

Safety and Quality use of Medication

Sector Round Table Report

December 2023

About National Disability Services

National Disability Services (NDS) is Australia's peak body for non-government disability service organisations, representing more than 1000 non-government service providers. Collectively, NDS members operate several thousand services for Australians with all types of disability. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Commonwealth governments. We have a diverse and vibrant membership, comprised of small, medium and larger service providers, supporting thousands of people with disability. Our members collectively provide a full range of disability services, from supported independent living and specialist disability accommodation, respite and therapy, to community access and employment. NDS is committed to improving the disability service system to ensure it better supports people with disability, their families and carers, and contributes to building a more inclusive community.



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1.0 Executive summary

People with disability experience poorer health outcomes and a significantly lower life expectancy than people without disability. In Australia there are 4.4 million people with a disability, and over 631,000 people accessing the NDIS (NDIS, 2023). Significant gaps and barriers have been identified for people with disability in accessing quality and safe medication. (Pharmaceutical Society of Australia, 2021; 2022; DRC, 2023; Duckworth and Wilson, 2021; NDIS Commission, 2021).

Access to appropriate use of medication is essential to maintaining health, and for many NDIS participants this means services and disability support workers (DSW) that are competent in the safe and effective use of medication are critical.

Disability services and workers have been supporting the essential function of medication management prior to and during the NDIS, often overseeing complex medication needs in diverse settings. However, services face multiple challenges in ensuring the Quality Use of Medication (QUM) is safe, effective and keeps the human rights of the person with disability central. In the current environment, each disability support provider needs to develop robust organisational and practice governance systems in the context of limited practice guidance. In most states and territories, there is limited legislation or official guidance regarding medication management. Implementation is further challenged by significant pricing misalignment, particularly for people with complex support needs, ongoing workforce pressures including turnover and training, and the varied interactions with health systems. DSWs can also be challenged by limited standardised training, unknown risks and a lack of clarity on their scope of practice.

To strengthen the delivery of QUM for NDIS participants the disability sector needs strengthened guidance, an uplift in workforce capabilities, technical advice and support to apply good practice across diverse service delivery settings and funding to support the systems and quality improvement for quality and safe services.

NDS Medication Round Table background

The NDS National Round Table on QUMs in the Disability Sector was held on 4 October 2023, in response to disability service provider feedback on the significant challenges in the QUM.

The Round Table was held online and brought together 280 participants nationally from disability service providers and health professionals to discuss the challenges and barriers to safe medicine use and put forward solutions and best practice to address these gaps. The Round Table event is part of the NDS Positive Health Outcomes Project, funded by the Australian Government Department of Social Services.

Medication Round Table Key Themes

There were six key themes which Round Table participants raised as challenges in the delivery of medication management. These were confirmed in sector consultations.

Key Themes:

Theme 1: Medication legislation and NDIS Commission guidance

Theme 2: Disability workforce and training

Theme 3: Medication management

Theme 4: Disability services policy and procedures

Theme 5: Universal health service interface

Theme 6: Participant experience

Next steps: Options analysis and insights

Based on the Round Table thematic analysis and sector consultation the following options were identified as potential opportunities for strengthening systems for QUM in disability services.

Each option is proposed as a starting point only and further consultation and consideration with disability services and people with disability is needed to guide future action. The opportunities outlined are interlinked, and a balanced approach is required to ensure improved QUM in disability services.

Systems Pillar 1: Leadership and governance:

- Legislative or practice guidance uplift: Clear guidance to disability services on the QUM is needed. A review of existing legislation and NDIS Practice guidance should be considered as a first step, with further guidance and tools made available to address identified gaps.
- Medication incident reporting: That the NDIS Commission provide clarification on the reporting requirements for disability service providers regarding medication error and incidents to the NDIS Commission.
- Medication incident reporting data: That the NDIS Commission makes data on medication errors and incidents available as part of regular reporting, to support continuous quality improvement in the disability sector.
- High Intensity Support Skills Descriptors (HISSDs): That the NDIS Commission provides clarity regarding the training requirements for HISSDs, and how the HISSDs will be treated in organisational registration processes.

Systems Pillar 2: Disability workforce

- Standardised training: Existing training courses for disability support workers on medication management are reviewed and where needed updated to reflect contemporary evidenced based practice.
- Inclusion of the training in relevant Certificate 3 and 4 disability courses is considered by government in consultation with Registered Training Organisations (RTOs) and disability services.
- Scope of Practice: In line with findings from the Own Motion Inquiry into Supported Independent Living (SIL) and the role of DSWs in health supports, a DSW medication scope of practice framework is developed, and this is used to inform risk stratified capabilities required for the QUM.

Systems Pillar 3: Financing

- The NDIA deliver a best practice approach to pricing that incentives quality and links to the objectives of the NDIS. Pricing and individual funding needs to support the QUM for participants with complex or high-risk medication needs with their service providers.

Systems Pillar 4: Disability service tools and delivery

- Medication chart: That a template for disability services medication chart and companion tools are developed in collaboration with people with disability, providers, medical professionals and other key stakeholders such as the NDIS Commission and the Australian Commission on Safety and Quality in Health Care.
- Promoting existing good practice: That NDS as part of the Positive Health Outcomes project will promote good practice in QUM including medication management and incident and risk reporting.
- Medication management resources for providers: That NDS will review and collate existing resources that support providers to deliver QUM for people with disability, and identify the gaps.

