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Disability and Health

Policy Lab

ONLINE SURVEY OCTOBER 2018 BRIEF SUMMARY OF RESULTS

Policy Lab Delphi Study

The Policy Lab of the Centre of Research Excellence in Disability and Health is the expert panel of 32 key stakeholders involved in disability and health policy. Policy Lab Members (PLMs) are taking part in a 4 year Delphi study which involves 2 rounds of data collection a year (in person/phone interview and online survey). The purpose of Delphi study is to identify stakeholder issues, map current and emerging policy concerns over time, and allow for the development of innovative ideas on policy reform. The results from each round of data collection with the Policy Lab will be shared with the other work programs of the CRE-DH to facilitate and guide evidence knowledge and production and help shape final policy recommendations on improving the health of working age Australians with disability.

Overview

The purpose of this document is to provide feedback to all PLMs on the results of the online survey which was distributed in October 2018. This is a brief summary of the results. A more in-depth summary is also provided in a separate document for those who would like more detail.

The online survey asked a number of questions following up on the results of the first in person/phone interviews conducted at the end of 2017. Questions in the survey focused on the social determinants of health and gaps and concerns with data collection. A total of 17 PLMs completed the survey. A summary of the results is provided below

Survey results

Missing social determinants of health (SDoH)

PLMs were asked to identify any SDoH they felt were missing from what was identified in the first round of interviews. Some responses included social determinants that have already been identified as important but these were elaborated on in greater detail. These responses are summarised below:

Social exclusion

In the first round of interviews many Policy Lab members commented that social exclusion issues such as negative community/societal attitudes towards people with disability. This was again mentioned in the survey with additional areas of concern:

Community/societal attitudes

- “Community attitudes” are both a cause and effect of some social determinants – work on Social Role Valorisation (SRV) can be instructive as part of the process gives focus to positively influencing community attitudes to disability
- Community attitudes and health provider attitudes sometimes place less value or worth on the life of a person with disability
- Need to change community attitudes to move away from the charitable view of people with disability
- There are a large proportion of matters where family members indicate a view to medical practitioners that the relative with a disability has a ‘poor quality of life’ and should receive ‘comfort care’ (palliative care). This is despite the person having a treatable condition (such as pneumonia). The wishes of the family are typically followed without question.
- While the difficulty accessing mainstream health services is being addressed via ‘reasonable adjustment’ obligations, as a society we have lower expectations for the rights of people with disability to seek services and expect they will be delivered in ways that make those services effective for them.
- The lack of support in our society to help people with disability maximise their potential, robs them of their capacity for self-actualisation
- Need to ensure digital/internet access as part of increasing social inclusion
- intergenerational disadvantage is shown to establish lower expectations and results in lower access to opportunities

Political access

- Access to political influence and engagement for people with disability is elusive if not impossible.
 - Only one current member of Federal Parliament with identified disability. There is only one current member of Federal Parliament with identified disability.
 - There are substantial difficulties to people with disability seeking representative roles at any level of government. Not only does this perpetuate the fact that disability issues continue to be advocated by those who do not have personal experience of disabilities, the feeling of representation by those with disabilities remains elusive. This is a potent barrier to both social inclusion and effecting change in community attitudes to disability.

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Relationships and sexuality

- Relationships and sexuality
 - Reluctance to acknowledge people with disability have the same needs and rights as those without disability
 - Community does not give full recognition of the human rights of those with disability in relation to their rights to intimate relationships and sexuality. Both are integral factors in overall health and neither are recognised in important contexts
 - NDIA appears to have permanently excluded funding for supports for participants to develop intimate relationships or engage in sexual activity. This is at odds with the NDIS legislation and consistent with community and political reluctance to acknowledge what is actually required under the NDIS Act and other Australian legislation and international conventions adopted by Australia.
 - While the securing of basic care and support is the priority it would be odd if we as a society accept that this should come at the expense of giving effect to other - perhaps less easy to deliver - needs and other rights

