JULY 2022

Medicine safety:
Disability Care

SAFER MEDICINES USE IN PEOPLE WITH DISABILITY

Pharmaceutical Society of Australia Ltd.

ABOUT PSA

PSA is the only Australian Government-recognised peak national professional pharmacy organisation representing all of Australia's 34,000 pharmacists working in all sectors and across all locations. PSA is committed to supporting pharmacists in helping Australians access quality, safe, equitable, efficient and effective health care.

PSA believes the expertise of pharmacists can be better utilised to address the health care needs of all Australians. PSA works to identify, unlock and advance opportunities for pharmacists to realise their full potential, to be appropriately recognised and fairly remunerated.

PSA has a strong and engaged membership base that provides high-quality health care and are the custodians for safe and effective medicine use for the Australian community. PSA leads and supports innovative and evidence-based healthcare service delivery by pharmacists.

PSA provides high-quality practitioner development and practice support to pharmacists and is the custodian of the professional practice standards and guidelines to ensure quality and integrity in the practice of pharmacy.

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Pharmaceutical Society of Australia

PO Box 42, Deakin West, ACT 2600

www.psa.org.au

This report was written by

Dr Renly Lim, Dr Susan Semple, Dr Lisa Kalisch Ellett and Professor Libby Roughead

Quality Use of Medicines and Pharmacy Research Centre

UniSA Clinical and Health Sciences

University of South Australia

GPO Box 2471, Adelaide, SA 5001

www.unisa.edu.au

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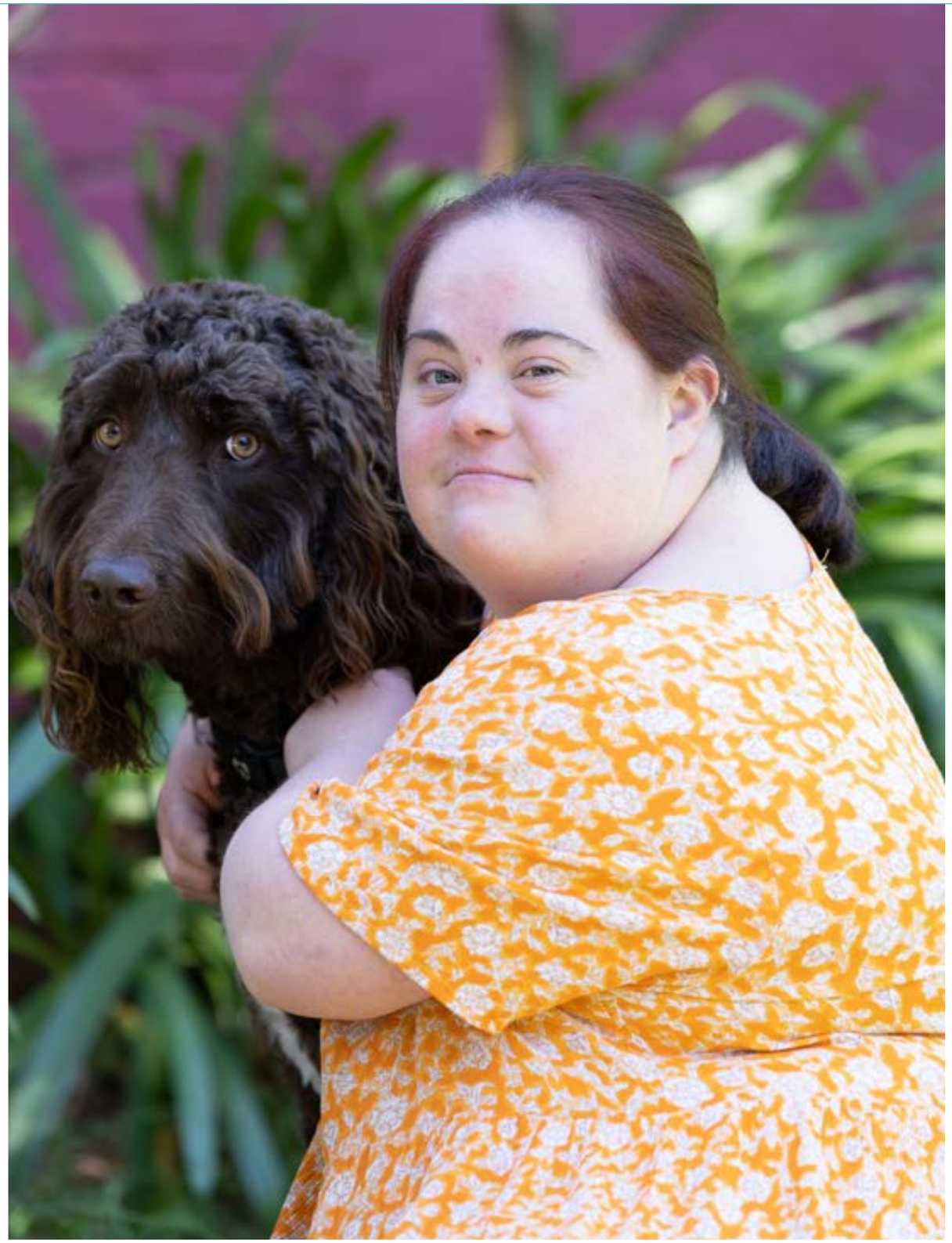


FOREWORD

Approximately 4.4 million Australians live with a disability, many requiring complex medical care. The Pharmaceutical Society of Australia's *Medicine safety: disability care report* highlights the many barriers to safe medicine use, ranging from prescribing and dispensing, to administration, and medication management.

The result is a health system that is failing Australians with a disability.

In PSA's 2019 *Medicine safety: take care report*, we estimated that medicine-related problems result in 250,000 hospital admissions each year, with an annual cost of approximately $1.4 billion. Not only is this a significant burden on our health system, but with half of these hospital admissions being preventable, there is an imperative to act urgently.

This *Medicine safety: disability care report* is the fifth in our medicine safety series that have recently focused on medicine safety as the 10th National Health Priority Area, aged care, and rural and remote Australia.

Medicine safety: disability care focuses on the challenges that people with disability face in using medicines safely and effectively, and makes a series of recommendations to improve safety across the disability sector.

There is a clear and pressing role for pharmacists to be engaged in medicine safety for people with disability. Pharmacists must be recognised as an essential service provider for people with special medicine needs and should be embedded everywhere that medicines are used.

A greater focus on medicine safety is needed to help address the health and life expectancy gap for people with disability.

Pharmacists are the key, and we look forward to working with state, territory and federal governments, the disability sector, patients, and their families to improve the provision of care to Australians with a disability.

"A greater focus on medicine safety is needed to help address the health and life expectancy gap for people with disability.

Dr Fei Sim
PSA National President

EXECUTIVE SUMMARY

Nearly all people with intellectual disability use medicines

- Up to 90% of people with intellectual disability are taking medicines.

Safety problems with medicines are very common

- The Royal Commission into disability heard that medicine safety problems mainly relate to:
  - accessing health professionals,
  - inappropriate prescribing,
  - difficulty taking medicines and
  - inadequate access to medication management review services.
- Chemical restraint is only justified for short-term use and as a last resort for behavioural challenges.
  - Despite this, Australian research found chemical restraint use continued beyond five years in 74% of people with an intellectual disability who live in a residential facility.

Emergency services frequently used for routine advice

- Calls to the NSW Poisons Information Centre from disability service providers increased by 111% from 2015-2020.
  - 11,197 calls were received in 2020 alone.
- Most of these calls relate to simple medicine safety issues that can easily be resolved by better access to pharmacists.

Many medicine safety problems are likely unreported

- Many safety problems with medicines are likely unreported, meaning reported data represent the tip of the iceberg.
- Data generally do not include people with disability living independently, family in-home care or residential care.

We can't improve what we don't measure

- There are very few Australian studies on medicine safety issues experienced by people with disability.
- Despite the existence of National Disability Insurance Scheme (NDIS) standards for medicine safety and reporting of use of chemical restraint, data to inform sector-wide improvement are not readily available.

