of the health inequalities between people with and without disability nor do they have evidence about how to address them.

The data that are available paint a dim picture that clearly requires immediate action. For example, studies of people with disability who accessed disability supports (prior the NDIS) found that they had 4.7 times the death rate and 3.6 times the level of potentially avoidable deaths than the general population. People with acquired brain injury, vision impairments and psychosocial disabilities had the highest rates of avoidable deaths as well as people with disability receiving accommodation support[11].

Participants noted the lack of evidence regarding the efficacy and cost effectiveness of policy interventions that impact on the lives of people with disability. Improvements in data quality and access, including outside of government, is a necessary foundation for this work to occur.

Other data challenges include the lack of disability identifiers across administrative datasets, with only recipients of the Disability Support Pension and NDIS participants consistently identified[12]. Participants highlighted a significant gap in the inclusion of disability-related information within health records, in particular primary care[13]. Participants suggested that there was the potential to ask questions about disability through the Voluntary Patient Record, emphasising that such data should be collected exclusively on an opt-in basis. We note that CRE-DH has illustrated the process for accomplishing this in primary health care[14].

Finally, the integration of datasets across jurisdictions, and Commonwealth Statutory bodies and sectors was identified as lacking and a key priority. However, the participants emphasised the need for strong ethical oversight of these processes to ensure that the necessary safeguards were in place.

Without integration of datasets across sectors, it is impossible to understand the pathways people with disability take across different service systems. This limits knowledge about the structural and systemic barriers people with disability face, the point at which the systems may be failing, and comparisons between systems and over time to understand what works and why.

A multipronged approach is needed to improve data quality including:

- Construction and inclusion of disability identifiers in all population datasets. This will assist in understanding how people with disability interact with health and other service systems and how these interactions influence health outcomes for people with disability.
- Collection of information on disability in primary care
- Include more information on service types across administrative datasets
- Integration of data across jurisdictions, Commonwealth Statutory bodies, and sectors

We note that many of these activities are now being planned as part of the NDDA.

Section 2 – Health system reforms

In this section, we highlight participants' reflections about how health systems and services can address barriers for people with disability in accessing quality health services. Participants recognised that all parts of the health system (prevention, primary care, and hospital care) were failing to meet the health care needs of people with disability. The challenges identified relate to improving individual's experiences with health services as well as the health system.

Main challenges with the health care system:

Challenges with health services

5. Policies and programs are not assessed prior to implementation in terms of the likely impacts on the health of people with disability.
6. Health services are often not accessible to people with disability and do not address their needs.
7. Particular groups of people with disability experience considerable barriers to access mainstream services and do not have their specific needs met in the health care system.

Challenges with health policies and systems of government

8. Health care systems do not adequately incentivise the promotion of health.
9. While responsibilities for health are the responsibility of Commonwealth and State and Territory governments, actions are often uncoordinated and boundaries unclear.

Recommendations to improve health system for people with disability

Recommendation 5: Conduct Disability Impact Assessments to understand the potential impacts of policies on the health of people with disability.

Recommendation 6: Health services should be high quality, person-centred, accessible and address the needs of all people with disability.

Recommendation 7: Tailored health care services where necessary and building the capacity of mainstream services for all people with disability.

Recommendation 8: Health care systems should incentivise the promotion of health and equity outcomes, including for people disability, rather than simply funding activity (i.e., delivery of a service).

Recommendation 9: Commonwealth, State and Territory governments work together to achieve optimal health outcomes for people with disability through a National Disability and Health Strategy and a specific action plan through the Australian Disability Strategy.

Recommendation 5: Conduct Disability Impact Assessments to understand the potential impacts of policies on the health of people with disability.

Disability Impact Assessments were seen as a way to ensure that policies and programs improve the health of people with disability and do not inadvertently cause harm.

Disability Impact Assessments[4] are used to assess policies and programs to see whether they address the experiences, needs, and rights of people with disability. This approach can be used to assess policies and programs that are universal as well as those that are specifically designed for people with disability. This is important because universal programs may unintentionally widen the gap in social, economic and health outcomes between people with and without disability. Adopting these assessments will enable existing and future policies and programs to be more inclusive and accessible for all people with disability and avert adverse consequences that might arise. This approach is currently being considered in the Victorian Disability Inclusion Bill.[5]

Recommendation 6: Health services should be high quality, person-centred, accessible and address the needs of all people with disability.

Participants agreed that people with disability still experience challenges accessing quality health care that must be addressed.