Systems Pillar 5: Universal service interface

- National Roadmap QUM integration: That the Department of Social Services liaise with the Department of Health and Ageing to review the National Roadmap for Improving the Health of People with Intellectual Disability action plan, and identify opportunities to integrate QUM in existing actions.
- General Practitioner (GP) guidance: Relevant stakeholders consult with GPs and review guidance for GPs regarding prescribing requirements including where NDIS services are involved including documentation and medication charts, and prescribing chemical restraint medications.

2.0 Overview of the Quality Use of Medication

2.1 Introduction

The NDS Quality Use of Medication Round Table was undertaken following NDS engagement with the disability sector through the NDS National Quality and Safeguarding Communities of Practice in 2023. Attendees raised specific concerns regarding the challenges and gaps in the Quality Use of Medication (QUM) including the NDIS Commission guidance and practice standards.

The purpose of the Quality Use of Medication Round Table was to bring together disability service providers and other key stakeholders including nurses, pharmacists, and allied health professionals to discuss the challenges and gaps within QUM for disability services, which may be impacting on the health outcomes of people with disability.

The Round Table discussions and analysis are captured within this report with recommendations focused on improving the quality and safeguarding of services, for government and actions for NDS address these challenges.

2.2 NDS Positive Health Outcomes project

The Quality Use of Medication Roundtable is part of the NDS Positive Health Outcomes Project, funded by the Australian Government. The project is focusing on engagement and education to support positive health outcomes for people with disability.

The project objectives are:

- Build knowledge, skills and confidence among disability organisations, senior leaders, managers, and frontline workers regarding safe, quality health supports for people with disability.
- Create a sustainable resource for providers to return to and give opportunity to discuss and hear about contemporary good practice.
- Develop a deeper understanding of the issues impacting NDIS provider delivery of health supports for people with disability and the interactions with health care systems.

The Round Table and this subsequent report includes insights and options for government agencies and other key stakeholders, as well as identifying actions within the scope of the NDS Positive Health Outcomes project.

3.0 Setting the scene: Quality Use of Medication in disability services

3.1 Quality Use of Medication in the NDIS

QUM is the use of medicines in a safe and effective manner and is an essential element of disability services.

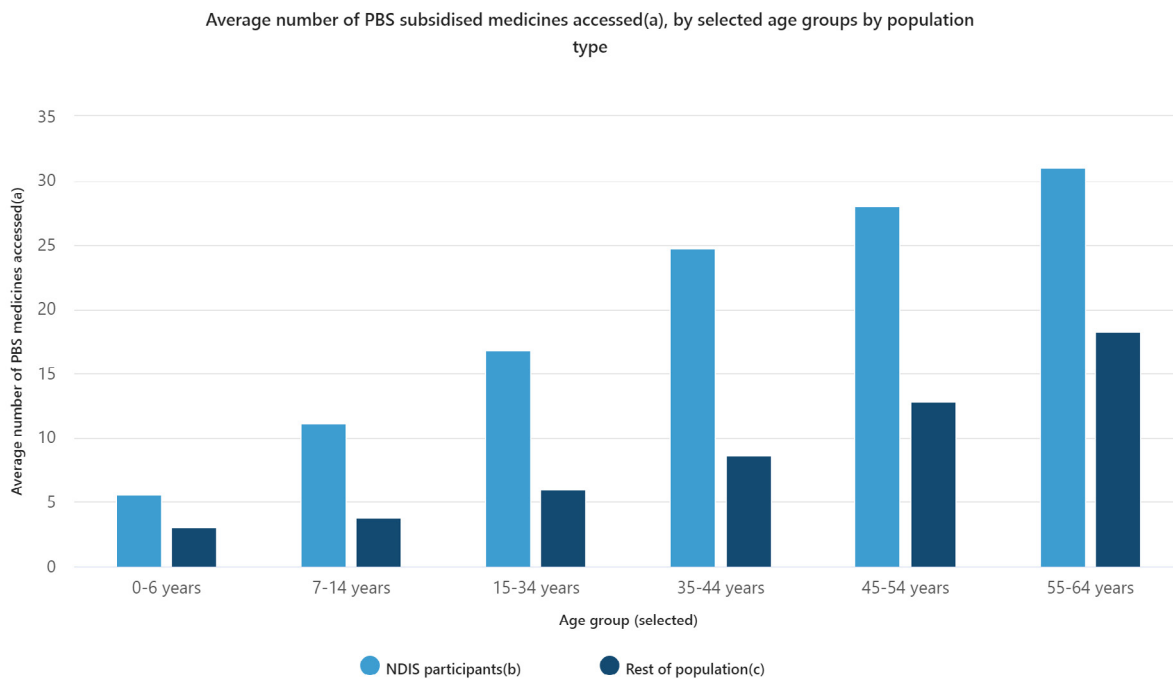
In Australia there are 4.4 million people with a disability, and over 600,000 people accessing the NDIS (ABS, 2021). People with disability experience poorer health outcomes and a significantly lower life expectancy than people without disability (DRC, 2023).

One aspect of maintaining wellbeing and quality of life is the appropriate use of medication, however the Take Care Report from the Pharmaceutical Society of Australia Medicine Safety Facts (2019) identified people with disability face significant barriers to access to quality and safe medication from prescription through to medication administration.

Unsafe use of medication can cause significant harm. The World Health Organisation work to address harm in health care settings, and the WHO recognises “unsafe medication practices and medication errors are a leading cause of avoidable harm in health care systems across the world” (WHO, 2017). In Australia, 250,000 people are hospitalised each year because of medication error, misuse, and misadventure (PSA, 2021). A further 400,000 presentations to emergency departments are likely to be due to medication related problems and 50 per cent of this harm is preventable.

