Responding to the health care needs of people with disability

Summary The Policy Directive outlines the requirements for NSW Health staff planning and delivering health services for people with disability across the lifespan. It applies to all NSW Health admitted and non-admitted services.

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Applies to Ministry of Health, Public Health Units, Local Health Districts, Board Governed Statutory Health Corporations, Chief Executive Governed Statutory Health Corporations, Specialty Network Governed Statutory Health Corporations, Affiliated Health Organisations, NSW Health Pathology, Public Health System Support Division, Cancer Institute, Government Medical Officers, Community Health Centres, NSW Ambulance Service, Dental Schools and Clinics, Public Hospitals

Distributed to Ministry of Health, Public Health System, Divisions of General Practice, Government Medical Officers, NSW Ambulance Service, Private Hospitals and Day Procedure Centres

Audience All Staff of NSW Health

Secretary, NSW Health

This Policy Directive may be varied, withdrawn or replaced at any time. Compliance with this directive is mandatory for NSW Health and is a condition of subsidy for public health organisations.

NSW Health

Policy Directive

Responding to the health care needs of people with disability

Policy Statement

NSW Health services and staff must provide safe, inclusive, person-centred, integrated and trauma-informed care to all patients. This includes recognising that care and processes for access, communication and participation will look different for different people.

It involves partnering with people with disability and their carers, family and supports in all aspects of a person's healthcare journey.

Summary of Policy Requirements

Everyone seeking or receiving care in the Australian health system has certain rights regarding the nature of that care. NSW Health adheres to the Australian Charter of Healthcare Rights, which describes what consumers, or someone they care for, can expect when receiving health care. People with disability have the same rights as people without disability.

In line with legislation and NSW policy, NSW Health services and staff must:

- actively support the human rights and fundamental freedoms of people with disability, respect their dignity and facilitate their independence, choice and control in accessing health services
- promote the inclusion of people with disability and improve their access to mainstream services for management of health or acute medical conditions
- provide care that meets a person with disability's specific needs, including making any adjustments that support the person's participation in their care
- respectfully partner with the person with disability and their carers, family, and supports to improve their health and optimise their healthcare experience
- respect and promote the rights of carers and support the health, wellbeing, and socioeconomic participation of carers
- promote the inclusion of carers and provide sufficient supports and facilities for them in healthcare settings
- partner with people with disability and carers and involve them in developing policies that impact them
- proactively collaborate and coordinate with partner service providers in providing supports and services for people with disability and their carers.

NSW Health staff must be adequately skilled and equipped to respond to the needs of people with disability and their carers, families, and supports. This includes recognising the needs of particular groups including:

- Aboriginal and Torres Strait Islander people
- people from culturally and linguistically diverse backgrounds
- people from refugee backgrounds
- LGBTIQ+ people
- children
- women
- older people, and
- people from rural and remote areas.

NSW Health staff must be culturally responsive to these priority groups.

Local health districts, specialty health networks and NSW Health organisations must monitor local compliance with this Policy Directive. Implementation will form part of implementing the *Disability Inclusion Action Plan*. All staff are to be familiar with relevant disability inclusion action plans and local implementation priorities. Related education and training will be offered to staff.

Revision History

Version	Approved By	Amendment Notes
PD2024_030 September-2024	Deputy Secretary, Health System Strategy and Patient Experience	Policy updated to reflect, the current context, including establishment of the NDIS. Additional detail on the rights of people with disability and application of the legal framework, consent, diversity, examples of adjustments and links to tools and resources. The title changed to *Responding to the health care needs of people with disability*.
PD2017_001 January-2017	Deputy Secretary, Strategy and Resources	Replaces PD2008_010 Policy updated and title changed to *Responding to the Needs of People with Disability during Hospitalisation*.
IB2015_031 July-2015	Director-General	Advises NSW Health Policy Directive *Disability-People with Disability: Responding to Needs During Hospitalisation (revised Jan 08)* (PD2008_010) is being reviewed.
PD2008_010 February-2008	Deputy General, NSW Health	Replaces PD2005_625 Policy updated and title changed to *Disability- People with a Disability: Responding to Needs During Hospitalisation*.
PD2005_625 October-2005	Deputy General, NSW Health	New policy.

Contents

1. Background

This Policy Directive was developed following extensive statewide consultation including with disability peaks, people with a lived experience of disability and people with a lived experience of caring for people with disability.

1.1. About this document

This Policy Directive outlines the requirements for NSW Health staff planning and delivering health services for people with disability across the lifespan. It applies to all NSW Health admitted and non-admitted (outpatient and community) services.

The key procedures covered are:

1. Taking an inclusive, person-centred and trauma-informed approach
2. Making adjustments
3. Partnering with other supports
4. Integrating healthcare and social supports
5. Enabling a capable workforce, and
6. Monitoring high-quality care.

The purpose of the policy is to provide quality health care for people with disability with particular focus on :

- health outcomes that matter to patients
- experiences of receiving care
- experiences of providing care
- effectiveness and efficiency of care.

1.2. Key definitions

Adjustments	The individualised adaptions or modifications made to remove or minimise barriers for any person to participate and be included in their health care.

Carer	The family member or friend who provides **unpaid** ongoing care and support for the person because of disability, chronic, terminal or mental illness or ageing [1]. For the purpose of this Policy Directive, 'carer' refers to all forms of carer as designated in NSW Health Information Bulletin *Identifying the Carer at Patient Registration* (IB2019_031), including Principal Care Providers and Designated Carers under the *Mental Health Act 2007* (NSW).
Diagnostic overshadowing	Diagnostic overshadowing is the attribution of symptoms to an existing diagnosis rather than a potential co-morbid condition [2].
Disability	Disability is an umbrella term for impairments of body function or structure, activity limitations or participation restrictions. People experience different degrees of impairment, activity limitation and participation restriction. Disability can be related to genetic disorders, illnesses, accidents, ageing, injuries or a combination of these factors. How people experience disability is affected by environmental factors – including community attitudes and the opportunities, services and assistance they can access – as well as by personal factors.
Disability support worker	A person who is **paid** to provide supports which may include care, emotional support, physical assistance and supervision to people with disability in their home, residential settings, or community. A disability support worker is not a decision-maker for the person with disability, but can provide information around the person's usual needs, preferences and functioning where they are familiar with the person and have consent.
Enduring Guardian (Guardian)	A legally appointed person who is able to make decisions about health and lifestyle on behalf of the person who lacks the capacity to consent.
National Disability Insurance Scheme (NDIS)	Australian insurance-based scheme that provides individual funding packages for people with permanent and significant disability so they can access specialist disability support services. The NDIS also funds Tier 2 Supports designed to help all people with a disability, including those not eligible for an individual funding package, to access community and mainstream supports.

