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Health Interface for People Living with Disability

ADVOCACY WA

Introduction

This paper investigates and discusses issues people living with disability face because of a broken health interface in Australia. The paper begins with an overview of disability, definitions of key terms, and current government support systems for people living with disability. While the paper is broad in its overview, the data gathered is specific to regional South West WA. The paper discusses this data in response to the broader issues regarding the health interface and recommends an overhaul of the current system to alleviate the disadvantages people with disability face.

Overview of the Population of People with Disability in Western Australia and Australia

People Living with Disability: Australia

To understand the challenges faced by people living with disability in Australia, it is crucial to analyse key population statistics to understand the dynamics within this sub-population. The Australian Institute of Health and Welfare (AIHW) and The Australian Bureau of Statistics (ABS) provide comprehensive and up to date information.

> Note: Disability can have various meanings across different organisations and institutions. This paper aligns it's definition of disability with the AIHW and the World Health Organization (WHO): disability is a term that encapsulates conditions/impairments that impact body function or structure, limit and create difficulty in executing activities, and restrict the experience of participation in life. Disability is an interaction between the social environment and one's impairment that creates and perpetuates unequal opportunity for full participation in society.

In 2022 approximately 5.5 million Australians had at least one disability, accounting for 21.4% of the country's total population. (Australian Bureau of Statistics, 2022) Australia's ageing population means that people are living longer. (Australian Institute of Health and Welfare, 2024). Disability and age are linked, the likelihood of developing disability increases as age increases meaning the oldest age group experiences the highest rates of disability. Table 1 breaks down disability prevalence by age group in the Australian population according to 2018 data.

Age Group	Disability Prevalence
0-14 years	7.6%
15-64 years	13
65+ years	50%

Table 1 Disability Prevalence by Age Group in Australia 2018

A further breakdown of the population of people with disability from 2018 and 2022 reveals:

- 21.8% of females had disability
- 21% of males had disability
- 23.1% live in rural or remote areas

There is a little data on the different cultural identities and languages spoken by people with disability.

People Living with Disability: Western Australia

The population of people living with disability can vary in prevalence and characteristics across states in Australia. In Western Australia (WA) there is approximately 411,500 people who have at least one disability, accounting for approximately 15% of the state's population. (Government of Western Australia, 2024).

The WA State Government is 4 years into their 10 year strategy aimed at building a more inclusive state that empowers people with disability to 'participate meaningfully in all parts of society and have the resources to do so'. A recent report on the progress of this plan from 2022 outlines some completed actions. Examples include the development of twelve accessible social houses for people with newly acquired spinal cord injuries post hospital discharge, workshops designed to boost the knowledge and confidence of employers to employ people with disability, and launching the Transport Portfolio Disability Access and Inclusion Plan 2022-2027 (Department of Communities, 2022).

People Living with Disability: The South West Region of Western Australia

The South West region of WA covers an area encapsulating 12 local government areas:

- City of Bunbury
- City of Busselton
- Shire of Augusta-Margaret River
- Shire of Boyup-Brook
- Shire of Bridgetown-Greenbushes
- Shire of Capel
- Shire of Collie
- Shire of Dardanup
- Shire of Donnybrook-Ballingup
- Shire of Harvey
- Shire of Manjimup
- Shire of Nannup

(South West Development Commission, 2024)

ABS data from 2021 states that the population of the South West is approximately 202,044. There is limited data on people living in this region with a disability, however, SA4 data on the health profile of the South West region published in 2021 states that 5.2% of residents had a core need for assistance with daily living, 11.6% provided unpaid care to a person with disability and 42.8% have a long term health condition.