QUM is particularly important for people with disability as analysis of the Australian Pharmaceuticals Benefits Scheme (PBS) data from 2019–2020 found that NDIS participants

accessed both a higher number of medicines and a higher number of total scripts compared with the rest of the population (ABS, 2021). Of note, NDIS participants aged between 17 to 44 years had an average number of scripts almost three times higher than those of the same age in Australian population.



Source: Australian Bureau of Statistics, Characteristics of National Disability Insurance Scheme (NDIS) participants, 2019: Analysis of linked data 22/09/2021

The analysis also reviewed Medicare items, and highlighted that NDIS participants engaged with GP services and specialist more than non-NDIS participants, however were less likely to have used pathology and collection services, diagnostic imaging and optometry services (ABS, 2021).

UNSW Department of Developmental Disability Neuropsychiatry 3DN undertook a scoping review of causes and contributors to deaths of people with disability in Australia (Salomon, C. And Troller, J., 2019). Key findings revealing that the median age at death was between 20-36 years lower than the general population. Risk factors and vulnerabilities included a high proportion of people who died experienced issues including medications and disease processes, and identified high rates of polypharmacy.

3.2 Reforms in the disability sector

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) handed down its report and recommendations on 20 September 2023. The DRC heard matters regarding QUM including inadequate access to health professionals including GPs, inappropriate prescribing particularly regarding psychotropic medication and inadequate access to medication management review services. Medication was also highlighted regarding family violence, with both the withholding of medication and overuse of medication used as a form of family violence.

The DRC recommendations related to medication management included:

- 6.37 Data collection and public reporting on psychotropic medication.
- 7.38 Minimum service standards and monitoring and oversight of supported residential services and their equivalents. (The recommendation references participants living in residential services requiring detailed health plans, which often include medication).

The NDIS Review Working Together to Deliver the NDIS was released in December 2023, with 26 recommendations and 139 supporting actions (Commonwealth of Australia, 2023). The review acknowledged many of the challenges in deliver quality and safe health supports in medication management from workforce capability, training costs, as well as addressing the essential issue of improved access and integration of foundational and general health services.

The NDIS Quality and Safeguards Commission undertook an Own Motion Inquiry into Supported Independent Living (NDIS, 2021) prompted by a significant number of serious incident reports. The Own Motion Inquiry acknowledged the challenges of SIL residents in accessing appropriate health care, and the essential role SIL workers play in supporting and coordinating access to health services and information, which encompasses medication management.

3.3 Responsibilities for health supports between NDIS and health services

NDIS participants have the right to access mainstream health services, and the Council of Australian Governments (COAG) agreements established the roles for the NDIS and universal health services in delivering services (Commonwealth of Australia, 2012). The agreement establishes that the NDIS is responsible for providing participants with maintenance supports that arise as a result of a participant's impairment, and universal health services are responsible for providing diagnosis, early intervention, and treatment of health conditions.

The division of roles and responsibilities for health supports between the NDIS and health services was further clarified through a ruling in the Administrative Appeals Tribunal (AAT) in 2018 regarding a person with an intellectual disability request for support in managing their diabetes including insulin management. The ruling established that for this person that the NDIS was responsible in funding these identified health supports, due to a range of factors including the impact of the person's disability precluding them from self-managing their diabetes medication. While the AAT ruling didn't establish a precedent it did see increased access to nursing care to oversee and support people with disability to address their health needs.

The division of responsibilities and services has been a point of contention within the NDIS and universal health services, due to the gaps and challenges some NDIS participants have faced in accessing health services. The need for health services and their workforces to improve the responsiveness and accessibility for people with disability has been acknowledged in Australia's Disability Strategy (2021).

4.0 Quality Use of Medication

4.1 Medication management processes

The medicines management pathway describes the processes and stakeholders involved in the use of medicines including prescribing, dispensing, administration and monitoring (Stowasser et al 2004). The processes include a range of tasks including informing a person about a medication, how it will assist them and the possible risks, involving them in the decision to take medication, administration of complex medication regimes, side effect monitoring and documentation.

Health services and aged care facilities have a closed loop system where each component of the medication pathway occurs within the organisation, or the organisation is responsible for a function with clear parameters like in home nursing.

Medication management in disability services is often more varied in the support required between participants, and in diverse settings ranging from supported accommodation to community settings. The responsibility for supporting a participant may be required in all or just some elements of medication support and administration. Disability service providers also need to liaise across multiple prescribers and dispensers, and coordinate medication and documentation transfers with other disability services or family supports on a daily basis such as SIL and day programs.