Justice/Law

- For NDIS participants the ability to effectively access legislated rights is directly related to their health outcomes.
- The ability of people with disability to be able to advocate for themselves or for others to advocate for them is impinged by systems that not only do not promote accessibility for those with disability but appear to have modifiable features which actively discourage or effectively prohibit people with disability from getting what they need and have a right to expect.
- People with disability in custodian environments (prisons) should be included as a social cohort as people with disability are highly present in the criminal justice system.
 - Without appropriate means of supports upon release or within the prison, their cycle of interacting with the justice system also intertwines with other social determinants - housing, education, inclusion, employment/income and violence

Abuse/Neglect

- Mapped wellbeing and supports through disability institutions and residential care arrangements is important –
 - something to watch with the discussion around Aged Care Royal Commissions and the findings from this in relation to abuse and neglect of elderly people in institutional, for-profit providers

Maternal/Child Health

- Issues related to the first three years of life are often predictive of brain development and influence future trajectories
- intergenerational disadvantage is shown to establish lower expectations and results in lower access to opportunities
- Parenting

Health Care Access

As well as the social determinants listed above one Policy Lab Member also reiterated the issue of access to health care, which in itself is not a social determinant of health. However when social determinants of health are not addressed it can result in reduced access to healthcare and poorer experiences when accessing healthcare. Comments made on health care access were:

- People with disability die younger than those without disability
- Access to health care is more difficult and delays are longer (health practitioner needs to come to the person with disability).
- Capacity for self-care is often lower – need to rely on others to identify health needs, secure access for treatment, monitor treatment and then provide care if needed.
- Situation exacerbated for NDIS participants as NDIA declines funding for clinical supports where the need is directly related to a persons disability (i.e. defunding for

Importance of social determinants for policy reform

PLMs were asked to indicate given limited resources how important they thought a range of social determinants were as a target for policy reform. Results are presented in Figure 1.

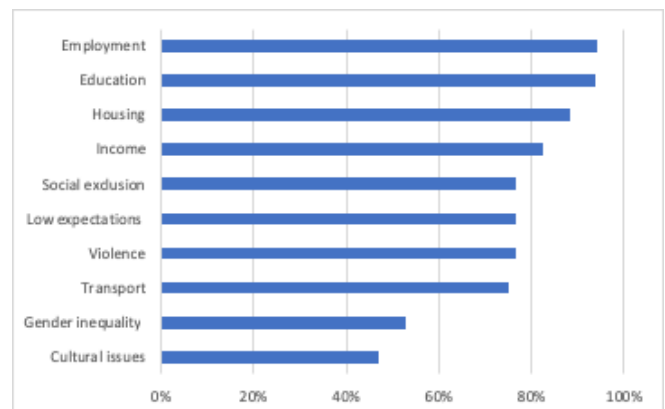


Figure 1. Percentage of respondents indicating social determinant as important or very important to target for policy reform

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Initiatives to address the social determinants of health

There were a number of suggestions provided on specific topics such as housing, justice, and transport. Other comments reflected a desire for reform around the structure of engagement and participation of [people with disability in the policy and decision making processes of governments and health services. Lastly, there were comments on the need for increased education and awareness among the general public and health providers. The following dot points presents examples of each of these:

- The National Disability Strategy is the vehicle through which to achieve change with an emphasis on measurable targets and strong governance arrangements. Improvements are required in data monitoring and reporting and people with intellectual disability need to be a priority group for policy and population health initiatives.
- Improved engagement and participation strategies. This could include appointment of people with disabilities as key advisors to politicians and CEOs. Other ideas presented were increased training and support for people with disability to advocate and form advocacy groups.
- Increased public education on disability and supporting people with a disability and specific training for groups such as GPs. This was seen as part of a larger social inclusion strategy with a strong community development approach.
- Increased focus on specific topics such as access to housing, transport, and health services. As an example, there needed to be specific focus on disability in any reform of the public transport sector. There were recommendations for more program focus on sexuality and parenting support.