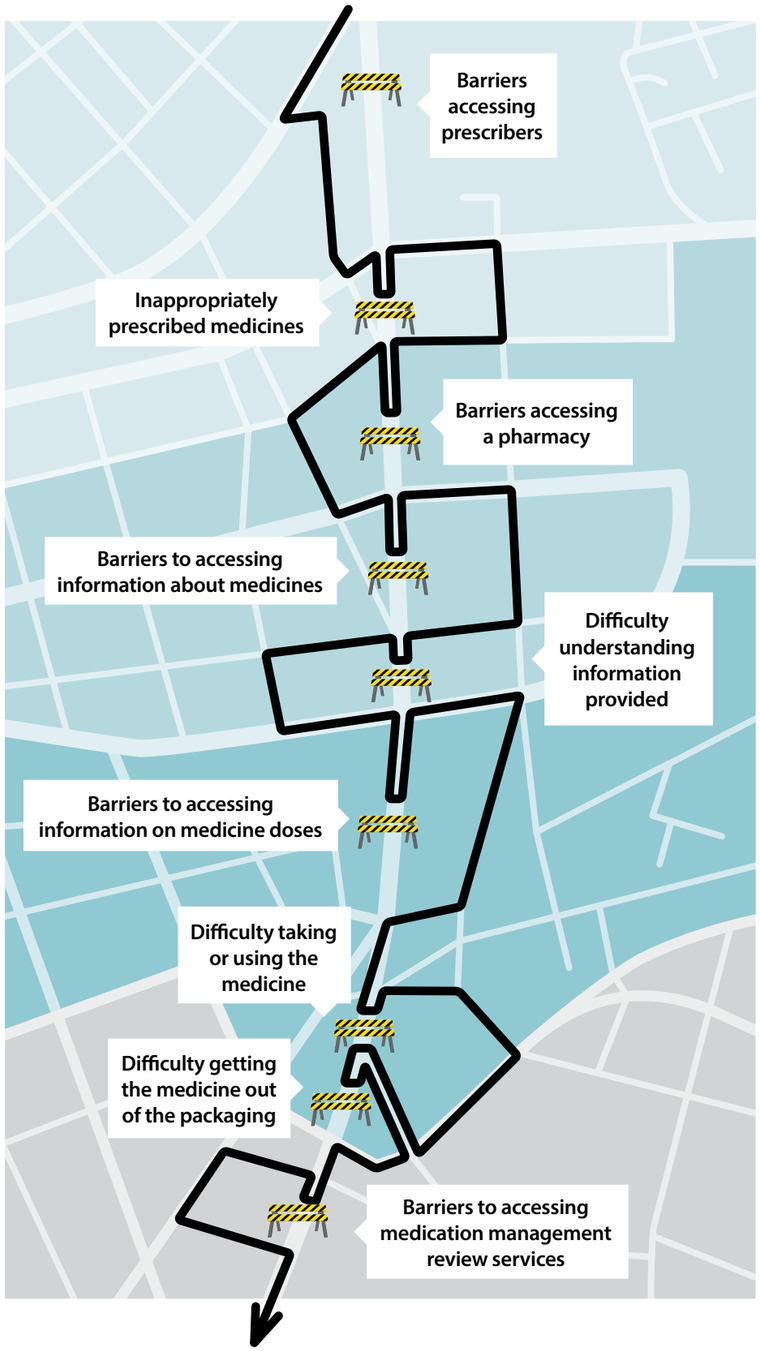
BARRIERS TO SAFE MEDICINE USE
FOR AUSTRALIANS WITH DISABILITY

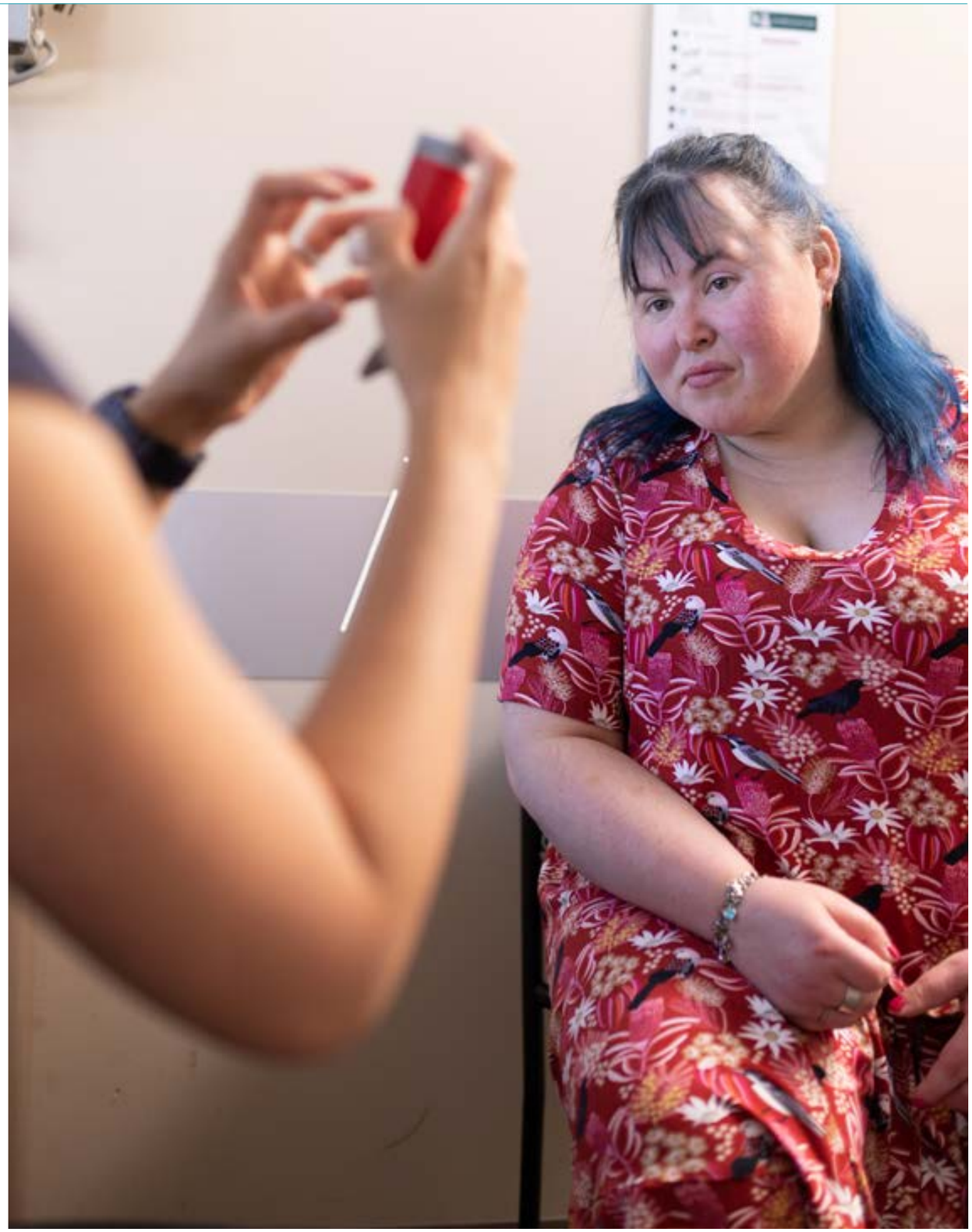
1 Prescribing

2 Dispensing

3 Administration and adherence

4 Monitoring





DISABILITY CARE:
MEDICINE SAFETY PROBLEMS

HOSPITAL

"I was forced to take medications not directly tethered to the treatment of my diagnosis but as a tranquilising sedative. Anon, Adolescent in Mental Health Ward[5]

CHEMICAL RESTRAINT

COMMUNITY PHARMACY

"Off-the-shelf medicine instructions are unreadable on both the packaging and the instruction leaflets. Anon[50]

LABELLING

"We usually don't understand what is written (in brochures) but we do see the pictures. If we want to understand what is written, we ask someone to explain it. That's what most Deaf people do.[47]

INSTRUCTIONS FOR USE

"It always amuses me that the pharmacist has to stick on a label telling you how to take the medication regardless of the fact that I can't read it.[5]

INSTRUCTIONS FOR USE

GROUP HOME

"I have swallowing difficulties. If they're giving me drinks or medication at the wrong angle or the wrong speed, I can choke on it. Anon (female)[73]

ADMINISTRATION

MEDICAL CENTRE

"I get frequent urinary tract infections... I can't get a pathology test done or get a script for antibiotics if I don't attend the GP's office, but the simple fact of having a UTI means I am even less able to do that. I have ended up in hospital with a severe kidney infection on a number of occasions, despite the fact that my GP is 100m from my house and could have prevented the infection getting this bad. Julia[46]

PRESCRIBER ACCESS

PRIVATE HOME

"I had rung the locum my doctor recommended, only to be told they don't do prescriptions, and when I asked what housebound people with chronic illness did then, they said that's 'when I would be admitted to a care facility', though they did offer a single script to tide me over. My doc's surgery said only 'don't know' and 'try Google'. Anon, homebound with ME/CFS[46]

PRESCRIBER ACCESS

PRIVATE HOME

"When I lived in a nursing home for the aged (I was aged 39) my GP would do visits and all charged at bulk bill rate. My scripts would be collected by the local pharmacy and the medicated (medications) delivered back to the nursing home. As soon as I left the nursing home, the GP would not visit me, unless I paid heaps of money for a home visit. I had to collect my own scripts from the chemist. I did not leave the nursing home because I was 'better'. Hunter, who experiences dyautonomia[46]

CARE PACKAGES

PRIVATE HOME

"I feel like we're just invisible. Like this problem isn't even on anybody's radar because nobody knows we exist. Ricky[46]

ACCESSING CARE

"A pharmacy who is willing and able to pack DAA packs, and who can deliver medications when required is a godsend to those who are homebound/bedridden. Ricky[46]

MEDICINE PACKING SERVICES

PSA RECOMMENDATIONS

PSA recommends the following actions to ensure equity of access for people with a disability to be supported to use medicines that they need, safely and effectively:

01

Ensure disability service providers have access to quality use of medicine (QUM) services by funding on-site pharmacists' roles in disability provider organisations.

02

Enable pharmacists to register as providers under the National Disability Insurance Scheme (NDIS) to increase access for people with disability to medication management services tailored to their needs, referred by suitably qualified NDIS service providers.

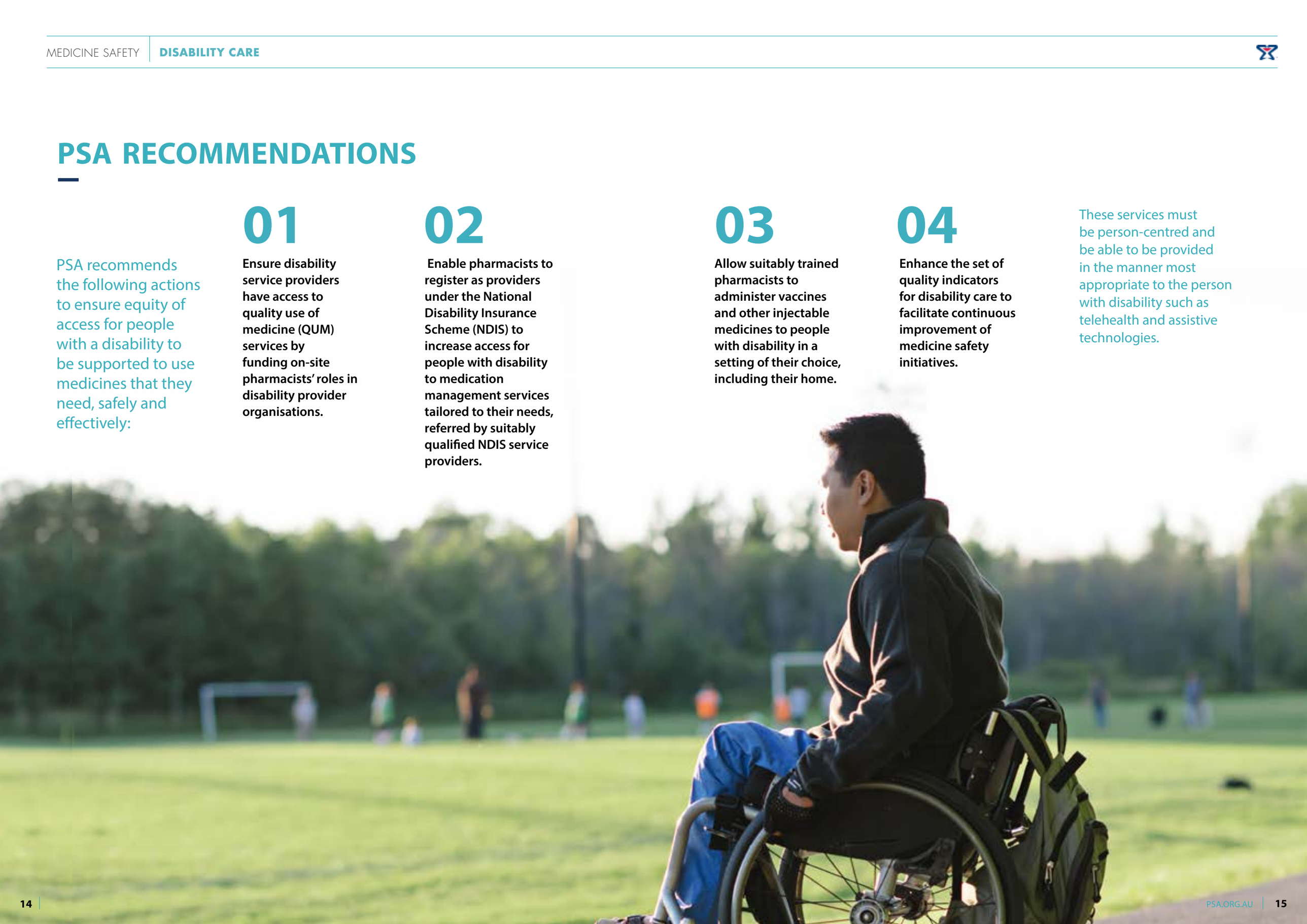
03

Allow suitably trained pharmacists to administer vaccines and other injectable medicines to people with disability in a setting of their choice, including their home.

04

Enhance the set of quality indicators for disability care to facilitate continuous improvement of medicine safety initiatives.

These services must be person-centred and be able to be provided in the manner most appropriate to the person with disability such as telehealth and assistive technologies.



MEDICINE SAFETY
FOR ALL AUSTRALIANS

4.4m

Approximate number of people with disability in Australia

The use of medicines is the most common intervention in health care, which means that problems with medicine use are also common. In our 2019 ***Medicine safety: take care*** report, we estimated that 250,000 hospital admissions are a result of medicine-related problems each year, with an annual cost of $1.4 billion.[1] In response, the Australian Government announced "Quality Use of Medicines and Medicines Safety" as the 10th National Health Priority Area.[2,3]

At the heart of quality use of medicines and medicine safety is the primacy of consumers; the first principle of Australia's National Strategy for quality use of medicines.[4] This principle acknowledges consumers as central to attaining quality use of medicines.[4] This means that consumers are active members in all aspects of their care, able to make their own decisions about their medicines and health, and are given care that is tailored to their individual needs. People who need extra support include vulnerable groups such as older people and people with disability.

The primacy of consumers is particularly important and relevant to people with disability as they are not always included in their own decision-making. However, it should be noted that this primacy often relies on carers and healthcare professionals to provide an inclusive, person-centred focus. That is, recognition must also be provided to carers of people with disability who play a key role in providing this support and advocacy.

People with disability face many challenges in achieving the best possible health outcomes. These challenges may be the result of a lack of judicious selection of management options, appropriate selection of medicines, and safe and effective medicine use. Their health journey begins with appropriate diagnosis; social, psychological, nutritional and physical activity supports and therapeutic considerations involving medicine use. Once medicines have been selected as an appropriate management option, challenges can arise at many stages of the medication management process. These challenges may be in relation to receiving a prescription from the doctor, obtaining medicines from pharmacies, administering or taking the medicines, monitoring the effects of the medicines and accessing services such as medication management review by their healthcare professionals.

In this ***Medicine safety: disability care*** report, we focus on the challenges that people with disability may face in terms of quality use of medicines and medicine safety.