Reducing barriers to accessing quality health care requires action on multiple fronts including:

- Eliminating financial barriers to health care for people with disability (who spend more on health services) by removing **out-of-pocket costs**. This could be achieved by providing greater access to bulk billing practitioners or the introduction of other funding models such as capitation, block funding or strategic purchasing of health services or a combination of models.
- Address transport barriers to health care by:
    - Improving the accessibility of public transport, noting that this action sits outside the health system
    - Provide transport assistance to all people with disability who are unable to travel to health services independently
    - Incentivise health care practitioners to do home visits
- Address health care practitioners' discriminatory attitudes towards people with disability and their lack of knowledge about the health needs of people with disability through training and accreditation. Participants identified this as being particularly important in primary care settings as GPs are the first point of access to the health system and other service systems (e.g., income support). Participants recommended that training include how to provide **timely and accessible format communications** of treatment plans. Information on how to create more **welcoming and accessible** environments such as removing physical barriers to access (e.g., ramps, examination tables) and providing low sensory environments for autistic people were also considered important.

- Population-based prevention and health promotion programs must be accessible to all people with disability. This includes accessible information and facilities.

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[4] An example of questions to help guide disability impact assessments includes Appendix 5 of the Australian Disability Strategy. For an example of an application of disability impact assessment using the Disability Policy Lens (2nd ed.) see the Canadian Disability Policy Alliance (2017) Bill C-7

[5] See https://www.dffh.vic.gov.au/disability-inclusion-bill-public-consultation or part 3 of the exposure draft available at https://engage.vic.gov.au/disability-act

Recommendation 7: Tailored health care services where necessary and building the capacity of mainstream services for all people with disability.

While there was agreement that all health services should be accessible to people with disability providing health care on an equal basis, there was recognition that tailored services were needed for some people with disability particularly in the light of significant shortcomings in current services.

A few participants were of the view that by ensuring that all health services are accessible for people with disability, all people with disability would be able to receive quality care. Other participants thought that some people with disability (or groups of people with disability, such as people with intellectual disability, those with complex needs, people with disability in group homes) require tailored support embedded within or aligned with mainstream health care. Their view was that while all mainstream health services should be disability-inclusive, the need for tailored services remains due to the specialist skills and knowledge needed to provide optimal health care for some groups of people with disability.

The combined approach of health and disability systems in some States and Territories to the delivery of disability health care worked well during COVID-19 where the unique needs and barriers to health care experienced by people with disability became evident. This led to the introduction of highly successful tailored programs such as Disability Liaison Officers, Flying Squad vaccination teams to group homes or community centres, and low sensory vaccination clinics. The view of participants was that these types of initiatives should remain and be embedded in regular health care delivery.

Based on these reflections, we recommend governments implement a combined approach that ensures all health services are disability-inclusive, but where certain groups of people with disability who may not have their needs fully met within the current health service system are provided with specific services (e.g., dental services, vaccination clinics).

Recommendation 8: Health care systems should incentivise the promotion of health and equity outcomes, including for people disability, rather than simply funding activity.

There was a recognition that funding models and health policies should be designed to incentivise health equity for people with disability.

The workshop discussions emphasised the importance of designing health care systems that enable people with disabilities to have the same opportunities for good health as people without disability. This could be by the introduction of new funding models to reduce or eliminate out of pocket expenses (see Recommendation 6 for reducing financial barriers to access). The current fee for service scheme was not considered adequate to provide financial incentives to improve health and health outcomes of people with disability.

Recommendation 9: Commonwealth, State and Territory governments work together to achieve optimal health outcomes for people with disability through a National Disability and Health Strategy and a specific action plan through the Australian Disability Strategy.

Improvements in health care across all levels of government is needed to improve health outcomes for people with disability.

While the working group discussions focussed on actions at a national level, participants recognised that the State and Territory governments played an important role in ensuring people with disability had access to high quality health care, particularly in relation to hospitals and community health. In addition, primary health care networks and local area health services were well-placed to respond to local issues and share knowledge within communities. A National Disability and Health Strategy would help articulate how this could occur and enable coordination of activities across the Commonwealth and State and Territory governments.

Section 3 – Cross-sectoral disability and health system reforms

Participants agreed that that health and disability service systems must work together more effectively to address the urgent problem of the poor health of people with disability. The lack of attention to the importance of the social determinants of health for people with disability was highlighted and the importance of cross-sectoral collaboration in addressing these determinants was emphasised. It was noted that some groups of people with disability were at risk because of segregation – in particular, people with disability living in group homes.

In this section we focus on how health and disability service systems can work together to facilitate the achievement of optimal health outcomes for people with disability. This discussion covered how to enhance individual experiences across both systems as well as policy and practice levers to improve cross-sectoral collaboration.