Partner service providers	Organisations providing services commonly used by people with disability. NSW Health services often partner with these providers in care. See Section 5.2 for examples of partner service providers.
Person responsible (Guardianship Act)	Someone who is legally able to consent to medical and dental treatments on behalf of a person who lacks the capacity to give their consent. The Medical Officer will identify the person responsible in accordance with the hierarchy in the *Guardianship Act 1987* (NSW). The person responsible may be someone different to the carer. See the NSW Health Policy and Procedure Manual *Consent to Medical and Healthcare Treatment Manual* Section 7. For minors, see the NSW Health Policy and Procedure Manual *Consent to Medical and Healthcare Treatment Manual* Section 8.
Public Guardian	A public official appointed to make healthcare, lifestyle and medical decisions for a person under a guardianship order.

1.3. The rights of people with disability

Everyone seeking or receiving care in the Australian health system has certain rights regarding the nature of that care. NSW Health adheres to the *Australian Charter of Healthcare Rights*, which describes what consumers, or someone they care for, can expect when receiving health care.

People with disability have the same rights as people without disability. These rights relate to access, safety, respect, communication, participation, privacy, confidentiality and providing feedback. The Easy English version of the *Australian Charter of Healthcare Rights* is available for sharing with people with disability and their carers and families.

1.3.1. Legal and legislative framework

Australia ratified the United Nations *Convention on the Rights of Persons with Disabilities* (UNCRPD) in 2008. *Australia's Disability Strategy 2021-2031*, the *Australian Human Rights Commission Act 1986* (Commonwealth), *Disability Discrimination Act 1992* (Commonwealth) and the National Disability Insurance Scheme (NDIS) all reflect the UNCRPD purpose to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity".

The *Disability Discrimination Act 1992* (Commonwealth) also applies to a carer, assistant, assistance animal or disability aid in the same way as it applies to a person with disability.

The *Disability Inclusion Act 2014* (NSW) echoes national legislation. It directs services to facilitate the exercise of the rights of people with disability, including in:

- promoting their independence and inclusion
- enabling their choice and control in pursuit of their goals

- planning and delivery of their supports and services
- their right to live free from discrimination, abuse, neglect and harm.

Under the *Disability Inclusion Act 2014* (NSW), services must also provide safeguards in relation to the delivery of supports and services and recognise the needs of particular groups including: Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse (CALD) backgrounds, LGBTIQ+ people, children and women.

The *Carers (Recognition) Act 2010* (NSW) recognises the important role and contribution of carers to our community and to the people they care for. The NSW Carers Charter (see Schedule 1 of the *Carers (Recognition) Act 2010* [NSW]) describes how to recognise, respect, and involve carers and provide timely, accessible and appropriate support for their needs, wellbeing and socioeconomic participation.

The *NSW Disability Inclusion Plan 2021-2025* outlines a whole of Government strategy aligned with the objects and principles of the *Disability Inclusion Act 2014* (NSW). The strategy focuses on promoting inclusion, improving access to mainstream services, and encouraging collaboration and co-ordination in providing supports and services with people with disability.

All health services in Australia are to adopt the Australian Commission on Safety and Quality in Health Care *Australian Charter of Healthcare Rights*. The Charter describes rights that consumers, or someone they care for, can expect when receiving health care.

NSW Health services must deliver care that protects the rights of children and young people as outlined in the *Convention on the Rights of the Child*, the *Charter on the Rights of Children and Young People in Healthcare Services in Australia* and the *NSW Child Safe Standards*.

NSW Health services must comply with the *Guardianship Act 1987* (NSW), which deals with matters including guardianship orders, financial management and consent for medical and dental treatment for patients who 'lack capacity'.

NSW Health services must also provide care for people with mental health issues in line with the *Mental Health Act 2007* (NSW) and *Mental Health and Cognitive Impairment Forensic Provisions Act 2020* (NSW).

Where a NSW Health service is a National Disability Insurance Scheme (NDIS) registered provider or an approved aged care provider they must meet their responsibilities under the *National Disability Insurance Scheme Act 2013* (Commonwealth) and the *Aged Care Act 1997* (Commonwealth).

1.3.2. What this means for NSW Health services

In line with legislation and NSW policy, NSW Health services must:

- actively **support the human rights and fundamental freedoms** of people with disability, **respect their dignity** and **facilitate their independence**, **choice and control** in accessing health services
- **promote the inclusion** of people with disability and **improve their access to mainstream services** for management of health or acute medical conditions

- **provide care that meets a person with disability's specific needs**, making any **adjustments** including those that support the person's participation in their care
- **respectfully partner with the person with disability and their carers, family, and supports** to improve their health and optimise their healthcare experience
- **respect and promote the rights of carers** and **support the health, wellbeing, and socioeconomic participation of carers**
- **promote the inclusion of carers** and provide sufficient supports and facilities for them in healthcare settings
- **partner with people with disability and carers** and involve them in developing policies that impact them
- **proactively collaborate and coordinate with partner service providers** (see Section 5.2) in providing supports and services for people with disability and their carers.

1.4. Related NSW Government documents

Relevant NSW Health guidance is referred to throughout this Policy Directive. Table 1 identifies other NSW Health policies and strategies to be read in conjunction with this Policy Directive.