The Current Government Support Systems for People with Disability in Australia

Disabilities recognised in Australia can be separated into eight types:

- Physical disability: Impacts mobility or dexterity
- Intellectual disability: Impacts ability to learn or process information
- Mental illness: Impacts thinking processes
- Sensory disability: Impacts the ability to see or hear
- Neurological disability: Impacts the brain and central nervous system

- Learning disability: Impacts acquisition, organisation, retention, and understanding of information
- Physical disfigurement: Impacts physical appearance
- Immunological disability: Impact due to the presence of organisms causing disease in the body

(Australian Disability Network, 2024)

People living with disability are supported by Australia's Disability Strategy 2021-2031, the National Disability Insurance Scheme (NDIS) (Department of Social Services, 2021) and in WA, the State Disability Strategy 2020-2030. Australia's strategy was created in line with our commitments under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The strategy aims to provide national leadership towards greater inclusion of people with disability, guide activity across all areas of public policy to be inclusive and responsive to people with disability, drive and improve mainstream services and systems for people with disability, and engage, inform and involve the whole community in achieving a more inclusive society.

The NDIS, with 649,623 people as participants, is a recently implemented system aiming to identify individuals' support needs and provide funding so that people with disability have equal opportunity to achieve their goals in all aspects of life (Department of Social Services, 2023) (National Disability Insurance Agency, 2024).

Department of Health, Allied Health and Health Interface for People with Disability

Note: Many people have more than one disability, and they are not necessarily in the same 'category'. For example, someone may have a physical disability and a neurological disability. It is important to understand that despite being able to separate types of disabilities into logical categories, it is not easy to pinpoint the impact of particular types of disabilities, as the impacts may vary depending on individual circumstances. Therefore, it is important to avoid developing perceptions that some types of disabilities are 'better' or 'worse' or more/less impactful.

Department of Health

WA Health is Western Australia's public health system. It includes WA hospitals, GPs, dental services, mental health services, psychology, nursing and speech and language therapy. It also includes the WA Country Health Service comprising regional hospitals, health centres, community mental health, and residential aged care. The department's strategic priorities are focused on ensuring that Western Australians receive safe, high quality and accessible health care, no matter where they live.

Allied Health Definition

There is no single definition of "Allied Health" and there is some debate over exactly which professionals should be considered part of this broad term. For the purposes of this paper allied health is defined as health services and professionals who fall outside of the typical medical, dental and nursing fields (Allied Health Professions Australia, 2024). For someone to be considered an allied health professional they must be qualified in their discipline and work to prevent, diagnose or treat at least one condition or illness.

Health Interface Definition

A health interface can be defined as a platform or system that enables patient information to be securely and easily collated and transferred between different areas of health care (HDFC ERGO Team, 2024). For example, interfaces may exist in health systems where patients may be required to move between primary and secondary care services to ensure a continuum of care is provided (Royal College of General Practitioners Scotland, 2017). The benefits of an effective health interface may include improved data uniformity, automated workflow, and streamlined regulatory compliance which in turn leads to improved patient care and understanding (Surety Systems, 2024).

In Australia, the healthcare system comprises of both public and private service providers and resources which can create complex issues for people when navigating a health issue (Australian Institute of Health and Welfare, 2016). The public and private division of Australia's healthcare system is further complicated when considering the roles of different systems within the health sector, the allied health care system and the medical system generally work independently of each other. The independent workings of health sectors can cause issues for everyone, however vulnerable populations such as people with disability are at a particular disadvantage given that they are more likely to require or be receiving care from multiple different service providers. Navigating the healthcare system for someone with a disability has been complicated by the lack of an effective interface between health sectors.

Allied Health Services Utilised by People with Disability in Australia

People with disability frequently come into contact with health and allied health services, especially highly specialised services. Health and allied health professionals work with people with disability to help improve overall health and wellbeing and to assist them in increasing their capacity to participate in life through treatment, health education and/or therapeutic care (Allied Health Professions Australia, 2024). Additionally, both health and allied health professionals are part of the diagnosis process, whether that is for a specific disability or for a condition or illness arising as a result of a pre-established disability.

AHPA have created a summary of the types of allied health services, outside of department of health services, that are frequently used by people with disability, along with their primary functions.