Main problems with cross-sectoral disability/health system responses:

Individual experiences across service systems

10. Difficulties understanding and navigating complex and poorly connected disability and health service systems.

Problems with working across systems

11. Lack of incentives, structures and processes that enable sharing of knowledge and collaboration within government.
12. Lack of accountability for the health of people with disability.

Recommendations to improve cross-sectoral collaboration

Recommendation 10: The health system should proactively collaborate with other organisations to guarantee accessible and timely availability of information and services catering to the broader health and wellbeing needs of people with disability.

Recommendation 11: Provide funding and opportunities for Commonwealth departments and agencies to work together.

Recommendation 12: Build on current cross-sectoral forums and committees that include people with disability and other stakeholders to identify opportunities for reforms across the sectors.

Recommendation 10: The health system should proactively collaborate with other organisations to guarantee accessible and timely availability of information and services catering to the broader health and wellbeing needs of people with disability.

The responsibility for joining up systems should not be left to individuals.

The disability and health services systems are complex and overlap. Without expert knowledge, it is difficult for people with disability and their supporters to access the services and supports they need. It was agreed that there should be a ‘no wrong door’ approach whereby people are able to access the services and supports they need no matter where they enter the health and disability service systems. Participants were of the view that it is the responsibility of integrated service systems to comprehensively support individuals, not the other way around.

Participants discussed one potential solution: disability and health service systems navigators. Disability Liaison Officers (DLO) are one example of system navigators. In response to COVID-19 the Victorian government initially established the DLO program in hospitals to enable people with disability to be vaccinated and assist in access to testing and protective equipment including masks. Their role has been extended to include assisting people with disability to navigate the hospital system, assist in applications to the NDIS and hospital discharge for NDIS participants. The DLO program is now being delivered in all States and Territories however the extent of the program and their roles and responsibilities vary.

It is noted however that while system navigators may help *individuals* navigate the disability and health systems the overarching responsibility to connect the systems must be the responsibility of the health and disability service systems. It was also noted that disability and health systems navigators may miss disadvantaged individuals in other service systems such as justice or housing.

Recommendation 11: Provide funding and opportunities for Commonwealth departments and agencies to work together.

While COVID-19 had seen greater collaboration between the health and disability service sectors, ongoing resources are needed to embed this within 'business as usual'.

The emergency response to the COVID-19 pandemic facilitated greater collaboration across the health and disability sectors. Some participants thought that the much poorer health of people with disability was also a national health emergency, yet it was not being perceived as such. Funding and resources to respond to COVID-19 facilitated greater collaboration and a willingness of different sectors to take actions outside their usual remit (e.g., NDIS contacting participants regarding vaccination) as this funding took the pressure off individual department or agency budgets. Participants recommended a multipronged approach to facilitating cross-sectoral collaboration within the Commonwealth government. Potential actions included:

- Department specific funding to support cross-sectoral collaboration
- Shared online spaces, joint projects and co-location of policy makers
- Meeting around shared areas of interest such as **workforce planning** with health, disability and aged care sectors competing for similar workforce (e.g., allied health professionals, care workforce)

Recommendation 12: Build on current cross-sectoral forums and committees that include people with disability and other stakeholders to identify opportunities for reforms across the sectors.

Cross-sectoral committees and forums are part of 'business as usual', enhancing cross-sectorial policy and service reform.

The lack of collaboration across sectors was highlighted as an issue when responding to the pandemic because protecting the health of people within disability required a cross-sectoral response. In response to COVID-19 the Commonwealth government established two committees to inform their response: the Advisory Committee for the COVID-19 Response for People with Disability and the Disability and Health Sector Consultation Committee. These Committees were seen as a positive step that enabled coordination and collaboration across the health and disability sectors. The voices of people with disability were enabled through participation on committees and through direct influence on policymakers and politicians. Additional funding to support the public health response in COVID-19 was seen as an important enabling factor for these collaboration across the disability and health systems.

Participants thought it was important to continue large forums, such as the Disability and Health Sector Consultation Committee, to discuss broad issues related to health and smaller groups to work across sectors and jurisdictions to address specific problems such as hospital discharge. The Committee should include representatives from the States and Territories. Such a forum should play a pivotal role in driving change, designing solutions to achieve better health outcomes, and serving as an accountability mechanism for the government.