Table 1. Related NSW Health documents

Reference	Document title
GL2012_007	*Animal Visits and Interventions in Public and Private Health Services in NSW*
PD2013_007	*Child Wellbeing and Child Protection Policies and Procedures for NSW Health*
GL2015_007	*Management of patients with Acute Severe Behavioural Disturbance in Emergency Departments*
GL2017_013	*The Guardianship Application Process for Adult Inpatients of NSW Health*
PD2017_044	*Interpreters – Standard Procedures for Working with Health Care Interpreters*
PD2018_010	*Emergency Department Patients Awaiting Care*
GL2019_008	*Communicating positively: A guide to appropriate Aboriginal terminology*
IB2019_031	*Identifying the Carer at Patient Registration*
PD2019_045	*Discharge Planning and Transfer of Care for Consumers of NSW Health Mental Health Services*
PD2020_004	*Seclusion and Restraint in NSW Health Settings*
PD2020_006	*Responding to Sexual Assault (adult and child) Policy and Procedures*
PD2020_018	*Recognition and management of patients who are deteriorating*
PD2020_026	*Assistive Technology*
GL2021_004	*End of Life Care and Decision-Making*
PD2022_012	*Admission to Discharge Care Coordination*

Reference	Document title
PD2022_053	*The Safety and Wellbeing of Children and Adolescents in NSW Acute Health Facilities*
PD2023_009	*Domestic Violence Routine Screening*
PD2023_023	*Identifying and responding to abuse of older people*
	NSW Health Consent to Medical and Healthcare Treatment Manual
	NSW Health Privacy Manual for Health Information
	It Stops Here: Standing together to end domestic and family violence and Safer Pathway (referral pathway)
	NSW Refugee Health Plan 2022-2027
	NSW Aboriginal Health Plan 2013-2023
	NSW Youth Health Framework 2017-2024
	NSW Health Recognition and Support For Carers Key Directions 2018 – 2020
	NSW Disability Inclusion Plan 2021-2025
	NSW Health Strategy for Preventing and Responding to Domestic and Family Violence 2021-2026
	NSW Regional Health Strategic Plan 2022-2032
	Integrated Trauma-Informed Care Framework: My story, my health, my future (2023)
	Trauma-informed care and practice in mental health services – A Framework for Change
	NSW LGBTIQ+ Health Strategy 2022-2027
	Children First 2022-2031
	Culturally and Linguistically Diverse Communities – Consumer enablement guide
	Elevating the Human Experience – Our Guide to Action
	Building capability in health services for people with intellectual disability: the Essentials
	Future Health – Guiding the next decade of care in NSW 2022-2032

2. Taking an Inclusive, Person-centred, Integrated and Trauma-informed Approach

Inclusive, person-centred care for all NSW Health patients is based on the NSW Health CORE values of collaboration, openness, respect and empowerment. It involves codesigning services with people with disability and their family, carers and supports (such as disability support workers and guardians) and partnering with them in all aspects of a person's healthcare journey.

Guidance on respectful engagement of people with disability, their family, carers and supports can be found in All of Us: A guide to engaging consumers, carers and communities across NSW Health. Also refer to the NSW Health Guideline *Consumer, carer and community member remuneration* (GL2023_016), which sets out NSW Health's commitment

to remuneration and reimbursement of consumers, carers and community members for their time and contributions to agreed engagement activities.

2.1. Inclusive

Any adjustments required to support a person's health and social needs must be identified as early as possible in their health care journey. NSW Health staff are to ask if the person has a disability and whether they are a National Disability Insurance Scheme (NDIS) participant. It is the person's choice to disclose this information. They are also to ask if the person and/or their carer (with consent) have any suggestions about supports they require to make their experience easier.

It is important to ensure information about person and carer needs and preferences are identified early so the healthcare journey can be as smooth as possible. This information is to be included in patient records to assist in care planning and discharge planning.

Although some specialty disability health services are available in NSW, most health needs of people with disability will be provided by mainstream services and amenities. As directed by legislation (see Section 1.3.1), people with disability must receive equal access to the health services they need, recognising that at times adjustments (see Section 3) will be required to achieve it.

Local policy and practice must support a culture of inclusion and accommodate the differing requirements and identities of individuals with disability. Inclusion also applies to the person with disability's carer, disability support worker (assistant), assistance animal or disability aid [3].

Inclusive, person-centred care for people with disability considers and responds to the needs of vulnerable groups including Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse (CALD) backgrounds, people with a refugee background, LGBTIQ+ people, children, women [4], older people, and people living in rural and remote areas [5].

2.2. Person-centred

A person-centred approach to care must be taken for all patients of NSW Health. This involves placing the person at the centre of decision making throughout all stages of their journey. It means partnering with the person, their carers, family and supports as genuine partners in care.

The principles of a recovery-oriented approach should guide NSW Health service practice. This involves understanding that each person is different and should be supported to make their own choices. They must be listened to and treated with dignity and respect. NSW Health staff are to consider the person as the expert of their own life.

In line with *Elevating the Human Experience – Our Guide to Action*, NSW Health services are to focus not only on health outcomes, but also on providing a positive experience of care for patients, their carers and family members.

Respecting and including the perspectives and lived experiences of people with disability and their carers is key to delivering person-centred care. Section 6 outlines workforce capabilities

required to deliver safe, person-centred, integrated and trauma-informed health care for people with disability and their carers and families.

2.3. Integrated and trauma-informed

People with disability often have complex health needs and require services from a range of health, mental health and support services to live a healthy life in the community. This may include services delivered by NSW Health, primary health care, aged care providers, supported accommodation services, specialist health, dental, social and employment services. Some people will be National Disability Insurance Scheme (NDIS) participants and some people will need support to access the NDIS.

Trauma is a significant factor contributing to poor health and wellbeing outcomes for people experiencing vulnerability and disadvantage. In line with the NSW *Health Integrated Trauma-Informed Care Framework*, NSW Health services must provide integrated trauma-informed care for people with disability and their carers and families. Care is to consider the whole person and their range of needs, preferences and networks of support.

People with disability are significantly more likely to have acts of violence and abuse committed against them. These acts may include physical, sexual, or intimate partner violence, emotional, financial or economic abuse, or stalking [6]. People with disability and their carers are to be supported to report abuse and raise concerns about quality or safety of care. The NSW Ageing and Disability Commission can be contacted to report concerns of abuse, neglect and exploitation of older people and adults with disability in their family, home or community**.** NSW Health policy guidance is to be followed with respect to identifying and responding to abuse. These include:

- NSW Health Policy Directive *Domestic Violence - Identifying and Responding* (PD2006_084)
- *NSW Health Integrated Prevention and Response to Violence, Abuse and Neglect Framework*
- NSW Health Policy Directive *Domestic Violence Routine Screening* (PD2023_009).