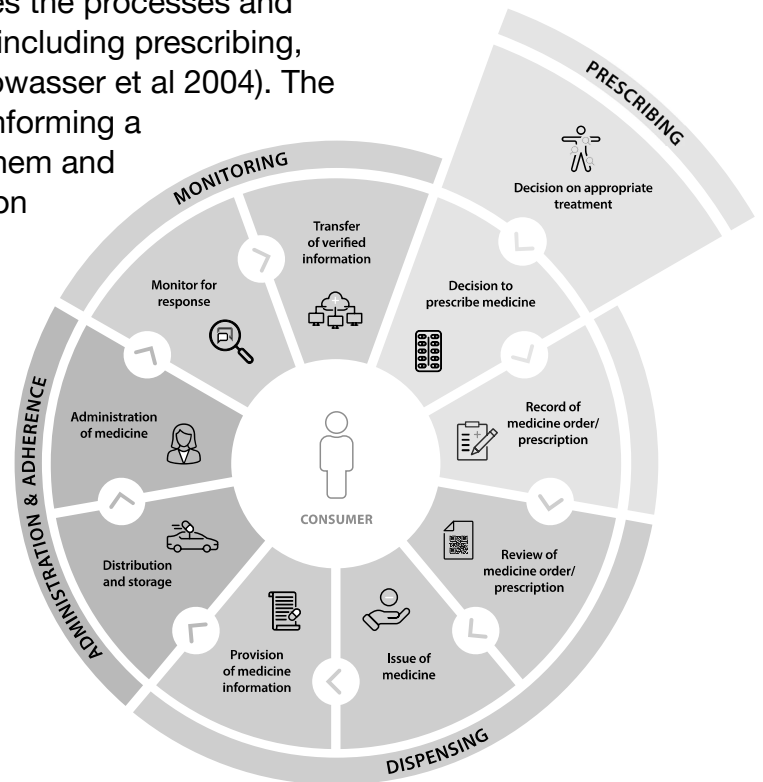


Figure 1: Medication cycle taken from the Pharmaceutical Society of Australia Medicine Safety: Take Care Report.

4.2 Medication management continuum

Participants take varying approaches to their medication management, and medication self-administration needs to be promoted and developed where possible. The Tasmanian Framework (Tasmanian Government 2021) proposes a medication management continuum that conceptualizes medication management for people who engage with disability services and articulates the role of DSWs and organisations.

The continuum outlines the differing levels of support for medication management from participants, and is unique to every participant’s medication requirements and support needs. The continuum includes those who fully self-manage their medication, through to participants whose medication is managed fully by the DSW and their service provider. Partial self-management and partial DSW managed may include processes such as being independent in

prescribing and dispensing of medication and accessing physical support to take medication or reminded on medication dose timings.



Figure 2: Medication Management Framework from the Tasmanian Disability Services Framework

The continuum demonstrates the range in complexities in medication management and the skills, knowledge, and organisational processes in place to provide the appropriate medication management for participants.

5.0 Medication management legislative environment and NDIS guidance

“The intersections between disability and health; national and state governments; the rights of the patient; the role and responsibility of support staff and disability support providers; the place and availability of community, practice, and specialist nurses; and the professional responsibility of doctors are currently inadequately defined and regulated with respect to medication use, oversight, and monitoring.”

Dr Jane Tracey 2022

5.1 NDIS Quality and Safeguards:

QUM in disability services is governed by state and territory -based legislation, as well as the NDIS Quality and Safeguards Commission Practice Standards and Quality indicators (NDIS, 2022).

The NDIS Commission provides guidance on medication administration across a number of regulatory tools and guidance publications. This includes the legislated Practice Standards and High Intensity Support Skills Descriptors for registered providers, and detailed guidance regarding regulation and protocols for medication prescribed to control behaviour (chemical restraint). The Commission also provides education through Practice Alerts on specific medication issues including midazolam and polypharmacy.

The NDIS Practice Standard for the Management of Medication (2021) aligns with some processes of the medication management pathway, and states:

‘Outcome: Each participant requiring medication is confident their provider administers, stores, and monitors the effects of their medication and works to prevent errors or incidents.

To achieve this outcome, the following indicators should be demonstrated:

- Records clearly identify the medication and dosage required by each participant, including all information required to correctly identify the participant and to safely administer the medication.
- All workers responsible for administering medication understand the effects and side-effects of the medication and the steps to take in the event of an incident involving medication.
- All medications are stored safely and securely, can be easily identified and differentiated, and are only accessed by appropriately trained workers.’

Other Practice Standards relate to proactive and responsive service provision to ensure the health and well-being needs of participants are met. These include Practice Standards and quality indicators for Responsive Support Provision, Support Planning and providing a Safe Environment.

The High Intensity Support Skills Descriptors also make reference to skills and knowledge required for medication requirements in the context of complex health needs including dysphagia, complex bowel care and subcutaneous injections (NDIS, 2022).

The NDIS Commission provides significant guidance on regulation regarding restrictive practice (NDIS, 2020), and chemical restraint. However the focus is on strategies to raise awareness of the impact of chemical restraint, the requirements for behaviour support plans, protocols for use and authorisation. The guidance does not address core processes of the medication of management that underpin the safe management of chemical restraint.

The NDIS Commission Workforce Capability Framework (2023) translates the practice standards into the ‘observable behaviours’ required for quality supports. Medication management is recognised against the specialised support capabilities descriptors, with one descriptor including ‘support me to implement my medication plan’.

5.2 State and territory based legislation

Analysis undertaken of state-based legislation highlights state-based legislation falls under poisons /therapeutic goods legislation (Duckworth and Wilson, 2021). The analysis identified only three jurisdictions – ACT, Queensland, and Tasmania – had legislation that specifies disability services in any way. Tasmania is the only state or territory which has a corresponding Disability Services Medication Management Framework, introduced in 2021 provides detailed guidance on stakeholders’ roles and responsibilities, training and competency, management and administration of medication, record keeping, incident management, storage and disposal, and off-site medication management.

Disability services have a unique position in the QUM due to the variety of settings in which services are delivered, funding arrangements for health supports, the variable oversight of

the NDIS workforce (registered and unregistered) and not having a minimum requirements for qualifications. Within these varied contexts providers are independently needing to develop their own full suite of policy and procedures, and supporting tools to guide medication management.

6.0 Funding of health supports

6.1 NDIS funding related to medication

The NDIS is based on an individual insurance model where participants are funded for their specific needs. Support to access primary care or medication management is an activity that falls under a participant's core funding, and is often undertaken by supported accommodation services, and day programs.

Participants with specified health supports may receive additional funding for health plan development, clinical health supports, and staff training (NDIS, 2022). Health supports which may be linked with medication including behavior support plans, medication plans, dysphagia supports, diabetes management and epilepsy supports.