Concluding remarks

Summary of findings and recommendations

The facilitated working group sessions at the Policy Forum found consensus that:

- The poor health of people with disability requires urgent action
- Improving the health of people with disability requires addressing the social determinants of health as well as improving access to preventative health and primary health care and hospital
- All government departments and levels of government have an important role in enabling better health for people with disability

Recommendations for reform ranged from high-level whole-of-government initiatives to the introduction of specific services and supports.

Given that all government departments and levels of government have a role in enabling people with disability to achieve the highest standard of health, there was a recognition that it was important to have some overarching initiatives to guide action. A co-designed National Disability and Health Strategy that addresses the needs of all people with disability was seen as an important initiative and would assist governments to ensure they met their obligations under the CRPD. While there are co-designed strategies developed, or under development, for people with intellectual disability and autism there is not an overarching strategy. There is a risk that many people with disability will be left behind and that a condition-specific approach reinforces medical approaches to disability and are less effective at delivering systemic change.

The development and implementation of an instrument (e.g., Disability Impact Assessment) to assess the likely impacts of current and future policies on the health of people with disability was also seen as crucial as it would provide a tool that could be implemented by Commonwealth and State and Territory governments to ensure the poorer health of people with disability does not continue. Other overarching recommendations included the formation of a National Disability Agency and the improvements in the quality of disability data to monitor outcomes to evaluate policies and programs.

Recommendations for health care system reform ranged from enabling individuals to access the highest quality health care to funding models that incentivise health and equity in health care.

In relation to cross-sectoral action across disability and health systems, recommendations ranged from interventions that enable people with disability to navigate the complex disability and health service systems and their intersections to system changes to promote collaboration across sectors and levels of government.

Many of the recommendations could be a starting point for a National Disability and Health Strategy and in guiding a national overarching body on disability policy.

Since the forum in September 2022, there have been reforms in disability and health policy and the National Disability Data Asset is about to be launched and there are ongoing improvements to other population-based linked datasets such as the Person Level Integrated Data Asset (PLIDA, formerly known as MADIP). The Disability Royal Commission's findings and recommendations have also been tabled.

Below we outline these reforms and discuss the degree to which they align with the recommendations in this report. We also discuss how the outcomes of the CRE-DH's forum might assist governments to respond to the recommendations of the Disability Royal Commission.

Current policy context

Health system reforms

Commonwealth government initiatives to improve primary care have the potential to enable higher-quality affordable health care for people with disability. These include:

- The tripling of the financial incentive that GPs receive to bulk bill specified services for pensioners, health care card holders and children
- Expansion of team-based multidisciplinary care by: 1) increasing of workforce incentive program for GPs to employ various health professionals and 2) primary care networks being enabled to commission multidisciplinary care through nurses and allied health professionals
- Incentives for GPs to provide 'wrap around' care for people with complex and chronic health care conditions including frequent users of hospital services
- Greater access to primary care through Medicare Benefits Schedule (MBS) nurse practitioner services
- Implementation of MyMedicare – a voluntary patient registration that aims to strengthen relationships between patients, GPs and primary care teams
- Two-month prescriptions to reduce GP and pharmacy visits and co-payments

These reforms have the potential to improve health outcomes for people with disability by reducing financial barriers to access (bulk billing incentives and access to cheaper medicine) and more coordinated multidisciplinary primary health care. However, it remains to be seen whether the incentives will deliver the intended outcomes. The use of a disability health impact assessment may assist in identifying the potential impacts of these and future policies on the health of people with disability. Improvements in high quality data on health and disability can be used to monitor and evaluate the impact of these reforms on people with disability.

Disability policy reforms

Since the conduct of these workshops two major reports have been delivered – the final report of the Royal Commission into Violence, Abuse, Exploitation and Neglect of People Disability (DRC) and the outcomes of Independent Review of the NDIS[15, 16]. There are considerable overlaps between the recommendations in this report and recommendations from the DRC and NDIS Review. Action 2.4 of the NDIS review and recommendation 4.15 of the DRC recommend the implementation of Disability Impact Assessments to guide policy assessment. Recommendation 5 of this report also proposes the implementation of Disability Impact Assessments with a focus on how policy reforms affect the health of people with disability.

The DRC and NDIS Review recommended centralised, whole-of-government, processes to support integrated decision-making across systems. The NDIS Review recommended extending the current inter-government agreements on disability and the establishment of a new Disability Advisory Committee that reports to the Disability Reform Ministerial Council. The DRC recommended the establishment of National Disability Commission as an independent statutory body chaired by a person with disability and with the majority of commissioners being people with disability. Our recommendation for a National Disability Agency aligns with the NDIS Review's and DRC's recommendations to provide an overarching structure to facilitate input and governance from people with disability and establish cross-sectoral ways of working.