The NSW Health Education Centre Against Violence provides additional information and resources including Easy Read Guides for People who have been sexually assaulted.

Trauma informed responses should incorporate this awareness and be adapted to ensure that they best meet the person with disability and/or carer's needs.

Age-related needs are to be considered in integrated care planning, such as schooling and developmental needs of children and aged care needs of older people.

2.4. Decision making capacity and consent

Decision making capacity is a person's ability to make their own life decisions. Decision making capacity is time specific and decision specific. The NSW Health Policy and Procedure Manual *Consent to Medical and Healthcare Treatment Manual* (Consent Manual) [Section 4] provides guidance for health professionals to follow in assessing a person's decision making capacity.

The Consent Manual (Section 4.3.1) identifies that a person has decision making capacity if they can understand the facts and choices involved, understand and weigh up the consequences, and communicate their decision.

Communication must be via the preferred modality/modalities used by the person with disability (such as Australian Sign Language [Auslan], picture symbols). If a person is unable to follow this process, they are said to 'lack capacity' to make that particular decision.

Treating health professionals should assume that a person who is of an age to consent to medical treatment has decision making capacity unless there is evidence otherwise (Consent Manual Section 4). Treating health professionals are responsible for determining a person's decision making capacity and identifying any assistance they might need to maximise their participation (see Section 2.4.1). A person's capability to be involved in decision making and consent should be assessed in the context of appropriate supports and adjustments being provided if they are required. This includes allowing adequate time for decision making when the decision is not time-critical to save a person's life or to prevent serious damage to their health.

Capacity or lack of capacity should not be assumed on the basis of a person's diagnosis or condition. People may be able to make decisions if the information is provided to them in an accessible way and they are supported to understand the information[1]. Where appropriate, carers and family members may be able to support a person with disability to understand the information or provide advice to staff on adjustments required to support communication and understanding.

When a person with disability is unable to provide consent (for example as a result of their cognitive impairment), their Person Responsible (often a parent, carer or guardian) will provide consent as their substitute decision maker. Paid support workers (including disability support provider organisations) are not decision makers for the person with disability.

2.4.1. Supported decision making

People with disability need to be involved in decisions about their health care and must be supported to make their own decisions as far as possible[2]. This may include, for example, decisions about their preferred treatment option, whether family and carers are to be involved and how they are to be involved, end-of-life planning and palliative care.

Like everyone, people with disability can benefit from support when making decisions and should be asked whether they need any support to access NSW Health services. A person may choose to have formal or informal support for decision making. Providing support or making adjustments (see Section 3) to meet a person with disability's needs can help them to make their own decisions and have control over things that are important to them.

NSW Health staff need to understand the individual health literacy needs of people with disability and their carers and family members to tailor communication methods to support

[1] The NSW Department of Communities and Justice provides information, resources and an e-learning course for health professionals on decision making and capacity.

[2] The NSW Trustee & Guardian provides information for the public and health care providers on supported decision making, capacity and consent.

decision making. Information is to be provided in a format typically used by the person (such as picture symbols, large print, Easy Read, braille, Auslan, aphasia-friendly resources, translations in appropriate community language) and communication strategies used (for example, short sentences, Teach Back, use of interpreters). Wherever possible, adequate time must be allowed for decisions. Where appropriate and, with consent from the person with disability, engage carers, family members, and make adjustments to assist the person in understanding and communicating about decisions.

Some decisions require capacity for informed consent and other choices do not. It is important that people with disability who cannot provide consent are still involved in conversations about their care and supported to choose and participate in their care to the fullest. Where consent is required a person's substitute decision maker will also need to be involved.

NSW Health staff must recognise and demonstrate respect for the autonomy, independence and aspirations of all people, including people with disability, by facilitating their right to choose and have control over their health. It is important to avoid making assumptions or unnecessarily limiting a person with disability's participation in decisions. This can reduce their experience of care and lead to poor outcomes.

2.5. Identifying and supporting carers

When a health service is first provided to any patient, in line with NSW Health Information Bulletin *Identifying the Carer at Patient Registration* (IB2019_031), it is mandatory to record whether the person has a carer or whether they are a carer. Many carers do not recognise themselves as a carer and some patients may not be sure if they have a carer or if they are a carer. People with disability may be a carer for others. This is to be considered in care planning.

NSW Health staff should investigate the care situation. Multidisciplinary team members such as social workers may be able to assist.

In line with the *Carers (Recognition) Act 2010* (NSW), NSW Health services must recognise the important role and contribution of carers and partner with them in providing health services and supports for people with disability. NSW Health services must also make adjustments to support a carer in participating in and supporting the healthcare journey of the person with disability they care for. NSW Health services must involve carers in developing policies that impact them. The *NSW Health Recognition and Support for Carers: Key Directions 2018-2020* provides system-wide guidance on responding to the needs of carers across the NSW public health system.

Referrals and information are to be routinely provided to carers with consent from the patient. The NSW Health resources for carers internet page has a range of links to supports and services for carers, including the Australian Government Carer Gateway.

2.5.1. When no family or carers are identified

In circumstances where a person with disability has no identified carer, family or informal supports, treating health professionals are to partner with the person, other multidisciplinary team members and specialist disability staff to identify supports for the person and assess their need for substitute decision makers (such as appointed or public guardians).

People who are paid to provide supports to a person with disability are not substitute decision makers.

2.6. Privacy and consent

A person with disability who has identified carers, family members and supports may still prefer to meet with the treating team on their own. They may prefer to be independent in their engagement with NSW Health staff and there may be confidential information they would like to share with staff. NSW Health staff must consult the person with disability and seek consent to disclose information they would like shared with each person involved in their care (such as carers, family members and supports).

With consent from the person with disability, carers, family members or paid support workers may also be invited into an appointment to be given information or fill gaps in information. They may also be able to support communication and the understanding of all parties. They are not to be used to interpret information (see Section 2.7).