PEOPLE WITH DISABILITY
IN AUSTRALIA

The term "**people with disability**" is defined as "people with any kind of impairment, whether existing at birth or acquired through illness, accident or the ageing process, including cognitive impairment and physical, sensory, intellectual and psychosocial disability".[5,6]

"**Disability**" is defined as "any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months".[7] Disability is also considered "an umbrella term for impairments, activity limitations and participation restrictions, all of which can interact with a person's health condition(s) and environmental and/or individual factors to hinder their full and effective participation in society on an equal basis with others".[8]

There are 4.4 million people with disability in Australia; one in twelve children under 18 years, one in eight adults aged 18 to 64, and one in two adults over 65 years have a disability.[7]

Physical disability is experienced by 77% of people with disability, and mental or behavioural disorders are experienced by 23% of people with disability.[7] Physical disability usually includes conditions affecting the musculoskeletal systems (e.g. arthritis), nervous system (e.g. cerebral palsy), circulatory system (e.g. stroke), hearing and vision.[7]

Mental or behavioural disorders can include intellectual disability, mood disorders (e.g. severe schizophrenia) and dementia.[7]

Intellectual disability

It has been reported that approximately 3% of people in Australia have an intellectual disability, with 60% of this population considered to experience 'profound or severe' impairments which affect their daily life.[9] This equates to around 350,000 Australians. Intellectual disability is a lifelong condition and is classified as mild, moderate, severe or profound.

Cognitive disability

People with cognitive impairment may have problems with memory, thinking or communication which can be permanent or temporary.[10] Cognitive impairment may be the result of a brain injury, dementia, stroke or critical illness and can affect people of all ages.

A Disability Royal Commission issues paper[11] defined people with cognitive disability to include "people with intellectual disability, autism, acquired brain injury or dementia". It is difficult to provide absolute figures related to the prevalence of cognitive impairment in Australia because it has been noted to be under-recognised, under-diagnosed and the impairment can be temporary.

Hearing disability

People experiencing hearing loss may not be able to understand verbal instructions on how to use their medicines. This can be particularly problematic when health providers are required to wear masks dramatically reducing their ability to lip read or pick up facial expressions, gestures and contextual cues.

In Australia, one in five people experiences some form of hearing loss, including 150,000 Australians with severe or complete hearing loss.[12] The incidence of hearing loss increases with age; approximately one in four Australians aged 65 to 74 years old experience hearing loss, and three in five Australians aged 85 years and over have hearing loss.[13]

Vision disability

It can be challenging for people who are blind or have low vision to access medicine information because they cannot read the information or distinguish between the medicines dispensed. Over 500,000 Australians have some form of loss of vision, including 130,000 people who are blind.[13,14]

Dual disabilities further exacerbate challenges with information provision; 49% of people with intellectual disability have vision impairment and 17% have a hearing impairment.[15]

Access to health services

Access to health care should be equal for all Australians; however, people with disability report experiencing many challenges when accessing health services.[7] Barriers commonly identified by people with disability or their carers include physically inaccessible buildings, discrimination by healthcare professionals, long waiting times, high costs, and a lack of communication between the health professionals who treat them.[7]

These barriers may also affect the decision of when to access health care, as one in 12 people with disability report delaying or not seeing a GP when needed.[7] This compares to one in 25 people without disability.[16] Approximately 2.5 million people (60% of people with disability) required assistance in their daily life, most commonly with health care. Activities captured by "health care" were: foot care; taking medication or administering injections; dressing wounds; using medical machinery; and manipulating muscles and limbs. Of those who needed assistance with health care, one in two (49%) received assistance from informal providers such as a partner, their child or their parent.[7]

Geographical location may affect access to health care with more people with disability who live in outer regional and remote areas reporting difficulties accessing health services compared to people with disability living in major cities.[7,17]

60%

Proportion of people with disability who require assistance in their daily life.

20-32 yrs

Shorter lifespan experienced by people with intellectual disability compared to those without.

2x

Potentially avoidable deaths in people with intellectual disability compared to those without.

Use of health services

People with disability in Australia use health services frequently. In a 12-month period, nine in ten people with disability will have seen a general practitioner (GP), two in three will have seen a medical specialist, and one in four will have visited the emergency department.[7,17]

People with disability use health services more frequently than people without disability[16,18]; approximately 10% more people with disability see a GP in a 12-month period compared to people without disability, while almost twice as many people with disability see a specialist or have an emergency department attendance in a year compared to people without disability.[16]

When considering the use of mental health services, approximately one in 16 people with intellectual disability use mental health services compared to 1 in 100 people without intellectual disability.[18]

Health outcomes

Not only do people with disability experience barriers to health care access, they may also have poorer health outcomes than people without disability. People with intellectual disability have a life expectancy that is 20 to 32 years shorter than people without intellectual disability.[19-21]

The focus of much of the available research related to health outcomes has been collected for people with intellectual disability specifically, and may not accurately represent all people with disability.

People with intellectual disability are more likely to report poorer health status and more likely to have medical conditions such as depression and diabetes when compared to people without intellectual disability.[15,19,22-25] Potentially avoidable deaths are twice as frequent in people with intellectual disability (38%) compared to people without intellectual disability (17%).[19] The leading causes of potentially avoidable deaths in people with intellectual

disability are physical conditions including diseases of the circulatory systems; and infections.[19]

People with intellectual disability are also more likely to experience potentially preventable hospital admissions with rates four times that of people without intellectual disability.[24] The higher rates of potentially preventable hospitalisations are related to conditions such as chronic obstructive pulmonary disease, convulsions and epilepsy,[24] some of which may be explained by the higher prevalence of these conditions in people with intellectual disability.

However, higher rates of potentially preventable hospitalisations are also noted for acute conditions such as dental conditions, urinary infections and ear, nose and throat infections, which occur at a frequency three to six times higher for people with intellectual disability than in people without intellectual disability.[24]

Outcomes after hospital admission are also poorer for people with an intellectual disability, who are three times more likely to present to an emergency department following a hospital admission compared to people without intellectual disability.[23]

The proportion of hospital admissions that are due to medicine-related problems for people with disability has not been reported, but a New South Wales study found that people with neurodevelopmental disorders who were admitted to hospital due to adverse medicine events were more likely to have a longer hospital stay than people without neurodevelopmental disorders.[25]

3x

How much more likely an emergency department presentation following a hospital admission is for people with intellectual disability compared to those without.

Carers of people with disability

Carers may be formal, such as those employed by disability care organisations, or informal such as friends or family members. Carers play a significant part in the lives of people with disability as many rely on their carers for some, if not all of their medicine management.

Carer arrangements and the support they are able to provide to people with disability can vary as many often have little or no formal training, even when employed to provide disability care. Furthermore, medicines used by individuals with a disability may be affected by the policies and protocols, culture, and risk management strategies that disability care organisations have in place for medicine management. In turn, these policies and protocols can affect the way support workers provide care for their clients.

It is vital that carers also have access to health and medicine information in a format and language that they can understand, as well as guidance and training in providing medicine management support. It is important that support for carers complement support for the person with disability rather than replace it; hence there is a need for collaborative care models that include carers.

Disability organisation staff play a key role in establishing and maintaining safe practices with the handling and administration of medicines for people with disability. Optimising medicine-related activities remains a priority for such organisations; however, there is an indication of significant gaps in the understanding of what factors influence or support safe and appropriate medicine use and what role pharmacists could play.

MEDICINE SAFETY
IN PEOPLE WITH DISABILITY

Medicine safety problems can occur at any stage of the medicine management cycle.

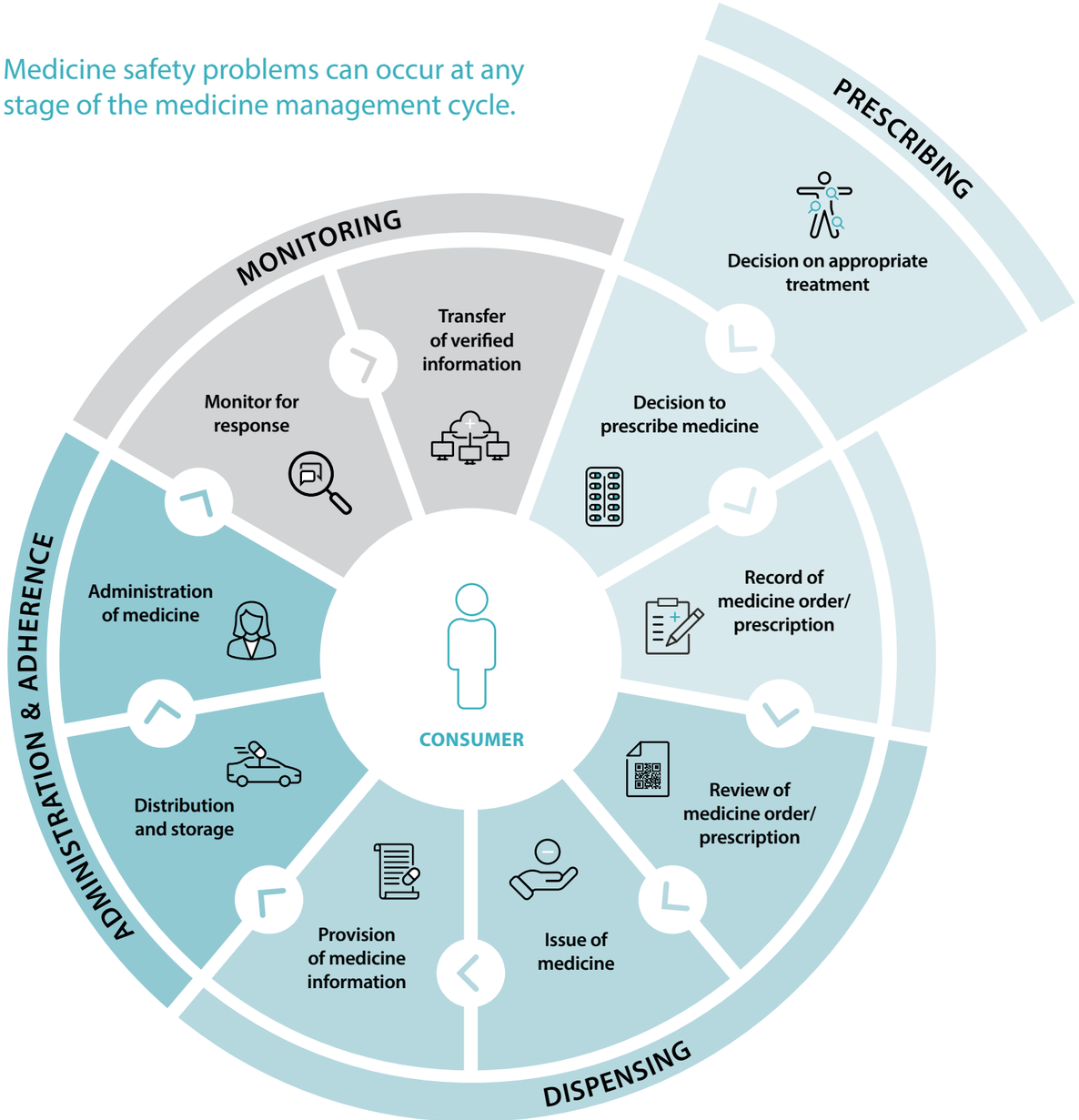


Image: Simplified medicine management cycle.[26,27]

Prescribing for people with disability

Medicines are prescribed with the intention to improve our health; however, errors may occur during the prescribing process, or the decision to prescribe a medicine may not be appropriate.[1,28] Examples of medicine safety issues that can occur during prescribing are: errors in prescription such as errors in doses, over- or under-prescribing of medicines, prescribing of medicines considered inappropriate, prescribing of medicine without consent and prescribing without an indication.[1,28]

One of the challenges in understanding the extent of medicine-related problems for people with disability is identifying this at-risk population. We did not locate any Australian studies that examined the extent of prescription errors affecting people with disability.

However, international evidence suggests errors in prescriptions are common in people with disability. A Dutch study involving 600 people with intellectual disability found that one in six (16%) prescriptions had errors.[29] The most common errors were the use of two or more medicines with the potential to interact, use of a contraindicated medicine, or prescription of a "when required" medicine with no maximum daily dose specified.[29]

Whilst there were challenges in locating studies involving medicine use in people with any disability, much of the available research focused on people with intellectual disability. This issue is evidenced by the lack of data focused on people with physical disability included in the report.