The NDIS Review focussed on building unified system of support for people with disability which includes greater investment in support and services outside the NDIS including health. In order to coordinate access to foundational supports the Review recommended the establishment of local system navigators and accessible information. This is congruent with our Recommendation 10 however we emphasise that there is a potential danger in relying on navigators to 'join-up' systems. Systems navigators will need to have a broad knowledge and skill base. Additionally, navigators must not be seen as the only, or main, solution to poorly integrated systems, the onus should be on intersecting systems to become integrated and inclusive.

Like our workshops, the NDIS Review and DRC emphasised the need for better data. The establishment of the National Disability Data Asset, an $80M investment to bring together data sets across jurisdictions and portfolio areas should see great improvements in how we can investigate the impact of policies and monitor outcomes.

Ways forward

We recommend serious considerations is given by the Commonwealth government to the outcomes of the Policy Forum workshops and further exploration of the recommendations with State and Territory governments and a broader range of Disability Representative Organisations, the research community, and stakeholders from the health and disability sectors. The recommendations emanating from our workshops align with those from the NDIS Review including Disability Impact Assessments and data improvements. Further investments need to be made to identify the tools and processes to conduct disability impact assessments.

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Appendix 1. Organisation of the policy forum

The NHMRC Centre of Research Excellence in Disability and Health (CRE-DH) held an online policy forum on Thursday 15 September 2022 and Friday 16 September 2022 to consider how the health and disability systems could be reformed to improve the health of people with disability. The forum specifically focussed on reforms at a national level while acknowledging the importance of all levels of government in achieving better health of people with disability.

The virtual forum included Disability Representative Organisations and other advocacy groups, those from the CRE-DH Partner Advisory Group, senior officials across the Commonwealth Departments of Health and Aged Care, and Social Services, as well as representatives from government agencies including the National Disability Insurance Agency, the NDIS National Quality and Safeguards Commission, the Australian Bureau of Statistics, the Australian Institute of Health and Welfare and the Australian Human Rights Commission.

Participants were invited to take part in one of the two days of the policy forum. The same topics were covered over both dates with different participants. The first topic focused on how the health care sector could be designed to ensure that people with disability receive the support and services they need to achieve health on an equal basis to others. The second topic was on the coordination of systems and aimed at understanding how health, disability and related service systems could work together to help achieve optimal health outcomes for people with disability.

Participants were sent a policy paper ahead of the virtual event (see Appendix 4). Participants were welcomed at the beginning of each day by the Chair. The policy forum was held over the morning and organised around two 40-minute working sessions, each covering one topic. Participants were divided in smaller groups for the working sessions. At the end of each working session, a facilitator summarised the points raised in their working group to all participants. In between the two sessions, there was a break after which the Chair introduced the second topic for the second working session to take place. For each morning, the policy forum ended with a 20-minute summary by the Co-Director of the CRE-DH.

In a given session, each working group was assigned identical questions. Before each working session, a 10-minute overview of the topic's issues - which were covered in the Background document - was presented by the Chair. At the end of the overview, participants were assigned a breakout room (a virtual room with three to five participants) to discuss the points raised by the chair. The breakout rooms operated under Chatham House rules to provide the opportunity for free and open discussion. Participants knew that unless requested their name would be acknowledged on the communique produced, but not to any specific comments.

Within each working group a facilitator and a rapporteur both from CRE-DH were assigned. The facilitator's role was to help start the conversation and make sure each participant's point of view was shared in an inviting and safe way. The rapporteur was both the scribe for the working group and the one sharing the key points raised during the working session to the larger group at the end of the working session. In general groups were assigned so that both policy makers and disability advocates would work in the same session.

For each topic, guiding considerations were provided (see Appendix 2 which presents the details for the organisation of the working group sessions).

Appendix 2. Background paper

NHMRC CENTRE OF RESEARCH EXCELLENCE IN DISABILITY AND HEALTH (CRE-DH) POLICY FORUM

BACKGROUND PAPER

The COVID-19 response has exposed the many challenges people with disability face in achieving optimal health. It saw people with disability left behind, but it also generated solutions to entrenched problems. What can our experiences of COVID-19 tell us about what needs to be done nationally to give people with disability the best opportunity to attain the highest standards of health?

Forum objectives:

- Facilitate a cross-governmental, cross-sectoral discussion and approach to answering the below questions.
- Develop a discussion paper on the debate and consensus from these meetings.

