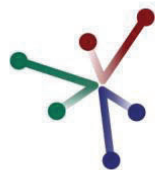# Services and supports used by people with disability and mental illness/psychological distress in Victoria

Summary of NDDA pilot findings

December 2021

National
Disability
Data Asset

Information Gap

- The purpose of this research is to provide a more holistic picture of disability and mental health service users in Victoria than would otherwise be possible from state-based data sources. A better understanding of their characteristics, service needs and service use patterns will support the development of improved health and mental health services for this population.

Key findings from the NDDA Pilot for people with disability and mental illness and/or psychological distress in Victoria

- The Victorian disability population has high levels of mental health service use. Between 2008 – 2018, around 93 per cent of the Victorian disability population have used some mental health related service in Victoria. Both their number and share compared to the disability population without disability have increased during this period. [1]
- Based on the most recently reported primary disability type, most people in the Victorian disability population had a physical disability, psychosocial disability followed by intellectual and learning disabilities. The most intensive users of specialist mental health services are people with psychosocial disability and acquired brain impairment.
- The proportion of people in Victoria using National Disability Agreement (NDA) funded services with an equivalent NDIS support who then went on to transition to the NDIS varies significantly across primary disability types. There is potentially a large number of previous Victorian clients who no longer access specialist disability services under the NDIS.
- The research also produced rates of mortality and hospitalisation for self-harm for a cohort of people with disability in the NDIS.

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[1] See Finding 1 for further detail.

1. Background

- In general, the Victorian disability population reports poorer general health and higher levels of psychological distress than people without disability and has difficulty accessing healthcare services. This is particularly true for those with severe or profound disability. People with a disability or restrictive long-term health condition also have higher than average rates of mental illness and/or psychological distress. It is estimated that the prevalence of mental illness and/or psychological distress is as high as 58 per cent for people with profound or severe 'core activity' limitations (for example, limitations related to mobility, self-care or communication) and 42 per cent for people with other disabilities or restrictive long-term health conditions. In comparison, around 14 per cent of people without these conditions live with mental illness and/or psychological distress (RCVMHS, 2021, Volume Three p.215).

- The Royal Commission into Victoria's Mental Health System also found the Victorian mental health system is complex, fragmented and not well connected to other support services, including disability, housing and social services (RCVMHS, 2021). People with disabilities and mental health illness and/or psychological distress face particular challenges navigating between disability and mental health services. Addressing these challenges, including the identification of mental health need for people with disabilities, developing services tailored to these needs and improving integration between the service systems have been key aims of the Victorian Mental Health Reform Strategy 2009 –2019 and the State Disability Plan 2017-2020.

- The purpose of this research is to provide a more holistic picture of the disability and mental health system in Victoria than would otherwise be possible from state-based data sources. This will provide evidence to inform the development of improved health and mental health services for this population.

- The overall project focuses on identifying the cohorts of people living in Victoria with disability and mental health illness and/or psychological distress (particularly psychosocial disability, but also including psychosocial and other co- existing disability, and other disabilities with mental health illness and/or psychological distress) and the supports regularly accessed by these cohorts. The project also aims to demonstrate how linked disability and health data can be used to provide baseline results on the overall health and mental health of people with disability.

2. Key findings from the NDDA Pilot for Victorian service users

Note that these are selected interim findings only and the test case team continues to generate more in-depth, detailed outputs.

- **Finding 1**
Victorian people who fall within disability cohorts[1] have high levels of mental health service use. Between 2008 – 2018, around 93 per cent of people who fall within these disability cohorts have used some mental health related service[2] in Victoria. Around 79 percent of these people used MBS and PBS services only (Figure 1). Among the remaining 21 per cent who used Victorian specialist mental health services, public hospital patients account for more than 70 per cent and approximately a quarter visited an emergency department for mental health reasons only.

    Further work is being done to examine the disability cohorts on an annual basis, however early findings suggest that each year, over half of the people who fall within a disability cohort have also used mental health services in the same year. Over the 11 year period from July 2009, this rate has been increasing, from 50 to 59 per cent or from around 345,000 to 416,000 people.