This further highlights the necessity for research focused on this population.

> *"I feel like we're just invisible. Like this problem isn't even on anybody's radar because nobody knows we exist.*
>
> Ricky, who is homebound with Ehlers-Danlos Syndrome, dysautonomia, mast cell activation disorder and chronic fatigue syndrome[46]

> *"I get frequent urinary tract infections. I need to have a pathology test to determine what type of infection, but meanwhile I need to start antibiotics because UTIs make me very unwell and result in other complications. I can't get the pathology test done, or get a script for antibiotics if I don't attend the GPs office, but the simple fact of having the UTI means I am even less able to do that. I have ended up in hospital with a severe kidney infection on a number of occasions, despite the fact that my GP is 100m [metres] from my house and could have prevented the infection getting this bad if I could have had these routine measures in place from home.* Julia[46]

Under-prescribing

Evidence published in an Australian study suggests there is potential under-use of medicines for chronic conditions in people with intellectual disability. A survey of 328 adults with intellectual disability living in Western Australia appeared to indicate some degree of under-treatment for chronic conditions. Only around two-thirds of participants who reported having epilepsy were receiving medicine for that condition,[30] while only 40% of people with intellectual disability with eczema or other skin rashes used a medicine to manage the condition. Further, less than 20% of people with intellectual disability who reported having asthma were using a medicine to manage their chronic condition.[30]

Over-prescribing

An Australian-based study found there was increasing use of psychotropic medicine in people with intellectual disability and inappropriate use of these medicines. The study, based in Queensland, found that 65% of participants with an intellectual disability used at least one medicine between 1999-2001, with 44% using a nervous system acting medicine, including analgesics and psychotropic medicines.[31] By 2012-2015, 90% of participants used at least one medicine and 86% used a nervous system medicine.[31] The prevalence of antidepressant use doubled from 17% in the 1999-2001 period to 36% in 2012-2015.[31]

A Queensland-based study involving 429 adolescents with intellectual disability found psychotropic medicine use was inappropriate for 82% of people prescribed this medicine.[32]

A study based in South Australia, while small, also confirmed the overuse of psychotropic medicines.[33] The study audited 20 antipsychotic prescriptions for young people with intellectual disability, finding that the prescribing was in line with current Australian treatment guidelines in only four cases.[33]

A fourth Australian study involving 114 older adults with intellectual disability found 76% of people prescribed central nervous system-acting medicines were using more than one central nervous system-acting medicine, including 21 (30%) using more than one anticonvulsant and 19 (27%) using both an antipsychotic and anticonvulsant.[34] Only about half of the people prescribed the central nervous system-acting medicines had a diagnosis for which the medicine could be considered first- or second-line treatment.[34]

There is potential for harm due to the use of medicines that act on the central nervous system.[35,36] Older people aged 65 years and over on two central nervous system-acting medicines are twice as likely to be admitted to hospital for falls, confusion or delirium than older people not taking these medicines.[35,36]

> *"I had rung the locum my doctor recommended, only to be told they don't do prescriptions, and when I asked what housebound people with chronic illness did then, they said that's 'when I would be admitted to a care facility', though they did offer a single script to tide me over. My doc's surgery said only 'Don't know' and 'try Google'.*
>
> Anon[1], who is homebound with ME/CFS[46]

CASE STUDY[37]

Multiple psychotropic medicines prescribed without clear reason for use or duration, and with no behaviour management support

A 15-year old boy with autism spectrum disorder and intellectual disability living in a specialised care home was taking five psychotropic medicines (quetiapine, lamotrigine, clonidine, olanzapine and sertraline). The boy was overweight with a body mass index of 40. Weight gain is a frequent side effect of the medicines that the boy was taking. He was referred for a psychiatric consultation due to ongoing behavioural problems. At the initial consultation, there was no documentation of the reason for the use of these medicines nor the intended duration of use.

A management action plan was developed for the boy, which included behavioural modification interventions, medicine changes and close monitoring. Over approximately 10 months, four psychotropic medicines (quetiapine, lamotrigine, clonidine, and sertraline) were tapered without any apparent behavioural deterioration. Due to a history of aggression that led to staff injury when olanzapine was discontinued in the past, an atypical antipsychotic, ziprasidone, was initiated prior to olanzapine being weaned off.

The care staff reported that the severe aggressive behaviour that was observed prior to the consultation did not reappear and that there was an overall behavioural improvement. During the final psychiatric assessment at week-78, the boy had lost 45kg with a body mass index of 25.5.

Inappropriate prescribing

Restrictive practice refers to any practice or intervention that has the effect of restricting the rights or freedom of movement of a consumer.[38] Chemical restraint, the use of medicines as a form of behavioural control, is one type of restrictive practice. While it is difficult to determine just how widespread the practice of chemical restraint is, Australian studies provide some estimates into the frequency of psychotropic medicines use as chemical restraint in people with disability.

Between June 2007 and July 2008, there were 25,578 instances of chemical restraint reported amongst 2023 people with disability in Victoria.[39] Atypical antipsychotics were the most commonly used medicine as chemical restraint (53% of people who received a medicine for chemical restraint), followed by antidepressants (33%), mood stabilisers (32%), and typical antipsychotics (31%).[39] Almost 60% of people who had experienced chemical restraint received more than one type of medicine used as a chemical restraint in the year.[39] Prevention of harm (both self-harm and harm to others) was the most commonly listed reason for the use of chemical restraint.[39] Consumer or carer consent for the use of chemical restraint and the appropriateness of chemical restraint was not reported in this study.

Where chemical restraint is required, it should be a short-term solution wherever possible.[38] One Victorian study of adults with intellectual disability living in residential care showed that the use of medicines prescribed as chemical restraint tended to be long-term.[40] Among 1,414 adults with intellectual disability living in residential care who received chemical restraint between 2008 and 2010, almost three quarters (74%) continued to be prescribed medicines as chemical restraint between 2013 and 2015.[40] That is, some of the people in this study had been prescribed medicines as chemical restraint for up to 5 years. Chemical restraints were used, on average, 50 times per person in the two year baseline period and 65 times per person in the two-year follow-up period.[40]

While changes to regulations related to the use of chemical restraint in residential aged care facilities may have changed this practice somewhat[41]; further research will need to be conducted to identify the impact this change has had on people with disability.

> *"I was forced to take medications not directly tethered to the treatment of my diagnosis but as a tranquilising sedative.*
>
> Person with disability in a paediatric mental health care ward. (Submission to the Disability Royal Commission)[5]

> *"I take medications that require authority from the health department. There are limits on the number of these meds that can be prescribed and the time between prescriptions, which leaves a small window during which I need to get back to the doctor to refill the prescription. If I can't see the GP (or other doctor) during that time, the medication runs out, and my ability to go anywhere or do anything is reduced even further. Then I start cancelling things I have been waiting months for, and saving my energy for, because I don't have the medications to be able to cope with them.* Julia[46]

Prescribing without an indication

Best practice dictates there should be a documented reason for the use of all medicines prescribed.[38,41] Medicines prescribed without an indication is another challenge to medicine safety experienced by people with disability living in Australia. Australian studies estimate that between 13% and 55% of people with autism spectrum disorder are prescribed psychotropic medicines.[42-45]

One study found that adults with autism spectrum disorder (n=188) were four times more likely to be prescribed a psychotropic medicine than people without autism (n=115).[45] There was no indication recorded for 14% of psychotropic medicines prescribed to adults with autism. Prevalence of prescribing without indication may be higher for specific classes of psychotropic

> *"I've been looking into [how to get repeat scripts while homebound] and it's been horrendous. I can get a prescription for one month from them, but after that, have to go back to my docs. I'm too ill to go to docs, so have been trying to find out what to do to get meds repeats (including antideps) and it's been awful. Apparently there is no solution.* Anon1, who is homebound with ME/CFS[46]

medicine; for example, in this study, 25% of antipsychotic prescriptions and 25% of antiepileptic prescriptions had no indication recorded.[45] These figures are important as this increased level of prescribing in adults with autism is not explained by any form of 'neurological or psychiatric disorder'.[45] Rather, the figures may indicate that psychotropic medicines are being used to manage behaviour in people with autism spectrum disorder.[45]

The majority of available data related to challenges experienced by people with disability at the time of prescribing has focused on people with intellectual disability. Evidence relating to the challenges that people living with other types of disability face during the prescribing process is limited. Case reports from consumers themselves suggest that physically accessing either the doctor or the pharmacy is a significant barrier for many.

> *"When I lived in a nursing home for the aged (I was aged 39) my GP would do visits and all charged at bulk bill rate. My scripts would be collected by the local pharmacy and the medicated [medicines] delivered back to the nursing home. As soon as I left the nursing home, the GP would not visit me, unless I paid heaps of money for a home visit. I had to collect my own scripts from the chemist. I did not leave the nursing home because I was "better".*
>
> Hunter, who is restricted in his ability to travel anywhere in an upright or sitting posture due to dysautonomia[46]

Dispensing: 'obtaining medicines'

Once a medicine has been prescribed, people with disability need to obtain the medicine from the pharmacy, where a number of challenges may be encountered. These challenges include barriers to accessing pharmacies and pharmacists, difficulty accessing the information they need and communication barriers.

It is important to note that people with disability may regularly rely on assistance from carers, family members and support workers. This can add complexity to accessing healthcare services or health and medicine information for a person with disability, due to factors such as the support person's knowledge and understanding or miscommunication. As noted, it is important support workers and carers are also provided with information related to the person's care which they are able to understand.

Accessing pharmacies and pharmacists

People with disability who are homebound or bedridden may not be able access health services including going to a pharmacy to purchase medicines they need. A report written by Ricky Buchanan, a woman living with disability, highlighted the many challenges people with disability who are bedridden face when accessing medicines and health services.[46]

Community pharmacists who home deliver medicines and liaise with GPs to organise repeat prescriptions for long-term medicines have been described as a "godsend".[46]

One consumer also described how her pharmacist kept her prescriptions on their premises and contacted her GP directly to obtain repeat prescriptions, which allowed her to avoid the 'ongoing nightmare' of accessing prescriptions and medicines when they were required.[46]

> *"A pharmacy who is willing and able to pack Webster packs, and who can deliver medications when required is a godsend to those who are homebound/bedridden.*
>
> Ricky, who is homebound with Ehlers-Danlos Syndrome, dysautonomia, mast cell activation disorder and chronic fatigue syndrome[46]

Accessing medicine information

Accessing medicines information can be challenging for people with disability, including people with hearing disability, vision disability, intellectual disability or cognitive disability.

Hearing disability:

We found only one Australian study exploring the barriers people with disability face when accessing health information, which involved people with hearing loss. A qualitative study involving 72 people with hearing loss who use Auslan, reported that people with hearing loss experience difficulty accessing or were unable to access the health information they needed.[47] The participants in this study reported their perceived lower level of English literacy and the lack of information provided in Auslan meant reduced access to health information.[47] That is not to say these results are applicable to the wider population of people who are deaf or hard of hearing, although it does highlight a challenge experienced by some. International evidence shows that people with disability experienced barriers when accessing health and medicine information.[48]

Vision disability:

Nine in 10 people who are blind or have low vision in Scotland found information on medicines difficult or impossible to read.[49] In an earlier survey, nine in 10 people who are blind or have low vision said they had never received information in their preferred format.[50] Preferred formats include audio information, large print or a combination of both.