The policy forums will be organised around two questions:

1. How can health care systems be designed so that people with disability receive the support they need to achieve health on an equal basis to others?
2. How can health, disability and related service systems work together to help achieve optimal health outcomes for people with disability?

Summary of background

Below we set out some background as context for the discussions in the policy forums. The key points are:

- Through the CRPD Australia has committed to provide equal access to the highest attainable standard of health without discrimination on the basis of disability.
- Health services are not the only driver of health status and the social determinants of health are also crucial.
- Australians with disability have poorer health than their peers without disability across a range of health conditions.
- A significant proportion of the inequalities in health for people with disability compared to people without disability are avoidable; that is, they are unfair or inequitable.
- COVID-19 has posed significant risks for people with disability due to existing socio-economic disadvantage, high prevalence of chronic conditions, and systemic issues relating the access to quality and affordable health care, health promotion and prevention.
- People with disability have and continue to face significant risks and challenges with respect to COVID-19.
- But a number of positive actions have arisen in the pandemic context showing that it is possible to make meaningful reform.
- The policy forum will discuss what else needs to happen to deliver the best possible health outcomes for people with disability.
- A discussion paper will be produced based on these conversations, which participants will have an opportunity to provide comment on.

Convention on the Rights of Persons with Disability (CPRD) and the Australian Disability Strategy

Article 25 of the CRPD sets out an obligation for States parties to provide equal access to health care: "the highest attainable standard of health without discrimination on the basis of disability", prohibiting discrimination against persons with disability and preventing discriminatory denial of health care or health services. In relation to the provision of health care, Article 25 requires governments to provide:

- the same range, quality and standard of free or affordable health care including public health programs as persons without disability
- health services that are needed because of a person's disability
- health services as close as possible to people's own communities, including in rural areas

However, while access to health services is a core feature of article 25, they

are not the only driver of health outcomes. The social determinants of health (the

environments in which people live, play, work, and interact) are also crucial for health outcomes[6]. Although Article 25 has a focus on health, other articles in the CPRD therefore play a role in influencing health outcomes, underscoring the importance of Australia meeting its obligations in other areas such as employment and education and cross-sectoral collaboration. Indeed, CRE-DH research shows that while policymakers and advocates recognise the importance of the social determinants of health for people with disability, this is not reflected in policy decisions where the major focus is on improving the experiences of, and access, to health services[7].

Health and wellbeing is one of seven outcome areas in the Australian Disability Strategy with four priorities for action including:

- Improving capability of health service providers to meet the needs of people with disability
- Prevention and early intervention to improve long-term health outcomes
- Mental health supports that are affordable, effective, and accessible by people with disability
- Disaster preparedness, risk management plans and public emergency responses that are inclusive of people with disability, and support their physical and mental health, and wellbeing.

Health and health care for Australians with disability

Despite Australia being a signatory to the CPRD, available evidence suggests Australians with disability have poorer health than their peers without disability across a range of health conditions[8][9]. A significant proportion of the inequalities in health for people with disability compared to people without disability are avoidable; that is, they are unfair or inequitable.

For example, CRE-DH research shows the reasons for inequalities are often structural and can be explained and/or modified by the disadvantaged circumstances in which people with disability live including unemployment and underemployment, poverty, lack of safe and affordable housing, social isolation, and

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discrimination[10][11]. This means that policies that improve the living conditions of people with disability will improve their health.

In terms of health promotion, public health programs and health care, people with disability face systemic barriers to access. These include:

- Lack of tailored health promotion programs such as smoking cessation[12]
- Lack of accessible communication and information about health[13]
- Low levels of participation in preventive health care, including vaccination[14]
- Inadequate health care workforce capacity including in primary care[15]
- Difficulties accessing quality health care due to disability (e.g., lack of in-reach, distance travelled, cost and discrimination)[16]

Further challenges arise in achieving optimal health for people with disability due to the lack of coordination across sectors including health, education, and disability services and across different levels of government.

Finally, Australia does not collect information about people with disability in health care data, including primary care. The CRE-DH has previously argued that health datasets should include a disability identifier so that:

- Disability-related health inequalities can be identified and acted upon
- Health care providers can better support individuals with disability and their families and supporters to plan and tailor health care responses in emergencies and routine care.

COVID-19 and people with disability in Australia

As the CRE-DH and others have noted, COVID-19 has posed significant risks for people with disability due to existing socio-economic disadvantage, high prevalence of chronic conditions, and systemic issues relating the access to quality and affordable health care, health promotion and prevention. In addition, people with disability who rely on paid services and supports, sometimes in congregate settings such as group homes or boarding houses, are at heightened risk of exposure to COVID-19 infection.