- **Finding 2**
Based on the most recently reported primary disability type[3], between 2008-2018 most people had physical disability (35 per cent), psychosocial disability (27 per cent) followed by intellectual and learning disabilities (17 per cent) (Figure 2).

    The most intensive users of specialist mental health services are people with psychosocial disability and acquired brain impairment. People in Victoria with physical disabilities have mostly used MBS and PBS mental health related services (Figure 3).

- **Finding 3**
The proportion of people in Victoria using National Disability Agreement (NDA) funded services with an equivalent NDIS support who then went on to transition to the NDIS varies significantly across primary disability types. For example, from June 2015, around 80 per cent of people with intellectual and learning disabilities and around two thirds of people with physical and diverse disabilities have transitioned to the NDIS[4], every year. Conversely, transition rates for people with psychosocial disabilities and sensory and speech impairment disabilities were much lower, at approximately 50 per cent and 33 per cent respectively (Figure 4). Although this includes people not transitioning due to reasons such as no longer needing services and deceased, there is potentially a large number of previous state clients who no longer access specialist disability services under the NDIS.

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[1] Defined in the Appendix
[2] Defined in the Appendix
[3] Defined in the Appendix
[4] Based on the number of people receiving these NDA services in each year, who transitioned to the NDIS by June 2019.

- **Finding 4**

  In demonstrating how linked disability and health data can be used to provide baseline results on the overall health and mental health of the Victorian disability population, the research focused on two exemplar outcomes, including inequities in all-cause mortality and rates of hospitalisation from self-harm.

  Based on a Victorian cohort of NDIS participants, the analysis found that people with disability experience higher rates of death than the general population. For example, the rate of all-cause mortality for participants with psychosocial disability is five times higher than seen in the general population with the same age profile (Figure 5).

- **Finding 5**

  For the same cohort of people with disability in the NDIS, rates of hospitalisation for self-harm are 1,288 per 100,000 person years in female participants in comparison to 338 per 100,000 person years in male participants. Rates are highest in the 25-44 age group. Regarding disability groups, rates are 3,708 per 100,000 person years in participants with psychosocial disability.

3. Implications

A large number of the Victorian disability population use mental health related services and supports and about 21 per cent of this population uses specialist Victorian mental health services. Most of these services are provided through the public hospital system. However, as evidenced from the findings of the RCVMHS, the Victorian mental health service system is overwhelmed with the number of people who seek treatment, care and support, and there is a large gap between the estimated demand and the services provided. As a result, people receive inadequate treatment, care and support, or none at all. Unfortunately, people with disabilities that also need to access mental health services, are faced with additional challenges of having to navigate across two stressed service systems.

People with psychosocial disability are among the highest users of specialist mental health services across state and national services. This preliminary exploration of the data sets the scene for exploring a multifaceted definition[5] of a psychosocial disability cohort by providing a greater understanding of how information about disability is captured and available from the different service systems.

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[5] Defined in the Appendix

Further work is required, however there is some indication that high mental health related bed days and mental health legal status may be very helpful in identifying people with psychosocial disability, for example.

Keeping in mind that most people who use mental health services will not experience psychosocial disability, this preliminary analysis does provide an initial sense of the broader mental health and disability service context and is essential to future analysis which could establish an improved understanding of the service use trajectory of people who experience psychosocial disability in our community.

This preliminary analysis indicates that this linked data could provide important new information about disability and mental health service use from which to develop complex understandings of this population; this may in turn lead to more opportunities to contribute to understanding people who experience psychosocial disability and further exploring potential indicators of eligibility and access to services.

The analysis also found that basic health and mental health outcomes, including mortality and self-harm are significantly worse for people with disability in Australia than for people without disability. International evidence is emerging that this health inequity is avoidable. But without linked disability and health data, we are unable to produce even basic information about key health outcomes. We also have no way of measuring whether policy or practice changes are having an impact. The NDDA has the potential to change this. Linked disability and health data could establish a high-quality baseline evidence for health inequities for people with disability and provide some direction on how these inequities could be closed.

Although the AIHW have previously published on mortality patterns among people using disability support services, this is the first time mortality inequalities and rates of hospitalisation for self-harm have been produced for NDIS participants[6]. This could represent the first step in a significant improvement in the evidence base on health outcomes for people with disability. To enable analysis that shows how health inequities for people with disability can be closed, future iterations of the NDDA need to include people without disability as a comparator population.