Intellectual disability:

It may be challenging for people with intellectual disability to access medicine information in an appropriate format, due to challenges with learning or comprehending information.[9]

Cognitive disability:

It may be challenging for people with cognitive impairment to access medicine information that is appropriate for them due to issues with interpreting or remembering information.[10]

> **"Off-the-shelf medicine instructions are unreadable on both the packaging and the instruction leaflets.**
>
> Consumer with low vision[50]

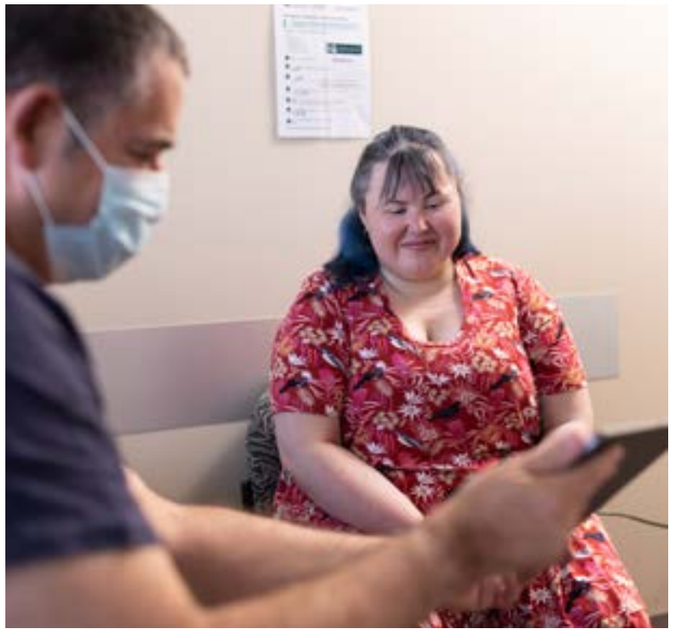
> **"It would be hard for me to read because I'm almost blind in one eye and I read things back to front.**
>
> Consumer with low vision[51]

In many cases, there is an absence of accessible materials, Easy Read or other inclusive measures that could facilitate appropriate information provision. Easy Read is a way of presenting information in a more accessible format, often using images to complement written text.[52] The availability of several other helpful examples is noted, including Easy Health in the United Kingdom which provides health and medicines resources.[53]

Understanding medicine information provided

A qualitative study involving 72 Australians who are deaf or hard of hearing and use Auslan, reported that most people who are deaf or hard of hearing had difficulty understanding health information.[47] An Australian study evaluated the level of understanding 17 people with intellectual disability had about their asthma medicines.[51] Some participants reported that written information provided can be challenging to understand.[51]

We did not find any studies that quantified the extent to which difficulty accessing the pharmacy, difficulty accessing or understanding medicine information, and difficulty communicating with pharmacists contribute to medicine-related harm in people with disability. Qualitative and anecdotal reports highlight that all these issues are challenges for many people with disability. Each person with disability experiences these challenges differently, with physical access challenges for some, and information access challenges for others, be it due to vision, hearing or intellectual disability. The evidence clearly indicates that solutions tailored to each individual's circumstance are necessary to promote medicine safety.



> "We usually don't understand what is written [in brochures] but we do see the pictures. If we want to understand what is written, we ask someone to explain it. That's what most Deaf people do.[47]

Administration and adherence: 'Taking the medicine'

Simply consuming medicine can be a challenge for many people with disability, which in turn may lead to difficulties taking the medicines as prescribed. The administration of medicines in people with disability can be complicated by factors including the packaging, the size of tablets, the taste, or a person's capacity to swallow the medicine due to dry mouth, seizures or difficulty swallowing.[54]

Changes in the appearance of medicines (e.g. when brands are substituted) or changes to the medication administration routine (e.g. when the time the medicine is taken is altered) can also increase the complexity of taking the medicines, and be challenging if the person does not understand why these changes have occurred or the changes are not in alignment with personal preferences.[54]

There may also be challenges for people with sensory processing disorder with sensory sensitivity leading to decreased tolerability of certain textures, flavours or dosage forms.

Challenges that people with disability face when obtaining medicines from the pharmacy will also directly impact on whether or not they take the medicine and their ability to take the medicines correctly.

This section discusses the challenges people with disability face when taking their medicines. These include the inability to discriminate between medicines, difficulty opening medicine packaging, difficulty using inhalers, patches, injector pens or drops, and difficulty swallowing, all of which can lead to medicine-related problems and harm.

> "It has always seemed ludicrous to me as someone who has used eye drops since birth that the info sheet for eye drops which are used by people with problematic vision is so small and virtually inaccessible.[55]

Medicine administration challenges

- **Unable to see or read medicine name and instructions**
  Difficulty reading the label means people with disability may experience barriers when taking medicines as prescribed. A Scottish study involving people who are blind or have low vision found that nearly half (45%) reported that it was 'impossible to read the instructions on medicines'.[49] These results are confirmed in multiple countries with a United Kingdom survey reporting that 97% of people who are blind or have low vision had difficulty reading medicine labels and 24% had difficulties distinguishing tablets.[56]

  In a Malaysian study, nine in 10 adults who are blind or have low vision were unable to read the labels of their prescription medicines completely, and one in five reported that they were 'often' or 'always' unable to differentiate between tablet or capsule dosage forms.[57]

About 15% of people who are blind or have low vision are also carers for other people, with a Scottish study identifying that 30% of people who are blind or have low vision and were carers were collecting or administering medicines for the people for whom they cared.[49] There is potential for the risk of harms due to lack of information tailored to the needs of individuals with disability extending to the wider family or carer network.

No equivalent studies in the Australian setting were located; however, the Blind Citizens Australia submission to the Therapeutic Goods Administration (TGA) Medicine Labelling and Packaging Review in 2012 provided perspectives from their members that highlighted similar medicine-related problems in the Australian community, including difficulty reading medicine labels and directions and difficulty reading the consumer medicines information.[55]

In European Union countries and the United Kingdom, it has been mandatory since 2005 for the medicine names to be displayed using Braille, and for consumer information leaflets to be provided in a format that is suitable for people who are blind or have low vision.[58,59] Despite the inclusion of Braille on medicine packaging, many people who are blind or have low vision still reported problems reading the Braille due to poor quality Braille or issues such as pharmacists covering the Braille with labels. However, most people in the study considered having Braille on medicine packaging very useful.[60]

It is not mandatory in Australia for manufacturers to include Braille on medicine packaging nor is it compulsory to make medicine information available in formats suitable for people with visual or hearing disability. High contrast lettering, large text, and upper and lower case font have been added to dose administration aids to make it easier for people with low vision to interpret instructions. One Australian example is Webster-pak® Low Vision,[61] which uses Braille to identify days of the week, however not the person's name or when the medicine should be taken. This initiative is useful for people with low vision but not those who have very low vision or who are blind.

No Australian studies have evaluated the effectiveness of Braille on prescription or medicine packaging in reducing medicine error; however, international evidence suggests Braille has the potential to reduce medicine errors when used as part of medicine packaging.

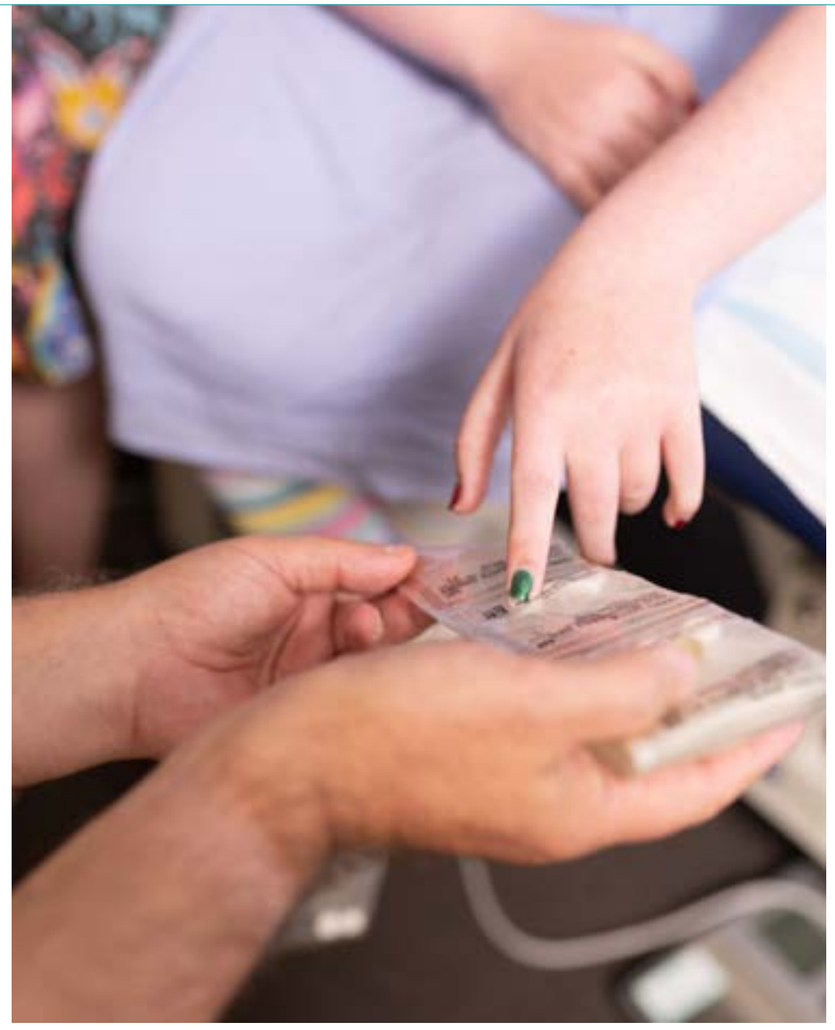
A study in India which included 100 people who are blind or have low vision reported that by providing prescriptions in Braille, with details such as medicine name, dose, instructions, expiry date and side effects, medicine error rates were reduced from 46% to 5%.[62]

> "Look, it has a band. And you have to pull it open, which costs a huge effort. I also have to turn this and I am not able to do this. So, my cleaning lady comes every Wednesday, and then I ask her in case a bottle needs to be opened.[67]

> "I'm planning on going to university when I finish school, but my inability to see what medication I'm taking is frightening.[63]

- **Difficulty opening medicine packaging**
  People with disability may have difficulties with opening medicine packaging. A United States study of people who are blind or have low vision found child-resistant packaging and containers with small caps as being particularly difficult to open.[64] Other difficulties identified were the spilling or dropping of tablets or pills. A United Kingdom study reported that almost half of adults, either with or without blindness or low vision, had difficulties opening medicine packaging, especially blister packages.[56]

  Difficulties with using inhalers has been shown to be a problem for people with intellectual disability.[65,66] A study conducted in an Australian outpatient clinic identified a range of problems with inhaler use in people with intellectual disability, as noted in the patients' care record.[66] The same group of researchers also examined the inhaler technique of people with intellectual disability and asthma.[65] Fourteen of the 17 participants (82%) stated that they had been shown how to use an inhaler, however no participant was able to use any inhaler device correctly.[65]



"The nurses decided Oliver wasn't in significant pain and could be given Panadol, Petra told us. She explained to them that Oliver couldn't swallow tablets and was in severe pain and needed IV medication. It took the doctor's intervention to make this happen.

*Names changed and some details removed to protect people's identities. Narrative based on a submission to the Disability Royal Commission[5]

- **Difficulty swallowing (Dysphagia)**

Dysphagia refers to difficulty in swallowing either solids or liquids. Administration of oral medicines to people with swallowing difficulties can present various problems, including choking and gagging on medicines, spitting medicines out and not swallowing medicines.[68]

As a result, medicines may need to be administered through a nasogastric tube.

It is estimated that between 7% and 22% of Australians have dysphagia, and up to one in two older people in long-term care facilities.[69] People with neurodegenerative or neurological diseases and with head or neck diseases are at high risk of dysphagia.[70] The prevalence of dysphagia varies depending on the disability, with international evidence showing the prevalence varied from 1% among adults with intellectual disability but without cerebral palsy,[71] one in two people with cerebral palsy,[72] and up to 99% among children with severe generalised cerebral palsy and intellectual disability.[71]

We did not find any Australian studies examining problems with medicine administration due to dysphagia for people with disability. Nor did we find any Australian studies related to challenges that carers may experience when attempting to administer medicines to people with disability for whom they are caring, however, consumer stories provide some insight into this problem.[71]

For people with swallowing difficulties or those using nasogastric tubes, best practice is to select a formulation of the medicine that can be easily administered (e.g. liquid formulations or patches).[74] Frequently, however, healthcare workers resort to modifying oral medicines themselves, for example by crushing or splitting tablets and opening capsules.[68] It is not always safe practice to alter medicines, and Australian studies show that 24% to 32% of altered medicines were classified as inappropriate or not suitable for modification.[75,76] Incorrect alteration can lead to inappropriate dosing and other medicine safety issues.

"I have swallowing difficulties. If they're giving me drinks or medication at the wrong angle or the wrong speed, I can choke on it. I'm just always having to be alert, working out how I'm going to ask for it in more than one way.