What we know of the health impacts of COVID-19 for people with disability

Despite the acknowledged risks for people with disability, research about the health impacts of COVID-19 on Australians with disability is limited. During COVID-19 governments have tried to overcome some of the

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challenges with the availability of data on disability in health datasets, through the linkage of existing datasets (e.g., NDIS participant data and data from recipients of the disability support pension with COVID-19 vaccination data at a Commonwealth level and NDIS data with infection, hospitalisation and death data in some States and Territories). However, this linkage occurred relatively late and except for data on vaccination among NDIS participants, the results of these analyses have not been reported publicly.

As of 1 September 2022, the two and three or more dose vaccination rates were 85% and 76% for NDIS participants compared to >95% and 71% for the general population. 91% of NDIS participants living in group homes have had three or more doses. Research led by CRE-DH researchers reported widespread difficulties in accessing vaccination among children and young people[17].

While Australia has not reported data comparing deaths among people with and without disability, international evidence clearly shows that people with disability had many times the risk of death from COVID-19, with people with intellectual and/or psychosocial disability being at the highest risk[18].

In the absence of Australian data, the CRE-DH analysed data from surveys in the United Kingdom and showed that people with disability disproportionately experienced the deleterious economic, social, and mental health impacts of COVID-19 and had more difficulties accessing health care than people without disability[19].

Our research with children and young people with disability during COVID-19 found many experienced deterioration in their mental health and wellbeing[20] with young people with disability who are unemployed having high levels of psychological distress[21].

Responses to COVID-19 for people with disability in Australia

While people with disability were not identified as a priority group in Australia's initial pandemic response, in April 2020 the Commonwealth government established a COVID-19 Advisory Committee for People with Disability and a Management and Operational plan to guide the pandemic response. The Committee included people with disability and supporters, disability representative organisations, disability service sector, researchers, health care provider and Commonwealth and State and Territory government representatives. A larger roundtable, the Disability and Health Sector Consultative Committee, was also established. This is the first time such a structure has existed in Australia.

CRE-DH research conducted in July 2020 with participants in these processes found that this was largely a positive process made possible through existing networks and inclusive leadership and championing by a senior public servant. Participants noted that both scientific research and individual experiences were valued but that progress was hampered a lack of data, challenges in 'joined up' approaches to government, and a lack of consultation and partnerships with people with disability[22], a finding similar to that of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (hereafter referred to as the Disability Royal Commission).

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In reviewing government responses for people with disability during the COVID-19 pandemic we note some positive developments:

- Australia's initial vaccine rollout prioritised some groups of people with disability, including in-reach to group homes for vaccination
- Establishment of COVID-19 specific information line for people with disability (disestablished in 2021)
- Establishment of telehealth within weeks through changes to Medicare
- Free access to Rapid Antigen Tests for people with disability on NDIS and in some States and Territories for all people with disability
- In 2022, prioritisation of people with disability for booster vaccination and antiviral treatments
- Some targeted communications for people with disability later in the pandemic
- Additional workforce to support during COVID-19 outbreaks

States and Territory governments also implemented a range of initiatives including:

- In-reach testing and later vaccination and treatment for people with disability unable to leave their homes
- Vaccination hubs for people with disability e.g., sensory clinics
- Direct contact with people with disability on NDIS to encourage vaccination
- Establishment of Disability Liaison Officers in some states, notably Victoria, to facilitate vaccination and access to treatment and testing
- Mandated vaccination for disability workers
- Paid pandemic leave for workers in some States and Territories to avoid workers coming to work sick
- Limitations on movement of workers between disability group homes and between aged care and disability services

While these positives are noted we also draw attention to some policy failures, including:

- Deprioritisation of people with disability for COVID-19 vaccination with vaccination rates for NDIS participants trailing general population rates for some time.
- The unique risks for people with disability have not been universally understood including at the highest level of government (i.e., Australian Health Protection Principal Committee, Australian Technical Advisory Committee on Immunisation, and the Pharmaceutical Benefits Advisory Committee) resulting in delay or failure to make policy decisions. Examples include:
    - Late guidance on how to manage outbreaks in disability residential settings
    - Initial denial of access to national PPE stockpile
    - Lack of targeted and accessible communication for people with disability and the sector
    - A concentration on NDIS participants rather than the whole cohort of Australians with disability
    - Challenges in the regulation and oversight of disability services who were not skilled in infection control and outbreak management
- Ongoing challenges in working across jurisdictions and sectors and lack of clarity around roles and responsibilities. Examples of these challenges include:
    - Failure to adopt the same in-reach approaches for influenza vaccination as have been adopted for COVID-19
    - Uneven access to antivirals
    - Lack of comprehensive approach to improving ventilation in settings which people with disability live and work
- Lack of comprehensive primary health care approaches with COVID-19 preparedness and management plans for people with disability
- Lack of knowledge about how to identify people with disability beyond NDIS participants.
- Inadequate disability data and lack of transparent reporting on which to base advocacy, planning and response during COVID-19
- With high levels of COVID-19 infection and most non-pharmaceutical measures (e.g., mask mandates, isolation of cases) being reduced or withdrawn, many people with disability feel 'left behind' and isolated as they remain at risk of poor outcomes from COVID-19.