2.6.1. Privacy

The collection, use, exchange, or disclosure of personal information about a person or carer must be undertaken in accordance with the NSW Health Policy and Procedure Manual *Privacy Manual for Health Information* (Privacy Manual). This includes sharing information with carers, family, NDIS providers, the National Disability Insurance Agency (NDIA) and other partners in care.

NSW Health staff are to be familiar with and provide to people with disability and carers the NSW Health *Privacy Leaflet for Patients* and the NSW Health *Patient Information and Privacy – A guide for carers and family*. Pamphlets are available in English and 5 other languages. These documents explain how NSW Health must protect a person's health information and the circumstances when it must be shared with others (such as carers or other health professionals). Information must only be shared to enable appropriate care and treatment for the person with disability. The documents also explain how NDIS documents may be used or disclosed to help health and non-health services meet a person's needs.

NSW Health Confidentiality information for young people and *We keep it zipped* factsheet explain privacy for young people. Health information can be shared with parents or guardians without asking the young person first if they are under 14 years. Generally, parents or guardians cannot see a young person's health record without their agreement if they are over 14 years.

NSW Health staff are required to consider a young person's right to privacy and their capacity to consent to the access or disclosure of their own health record (refer to Privacy Manual Section 5.5.2). This is a sensitive matter and may need consultation with senior NSW Health staff and the Privacy Contact Officer for the service.

Where child safety and wellbeing concerns affect a young person with disability, NSW Health Policy Directive *Child Wellbeing and Child Protection Policies and Procedures for NSW Health* (PD2013_007) is to be followed.

2.6.2. Consent

NSW Health services must inform patients and substitute decision makers about treatment options and the related risks and benefits of treatments and obtain consent where required. Consent, or the withholding of consent, can only be provided by a person who has capacity to consent.

The Consent Manual is to be consulted as it guides practice in line with NSW law about obtaining consent to medical and healthcare treatment from patients (including children or young people under 18 years) or their substitute consent providers. NSW Health staff are to confirm that the substitute decision maker has the required legal authority to make the decision in question.

The Consent Manual sets out the legal requirements for providing appropriate and adequate information to patients, including risks of specific treatments/procedures and obtaining valid patient consent for such treatment/procedures. It outlines legal obligations related to providing treatment to patients who do not have capacity to consent (see Consent Manual Section 7).

As a general rule, no operation, procedure or treatment may be undertaken without prior consent from the patient or, if the patient lacks capacity, from the patient's substitute decision maker (see Section 2.4.1). The only exceptions are in an emergency when the patient lacks capacity and the patient's express wishes are unknown; or where the law otherwise allows or requires treatment to be given without consent.

Health practitioners also have a legal obligation to provide patients (or substitute decision makers) with information, including warnings, about any risks involved in the proposed procedure or treatment. This information is to be provided in a format familiar to the person and with support to understand it as needed. Working with an accredited interpreter is essential when patients who require interpreters are required to give valid consent.

2.7. Working with interpreters

NSW Health staff may need to request the services of an interpreter if they have difficulty understanding a person or are unsure about whether the person has understood information given to them.

In line with NSW Health Policy Directive *Interpreters – Standard Procedures for Working with Health Care Interpreters* (PD2017_044), a person who is not fluent in English or who is deaf and/or has a hearing loss must be provided access to a health care interpreter when they access health care services. As a guide, a person is considered 'not fluent in English' if they hesitate or have difficulty understanding and communicating in English. Although some people may be able to communicate in English for everyday conversations, they may require support from interpreters to participate in medical conversations.

Professional interpreters are particularly important where the information to be discussed is complex, likely to be considered sensitive by the person or where the person may be at risk of harm. The gender of the interpreter should also be taken into consideration. When collecting information or seeking consent for the use of data, a professional interpreter should be used to ascertain the wishes of the patient and obtain informed consent if appropriate (see Consent Manual Section 15.5).

Communicating through a professional interpreter improves patient safety and avoids inappropriate responsibilities being placed on family members, carers and health practitioners. For a person who requires an interpreter, consent should only be obtained through someone other than a professional interpreter when an interpreter is not available in an emergency situation (see NSW Health Policy Directive *Interpreters – Standard Procedures for Working with Health Care Interpreters* [PD2017_044]).

NSW Health Care Interpreting Services provide access to 24 hour a day, 7 days a week interpreting services within NSW Health. Interpreting services are available in over 120 languages, including Auslan and are available to NSW Health patients free of charge.

The Australian Government Translating and Interpreting Service also provides after hours services or emergency interpreting services. The service is available face-to-face, by telephone or via virtual care.

3. Making Adjustments

3.1. Adjustments

Adjustments are sometimes required so people with disability can have the same access to safe, high-quality health care as people without disability. Adjustments are the necessary and appropriate individualised adaptions or modifications made to remove or minimise barriers for any person to participate and be included in their health care. Examples of adjustments made by health services are in Appendix 1.

'Reasonable adjustments' are adjustments made for a person with disability to prevent less favourable treatment and that do not impose an unjustifiable hardship on another person or organisation. The *Disability Discrimination Act 1992* (Commonwealth) Section 11 provides an exception to making reasonable adjustments if the cost or difficulties of providing access will place an unjustifiable hardship on a person or organisation. An example might be adjusting an existing public building to provide complete accessibility. In these instances, alternatives must be found so the person with disability can still access the services they need.

NSW Health services are required to make adjustments as part of good practice and in compliance with Australian and NSW legislation (see Section 1.3.1). The test of what is 'reasonable' is to be undertaken objectively and not based solely on an individual staff member's opinion. The goal is always to remove or reduce any disadvantage faced by a person with disability. Specialist NSW Health staff with expertise or disability support workers can educate and support mainstream NSW Health staff in this regard.

NSW Health staff must understand the needs and preferences of a person with disability before considering if adjustments are required. NSW Health staff must involve the person with disability and their carer in any determinations and should consider information from family and disability support workers, gaining consent where necessary. Information about adjustments is to be added to the person's clinical record.

3.2. Accessible communication and information

3.2.1. Communication

All people, including people with disability, have the right to be heard and understood. Accessible communication is central to a person with disability's experience of service and to the experiences of their carers, family members and supports. When communication is accessible, people's communication difficulties are understood and everyone can respectfully get their messages across, no matter how they communicate.