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[6] The AIHW has recently published mortality statistics for people who used disability services under the National Disability Agreement in Australia between 1 July 2013 and 30 June 2018 (AIHW, 2020). The Test Case analysis is building on these results to provide a more extensive and multifaceted picture.

4. Key tables /figures

Figure 1 – Mental health service use of Victorian disability service users (2008-18)
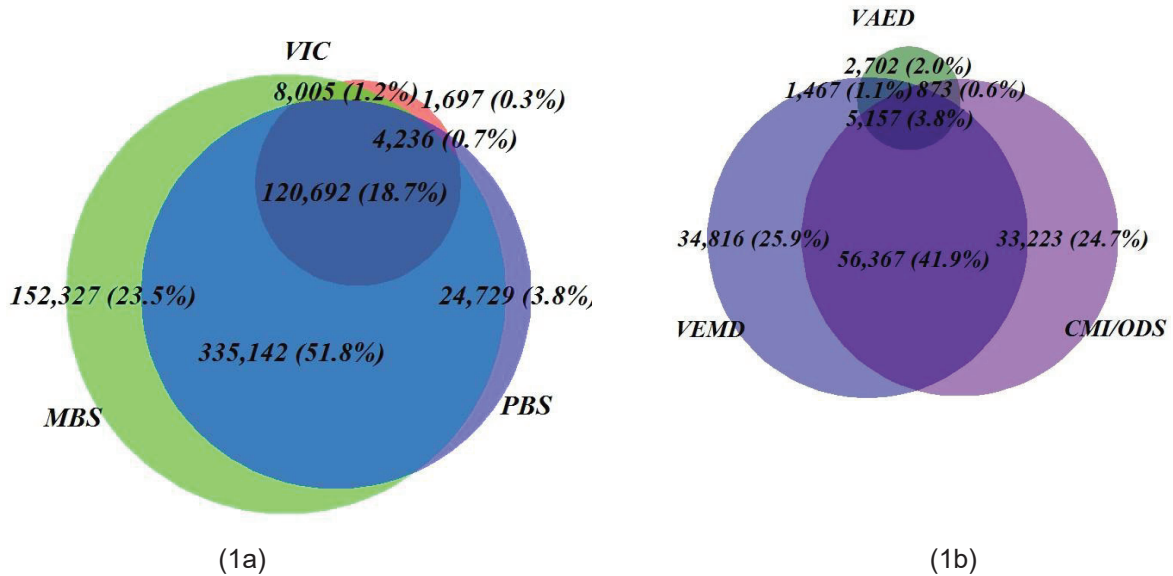

(1a)

(1b)

Figure 1a shows the overlap between users of Victorian specialist mental health services and MBS and PBS mental health related services. Figure 1b shows the overlap between users of Victorian specialist mental health services, including the public clinical mental health dataset (Client Management Interface/Operational Data Store); the Victorian Admitted Episodes Dataset – people admitted to private hospital mental health beds; and the Victorian Emergency Minimum Dataset– people presented to Victorian public hospital emergency departments for mental health reasons. Note: The set VIC in Figure 1a is the union of the three sets of mental health service users included in VAED, VEMD, and CMI/ODS.

1a

Intersect	unique clients
VIC ONLY	1,697
MBS ONLY	152,327
PBS ONLY	24,729
VIC & MBS	8,005
VIC & PBS	4,236
MBS & PBS	335,142
VIC & MBS & PBS	120,692
Total	646,828

1b

Intersect	unique MH clients
VAED ONLY	2,702
VEMD ONLY	34,816
CMI/ODS ONLY	33,223
VAED & VEMD	1,467
VAED & CMI/ODS	873
VEMD & CMI/ODS	56,367
VAED & VEMD & CMI/ODS	5,157
Total	134,605