The aim of the policy forums

Building on what we know from the existing evidence base and drawing on the insight and experience of participants from a range of government agencies and key advocacy groups we will discuss what needs to happen to better enable our systems so that people with disability can achieve optimal health outcomes.

From the policy forum sessions, the CRE-DH will develop a discussion paper. Ideas and debate will not be identified to individuals in this document, the aim is to set out where there is consensus on issues and where there are areas of debate. This initial draft will be circulated to participants for comment before a final version will be published by the CRE-DH and distributed.

Appendix 3. Topics and guiding considerations

Guidance for Working Group Sessions - CRE-DH Policy Forum 2022
15 & 16 September 2022
Microsoft Teams

There will be two 40-minute Working Group Sessions during the CRE-DH Policy Forum. You will be allocated into groups of 3-5 members with a facilitator and a rapporteur provided by the CRE-DH. You will focus on one topic per session.

Working Group Session 1

- How can health care systems be designed so that people with disability receive the support they need to achieve health on an equal basis to others?

Working Group Session 2

- How can health, disability and related service systems work together to help achieve optimal health outcomes for people with disability?

Goals:

- Discuss the topic using the guiding considerations provided (see below)
- Share insights on the topic from your organisation/department perspective as well as giving consideration to a cross-governmental, cross-sectoral approach
- As a group, reach consensus on the key points for each guiding consideration to be reported back to the forum

Expected output:

- A discussion paper on the debate and consensus from these meetings.
- Participants will be asked for their feedback on a draft of the discussion paper.

To note:

- This meeting will operate under Chatham House rules – we want to provide the opportunity for free and open discussion to produce the best ideas on these important topics. Names will be acknowledged on the communique produced (unless requested to omit), but not to any specific comments.

Topic 1: How can health care systems be designed so that people with disability receive the support they need to achieve health on an equal basis to others?	
Guiding considerations	**Key feedback and discussion**
What changes/adjustments need to occur to mainstream health care systems to remove, offset or overcome barriers for people with disability? *Share examples where adjustments have worked (we will include weblinks/policy documents in the discussion document)*	• *Scribe to record key discussion points to report back to the forum*
What new targeted services are needed if the health care needs of people with disability cannot be met by changes/adjustments to mainstream services? *Share examples where targeted services have worked (we will include weblinks/policy documents in the discussion document)*	
What are the data or evidence gaps where we need to know more?	
Additional comments	

<table>
<tr><th colspan="2">Topic 2: How can health, disability and related service systems work together to help achieve optimal health outcomes for people with disability?</th></tr>
<tr><td>Guiding considerations</td><td>Key feedback and discussion</td></tr>
<tr><td>Which sectors need to work together - name sectors, why and how?
Share examples where sectors have worked together well and how they did this (we will include weblinks/policy documents in the discussion document)</td><td>• Scribe to record key discussion points to report back to the forum</td></tr>
<tr><td>What types of working arrangements are needed at Federal and at state and territory levels to help achieve optimal health outcomes for people with disability?
Share examples where different levels have worked together well and how they did this (we will include weblinks/policy documents in the discussion document)</td><td></td></tr>
<tr><td>What are the data or evidence gaps where we need to know more?</td><td></td></tr>
<tr><td>Additional comments</td><td></td></tr>
</table>

Appendix 4. Stakeholder list

The 2022 policy forum was attended by representatives from:

- Australian Bureau of Statistics
- Australian Department of Health and Aged Care
- Australian Department of Social Services
- Australian Federation of Disability Organisations (AFDO)
- Australian Human Rights Commission
- Australian Institute of Health and Welfare
- Blind Citizens Australia
- Council for Intellectual Disability
- Disability Advocacy Network Australia
- Inclusion Australia
- National Disability Insurance Agency
- National Disability Services
- NDIS Quality and Safeguards Commission
- People with Disability Australia
- Women with Disabilities Victoria