People with disability, particularly intellectual disability or cognitive impairment are often excluded or denied the opportunity to communicate and make decisions about their own lives. Some people with a communication impairment do not have a cognitive disability. People with disability have the right to make decisions about their lives. It is essential that all NSW Health staff know how people make and communicate their decisions.

It is essential that all NSW Health staff working with a person with disability, their carers, family and supports are aware of the person's preferred method of communication and support communication accessibility. In some instances, people with disability who are National Disability Insurance Scheme (NDIS) participants may have access to concurrent supports from their NDIS plan to assist with communication (see Section 4.3).

Aboriginal patients and their families/carers must also be offered communication support by being linked with Aboriginal Liaison Officers or Aboriginal Heath Workers/Practitioners.

See NSW Health Policy Directive *NSW Health Accessible Communications* (PD2024_028).

Speak with the person with disability

In the first instance, NSW Health staff must address all communication to the person with disability and ask them for advice on their preferred method of communication. It is important to take time to communicate and to make sure that messages are easy to understand, particularly for people with cognitive impairment and/or communication impairment. If the person is unable to communicate with staff, staff are to consult the person's carers, family or disability support worker on the recommended approach.

NSW Health staff should always let people know what they plan to do and ask permission to proceed at each step before they act, for example before moving a person or giving them an injection. Communicating before acting helps the person predict and prepare for what will happen and is respectful of a person's self-determination and autonomy.

As with any patient, staff must check with the person with disability that they understand the information given. Easy Read guides or social stories can help the person with disability understand what is being communicated.

Quickly learn about the person with disability's communication preferences

People with disability may already have a disability care plan that contains information about them and their needs and preferences, including their communication preferences (such as NSW Health My Care and Communication Plan [Top 5]).

If a person has this information, NSW Health staff are to refer to it as early as possible in the patient's journey. If this information has not yet been developed, staff are to partner with the

person and carer, family and/or disability support worker to create it. Team members such as Speech Pathologists and Occupational Therapists may be able to assist.

If a person does not communicate verbally, staff are to talk with their carer or family to understand the person and how they communicate their needs and distress or pain.

Record information and share it with other team members

NSW Health staff must document information about the person with disability's communication needs and preferences in the communication profile within the care plan, electronic patient record and the discharge/transfer of care form. Information is to include how the person communicates and any communication aids, gestures, signs and behaviours they may use to convey their needs and responses.

Frequently used resources include Admission 2 Discharge, Clinical Excellence Commission Top 5, NSW Health My Care and Communication Plan (Top 5) Form and the Council for Intellectual Disability My Health Matters Folder.

This information is to be shared with all staff working with the person. Within privacy and consent guidelines, it is also to be shared with their carers, family and disability support workers in ways they can understand. Familiar support people explaining information in ways typically used by the person can be reassuring for the person with disability.

Opportunities for sharing information with other team members include: multidisciplinary team huddles, clinical handovers, in-depth case reviews and as relevant, Patient Journey Boards or Care and Connect Boards (such as My Care Board) used in hospitals at the patient's bedside to assist communication between all parties.

3.2.2. Information

NSW Health services must ensure that timely information is given to a person with disability, their carers, family and disability support workers in a way that they can understand. Information is to be provided throughout each phase of the patient journey and interpreters engaged when needed (see Section 2.7). Information is to be shared in line with NSW Health privacy guidance (see Section 2.6.1).

Information commonly required

Information that people with disability, carers, family and disability support workers commonly need includes:

- available health services and health facility amenities and how the person with disability can access them
- available cultural and diversity support services
- interpreter services
- consumer advocates
- consumer peer workers (mental health)
- disability advocates
- consumer health rights and responsibilities [7]

- confidential complaints mechanisms [8]
- the REACH pathway to escalate concerns about a change in a person's condition
- legal advocates and services (such as for guardianship advice and tribunal advice)
- dates and times (such as appointment times, estimated date of discharge)
- treating team staff members and their roles
- assessment and treatment options including potential risks and benefits
- medication management
- care plans, discharge planning and time frames
- partner services and referral information.

Information for carers, families and other relevant service providers

Information is to be directed to the person with disability in the first instance (or the Person Responsible) and with consent to carers, family and disability support workers.

It is important to consider the information needs of carers, family and supports. They will need to understand what is happening for the person they care for during health care contacts, procedures and planning.

Carers, family and supports also play an important role in supporting the person with disability's engagement with health services – for example by explaining the information, helping the person make decisions, providing transport, accompanying them to the service, and preparing them for engagement with the services or an admission.

Information is to be provided to family and carers on the available services and supports for family and carer health and wellbeing. Consent is not required from the person with disability to provide this information. Resources may include local health district (district)/specialty health network (network) and other local carers support programs or groups and the range of carer resources on the NSW Health Resources for Carers website.

Information for substitute decision makers

Guardians, Person Responsible and other substitute decision makers are to be provided with the information they need to make decisions on behalf of the person. NSW Health staff are to confirm that the substitute decision maker has the required legal authority to make the decision in question. The NSW Trustee and Guardian provides information on the various types of substitute decision makers.

Make information accessible

Provide information in a person-centred way, that meets a person's communication style. For people with low health literacy, intellectual disability or cognitive impairment, it is particularly important to make the messages accessible and easily understood. Districts and networks may have health literacy teams that can be consulted in simplifying health information to make it more easily understood by all.

Messages may be better understood by using:

- Visual aids as appropriate to the person's communication needs such as photos, drawings, gestures, pointing and/or signs to support spoken messages, physical models and demonstration.
- Easy Read resources featuring clear, everyday language matched with images.
- Resources such as Say Less, Show More.

Information must be accessible, for example:

- large font and visual aids must be available for people with a visual impairment
- hearing loops and hearing aids must be available for people with a hearing impairment
- Auslan interpreters must be available for people who are deaf and/or have a hearing loss
- Australian Government Access Hub services are available to people who are deaf, have a hearing impairment or have a speech communication difficulty.

Ensure information is available to people, their carers, family and disability support workers to help them navigate NSW Health facilities and services. Signage is to be clear and tools like the BindiMaps indoor navigation app may also be helpful, where available.