Allied Health Professional/Service	Disability/Impairment Support
Audiologists	Assess for hearing impairment and fit hearing devices
Occupational therapists	Assess and intervene with strategies that enable people with disabilities to be as independent as possible, and to participate in meaningful self-care, leisure and productive activities in a range of home and community contexts
Optometrists and orthoptists	Provide services for low vision
Podiatrists	Provide services for promoting foot health and mobility
Orthotists and prosthetists	Prescribe devices and promote mobility, limb function and independence
Physiotherapists, osteopaths, chiropractors	Can assist with musculoskeletal issues
Exercise physiologists, physiotherapists	Can provide health promoting wellness programs to develop strength, balance and prevent falls
Art therapists, music therapists	Provide services for people of all ages, including those experiencing dementia
Dietitians	Assess people who have nutritional needs requiring specialised nutritional support that may include tube feeding. They also advise on nutritional strategies to manage chronic conditions such as diabetes.
Speech pathologists	Can assess and treat people with speech and swallowing difficulties
Psychologists, social workers, occupational therapists	Can provide services for people with disabilities arising from ongoing mental illness

Table 2 Summary of Types of Allied Health Services

Places where people with disability use health/allied health services are widespread, as often people with different needs will be require different settings to achieve the best possible level of care. Some of the settings where allied health services are often used are as follows:

- Public and private hospitals
- Outpatient clinics
- Community health centres
- Private practices
- In the home
- In the workplace

- At school
- Aged care centres
- Mental health facilities
- Sport centres
- Disability facilities

The four most common functions across all health services for people living with disability are:

- Assessments, recommendations and support around functional tasks and activities of daily living, including personal care and eating
- Assessment of home and environmental aspects and assistance to identify equipment and sensory needs
- Therapeutic care related to the physical requirements of the disability
- Mental health support

The NDIS and Allied Health

Note: In the context of this paper, the NDIS is considered to be part of the health/allied health system in Australia. For people with disability the NDIS is an important health provider and source for support. The interaction between individuals with disability and the NDIS correlate strongly with their overall health and wellbeing.

The NDIS identifies allied health providers as one of the largest groups of registered providers for people with disability (NDIS, 2022). An important role of allied health professionals in the system of the NDIS is to help participants provide evidence through assessments and reports that assist in decision-making processes and disbursement of funding.

The NDIS Act allows allied health professionals to:

- Provide information about the NDIS and who is able to access it
- Provide evidence to support an application for accessing NDIS, this also permits the professional to assess the permanency of a person's disability
- Provide any documentation about the functional impact of a person's disability to help support an access request, including reports or assessments that were created prior to the person starting the application process

While allied health services are important for people with disability, participants of the NDIS still need to use the health/hospital system for services that aim to improve their health such as care in hospital, pharmaceuticals and preventative health. The NDIS funds daily personal activities, some transport, workplace help for employment, some therapeutic supports, mobility aides, etc. They do not fund responsibilities of another government system or community service, or day-to-day living costs that are not related to a participant's support needs (NDIS, 2021).

Challenges in Accessing and Using Health Services and Allied Health Services for People with Disability

The current lack of an effective health interface between health departments and allied health services, including the NDIS, has resulted in significant barriers to accessing vital healthcare for people with disability as well as challenges when accessing services that people without disability rarely face.

Many people with disability use multiple health services, including allied health services, and many are simultaneously in the process of applying for NDIS support or navigating the NDIS in other ways

(Australian Institute of Health and Welfare, 2016). This is especially true of the last few years, considering the NDIS officially started in WA on the 1st of July 2018 (Australian Institute of Health and Welfare, 2024). The complexity of navigating multiple health systems at the same time poses several challenges for people with disability, as identified by the AIHW (Australian Institute of Health and Welfare, 2016).

In AIHW's 2016 report on Australia's health, it was reported that there is a lack of understanding about the way that Australian's interact with the healthcare system. There is little information about which services people are using, what treatment or care is being provided, and the resulting health outcome (Australian Institute of Health and Welfare, 2016). There have been some initiatives aimed to combating this issue, such as 'My Health Record' however access to this system is complicated and not utilised by many service providers. This platform is limited in its abilities and is generally used by services that can access Medicare for payment purposes. While General Practitioners and hospitals have software systems that automatically upload patient information, other allied health professionals use different systems and when treating clients outside of Medicare (i.e., a NDIS client), client information is not uploaded to My Health Record.