Woman living with disability[73]

"If the medication is crushed
a) how much is the resident actually getting of the prescribed dose
b) the residue left in mouth or under teeth
c) the interacting of combining the medications
d) decreased efficacy of the medication
e) when mixed with dairy type products.[77]

- **Error in medicine administration**

We did not find any Australian studies that assessed the extent of medicine administration errors in disability residential care homes. However, when considering the breadth of this issue, it is expected that the problem is frequent.

The New South Wales Poisons Information Centre (NSWPIC) provides some estimates into the frequency of medicine administration error in disability residential care homes.[78]

Two-thirds of calls from disability care homes or carers of people with disability to the NSWPIC regarding substance exposure were for medicine administration error.[78] The most common medicines that were wrongly administered were psychotropic medicines.[78]

There has been a significant and sustained increase in calls from in-home carers and carers in group homes to the NSWPIC between 2015 and 2020. This increase of 111% over five years, is primarily driven by a significant increase in drug information queries in addition to exposure calls.

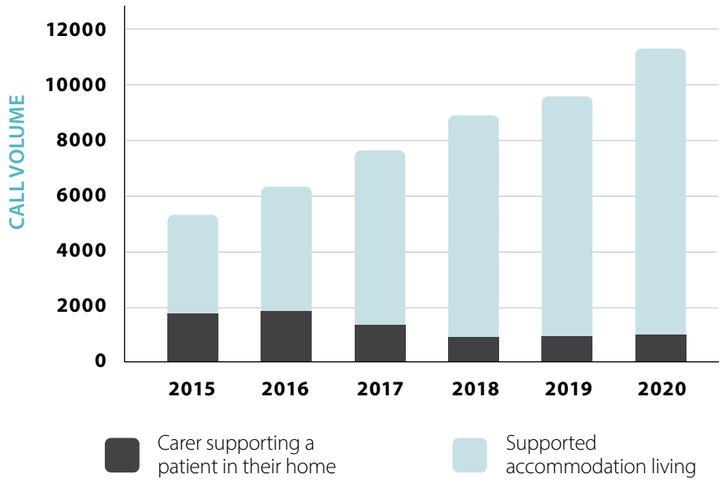
Exposure calls predominantly involved:

- Client being given someone else's medicines
- Client being given a double dose of their medicines
- Client being given morning medicines instead of evening medicines (or vice versa)

International evidence similarly suggests that errors in medicine administration are frequent. A Dutch study estimated that a quarter of medicine administration in a residential care setting for people with intellectual disability had an error associated with the administration.[79]

Call logs indicate psychotropic medicines and paracetamol are among the most common queries (See opposite page).[78]

Calls to NSW PIC from disability support workers (yearly)*



* The reduction in calls from carers may partly reflect change in practice of call takers coding calls.

Case examples highlight this issue further.[78]

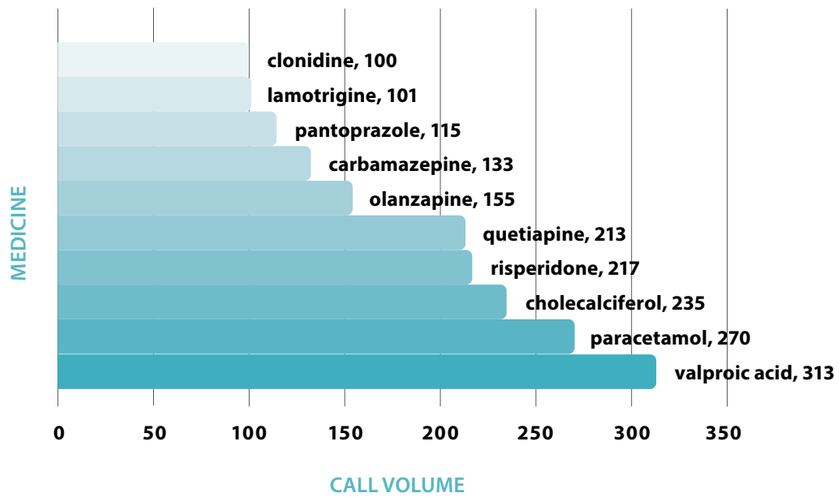
> *Carer in group home calls NSWPIC [New South Wales Poisons Information Centre] in the morning after giving another person's medicines* to a client about 5 minutes ago in addition to their own medications. The client has a history of seizures and is wheelchair bound.*

> *The medicines that were wrongly administered to the client included antidepressant, anticonvulsant, medicine for reflux and vitamins. The client's own medicines also included antidepressant, anticonvulsant and medicine for reflux.*

> *Group home called NSWPIC [New South Wales Poisons Information Centre] after a client drank another client's medication that was dissolved in a drink. Clonazepam [tranquilizer] 0.1 mg/drop 5 drops into a glass, about 3/4 remained when he drank it.*

Top 10 medicines - Calls from disability carers to NSW PIC

2015 - 2020



Monitoring: the effects of medicines

Medicines that have high potential for harm, such as opioids and psychotropic medicines, require regular monitoring by healthcare professionals.[80] Antipsychotic medicines have adverse effects that include weight gain, metabolic syndrome or movement disorders.[81] Further, it may be necessary to provide information and education to patients and carers regarding what symptoms, outcomes or behaviours could be regarded as possible side effects of a medicine and what action to take.

Medicines may also require specific monitoring (e.g. pathology) to ascertain their intended physiological effect, or therapeutic drug monitoring for some medicines. However, it is important to note that obtaining blood samples from people with cognitive disability may pose challenges and barriers may need to be overcome, or consideration needs to be given to prescribing certain medicines only if regular blood tests are feasible.[82]

Communication between consumer and carer is an important part of monitoring for side effects, as is ensuring behaviour changes are noted in the case of people with disability who are unable to communicate verbally.

A South Australian hospital required the use of an antipsychotic monitoring chart for young people with disability prescribed an antipsychotic, to monitor for side effects. An audit of 70 cases found that the chart was only in use for 20% of young people and the monitoring of adverse effects was only documented in four persons.[33] Although this study is small, it may indicate a larger problem; there is a lack of monitoring for side effects in medicines that have the potential for harm. A case example highlights this issue further.[83]

> *"Patient 001, who had no documented psychotic illness, was prescribed an antipsychotic (not TGA approved for management of behaviour in ID [intellectual disability]) at an average maintenance dose for psychosis as recommended in the AMH [Australian Medicines Handbook] 2020, and was prescribed two anticonvulsants concurrently in the absence of an approved indication (i.e. seizure disorder or bipolar disorder). They were experiencing symptoms consistent with medication-related adverse effects including weight gain, tremor and headaches. There was no evidence available of monitoring of the patient's medication, despite best practice requiring regular blood tests to monitor for toxicity of the anticonvulsants that they were prescribed, and therapeutic effect for one of the anticonvulsants. In addition, there was no evidence of monitoring for lipids or glycosylated haemoglobin which is a requirement if prescribed an antipsychotic. They were also prescribed a regular and PRN [as required] benzodiazepine when a seizure disorder and status epilepticus are the only approved indications for this medication."*[83]

Review of medicines

Medicine review or medication management review (MMR) is a process where pharmacists collaborate with consumers and GPs to ensure that consumers have a good understanding and knowledge of their medicines, that the medicines are all suitable, are used correctly, and are safe and effective. In Australia, government-funded comprehensive MMR programs include Home Medicines Review (HMR) and Residential Medication Management Review (RMMR).[84]

In-pharmacy medicine review services, MedsCheck and Diabetes MedsCheck, are also available and involve pharmacists reviewing a person's medicines against their listed medicines to create an up-to-date medicines history and action plan. They are services designed to improve the person's understanding of and adherence to their medicines and are funded under the Community Pharmacy Agreement.[84]

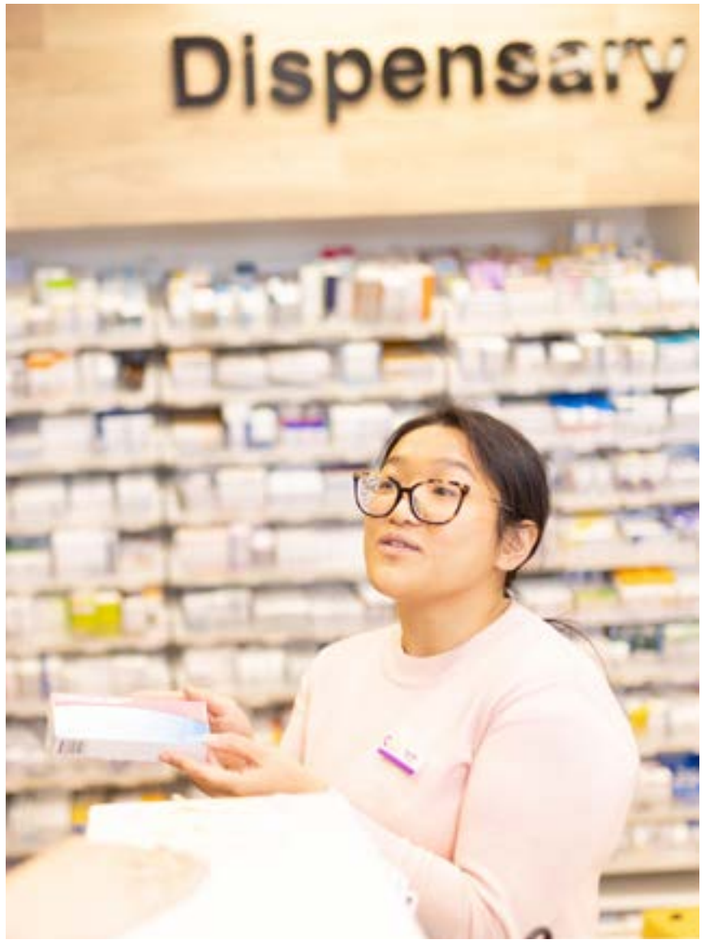
We did not find any Australian studies that looked at the number and types of medicine-related problems in people with disability, or that evaluated the effectiveness of MMRs in people with disability. However, based on studies that involve people without disability, it is likely that medicine-related problems are also common in people with disability. One Australian review found that MMRs are effective in improving quality use of medicines and health outcomes.[85,86]

Evidence from international studies suggests that MMRs are effective in identifying and reducing medicine-related problems among people with intellectual disability.[87] Four studies found MMRs reduced medicine side effects through changes in the medicine regimen or a decrease in medicine dose.[87-91]

> *"……Because of this low remuneration, and because the number of HMRs a pharmacist can conduct each month is capped at 30, I believe many accredited pharmacists shy away from conducting HMRs for people with intellectual disability and service delivery for this cohort is limited. As discussed above, until April 2020, a HMR could only be undertaken following a GP referral, and the apparent reluctance of GPs referring people with intellectual disability to accredited pharmacists for HMR has also been a barrier to service delivery."*[83]

OPPORTUNITIES
FOR IMPROVEMENTS

In this section, we propose opportunities to improve medicine use and health outcomes of people living with disability.