Data Gaps and Concerns

PLMs were asked about a number of data gaps and concerns and whether there had been any developments or initiatives to overcome gaps. Results are presented in Figure 3.

As the results show a number of people were not familiar with data sets and what gaps existed. However there were some consistent responses to problems particularly around sharing and linking of data sets:

- Some disability specific groups collect data but this is not common
- Concerns around privacy when data collected in small geographic areas and anonymity may be difficult to ensure
- There should not be a unique identifier for disability on both ethical grounds (could promote further exclusion and is not required for health conditions) and on practical grounds (challenge in identifying disability)
- There were some comments that certain jurisdictions were making improvements in data linkage, particularly NSW and ACT, and the AIHW was also doing work in this area. Victoria has been focusing on linking child protection and family violence data sets.
- Data on ATSI people is being collected but participants were unsure of the quality of this data or how it was being used.
- Data systems from human services are not linked, there is no incentive in place to share data, and the different methodologies used hinders data linkage. NDIS exemplifies these same problems.

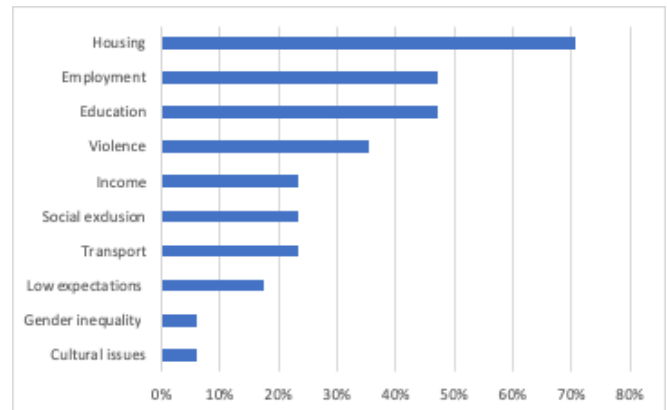


Figure 2. Percentage of respondents indicating social determinant as a priority for policy reform

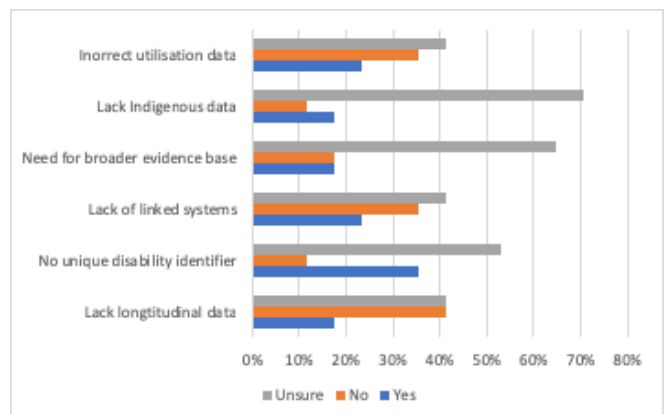


Figure 3. Percentage of respondents indicating initiatives or developments to address data gap

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Suggestions to address data gap and concerns

There were mixed opinions on whether a unique identifier for disability was important with some commenting on the benefit of including this in existing population data sets and others concerned about this as reflected in the previous question. There were some general comments on the need for leadership to address coordination issues between various levels of government. Also, some comments in relation to partnerships with universities that could address some of the data gaps present. Incentives for health agencies to collect data and some work on consistency in methodologies was also recommended. There were also some very specific recommendations for improving data systems and the following three dot points have been copied verbatim as illustrative of these suggestions:

- “Establishment of a National Disability institute funded as part of the National Disability Strategy with a charter and authority to collect and link data sources (non identified) and publish.”
- “Having a unique identifier is problematic as there is no easy way to identify disability. Assuming a suitable proxy could be agreed, it is feasible for the respective databases to be linked. Eventually this could be wider than disability and health and include, for example, community services, transport and education. The first step is for each government to agree to support a process to achieving the goal of having outcome data for people with disability and then a plan to achieve it. Delivery on the plan would need to be at the COAG level given that the responsibility for the various databases do not sit with any one COAG ministerial council. The national database and reporting should sit with the AIHW and jurisdictions should be required to adjust their internal arrangements to ensure that they can contribute in a meaningful way within stipulated timeframes. Investigation into the use of blockchain technologies to make the datasets publicly available should be investigated as a priority.”
- “Resourcing the ABS to undertake the survey of Disability, Ageing and Carers more frequently than the current three year cycle would be a good first step. Secondly, the HILDA database provides a very good (but under-utilised) longitudinal dataset - perhaps a specific disability module could be incorporated.”

Other policy gaps

PLMs made comments on a number of other policy issues in disability and health. These included:

Evaluation of programs and policies

There were a number of common responses that evaluations were sometimes not done at all, when conducted the evaluation is often poor or inadequate, and a lack of consistency in evaluation approach and methodologies. In addition, there is a lack of sharing of data and access to the evaluation results. There were comments in relation to the importance of doing cost benefit and making this process transparent to those groups affected. There were also general comments, similar responses to other questions, that there needs to be much greater connection between people with a disability and policy and program design, implementation and evaluation. Improved funding for evaluation and building this into program and policy design were the main recommendations for addressing these concerns.

Funding of advocacy

Respondents commented that there was funding available for organisations involved in advocacy but that it was insufficient and insecure. This meant it was difficult to sustain advocacy strategies over the long term and there was not strong connections between organisations involved in advocacy. There was a recommendation made that a more coordinated approach to advocacy should be implemented and that there should be a pooling of resources and efforts, potentially creating a peak organization which may have more impact.

Health and disability interface

NDIS has increased the disconnect between health and disability which was already problematic. Compounded by problems between Federal and State governments.

Comments on policy silos

The main issue identified was the lack of coordination between state and federal governments and the need for some way to coordinate different tiers of government. Coordination between the NDIA and other social services systems is also needed.

Consultation with people with disability

There was agreement that this was an area that was not done well. Engagement and consultation strategies were not inclusive of different disability types and people able to communicate their needs are often over represented in these processes. There are some good examples of co-design currently being implemented but these are isolated examples and not widespread across the sector.

The National Disability Strategy

Identified issues with the NDS were:

- Overshadowed by the NDIS
- Good framework on paper but lacks resourcing and funding
- Has not been given adequate authority and there is a lack of solid governance arrangements and independent oversight

Other Policy Gaps

Other policy gaps in disability and health identified were:

- Rehabilitation for people regardless of age
- Improving health of people with disability in prison system
- The relationship between chronic health conditions and disability

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What would a socially inclusive society for people with disability look like?

PWDs were asked what an inclusive society for people with disability would look like in three areas of housing, education, and transport.

Housing

The main message around housing for people with disability is that it needs to be safe, secure, accessible, and affordable. People with disability should be able to choose where they live and who they want to live with. People living in institutional and residential care should be given more choice and control and ability to live in the community. Ideas to achieve this included:

- changing the building code to ensure new builds are accessible and adaptable and are subsidised for affordability.
- Purpose built housing for people with disability

Employment

An inclusive society in the area of employment would see people with disability who want to work being able to secure jobs and be welcomed into workplaces. A number of comments were made in reference to how this could/should be achieved:

Workplaces

- All workplaces open to employing someone with disability and have a genuine culture of inclusion in addition to things like diversity committees and HR policies
- All workplaces be mandated to be accessible in building access, technology, and cultural practice
- Employment linked to productive contribution individuals can make in delivering goods and services – employers supported to employ people who may have less productive output in recognition that employment provides other benefits apart from income generation
- Wages are fair and equitable

Education

- Well resourced and supported schools to ensure students with disability can complete secondary education and engage with tertiary or TAFE opportunities if desired – this is required if employment is to become more than a token thought

Society/Community attitudes

- Societal/community expectations need to be radically changed to a normal expectation that people with disability should/can have a job and pay taxes etc. - this is fundamental to changing employer attitudes when considering people with disability for employment
- End discrimination against people with disability so they are not excluded or judged on their ability to do a job.