Convey information in the person's preferred communication method. Examples of important information to communicate include what is about to happen in an admission or during a procedure, follow-up actions and recommendations for the person's care at discharge.

3.3. Accessible environments and equipment

NSW Health services are to provide safe and accessible health service environments and amenities for people with disability and their carers, families and disability support workers. This includes providing access for assistance animals wherever possible and appropriate. Appendix 1 includes examples of how to make health service environments and equipment more accessible.

NSW Health facilities are also to have an appropriate range of equipment and assistive technology (such as hoists, wheelchairs, visual aids) available to support admissions. Consideration is to be given for people to bring in appropriate equipment (such as wheelchairs) and assistive technology that supports their needs, as part of making adjustments.

3.3.1. Accessible facilities

Accessibility must be considered in planning for new and refurbished facilities. NSW Health Guideline *Australasian Health Facility Guidelines – Use in NSW* (GL2018_024) recommends that the Australasian Health Facility Guidelines are used as a tool to assist in identifying acceptable standards for facilities and should form the basis from which planning and design progresses. Stakeholders in any planning process are to include people with disability, carers, disability peaks, carer peaks and other government organisations representing the needs of people with disability.

NSW Health services can improve accessibility by providing information in more than one modality. For example, informing people waiting for an outpatient clinic appointment that it is

their turn by using more than one cue (such as a verbal and visual cue). Another example is adding Auslan markers or braille to visual signage.

3.3.2. Assistance animals

Identified assistance animals and assistance animals in training are allowed in NSW Health services and on transport services. Assistance animals are working animals that are specially trained to help people living with disabilities complete everyday tasks and activities so they can be more independent.

In NSW the use of assistance animals is governed by the *Companion Animals Act 1998* (NSW), which states that a person with a disability is entitled to be accompanied by an identified assistance animal into any public space/building/transport.

The *Disability Discrimination Act 1992* (Commonwealth) sets out further requirements, such as the assistance animal being under effective control. It also allows individuals to refuse an assistance animal access to a public place if for example, the animal has an infectious disease, or it is necessary to protect public health or the health of other animals.

The definition of an assistance animal under the *Companion Animals Act 1998* (NSW) and the *Disability Discrimination Act 1992* (Commonwealth) is the same: *an animal accredited by a recognised body or training organisation, or one trained to assist people with a disability to alleviate the effect of the disability*.

For visitation by therapeutic or companion animals, NSW Health service practices are to align with NSW Health Guideline *Animal Visits and Interventions in Public and Private Health Services in NSW* [GL2012_007] (or related updated policy guidance).

3.4. Responsive and appropriate service models and procedures

Appendix 1 provides examples of service models and procedures which respond to the needs of people with disability and provide them with appropriate care. The examples focus on adapting business as usual care or offering alternative models to best meet the needs of a person with disability and their family, carers and supports.

Districts and networks have specialist disability services that can support health staff in the care of people with disabilities. NSW Health staff are to access these specialist services as appropriate. The Statewide Intellectual Disability Health Service is an example of a specialist disability service offered in each district/network.

3.4.1. Partnership models

Service models must support collaboration as a priority. This includes partnering with the person with disability and their family, carers and disability support workers as experts in their care needs. Disability support workers may be partners in care during hospital admissions if approved by the National Disability Insurance Agency (NDIA).

Other partners such as specialist healthcare providers and professionals working with the person with disability may also be involved. See Section 5.2 for common partners in care.

The roles and responsibilities of each partner in care are to be clearly described, negotiated and agreed, and documented to ensure coordinated care (see Section 4). Partners are to be identified as early as possible in the person's healthcare journey.

3.4.2. Holistic health care models

Both physical health and mental health needs are to be considered. It is particularly important for health practitioner to take time to assess the needs of people with disability as their health needs can be complex. When an assessment is required, it must be comprehensive, culturally appropriate and holistic. It must look further than the person's disability diagnosis so that other co-existing conditions if present, can be diagnosed and treated (avoiding diagnostic overshadowing).

For people with cognitive impairment or cognitive disabilities and people who do not communicate verbally, systematic, baseline physical health checks are particularly important (such as check ears, look in their mouth for any obvious dental issues). It is also important to actively involve the carer or family member who has regular contact with the person to provide a clear picture of usual behaviours and abilities.

If the person has behaviours of concern that make a physical examination difficult, the examination must not be avoided and appropriate least restrictive options to reduce agitation or distress considered. For example, holding the examination in 2 parts, taking more time to establish a rapport, checking the person's understanding and/or where appropriate, involving the person's identified carer.

If a person has a behaviour support plan in place, NSW Health staff must consult it to support the health assessment and minimise behaviours of concern. If there is no behaviour support plan in place and behaviours of concern prevent the delivery of holistic health care, services must seek specialist advice (see Section 6.2).

3.4.3. Models which aim to enhance understanding

Models which maximise opportunities for understanding include:

- allowing extra time to communicate during appointments
- offering a pre-admission appointment and tours to familiarise a person with a hospital ward, theatre or X-ray department
- developing a social script, social story booklet or video
- involving interpreters, carers and support workers for people with intellectual disability or cognitive impairment (as appropriate)
- tailoring ways to prepare the person with disability for procedures and admissions.

When taking a referral, ask if the person has a disability and if they will need more time for an appointment. Ensure the appropriate length of time is offered for appointments to allow time for communication and information sharing. This is to help the person with disability and their family, carers and disability support worker understand information related to their health care. It is also to assist staff in understanding the needs and preferences of persons and their family, carers and supports.

Where appropriate, people with disability are permitted to be accompanied by a support person in a health setting. For people with disability, having their regular supports in hospital can assist the person to benefit from the health care they are receiving.

3.4.4. Models which aim to minimise change

Some people with disability may be particularly sensitive to change and can be negatively impacted by it. Models which minimise change can reduce people's distress and improve their experience and outcomes. Consistency is to be maintained as much as possible for these people, including communication approaches, routines, procedures, health staff/family/carers/support staff, environments, food and drink.

Where possible, prepare people with disability for upcoming changes ahead of time to enable them to adjust to necessary changes as much as they are able.