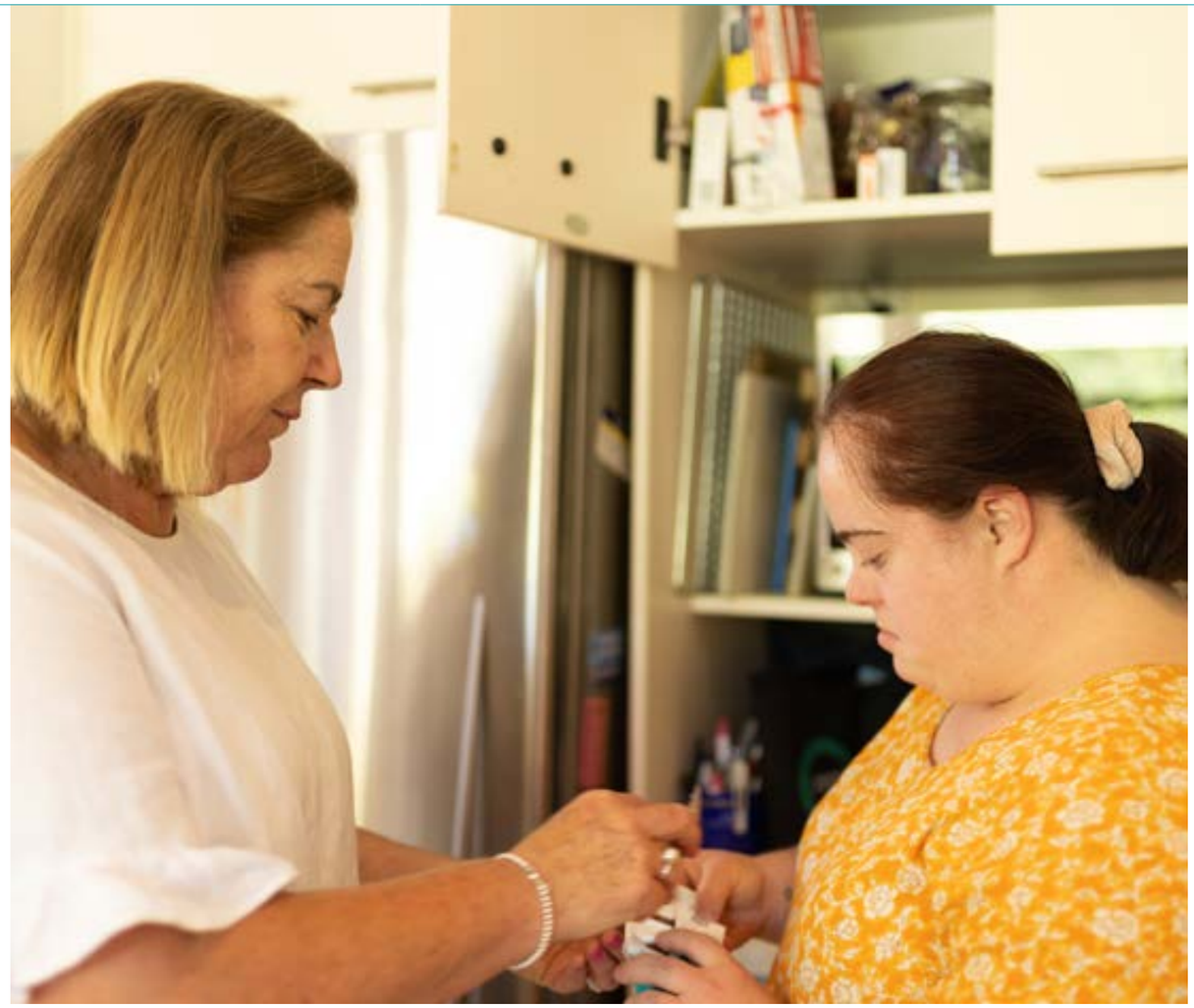
Improve access to pharmacists, medicines and medicine information

Strategies to improve patient access to pharmacists include making pharmacies more physically accessible, offering medicine home delivery services and providing telehealth services, as well as increasing the uptake of pharmacist-led services in the patient's home such as MMRs. The government currently funds telehealth services however, these services are only temporarily funded during the COVID-19 pandemic.[92,93] Mechanisms for supporting ongoing access to telehealth services to meet the care needs of people with disability are likely to be beneficial. However, it is important to recognise that such initiatives may have limitations, and they should complement face-to-face consultations, including embedded pharmacist roles.

One factor that determines the likelihood of people with disability taking their medicines correctly is whether they have been provided with information tailored to their needs by the pharmacist.[94] Mechanisms to enable provision of information in a format that is preferred by people with disability, such as Auslan instructions via interpreter, Easy Read or braille information, are required to ensure people with disability can understand the purpose of the medicines and how to take them correctly.

As part of the Disability Partnership's Pharmacy Project conducted in the United Kingdom, a checklist was developed for use by pharmacists to improve the way they communicate with people with disability, to check the person's understanding of the medicines dispensed, and to improve access to their pharmacies.[95] A similar checklist for use by Australian pharmacists is likely to be useful.

People with intellectual disability may require extra support when managing their medicines; tailored medicine education and adherence services for people with intellectual disability are needed. This education should include support for all members of the person's care and medical treatment team.



Support medicine administration for consumers, carers and service providers

Medicine administration can be challenging for people with disability who are blind or have low vision, swallowing difficulty, poor dexterity or a complex medication regimen.

Medicine administration may also be complicated by ethical considerations such as autonomy, informed consent, medicine refusal and responsibility for medicine self-administration. Mechanisms to enable easier management and administration of medicines are needed, such as the use of Braille on prescription and medicine packaging, alternative dosage forms, easy-open pill bottles and simplification of medicine regimens.

Pharmacists play a key role in supporting the self-administration of medicines by providing education and supporting decision making around missed or delayed medicine doses. Pharmacists also play an increasing role in medicine administration by providing immunisations and administering other injectable medicines. There is a significant opportunity to improve patient access to medicines by allowing appropriately qualified pharmacists to administer injectable formulations of medicines such as contraceptives, antipsychotics or vitamins.

Guidelines are available on the medicine labelling requirements for people who are blind or have low vision; however, adoption and implementation of the requirements have been limited. The Therapeutic Goods Administration (TGA) introduced requirements to make Australian medicine labels clearer and more consistent in August 2016.[96] In addition to the legislated mandatory requirements for medicine labels, there are other recommendations and best practice features of label design that may improve medicine safety for consumers.[96] These include colour contrast to improve legibility of text on labels, larger text size, use of Braille and inclusion of machine-readable code (e.g. a QR code that can be scanned to obtain the Consumer Medicines Information).

In July 2021, the Australian Commission on Safety and Quality in Health Care published a National Standard for Labelling Dispensed Medicines.[97] This standard provides guidance for labelling dispensed medicines clearly and consistently and incorporates recommendations of the American Foundation for the Blind and American Society of Consultant Pharmacists.[98] manufacturers, and healthcare professionals are more likely to adopt recommendations.

Medicines are often altered to ease medicine administration for people with swallowing difficulties; however, Australian studies have shown that in up to one-third of cases, alteration of the medicine has the potential to cause problems.[75,76]

For people with disability living independently, strategies to prevent inappropriate medicine alteration include documentation in prescription or dispensing software to ensure that pharmacists are aware of specific requirements for medicine administration (e.g. difficulty swallowing, poor dexterity).

For people with disability living in care homes, mechanisms to enable regular consultation and documentation between care staff and pharmacists may be helpful to ensure pharmacists are aware of specific requirements for medicine administration and where alternative formulations may be required.

Dedicated review, discharge and handover for all people with swallowing difficulties may go some way in preventing inappropriate alteration of medicines.

Simplification of the medicine regimen using tools employed in different settings, such as the Medication Regimen Simplification Guide for Residential Aged Care (MRS GRACE),[99] can reduce medicine administration errors in people with disability by reducing the frequency and number of medicines administered.

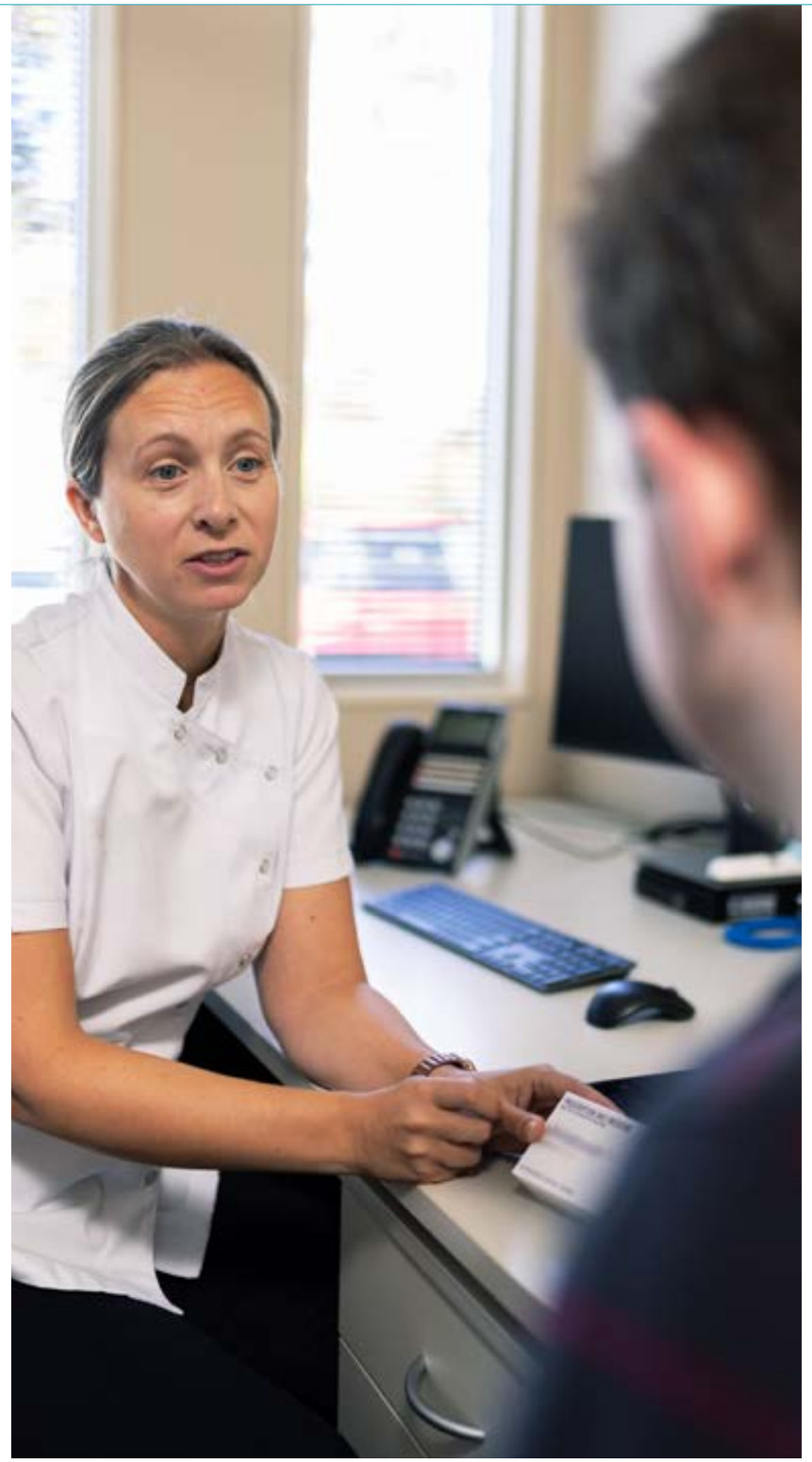
Increase use of and access to comprehensive medication management review services

Comprehensive medication management reviews[100] (MMRs) aim to identify, resolve and prevent medicine-related problems, and optimise patients medicine use. The process occurs in consultation with the patient, and in collaboration with a medical practitioner (e.g. general practitioners and some specialists) and other healthcare providers, to optimise each patient's medicine experience and clinical outcomes. Types of government-funded MMR programs include Home Medicines Reviews (HMRs) and Residential Medication Management Reviews (RMMRs).

Evidence suggests that MMR programs, such as the HMRs and RMMRs,[84] effectively identify and resolve medicine-related problems in people without disability living in the community or aged care facilities.[28,85,86] However, the service is implemented infrequently and identifies problems after they have occurred.

Mechanisms to support regular person-centred MMRs are fundamental to ensuring medicine safety and optimising medicine use in people with disability. A comprehensive MMR could benefit a person with disability who is at risk of medicine misadventure due to multiple chronic conditions, comorbidities, age, social circumstances, characteristics of their medicine (e.g. psychotropic medicines), complexity of their medicine regimen, physical factors (e.g. swallowing difficulties) or limited knowledge and skills to use their medicines effectively and safely.