The current NDIS pricing does not adequately allow for complexity, perversely creating an incentive to 'cherry pick' participants with the least complex needs. Additionally, the pricing approach does not cover the training needs when supporting participants with complex needs (NDS, 2023).

Some disability services, particularly larger organisations delivering health supports, have expanded to include multidisciplinary teams with clinical staff delivering services, as well holding practice and clinical governance roles. Services who employ RNs may also be able to delegate practice to DSWs as part of their approach. Whilst there are benefits to having a diverse workforce and additional health expertise, these roles often require organisations to absorb the costs of such roles. Many disability services are unable to afford to engage clinical staff, and need to seek support from external trainers and mainstream health services.

7.0 Quality Use of Medication in related sectors

Both the health care sector and the aged care sector are governed by state-based legislation, as well as their respective Australian Commission on Safety and Quality in Health Care (ACSQHC) and the Aged Care Quality and Safeguards Commission (ACQSC).

The ACSQHC oversees the National Safety and Quality Health Service (NSQHS) Standards, which includes Standard 4 medication safety standard. The ACQSC has 'guiding principles for medication management in residential aged care facilities and community settings', and these are reflected in Standard 3: Personal Care and Clinical Care (ACSQHC, 2022). In 2022 the ACSQHC released new guidance to include the aged care sectors, and as of 2023 became the custodian of the QUM in aged care.

Across all three sectors there has been a strong focus on the use of psychotropic medications,

as a form of chemical restraints. The ACSQHC, ACQSC and the NDIS Commission released the Joint Statement on the Inappropriate Use of Psychotropic Medicines to Manage the Behaviors of People with Disability and Older People (ACSQHC, 2021).

8.0 NDS National Quality Use of Medication Round Table and consultations

8.1 Round Table Overview

NDS convened the QUM Roundtable in October 2023, bringing together over 280 participants spanning disability services, allied health, pharmacy, and auditors. The Round Table aimed to better understand the challenges in delivering QUM in disability settings and the quality and safeguard supports required to address these challenges.

The Round Table was structured with interactive questions based on the medication cycle and stakeholders involved in each component of the cycle. Key questions were shared with attendees to frame the discussion and encourage a broad view of the challenges and opportunities for disability services delivering QUM for people with disability.

The following key questions were asked to guide discussion at the forum:

- Activity 1: What are the existing challenges and gaps which impact on the safe and QUM?
- Activity 2: What are the opportunities and solutions which could improve safe and QUM?
- Activity 3: What are your top three priority areas that should be progressed from today?

Participants were asked to provide initial themes using an online collaborative tool called Mentimetre, and these themes prompted further in-depth discussion through the use of a chat function and participants raising their hand to verbally share their input (See figure 2).

NDS undertook a thematic analysis of the Mentimetre themes, online chat, and discussion to define this report's themes, and has sense-checked these themes with a small number of attendees and stakeholders.

Additional sector consultation has also been done through one-on-one semi-structured interviews and interactive sessions as part of various NDS Communities of Practice, with input reflected in the report discussion.

Stakeholders highlighted issues as:

The NDIS Commission Practice Standards and Quality Indicators lack clarity regarding medication management, and

- The lack of detail within the NDIS Practice Standards impacts service providers when attaining and maintaining NDIS registration. Auditors are providing inconsistent feedback, and currently use the High Intensity Support Skill Descriptors as compliance indicators.
- There is a lack of clarity regarding DSWs' responsibilities between 'assisting' with medication, 'administering' medication, and providing care to a person where the person or their family administers medication.
- With the high-level guidance from the NDIS Commission, it is difficult for services to understand what is considered best practice, and if their service is meeting that level within their service context.
- The lack of standardised processes makes it challenging for service providers to coordinate medication management between services when working with one participant, such as supported accommodation and day program staff handover and documentation processes.
- Ongoing concern expressed for NDIS participants safety due to concerns some providers do not have the appropriate processes, skills, and knowledge to engage in medication support or administration.

Theme 2: Workforce and training

2.1 Workforce capabilities

Context: The disability workforce is diverse, with services experiencing challenges recruiting and retaining staff with competition for staff between providers and sectors. There are also currently no minimum disability qualifications required for DSW, and skills and knowledge vary greatly.

“The expectation of Disability Support Workers is high, and their training is at a low level, the disparity is too great.” **Disability Service Provider**

Stakeholders highlighted challenges as:

- The significant variance in DSW literacy, numeracy and health literacy which are key skills to providing quality services and medication administration.
- There are no minimum qualifications related to disability support service delivery or medication management for DSWs, and no professional registration process, as compared with some other professions such as nursing or allied health. This can create gaps in the workforce's understanding regarding their scope of work, responsibilities and risk involved in some elements of their work.
- Workforce recruitment and retention challenges can be seen in the regular staff turnover and the need to rely on agency staff. This can impact workers' knowledge of the participants they are supporting and can limit the opportunity to undertake training and supervision.

2.2 Medication training and competencies

Context: There is currently no defined scope of practice for DSWs regarding medication management, or clear delineation between assisting and administering medication.

There are two accredited training courses, HLTHPS007 Administer and monitor medications and HLTHPS006 Assist clients with medication, however these are not mandatory in relevant certificate 3 and 4 level qualifications. Many providers are also developing their own training packages specific to their service and policies.