Figure 2 - The Victorian disability population in the test case dataset by latest reported primary disability type (2008-18)
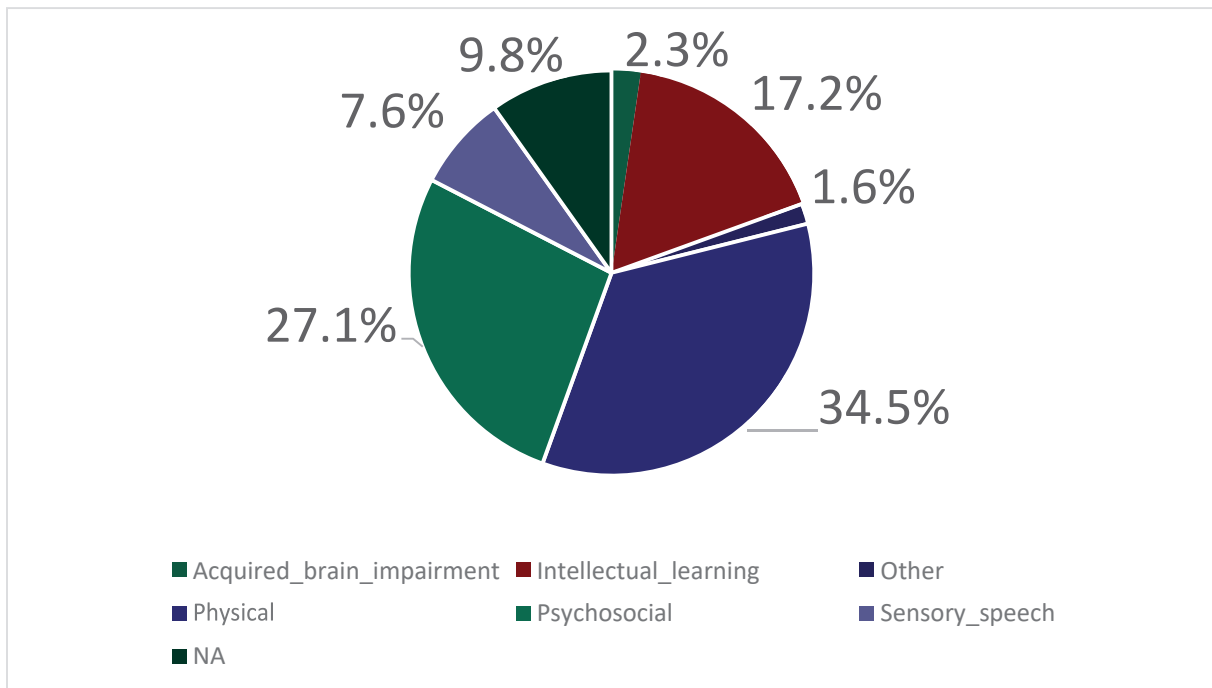

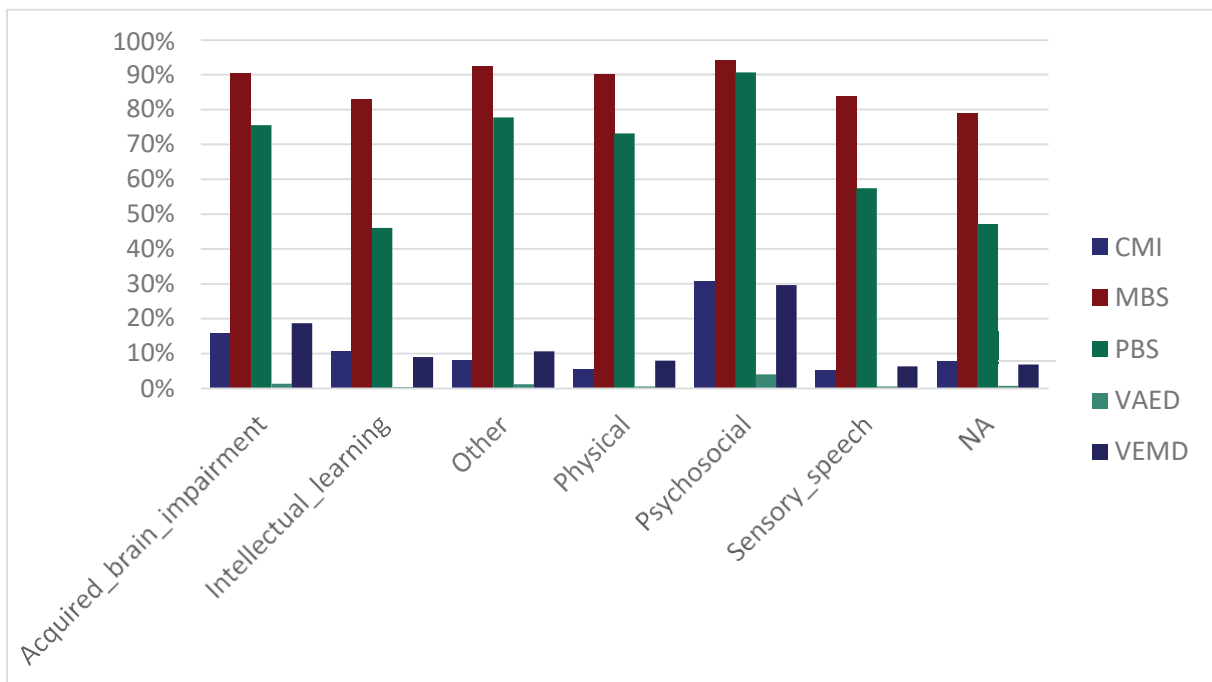Figure 3 – Types of mental health services used by latest reported disability type (2008 –2018)