Some common barriers facing people with disability accessing health services (Australian Institute of Health and Welfare, 2024) are:

- Unacceptable or lengthy waiting times
- Cost
- Inaccessibility of buildings
- Discrimination by health professionals
- Issues caused by lack of communication between the professionals treating them

The following statistics from 2018 were reported by the AIHW in support of their claims regarding lack of communication and discrimination (people under the age of 65 with a disability):

- 1 in 5 (21%) of those who saw 3 or more health professionals for the same health condition reported issues caused by lack of communication among health professionals
- 3.5% of those aged 15–64 experienced discrimination by health staff (GP, nurse, hospital staff)
- 1 in 8 (12%) of those aged 15–64 who need assistance or have difficulty with communication or mobility had difficulty accessing medical facilities (GP, dentist, hospital)

In 2022 the National Disability Services (NDS) published a summary report raising the alarm regarding allied health workers in Australia and implications of staff shortages in the sector for people living with disability (National Disability Services, 2022). The NDS reported on the difficulty people with disability faced when accessing allied health services resulting in underutilisation of services and NDIS plans. The Report stated:

- There has been a decline in employment of allied health workers
- The turnover rate for health workers is increasing
- Allied health worker hours have decreased from 26.6 hours per week to 18.2 hours

Advocacy WA South West Survey Data and Case Study

In 2023 and in 2024 (and continuing), Advocacy WA surveyed the South West community on systemic disability issues.

2023 Data Summary

2023 data was collected from 45 respondents living across 14 South West postcodes. Over 50% of the respondents were female and the predominant disabilities were physical, mental and neurological. 57% had a negative experience living with a disability in their town and 73% said there were not enough supports for people living with disability in their town. 30% said the NDIS is not working well for them. Regarding the interface between health/allied health (including NDIS providers) and people living with disability:

- At least half of respondents said the justice system, education support, specialty disability accommodation (SDA), the NDIS, transport system, employment services, and their community (access to buildings, facilities, etc) do not work together or communicate with each other to make things easier for people living with disability.
- 29% said hospitals did not work well with other services or communicate with others to make things easier for people living with disability.
- 33% said NDIS service providers do not work well with other services or communicate with others to make things easier for people living with disability.
- Community organisations were doing the most to help people with disabilities with problems identified, followed by helping self, an advocate and no one.

2024 Data Summary

Data for 2024 is still being collected. At present there are 13 respondents across 4 South West postcodes (all around Bunbury). Over 50% of the respondents were female and the predominant disabilities were physical, mental and neurological. 27% had a negative experience living with a disability in their town, 45% said it was okay and 33% said there were not enough supports for people living with disability in their town. 62% had a negative experience dealing with the NDIS (it was slow, stressful and not focussed on country people). 83% said the NDIS was effective in serving regional people. Regarding the interface between health/allied health (including NDIS providers) and people living with disability:

- 100% of respondents said hospitals work well with other health/allied health services and communicate with others to make things easier for people living with disability.
- At least half of respondents said the justice system, education support, specialty disability accommodation, transport system, employments services, and community access (buildings, facilities, etc) do not work together or communicate with each other to make things easier for people living with disability.
- 28.57% of respondents said the NDIS and NDIS service providers do not work well with others or communicate with other services to make things easier for people living with disability.
- 33.33% said Medicare did not work well with other services or communicate with others to make things easier for people living with disability.
- 45% of respondents said no one is helping with the problems identified while 45 % said an advocate was helping.

Advocacy WA Case Study: Amy

Note: The name and all personal details of the client have been changed to protect the privacy of Advocacy WA's client.