“The sector must have clear and explicit standards before any determination can be made on training requirements or competency levels.” **Disability service provider**

Stakeholders highlighted challenges as:

- The lack of detail and clarity within state legislation and NDIS Commission guidance makes it difficult for services to ensure staff are trained in the right content and competency levels. For example, providers expressed confusion about if there are requirements to have staff trained by clinical staff such as RN’s in certain competencies including the HISSD subcutaneous injections or who else qualifies as a ‘person that meets the expectations of this skills descriptor’
- The casualised workforce and NDIS funding model can make ensuring all staff are appropriately trained and provided with practice governance is difficult for services.

Theme 3: Medication management and documentation

“There needs to be recognition of the varying complexity - Panadol one-off during a social group compared to complex regimes, polypharmacy, multiple routes and schedule 8.” **Disability Service Provider**

3.1 Medication charts

Context: Both hospital and aged care services have nationally standardised medication charts, which aim to ensure consistent practice across services and to reduce error. Currently disability services do not have a standardised medication chart, with services adopting different approaches, and some using electronic software.

Stakeholders highlighted challenges as:

There is no standardised disability services medication chart or software which can create inconsistency.

- It can be difficult to have doctors to create and update medication charts, as there is a lack of understanding on the documentation requirements for disability services, and confusion between a medication chart and a medication purpose form (for chemical restraint).

- Costs associated with electronic medication management software are significant, and it can be difficult for services to cover the expense under existing funding models.

3.2 Schedule 4 and 8 medications

Context: All medicines and poisons in Australia are classified under state legislation. Medication ranges from schedule 1 which is available at a supermarket, schedule 4 which is prescription only and schedule 8 which is prescription only and may require the prescriber to hold a specific license. Schedule 4 and schedule 8 medications are commonly administered by disability services.

“SIL is sending medication in a bag to a day program in a taxi with participant, as they have no other way to send it in.” **Disability Service Provider**

Stakeholders identified challenges as:

- There is limited guidance (excluding Tasmania) regarding appropriate management including storage and transport, management, and auditing of scheduled medications for disability services. For example, how schedule 8 medication should be stored when a participant is in the community or attending day program.
- Some schedule 4 and 8 medications are at higher risk of being abused, including by staff as medication diversion.

3.3 PRN medication

Context: PRN medication (Pro re nata meaning medication taken as needed) presents challenges to disability support services, as PRN medication is “as needed basis” and there often no additional guidance on management.

Stakeholders identified challenges as:

- There is limited guidance as to the legal requirements of administering PRN out of its original packaging as PRN is not included in webster-paks;
- DSWs may face challenges administering PRN medication. Challenges can include limited clinical guidance on when to provide PRN, supporting decision making in moments of compromised capacity;
- Concerns regarding both the overuse of PRN and under use of PRN due to the ‘as needed’ nature of PRN and limited guidance from doctors;
- Challenges in working with GPs to meet compliance in medication prescribing including PRN documentation with clear instructions (e.g. often instructions only state ‘Take as needed’).

3.4 Higher Risk Medications

Context: The Australian Commission on Safety and Quality in Health Care (2023) classifies some medications as higher risk, including commonly used medications such as sedatives including midazolam used for seizures, opioids for pain and insulin in diabetes management. NDS heard concern from providers that existing guidance from the NDIS Commission does not provide additional guidance for these medications.

“Midazolam use should come under high intensity skill descriptors training.”
Disability Service Provider

Stakeholders identified challenges as:

- Concern that insulin management and midazolam is more complex to administer and therefore has greater risks for services to manage;
- Good practice would involve the DSW administering insulin in specific training and knowledge from a diabetes educator, however this is not always included in participant packages;
- Gaps in the guidance on DSW scope of practice for percutaneous endoscopic gastrostomy (PEG) feeding with medication, and appropriate delegation of practice;
- Some services have decided not to administer insulin and other more complex medications due to the concern regarding risk and administrative burden. This can negatively impact on participants' ability to access services.

Theme 4: Disability services policy and processes

4.1 Participants right to refuse medication

Context: Participants have the right to be included in their health care, including the right to refuse medications, as outlined in the Australian Charter of Health Care Rights. The reasons a person may refuse medication are complex, and the implications can be serious.

“Yes, right of refusal but are support workers knowledgeable enough to provide medication education?” **Disability Service Provider**

Stakeholders identified challenges as:

- Participants have the right to refuse medication, and this requires DSWs to have the skills to navigate medication refusal including understanding the impact of missed medication, skills in supported decision making and communicating key health information. Round Table participants were concerned these competencies are not captured in existing training.
- Organisations need robust systems to manage, document and respond to medication refusal both at the time of the medication refusal and in the medium and long term. This also applies for participants who engage with multiple services and where this information may not be handed over between services or family.

4.2 Monitoring side effects and adverse events

Current context: Monitoring for side effects of medication is essential to the safe administration of medication, however effective monitoring can be complex.

Stakeholders identified challenges as:

- Workers need the skills and knowledge to effectively monitor for side effects of medication including medication side effects, participant history with side effects, and appropriate responses to medication side effects.

- Organisations need robust processes to support escalation process for medication side effects and adverse events that include options beyond emergency service and hospital Emergency Departments.

4.3 Delegation of Practice

Context: Under the NDIS some service providers have developed a model with both DSW and clinical staff in service delivery and oversight roles. Some services with clinicians including RNs are implementing a delegation of practice model, where a RN can ‘delegate’ activities to a worker with supervision, including some medication responsibilities.

The NDIS Commission advises in the disability health supports webpage (2021) “It is the RN who must decide if a task can be delegated or not, as they remain responsible for the care being provided...When a RN delegates a task, they retain responsibility for the tasks being provided. Before a RN can delegate a task to someone else, they must make sure the person is trained and competent to do that task. They must also be available for direct and indirect supervision of the person doing the task.”