Figure 3 shows the users of both state and Commonwealth mental health services, including the Victorian public clinical mental health dataset (Client Management Interface/Operational Data Store); the Victorian Admitted Episodes Dataset – people admitted to private hospital mental health beds; and the Victorian Emergency Minimum Dataset– people presented to Victorian public hospital emergency departments for mental health reason, and relevant items from the Medicare Benefit Schedule and the Pharmaceutical Benefits Scheme.

Figure 4 Victorian disability population using NDA-funded services in 2015-16, by primary disability and whether they had transitioned to the NDIS by 2018-19
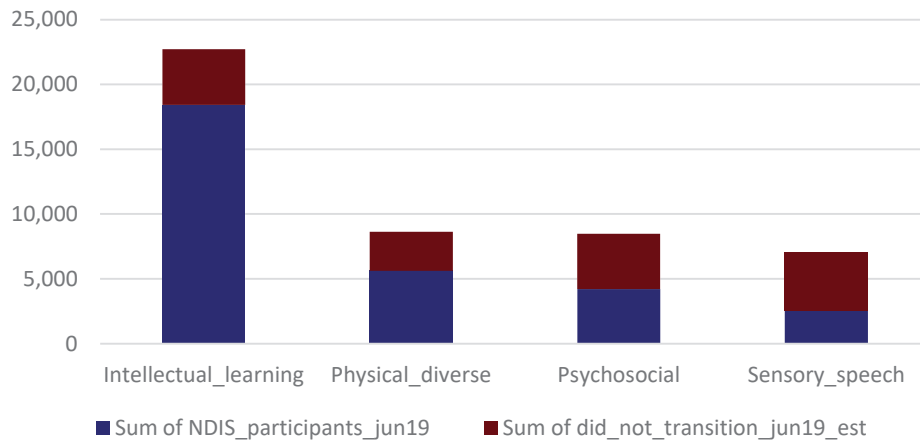
Notes: Excludes people whose primary disability was missing and people only using open employment services. 'Not transitioned' covers a range of reasons, including deceased and no longer requiring services and other factors, such as some disabilities are less 'permanent' than others, or may have irregular patterns of disability support service use. This needs to be taken into account when comparing the groups to each other. The analysis found that similar proportions of people have transitioned in subsequent years (not included in this report).

Figure 5 – Mortality estimates for the Victorian disability population in the NDIS