Amy is a 35 year old female diagnosed with chronic refractory epilepsy and intellectual impairment. She lives in a home unit purchased by her parents to allow her to live independently. Her disability causes her to have seizures which have led to falls and several admissions to the hospital. Seizures often happen at night when there is no support. Seizures can occur up to 20 times a day, and often cause her to fall backwards and lose awareness.

One of her recent falls during the night resulted in a bilateral subdural haematoma which required burr hole evacuation. Another resulted in a fractured leg, and she was not found until 8am the next morning by her support workers. Amy requested supported independent living (SIL) at a 1:1 ratio, due to her high risk of harm. This request aligned with medical advice from her occupational therapist (OT), her GP and her neurologist. The NDIA offered her a ratio of 1:3 in share accommodation (which she would need to rent) despite evidence her disabilities were not conducive to living with others and hospital discharge summaries showing that the incidence of falls increases at night when there is no support.

These types of appeals and cases require the submission of written reports and letters in support of the NDIS participants request, from treating medical specialists. Advocacy WA appealed the NDIA decision and despite owning and living in her own unit, the NDIA continued to refer her to a group home where she would be renting and sharing supports. After appeal, the NDIA requested evidence from her specialists to prove that she cannot share supports with other participants.

This evidence had been provided with the original request. The NDIA was referred back to the supporting written evidence. The NDIA continually asked medical specialists questions that had already been answered, leading Advocacy WA to question whether the evidence provided had ever been read or in fact if it had been lost by the NDIA. The NDIA continues to ask for more evidence, now from Amy’s neurologist in the public health system where it takes 6 months or more to get an appointment.

The specialist advised that they would write a new report and email it to Amy’s GP. Due to the high demand for specialists in the public health system this has not yet been provided. Advocacy WA and Amy’s mother requested that the NDIA make a formal request to the specialist or employ an independent practitioner to provide comment on her condition in order to get a quicker response, but the NDIA advised that they prefer to get evidence from Amy’s regular practitioner. This extended process has left Amy in a vulnerable state as her funding is not adequately covering her needs.

Discussion of Findings and Recommendations

The data and case study highlight an alarming problem in Australia’s and WA’s health systems, the lack of an effective interface between departments of health, allied health, the NDIS and NDIS providers. People living with disability bear the burden of this systemic failure, having to explain themselves again and again, across the health system, slowing access to health services and causing some people to cease seeking support. In regional, rural and remote Australia this problem is exacerbated by a lack of health services, specialists, transport, NDIS providers, disability accommodation, and inaccessible buildings and facilities. Further, little thought has been given to people with disability who have problems communicating, leaving them frustrated when they must struggle through telling the same story to every health service, allied health business, health department section, NDIS provider, etc.

Australia and Western Australia are not only failing to meet obligations under the UNCRPD (articles 3, 4.1c and h, 9.1 a and b, 9.2 g and h, and 25c) but are not meeting their own disability strategies. The WA strategy claims WA is an inclusive state that empowers people with disability to ‘participate meaningfully in all parts of society and have the resources to do so'. The lack of an effective health interface is an antithesis to this statement. Likewise, the commonwealth strategy claims to guide activity across all areas of public policy to be inclusive and responsive to people with disability, drive and improve … systems for people with disability, and … achieving a more inclusive society. Again, with an effective health information system being such an important part of life for a person living with disability, the lack of an effective health interface makes a mockery of this statement.

The NDIS requires both health and allied health professionals to be part of the diagnosis process for NDIS access and when considering change of circumstances or appeals. As previously stated, the most common purposes the health system plays for people living with disability are assessments of functional needs and assistance, therapeutic care and mental health support. Information and evidence about needs and required supports are currently provided via antiquated 20th century systems; mostly documentation sent via email or scanned and uploaded to the NDIS portal. As AIHW (2018) have indicated, communication is a major issue between health professionals, and between them and people living with disability. 21% of people who saw three or more health professionals for the same health condition reported issues caused by lack of communication among health professionals, and 12% of people who have difficulty with communication have difficulty accessing medical support. As indicated by Amy's case above, an interface accessible by all of Amy's health professionals and the NDIS would greatly assist in assessment and decision making, reducing wait times, avoiding the duplication and losing of evidence and reducing the anguish caused by ineffective systems.