Stakeholders identified challenges as:

- A lack of clarity about the structures needed to safely implement a delegated of authority model of care for practices usually undertaken by an RN as stipulated by the Nursing and Midwifery Board of Australia;
- Inequity in NDIS funding packages between participants with similar clinical needs – some participants are receiving funding to support clinical staff and some are not.
- DSWs who may not understand the limits of the delegation of authority model, and continue to practice delegated tasks when working as independent workers or within services without a delegation model.

4.4 Medication error and incident reporting

Context: Medication errors are one of the leading causes of injury and avoidable harm in health services globally, costing \$42 billion US dollars annually (WHO, 2017), and is likely a common occurrence in disability services. Individual services undertake incident reporting, however, there is no clear benchmarks on when to report medication incidences to the NDIS Commission, and there is no publicly available data regarding medication incidences in disability services.

Stakeholders identified challenges as:

- Whilst there is limited publicly available data for disability services. It is likely the level of medication errors in disability services are in line with health and aged care;
- Services need robust systems to identify and manage medication error both immediately and longer term with appropriate quality improvement processes however services report;
- The NDIS Commission reporting requirements for medication incidences are unclear and require clarification.
- There is a need for sector tracking of medication incidences and harm, with publicly available data on medication incidents to guide sector improvement.

4.5 Occupational Health and Safety (OH&S)

Context: OH&S risks have been identified for staff involved in the management of medication. Whilst the risks identified have always existed in managing medication for people with disability, the change in responsibilities from medical staff to disability workers has changed who is holding the responsibilities and risks involved.

Stakeholders identified challenges as:

- Psychological safety risks for staff being required to manage medications with significant risks associated, and limited training provided to disability support workers.
- Environmental risks in the workplace associated with discarding medications and medical waste.
- Physical risks involved in managing medication including needle stick injury, and potential harm from participant behaviours of concern where medication is involved or not appropriately managed. E.g., Seizures and diabetes.
- Disaster and emergency scenarios can make medication management difficult due to the need to evacuate with medication, scripts, documentation, medical equipment, and the ability for staff to safely administer, document, store and discard medical waste in an emergency setting.

Theme 5: Sector collaboration and coordination

Context: Sector and stakeholder collaboration across health and disability services are essential in the QUM. There are currently silos between the health and disability sectors as recognized in the, with significant opportunities in uplifting mainstream health services and building the health systems knowledge in disability services.

“There must be effective collaboration with prescriber, dispenser and provider who administers such a multidisciplinary framework and supports good clinical governance.” **Disability Service Provider**

5.1 Disability services

Context: Many NDIS participants who require medication administration will use more than one disability service day-to-day or may transition between a disability service and another setting which supports medication such as school or family. There are limited guidelines regarding transition of care and medication management in community settings, creating challenges for safe medication management.

Stakeholders raised challenges including:

- Appropriate documentation not being shared with relevant services to support medication management e.g., Medication charts.
- Lack of appropriate systems for handover between family or services regarding medication administration which creates risk for medication errors or poor documentation.
- Day services being excluded from Behavior Support Plan processes, which results in plans

not including day services, and services not being provided appropriate information or training to effectively implement.

5.2 General Practitioners (GPs)

Context: There were significant gaps and challenges raised regarding disability services and GPs working together effectively.

“GPs writing a medication chart and missing lots of information, and support workers unable to recognise the errors. There needs to be a national guideline for writing drug charts and a national drug chart, the same as hospitals have the national inpatient medication chart.” **Disability Service Provider**

Stakeholders raised challenges as:

- Ability to access a GP who can provide continuity of care in a timely manner.
- Not having sufficient time with a GP to allow for complex health matters, communicate effectively, ensure supported decision making and have relevant documentation completed.
- Difficulty in having GPs complete medication charts or not providing information as to why a medication was prescribed and other key information.
- GPs do not understand the role of DSW and the difference between a worker and family, or the ways in which a DSW can support a participant.

5.3 Pharmacists:

Context: Pharmacists play an essential role in dispensing medication, undertaking medication reviews, and educating people regarding their medication. The Pharmaceutical Society of Australia Medicine Safety: Disability Care (2022) report identified key barriers facing people with disability in safe medication use, and provided key recommendations on ways to increase access to pharmacists expertise, could play in improve QUM, and the need for quality indicators to drive quality improvement.

Stakeholders highlighted challenges as:

- Webster-pak issues - including a participant having multiple packs, PRN outside webster-paks and costs associated with webster-paks.
- DSW identifying errors in webster-paks, and there being no standardised process to report and address issues with pharmacies.
- Services ability to maintaining continuity with pharmacists and accessing pharmacy outside business hours.
- Accessing medication reviews for polypharmacy and higher risk medications.

5.4 Hospitals and health services:

Context: Access to universal health services has been acknowledged as a challenge for people with disability and has been addressed in the Australian Health Care Strategy and the Disability Royal Commission recommendations.

“Hospital discharge not reviewing updated medications in [the] context of existing medications, [or] taking into account the complexity of monitoring or following up with regular GP in a timely manner post discharge.” **Disability Service Provider**

Stakeholders identified challenges including:

- Participants unable to be appropriately supported when in hospital, which can result in participants not being able to participate in decision making and medication prescribing and dispensing that does not align with their existing treatment.
- A lack of discharge planning from hospitals resulting in new medications or support requirements for the participant without the appropriate information and handover to DSW/ services provider.
- Psychotropics classed as restrictive practice being used in hospitals, and disability services having to navigate the discharge and follow up, including arranging for assessment of the ongoing need or not.