Mortality inequalities, comparing NDIS disability groups to the general population
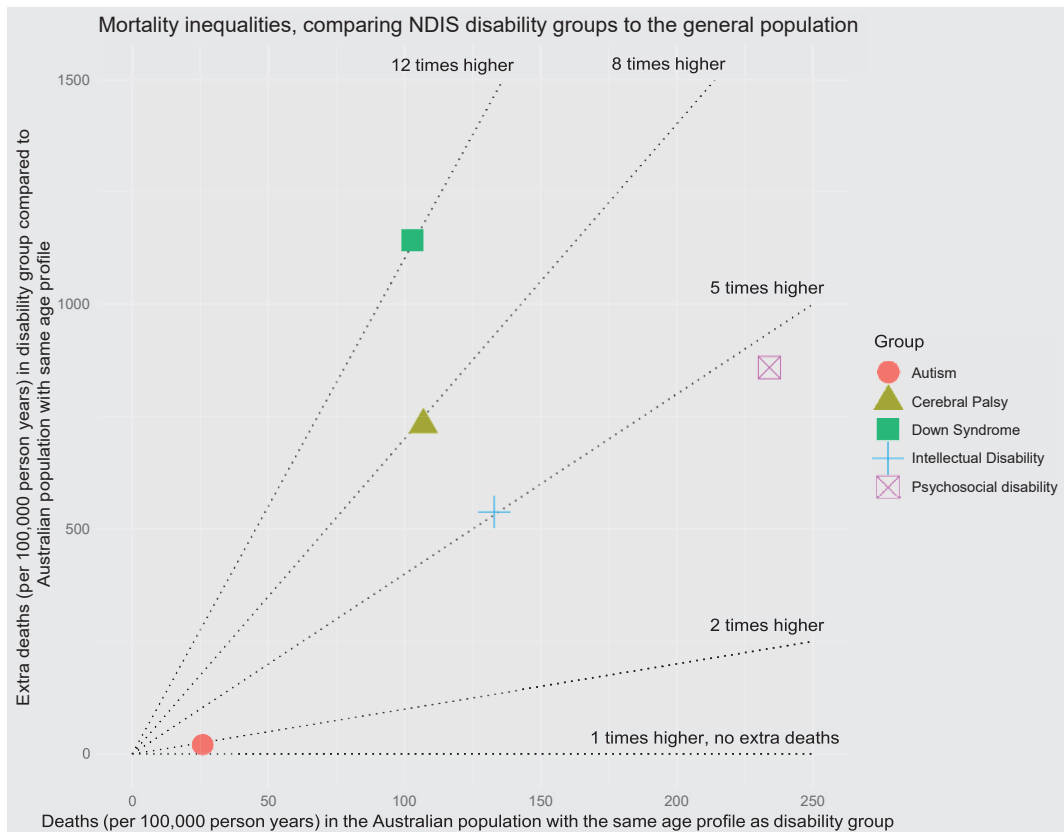
Notes: Mortality inequities comparing groups of NDIS participants to people in the general population with the same age profile. The x-axis is the expected death rate (per 100,000 person years) in people in the general population with the same age profile as the corresponding disability group. The y-axis is the additional deaths (per 100,000 person years) experienced by the disability group in comparison to people in the general population with the same age profile. The contour lines indicate the magnitude of the relative inequality experienced by NDIS participants.

APPENDIX: Overview of definitions and methodology

1. Overview of NDDA Pilot - Victorian Mental Health Test Case datasets

Data Set	Unique Clients	Unique Clients %
CMIODS	99,461	14.3%
PBS	484,799	69.6%
VAED	489,681	70.3%
VEMD	471,214	67.7%
MBS	646,121	92.8%
MCD	696,403	100.0%
CVDL	620,815	89.1%
DOMINO	694,036	99.7%
DS_NMDS	306,514	44.0%
NDIS	215,476	30.9%
MHCSS	38,209	5.5%
VINAH	373,524	53.6%
Map	696,403	100.0%
NDI	87,857	12.6%
Total	696,440	100.0%

2. Definition of people with disability

For the purposes of this analysis, people with disability are identified as disability service users in the key disability datasets. Data has been linked for those disability service users who had a valid Medicare Consumer Directory record and received disability related supports either through:

- Disability Support Pension (DSP) at any time between July 2008 – April 2020;
- National Disability Agreement (NDA) funded service at any time between July 2008 – June 2019;
- or applied for the NDIS between July 2013 – May 2020; and
- had Victorian residency at any time in any of these datasets.