Government

- People with disability provided with appropriate supports to enable them to engage in meaningful employment
- Industrial relations system which supports recruitment from the bottom (as opposed to the top) i.e. unfair dismissal laws exclude people who employers perceive to be “high risk”
- Encourage entrepreneurship which is supported by programs to support start ups
- Employers not hindered by red tape and bureaucracy when employing a person with disability and are supported to employ people in flexible and creative ways as well as traditional roles
- Employment as a default in all NDIS plans as a quotable item
- Welfare system should not force people to work when they can't and Disability Support Pensions available as a safety net
- Government should have quotas for people with disability working in the general employment market

Transport

It was generally agreed that there needs to be accessible, fast, affordable (or free), and efficient public transport for people with disability to enable them get to employment, visit family/friends, and participate in the community. Ideas around this included:

- Technologies made more accessible so people could drive themselves if needed
- Flying with a disability should be an accepted service delivery for all airlines and discrimination by budget airlines stopped
- All modes of transport and transport hubs designed as 100% accessible as a starting point not as an add on or later requirement
- Whole journey needs to be accessible including customer service
- All transport should comply with the Disability Discrimination Act
- Transport in NDIS packages if a core component of needs and person chooses this

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Priorities for policy reform

Housing

The stand out message for policy reform around housing was that there needs to be legislated changes to building regulations/codes/standards so that all new buildings meet disability accessibility standards. This could be at a federal or state level. Other policy priorities included:

Federal level

- Adequate income support to enable access to private rental market (i.e. Commonwealth rent assistance for people with disability)
- New program similar to Defense Housing Authority to build then rent/sell purpose built disability accommodation
- Increase the value of Commonwealth Rent Assistance so it is linked to the housing market

State or federal level

- Subsidies to retrofit housing to enable accessible and adaptable homes especially for rental properties
- All available disability accommodation vacancies are made available on an App in real time
- Increase social and affordable housing
 - Quotas could be used
- End rationing of places in NDIS plans for housing
- Affordable and accessible purpose built housing in remote communities

Employment

Federal level

- Increased subsidies for employers to employ people with disability who may have lower productivity levels – provide annual tax free bonus for retaining people over a specific time period
- Link employment and Disability Support Pension so people are not penalized if they work or don't work
- Set employment quotas for all large employers

State or federal level

- Improve educational outcomes to improve employment opportunities
- Changing community attitudes so people with disability seen to be citizens who expect to work and pay taxes
- Subsidised skill development and supports to ensure people with disability will succeed in employment
- Work with unions (ACTU) to ensure employment opportunities for people with disability are part of "normal operations" of employers
- Policies to encourage or incentivize modelling and leadership from CEOs, government ministers, government secretaries so that staff in all organisations can deliver increased access to interviews and jobs for people with disability
- Governments to lift rate at which they employ people with disability
- Ensure disability access legislation is enacted and consistent across federal/state levels
- Fair remuneration
- Real jobs in remote communities
- Change unfair dismissal laws to reduced perceived risks to employers in recruiting people with disability

Transport

State and federal governments need to ensure safe, accessible, affordable transport for all people with disability. Specific comments included:

- Remove Disability Discrimination Act exemptions on public transport
- Legislation so access is built in as an absolute requirement for all modes of transport and so that this cannot be disputed in the procurement of public transport vehicles (buses, trams, trains, rolling stock etc.)

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