Theme 6: Participant experience

“Participants being supported to understand their medication management options. Where self-management is chosen (there needs to be) support and safeguards to support safe use of medication.”

6.1 Chemical restraints:

Context: The NDIS Act 2013 defines chemical restraint as ‘the use of medication or chemical substance for the primary purpose of influencing a person’s behavior. It does not include the use of medication prescribed by a medical practitioner for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness, or a physical condition.

Chemical restraint is part of a larger complex area of restrictive practice. In the current context, the QUM for all purposes, including medications used as chemical restraint are impacted by all themes identified. Further challenges identified by stakeholders are:

- Concerns that some participants are being prescribed medication without clarity or appropriate consideration for the purpose. E.g. Where medication is prescribed for behaviors of concern, not a mental health diagnosis.
- There is some confusion regarding clear guidelines on chemical restraints, particularly regarding the prescribing from doctors and services needing to interpret if the medication is considered restrictive practice.
- Services are finding it can be challenging to engage an appropriately experienced Behavior Support Practitioner in a timely manner to write or update behavior support plans including chemical restraint.
- The compliance and reporting to the NDIS Commission regarding chemical restraint is high and can be complex.

- Some participants will be administered chemical restraint by other services including hospital or ambulance, which falls outside the purview of the NDIS Commission.

6.2 Supported decision making and accessible information

Context: Supported decision making is an essential human right. Informed decision making about health and medication can be more complex due to the health literacy, medical jargon, and working with health professionals. Accessible information is an essential part of this but currently legislation does not require all health services to provide accessible health information. Challenges identified in 4.1 Participants right to refuse medication are also of relevance here.

Stakeholders identified challenges including:

- Many participants are not appropriately supported to be part of decision-making process regarding their medication and the prescribing phase, and may not understand the medications they are taking and why.
- Participants are not always supported to make choices about how and who will support their medication management.
- Supported decision making and health literacy tools are needed.
- There is a lack of accessible and good practice information and resources for people with disability to understand and undertake medication management.

6.3 Collaborating with families:

Context: Disability services and workers collaborate closely with some participants families. When NDIS services are provided in a private home setting, challenges can arise due to the different legislation which applies to services which does not apply to private citizens such as family who provide care.

Stakeholders identified challenges as:

- Some families did not understand the legal responsibilities of disability workers and legislation governing their practice. This led to situations where workers were expected to follow family approaches to medication even when not safe or best practice.
- Some families have limited knowledge on medication and medications prescribed to the person they are supporting, resulting in some poor medication management processes.

9.0 Round Table next steps:

“The healthcare of people with intellectual disabilities requires respectful partnerships between all involved. The person themselves must remain central and be empowered, to the extent possible, to play an active role in decisions about their health and life” **Dr Jane Tracey (2022)**

Based on the Round Table thematic analysis and sector consultation the following options

were identified as potential opportunities for strengthening systems for QUM in disability services. Each option is proposed as a starting point only and further consultation and consideration is needed to guide future action.

Next steps options:

Systems Pillar 1: Leadership and governance:

- Legislative or practice guidance uplift: Clear guidance to disability services on the QUM is needed. A review of existing legislation and NDIS Practice guidance should be considered as a first step, with further guidance and tools made available to address identified gaps.
- Medication incident reporting: That the NDIS Commission provide clarification on the reporting requirements for disability service providers regarding medication error and incidents to the NDIS Commission.
- Medication incident reporting data: That the NDIS Commission makes data on medication errors and incidents available as part of regular reporting, to support continuous quality improvement in the disability sector.
- High Intensity Support Skills Descriptors (HISSDs): That the NDIS Commission provides clarity regarding the training requirements for HISSDs, and how the HISSDs will be treated in organisational registration processes.

Systems Pillar 2: Disability workforce

- Standardised training: Existing training courses for disability support workers on medication management are reviewed and where needed updated to reflect contemporary evidenced based practice.
- Inclusion of the training in relevant Certificate 3 and 4 disability courses is considered by government in consultation with Registered Training Organisations (RTOs) and disability services.
- Scope of Practice: In line with findings from the Own Motion Inquiry into Supported Independent Living (SIL) and the role of DSW in health supports, a DSW medication scope of practice framework is developed, and this is used to inform risk stratified capabilities required for the QUM.

Systems Pillar 3: Financing

- The NDIA deliver a best practice approach to pricing that incentives quality and links to the objectives of the NDIS. Pricing and individual funding need to ensure disability service providers are able to support the QUM for participants with complex or high-risk medication needs with their service providers.

Systems Pillar 4: Disability service tools and delivery

- Medication chart: That a template for disability services medication chart and companion tools is developed in collaboration with people with disability, providers, medical professionals and other key stakeholders such as the NDIS Commission and the Australian Commission on Safety and Quality in Health Care.
- Promoting existing good practice: That NDS as part of the Positive Health Outcomes project will promote good practice in QUM including medication management and incident

and risk reporting.

- Medication Management resources for providers: That NDS will review and collate existing resources that support providers to deliver QUM for people with disability, and identify the gaps.

Systems Pillar 5: Universal service interface

- National Roadmap QUM integration: That the Department of Social Services liaise with the Department of Health and Ageing to review the National Roadmap for Improving the Health of People with Intellectual Disability action plan, and identify opportunities to integrate QUM in existing actions.
- General Practitioner (GP) guidance: Relevant stakeholders consult with GPs and review guidance for GPs regarding prescribing requirements including where NDIS services are involved including documentation and medication charts, and prescribing chemical restraint medications.

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