Regular and targeted use of MMRs was raised by witnesses and in submissions during the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the 'Disability Royal Commission') with the possibility of considering ways to improve their access to people with disability,



particularly in the context of those on psychotropic medicine.[101]

Support workers at disability care homes often require medicine information or need to know what to do when there are medicine incidents, such as wrongly administered medicines. Between 2015 and 2020, there was a three-fold increase in the number of calls from disability care homes to the New South Wales Poisons Information Centre.[78]

Nearly all calls from disability care homes requesting information were queries for medicine information, while two-thirds of calls regarding substance exposure were for medicine administration error.[78] The frequency of queries for medicine information and medicine administration error in disability care homes reinforces the need for government-funded comprehensive MMRs as well as quality use of medicine (QUM) services in disability care homes, similar to those currently funded in residential aged care facilities.[84]

Face-to-face, person-centred comprehensive MMR services are preferred; however, in areas where face-to-face visits by pharmacists are not readily available, one strategy to improve the use of these services by people with disability is by adopting telehealth MMRs. Further, it may be advantageous for people who are hard of hearing to access telehealth MMRs that provide access to pharmacists and GPs who are Auslan proficient. A 2020 scoping review found that telehealth MMRs led to positive clinical outcomes, improvement in medicine use and cost savings,[102] although none of the studies involved people with disability.

Telehealth MMRs for eligible Australians are funded temporarily during the COVID-19 pandemic.[92] Ongoing access to telehealth MMRs will likely benefit people with disability who do not have access to home visits.

Improve monitoring of medicines used (including use of chemical restraints)

Many high-risk medicines such as psychotropic medicines should involve regular monitoring by the healthcare professionals when used; failure to monitor use and the effect of the medicines regularly can result in significant harm or death.[103] Medicine monitoring may also require objective measures such as blood tests to ensure medicine efficacy.

Mechanisms to improve monitoring of the effects of medicines are necessary. One such example is the antipsychotic monitoring programme developed in 2015 in South Australia which focuses on gaining informed consent, regular monitoring of the person's response and reducing adverse effects of antipsychotic medicines.[104] It is also important to ensure there are pathways in place for deprescribing of medicine due to the necessity to cease some medicines gradually. Analysis using existing datasets can help monitor use of medicines in people with disability, although this is only the case if the dataset allows identification of people with disability or are linked with disability status. The National Disability Data Asset, when available, may help us better understand variation in medicine use among people with disability.[105]

The Australian Commission on Safety and Quality of Health Care recommended obtaining informed consent and MMR every six months by a pharmacist when antipsychotic medicines are used as a form of chemical restraint for people aged 65 years or older.[106] From July 2021, residential aged care providers are required by law to abide by a set of requirements prior to using a restrictive practice, including use of a medicine as a chemical restraint.[41] The requirements include showing that the medicines are used only as a last resort, documenting alternative strategies that have been trialled, obtaining informed consent from consumers or authorised representatives and monitoring and reviewing use of restraint.[41] It must be noted that this issue may be specific to those with cognitive disability. Mechanisms for implementing these requirements among people with disability are similarly required to prevent use of medicines as a chemical restraint. Dedicated adverse drug reaction and safety monitoring services for people with disability are required to ensure on-going monitoring of the safety and effectiveness of the medicines used.

Data generation and use of existing data to improve medicine safety in people with disability

Despite our best efforts to find Australian evidence, what is remarkably clear and consistent is the lack of Australian data on medicine safety issues in people with disability.

Initiatives to improve medicine use and health outcomes in people with disability, whether by the government, researchers or healthcare professionals, can only be developed and implemented effectively if we know where problems have occurred.

Research is needed to generate data in areas where there is lack of Australian data, such as understanding the extent and types of medicine-related problems, inappropriate or incorrect medicine administration, frequency and effectiveness of MMR and medicine reconciliation services in people with disability.

Analysis using existing data can help address some of the evidence gaps. For example, it may be possible to quantify the number of MMR services that people with disability receive using data from the Australian Institute of Health and Welfare (AIHW).[107] The AIHW has developed a disability "flag" to identify records of people with disability.[108] Another way to better leverage use of existing data is by linking existing datasets. It must be noted that intellectual disability and autism spectrum disorder may not be 'flagged' so it can be difficult to extract information related to medicines use from existing datasets.

Data linkage is a method that brings together data about the same person from different sources to create a richer and more informative dataset. The National Disability Data Asset is an Australian data linkage initiative by the Commonwealth, state and territory governments and is currently in a pilot stage.[105] The pilot aims to cover areas such as education, income, health and disability supports using data from the Commonwealth, state governments (New South Wales, Victoria, South Australia) and the National Disability Insurance Agency.[105] Information on how to and who can access the data asset is not yet available. However, when this dataset is available, it may provide the opportunity to better understand use of medicines and health services and to identify medicine safety issues such as over- or under-use of medicines in people with disability.

NDIS Practice Standards[109,110] already include requirements for medicine management. The extent to which the NSWPIC is being contacted by providers suggests there are processes in place to meet them. Requirements to record, monitor and report use of chemical restraint also exist. However, the degree of compliance, and degree of medicine safety problems remains unclear as these do not appear to be publicly reported. Publication of this data would help guide medicine safety measures for NDIS participants.

Research to inform intervention implementation and service delivery

There is a wealth of literature to support implementation of interventions and services to reduce medicine-related problems and to improve health outcomes[111,112]; however, there is limited research that focused on people with disability. A 2021 systematic review of 182 studies showed that people with disability were systematically excluded from interventions to improve medicine adherence.[113] Considering people with disability often have more complex needs and different co-morbidities compared to people without disability, targeted research testing interventions and services to promote safe and effective use of medicines would assist.

It must be noted that there are several barriers to research involving people with disability such as challenges related to recruitment, lengthy consent processes and limitations to providing informed consent.

Despite these challenges, it is imperative more research is undertaken. Participatory action research methods using a co-design approach involving 'researchers with lived experience' in all aspects of the research will ensure a research program that reflects critical areas of disability need.[114]

Removing barriers

There is a clear and pressing role for pharmacists to be engaged in medicines safety for people with disability. Models of practice focused on medicine safety are urgently required to help address the health and life expectancy gap. Pharmacists must be identified as a required service provider for people with special medicine needs. Actions needed to achieve safer medicines use in people with disability include:

Appropriate medicine use	Ensure appropriate use of medicines by conducting medication management reviews after hospital discharge, at transitions of care, for all psychotropic use, and for complex medicine regimens, and by mandating consent for use of chemical restraint.
Remove barriers in accessing the pharmacy	Ensure all pharmacies are physically accessible and that home delivery services are available.
Remove barriers in accessing information about medicines	Ensure that medicines information is available in a variety of accessible formats including Auslan, Braille, audio and Easy Read, and that tailored and on-going educational sessions are available for those with an intellectual disability.
Remove barriers in medicine administration	Simplify with regular medication management review services, and ensure Braille packaging is available.
Improve access to medication management review and medicine safety services	Ensure that comprehensive medication management review services are accessible, such as through telehealth or with Auslan interpreters, and that medicine-related services are available and funded in disability care homes.
Improve monitoring of medicines	Provide monitoring services for psychotropic medicine use and complex medicine regimens, including adverse reactions.
Improve understanding of NDIS	Provide education and support to increase understanding of the NDIS system and how accessing services between Medicare and NDIS may increase safety and continuity of care.

TECHNICAL APPENDIX

Appendix 1: Search Strategy

Australian literature on medicine safety (from 2000 to July 2021) were identified from the following databases: Medline, Pubmed, Embase and Ovid Emcare. Criteria for inclusion of studies are that the studies address medicine-related problems including adverse medicine events, adverse medicine reactions or medicine incidents as a result of the therapeutic prescribing, dispensing or administration of medicines. The literature search was initially restricted to studies involving people with disability in Australia. Where there was limited or no Australian research, the report authors performed targeted search to identify international evidence. Reference lists of relevant studies were reviewed to identify additional papers. Case studies on medicine-related problems were identified and included in this report where available and relevant. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability,[5] national or state reviews and annual reports of the disability sector were reviewed to identify additional information on medicine-related problems in people with disability.

Based on the terms of reference in the Letters Patent of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, the term "people with disability" is defined as "people with any kind of impairment, whether existing at birth or acquired through illness, accident or the ageing process, including cognitive impairment and physical, sensory, intellectual and psychosocial disability".[5,6] The Australian Bureau of Statistics defines disability as "any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months".[7] The authors were guided by the definitions used by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and the Australian Bureau of Statistics when writing the current report and when deciding whether literature found was relevant to the report. All papers referenced in this report were deemed relevant by the report authors. A consensus was reached among the report authors where there was uncertainty whether or not a paper should be included in this report.

Example search strategy

1 Medication Errors/ 13743
2 Medication Reconciliation/ 1332
3 Medical Errors/ 17278
4 Safety Management/ 20857
5 "Quality of Health Care"/ 75573
6 "Drug-Related Side Effects and Adverse Reactions"/ 34411
7 Quality Assurance, Health Care/ 56607
8 Patient Safety/ 23295
9 patient* safety.mp. 50977
10 medication* safety.mp. 2750
11 adverse drug event*.mp. 4476
12 adverse drug react*.mp. 23355
13 medica* incident*.mp. 359
14 medica* mishap*.mp. 58
15 medica* mistake*.mp. 231
16 medica* misadventure*.mp. 129
17 drug misadventure*.mp. 15
18 drug* toxicity.mp. 6132
19 medication related harm*.mp. 96
20 medication related incident*.mp. 31
21 medication related problem*.mp. 577
22 medic* prescri* error*.mp. 80
23 drug* prescri* error*.mp. 21
24 prescri* error*.mp. 1208
25 medica* dispensing error*.mp. 32
26 drug* dispensing error*.mp. 18
27 dispensing error*.mp. 320
28 medication* administra* error*.mp. 385
29 drug* administra* error*.mp. 117
30 administra* error*.mp. 934
31 medication* related admission*.mp. 12
32 drug related admission*.mp. 56
33 Patient Transfer/ 9136
34 (medication review* or medicine review*).tw. 2420
35 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 279031
36 Australia/ or Australian Capital Territory/ or New South Wales/ or Northern Territory/ or Queensland/ or South Australia/ or Tasmania/ or Victoria/ or Western Australia/ or Australia.mp. or Victoria.mp. or Tasmania.mp. or New South Wales.mp. or Queensland.mp. or Australian Capital Territory.mp. or Australia*.mp. 222506
37 exp Australia/ 156222
38 australia.in. 644232
39 36 or 37 or 38 740023
40 Intellectual Disability/ or "International Classification of Functioning, Disability and Health"/ 57489
41 Disabled Persons/ 44384
42 Multiple Sclerosis/ 56416
43 Arthritis/ 36165
44 Deaf-Blind Disorders/ 142
45 Sign Language/ or Deafness/ or Persons With Hearing Impairments/ 30146
46 Vision Disorders/ 28707
47 Hearing Loss/ 17733
48 Autistic Disorder/ 22024
49 Attention Deficit Disorder with Hyperactivity/ or Autism Spectrum Disorder/ 43787
50 Blindness/ 20448
51 Schizophrenia/ or Schizophrenia, Childhood/ 106177
52 Down Syndrome/ 25129
53 Cerebral Palsy/ 21820
54 Spinal Cord Injuries/ 40001
55 Brain Injuries/ 53446
56 Amputation/ 22099
57 Cognition Disorders/ 65433
58 Learning Disabilities/ 14391
59 Developmental Disabilities/ 21276
60 (disabled or disabilit*).mp. 345030
61 physical disabilit*.mp. 7113
62 intellectual disabilit*.mp. 67817
63 learning disabilit*.mp. 18713
64 developmental disabilit*.mp. 24854
65 Sign language.mp. 3227
66 Multiple sclerosis.mp. 89919
67 Arthritis.mp. 233757
68 (vision impair* or visually impair* or vision disorder* or blind or blindness).mp. 348014
69 (deaf* or hard of hearing or hearing loss or hearing impair* or hearing disorder*).mp. 120698
70 (mental health condition* or mental health illness* or mental illness* or mental health illness* or mental disorder* or mental health disorder*).mp. 232611
71 acquired brain injur*.mp. 2519
72 (autism spectrum disorder* or autistic disorder* or attention deficit disorder*).mp. 78000
73 schizophrenia.mp. 150079
74 down syndrome.mp. 29755
75 cerebral palsy.mp. 29372
76 spinal cord injur*.mp. 53593
77 brain injur*.mp. 100777
78 amputation*.mp. 52856
79 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 1743745
80 35 and 39 and 79 724
81 limit 80 to yr="2000 -Current" 655

Database: Ovid MEDLINE(R) ALL <1946 to September 28, 2021>

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We need a greater focus on medicine safety to address the health and life expectancy gap for people with disability.