3. The definition of mental health related services includes the following services and items

a. Victorian Admitted Episodes Dataset (VA ED)
   Admissions to a mental health bed in a private hospital, where hospital type is private, and care type 5 (mental health)
b. Victorian Emergency Minimum Dataset (VEMD)
   Mental health related emergency presentations are those where:
   - referred by code are
     o 16: Mental health telephone assessment/advisory line
     o 18: Other mental health staff
     o 21: Apprehended under the Mental Health Act 2014 – Police/Protective Service Officer,

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or
  - seen by mental health practitioner date/time field not null in data, or
  - human intent code is
    - 2: Intentional self-harm
    - 18: Intentional self-harm – non-suicidal self-injury
    - 19: Intentional self-harm – suicide attempt
    - 20: Intentional self-harm – suicidal intent cannot be determined
  - diagnosis code is
    - F01-F99: Mental and behavioural disorders
    - Z004: General psychiatric examination, not elsewhere classified
    - Z046: General psychiatric examination, requested by authority
    - Z915: Personal history of self-harm
    - R4581: Suicidal ideation,

or
  - departure status code is
    - 17: Mental health bed at another hospital campus
    - 23: Mental health residential facility
    - 25: Mental health observation / assessment unit
    - 26: Other mental health bed – this campus
    - 31: Mental health and AoD hub short stay unit,

    and their type of visit code is not '19' (COVID-19 Assessment Clinic)) and triage category is not '6' (Dead on Arrival)

c. Client Management Interface/Operational Data Store (CMI/ODS)

All individuals included in the Victorian public clinical mental health dataset are considered as Mental Health service users.

d. Medicare Benefits Schedule
    Mental Health MBS items are those relating to:
    - GROUP A8, all required
    - GROUP T1 Subgroup 13 (Item 14224)
    - GROUP A20, all required
    - GROUP A6, all required
    - GROUP T10, Item 20104
    - GROUP M6, all required
    - GROUP M3 (Items 10956 and 10968)
    - GROUP M7, all required
    - GROUP A10
    - GROUP M11 (Items 81325 and 81355)
    - GROUP A15, Subgroup 2
    - GROUP M10 (Items 82000 and 82015)
    - GROUP A29, all required

e.   Pharmaceuticals Benefits Scheme

Mental health-related medications are defined as
- antipsychotics (code N05A)
- anxiolytics (code N05B)
- hypnotics and sedatives (code N05C)
- antidepressants (code N06A)
- psychostimulants and nootropics (code N06B)

4. SDAC definition of primary disability

The primary disability group follows the disability group definition in SDAC (survey of Disability, Ageing and Carers) https://www.abs.gov.au/ausstats/abs@.nsf/Previousproducts/4430.0Appendix202015?opendocument&tabname=Notes&prodno=4430.0&issue=2015&num=&view=

5. Definition of Psychosocial Disability

In order to assess the value of this linked data and the potential opportunities which arise from it a multidisciplinary expert team led by Professor Lisa Brophy, Discipline Lead for Social Work and Social Policy at La Trobe University worked with analysts from DFFH to explore how this linked data could be used to identify and understand the service use patterns of people who experience psychosocial disability. This team proposed to find indicators in the data that may help identify people with a psychosocial disability.
Each of these indicators is not in itself an intentional/explicit measure of disability, rather they are identified as potential proxy indicators of psychosocial disability. Thus it is first important to consider a conceptual definition. For this purpose, we have quoted here from the paper by Hayes et al (2018)[1].

The National Mental Health Consumer and Carer Forum refer to psychosocial disability as 'the disability experience of people with impairments and participation restriction related to mental health conditions', (NDIS, 2020 p.16) although the term is contested. For instance, the NDIS refer to disabilities that may arise from mental health issues" (Hayes et al, 2018 p.579).In addition to the above definition it is important to acknowledge that not everyone who has a mental health condition will have a psychosocial disability, but for people who do, it can be severe, longstanding and impact on their recovery. Further, social models of disability also recognize social determinants such as stigma, social exclusion and discrimination as contributing to people's experience of disability (UN, 2006)Psychosocial disability disrupts the ease with which one can live their daily life, including participation in community activities, employment, thinking clearly, the experience of full physical health as well as managing the social and emotional aspects of life (Hamilton, D. et al., 2020).

6. Health inequities analysis

An expert team lead by Dr George Disney at the University of Melbourne has provided research on the health and mental health outcomes of people with disability.

The team created a cohort of people with disability using NDIS data as this population of people with disability because is clearly defined and there is relatively high-quality information on the main disability group - psychosocial disability - for each participant.