Australia's My Health Record system has been poorly implemented, is complicated for small providers and does not require health professionals to upload important patient diagnosis and information. Systems within and across the health/allied health sector and the medical system seem to work independently of each other meaning vulnerable people with disability requiring care from multiple service providers are put at a disadvantage. This has resulted in significant barriers to accessing vital healthcare for people with disability, challenges that people without disability rarely face. While people should be given the opportunity to opt out of having their information recorded on a universal health database, they should also be given the option of receiving the advantages such a system offers to simplify their health assessments, evidence gathering, supports, diagnosis and care.

Australia's health interface must be a platform that enables patient information to be securely and easily collated and transferred between all areas of health care to ensure a continuum of care is provided. An effective health interface will result in improved health data, improved and more efficient workflows, better regulatory compliance, easy access to diagnosis from multiple health professionals, better decision making and improved patient care and understanding. It is not a difficult proposition, with interface engines readily available, enabling communication and data exchange between different health systems. Cost is surely not the issue, with the Australian government prepared to invest over a billion dollars on updating and implementing a single piece of legislation, the new Aged Care Act (Koutsoukis, 2024).

Further Recommendations

Regional towns are an important part of Australian society, responsible for the bulk of our primary production and mining wealth. As such it is important that services, infrastructure, and opportunities are equal to urban regions for people living with disability. An effective health interface, connecting all health services with each other (including the NDIS) would alleviate many of the issues regional, rural and remote people living with disability face when dealing with the health system from a non-urban setting. However, Advocacy WA's systemic survey highlighted other issues related to health for people living with disability.

Transport is a major issue in regional areas for people living with disability. A lack of public and taxi transport services means that people living with disability in regional towns are particularly vulnerable regarding access to health services. The WA Taxi User Subsidy Scheme needs to provide for people living with disability in regional towns by paying for taxi services travel costs to and from pick up/drop off locations and by extending the kilometre and monetary amounts to cater for distances regional people living with disability need to travel to access Health services.

Housing is a major issue in regional areas for people living with disability. A lack of SDAs, accessible state housing, and accessible private rentals means that people living with disability in regional towns are particularly vulnerable to homelessness (leading to significant declines in health outcomes). All state-owned housing should be built to Gold Building Standards, ensuring accessibility, and building codes should ensure minimum accessibility standards are followed for all new builds, particularly when subsidies (state and federal) are offered to first home buyers. In addition, greater policy intervention to protect people with disability in housing, mandatory disability awareness training for real estate agents, and a closer relationship between REIWA, the Office of Disability and the NDIS would result in better health outcomes for people living with disability in regional areas.

Access to buildings and recreational activities continues to be an issue in many regional locations despite government strategies and funding to address this over many years. There needs to be a greater focus on the effectiveness of shires' Disability Access and Inclusion committees, with many regional people with disability complaining that these committees are ineffective and exist only to check off a state government community consultation obligation. Greater monitoring and enforcement of government disability legislation, and alignment with the state disability strategy should be a performance metric for state funds for all shires. Better access to buildings and recreation can be linked to better health outcomes for people living with disability.

Conclusion

Australia's piecemeal health data system is not fit for purpose with patient data largely only being uploaded by hospitals and GP's who access the Medicare system for payment purposes. Allied health and NDIS providers very rarely use the My Health Record system, and the NDIA does not appear to use it at all. This is causing major disadvantage to people living with disability in Australia and putting up barriers to receiving health care. Failure to record important health information in a unified system means people with disability need to tell the same story again and again and provide the same evidence again and again as they are bounced around the health system. It is time to invest in a 21st century health interface, connecting all patient/client information across the health system and including health departments, medical practices, allied health, NDIS and NDIS providers. While an opt out option should be provided, for most people living with disability such a system would reduce the disadvantages they currently face when dealing with the health system.

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