Our health outcome data is taken from the National Death Index (all-cause mortality) and the Victorian Admitted Episodes (admission for self-harm) data.

All-cause mortality inequities

Methods

The analysis compared all-cause mortality in disability groups of NDIS participants to "expected mortality" in people with the same age profile in the general population. The comparison to the general population was made using published ABS death statistics. This provides a mortality comparison between NDIS participants and the whole Australian population.

It is important to note that direct comparisons of inequalities for different disability groups are not simple or straight forward. To do this we need to refine our analysis further from these initial findings. This expanded analysis will be included in the final report.

Results

Figure 5 shows three key results for each selected group of NDIS participants:

1) X axis: expected deaths (per 100,000 person years) in people in the general population with the same age profile as the selected NDIS disability groups.

- The right-hand side of the figure corresponds to higher mortality and reflects disability groups that are older – for example people with psychosocial disability (purple crossed square) in the NDIS are, on average, older than people with autism (red dot).
- This axis tells us for example that there would be 234 deaths per 100,000 people in a year from the general population with the same age profile as people with psychosocial disability included in our NDIS population

2) Y axis: absolute inequalities showing how many more deaths per 100,000 person years

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in an NDIS disability group compared to people in the general population with the same age profile

- The y-axis shows the extra deaths per 100,000 person years experienced by each disability group, in comparison people in the general population with the same age profile.

- Using psychosocial disability as an example, there are 859 more deaths per 100,000 person years in NDIS participants than there would be in the general population with the same age profile.

- Policy interventions need to be designed to lower the points on the graph toward the x-axis and close the inequities.

3) Dotted contour lines: Relative inequalities. This means how many times more deaths in an NDIS disability group compared to people in the general population with the same age profile

- The dotted lines show relative difference in mortality. If a given disability group had the same health, and therefore mortality, as people in the general population with the same age profile, the points on the graph would appear along the "1 times higher, no extra deaths" contour.

- For example, there is approximately 5 times more death in the psychosocial disability group than for people in the general population with the same age profile.

A major limitation of this mortality analysis is that it can only adjust for age and sex when comparing NDIS participants and the general population, as the test case dataset does not contain individual data on people without disability. This makes it particularly challenging to model how inequities for people with disability could be closed.

To produce high quality evidence on how inequities in health can be closed for people with disability, future iterations of the NDDA need to include either the whole Australian population or at least a sample of people without disability. This is best practice in linked data research internationally.

Hospitalisation from self-harm

Methods

The team calculated the time each NDIS participant has been in the scheme to establish the denominator for the analysis. The numerator – intentional self-harm - comes from the Victorian Admitted Episodes hospital data. The criteria used to identify intentional self-harm hospitalisations is detailed in the appendix.

It is important to remember that some participants contribute many admissions to the rate and most participants do not contribute any. The analysis is also "unadjusted", which makes comparisons of rates of self-harm between groups hard. For example, age is related to self-harm and different disability groups have different age profiles. As a result some of the differences in rates of self-harm between different disability groups could be due to differences in age profiles.

This analysis will be refined to take into account differences in age in the final report. We will also attempt to make comparisons to the general population in a comparable way to the mortality inequity analysis detailed above.

To ascertain hospitalisation from self-harm the analysis included records where the principal diagnosis is in the ICD-10-AM range S00-T75, T79 and the first reported external cause code is in the ICD-10-AM range X60-X84, Y87.0.
The criteria excludes the following hospitalisation records where:

- Mode of admission is reported as 'transfer from another hospital'

- Care involving the use of rehabilitation procedures (Z50) is an additional diagnosis; and for

- Newborn care (without qualified days), Hospital boarders, and posthumous organ procurement.

Exposed time is calculated for each participant as the time from the start date (one of decision date, first plan approval date or first payment date) and the date of death if there is one or the date for the end of the admission data.

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Hamilton, D. et al. (2020) 'The National Disability Insurance Scheme and people with severe and persistent mental illness/psychosocial disability: A review, analysis and synthesis of published literature', Australian & New Zealand Journal of Psychiatry, 54(12), pp. 1162–1172. doi: 10.1177/0004867420967747.