Refer to the person with disability's disability care plan or communication folder (or similar) and be guided by this information (such as Admission 2 Discharge, Clinical Excellence Commission Top 5. In some cases, such as for inpatient admissions, staff may need to refer to the person's behaviour support plan, if they have one.

Models which avoid hospital admission and provide care as close to home as possible are preferable wherever possible and appropriate (such as Hospital in the Home (HITH), outreach clinics, virtual care and home visits). The involvement of assistance animals and use of personal items which give the person with disability a sense of security are also to be promoted.

To reduce the need for multiple visits, wherever possible, health care is to be thoughtfully planned and organised to make optimal use of each contact, procedure or admission.

4. Clarifying Roles of Service Partners

When a person with disability uses health services, they may also be receiving support from family and carers, and/or services and supports funded under the National Disability Insurance Scheme (NDIS) or through other arrangements. NSW Health staff are to lead discussions with all partners in care to clarify each person's role. This is particularly important for people with disability who are receiving inpatient care.

NSW Health services must have local policies and procedures describing how staff will work with other service partners. If a person with disability is admitted to hospital, policies and procedures must consider the role of each partner before, during and after the admission, including:

- the roles of carers and family members (such as in assisting with an admitted person's basic needs) (see the *Carers (Recognition) Act 2010* (NSW), Schedule 1 NSW Carers Charter)
- the facilities and supports available to them (such as family/carer accommodation during a hospital admission, family and carer programs)
- the involvement of paid services and supports including NDIS funded disability support workers (see Section 4.2) and other service partners (see Section 5).

NSW Health staff are to be clear about these processes so they can welcome and value the involvement of family, carers, disability support workers and other partners in care from the first point of contact.

4.1. The role of NSW Health and the NDIS

The Applied Principles and Tables of Support to the Determine Responsibilities of the NDIS and other service systems outline the responsibilities of the NDIS and other service systems, including NSW Health [9]. NSW Health, the person with disability, their carers and family members and NDIS funded service providers are to work together using a person centred approach to plan and coordinate streamlined care for individuals requiring both health and disability services.

NSW Health staff should liaise with their local NDIS Lead or Disability Lead for current information on connecting with the NDIS as well as access to relevant NDIS related documents.

4.1.1. NSW Health responsibilities

NSW Health services are part of the broader health system of care. NSW Health services provide diagnosis, early intervention and treatment of health conditions, including ongoing or chronic health conditions. They are also responsible for providing time limited, recovery-oriented services and therapies aimed at supporting a person's physical and mental health and improving their functioning after a recent medical or surgical treatment intervention.

Local health districts (district) and specialty health networks (network) are responsible for providing quality health care for all and making adjustments so people with disability can receive the care they need and have a right to. Each district and network has an NDIS lead that can assist NSW Health staff with NDIS processes, particularly for inpatients.

4.1.2. NDIS responsibilities

The NDIS is responsible for funding reasonable and necessary disability related supports to eligible NDIS participants that are required due to the impact of a person's impairment/s on their functional capacity. This includes maintenance supports delivered or supervised by clinically trained or qualified health professionals:

- where the person has reached a point of stability in regard to functional capacity
- integrally linked to the care and support a person requires to live in the community and participate in education and employment.

4.2. Partnering with NDIS supports during a hospital admission

The National Disability Insurance Agency (NDIA) has established the role of Health Liaison Officers (HLO) who work with NSW Health NDIS Leads/Disability Leads to ensure communication between the hospital and the NDIA is as fast as possible, to ensure safe and timely discharge for NDIS participants. They also make sure that the NDIA receives the

information required to plan for discharge. All NSW Health staff should liaise with their NDIS Lead/Disability Lead in understanding the role of the HLO.

NSW Health and the NDIA have developed the Hospital Discharge Assessment (HDA) template, for use when NDIS participants are clinically ready for discharge.

The purpose of the HDA template is to inform the NDIA of the participant's support needs upon discharge from hospital. In outlining the person's functional ability and care requirements, the report will inform all supports required for discharge which may include NDIS funded housing, personal care and assistive technology supports.

All NSW Health staff supporting discharge should use the HDA template.

4.3. Concurrent supports

The NSW Health system has an obligation to make adjustments to ensure all people can access appropriate health care. For some people with disability, provision of NDIS funded behavioural supports, communication supports, or diversional or community-based activities may be required to meet their disability care needs during their hospital stay. These are known as concurrent supports.

Concurrent supports are supports that continue to be provided to a NDIS participant through the use of their NDIS funded supports at the same time as they are accessing health services.

NDIS funded service providers or support workers may come onto NSW Health sites to support a NDIS participant with activities such as:

- ongoing engagement in community access
- assisting hospital staff to communicate with the person
- assisting hospital staff to understand and implement a person's behaviour support plan.

The use of a participant's NDIS plan to provide these supports requires approval from the NDIA. NSW Health has developed a NDIS concurrent supports template that must be submitted to the NDIA when it is identified that a patient may require concurrent supports. NSW Health staff should liaise with their relevant NDIS Lead or Disability Lead for access to this form.

Districts and networks are to develop local procedures describing how NSW Health will partner with NDIS funded supports and other disability providers at the local level.

Documents that may guide the development of local policies and processes include:

- NSW Health Policy Directive *Work Health and Safety: Better Practice Procedures* (PD2018_013)
- Districts and Networks Visitation Policy
- *The Applied Principles and Tables of Support to Determine the Responsibilities of the NDIS and other Service Systems*
- NDIS Code of Conduct and NDIS Practice Standards and Quality Indicators.

In situations where NSW Health staff have concerns about engagement with NDIS providers, complaints can be made to the NDIS Quality and Safeguards Commission.

5. Integrating Health Care and Social Supports

People with disability often have complex physical and mental health care needs as well as housing, employment and other social care needs. It is essential that NSW Health services proactively partner with the person with disability, their family and carers and other health, disability and social support partners to plan, coordinate [10] and integrate care [11]. The aim is to deliver safe, appropriate and seamless care across all phases of the patient journey.

5.1. Care coordination

NSW Health Policy Directive *Admission to Discharge Care Coordination* (PD2022_012) outlines the process of care coordination through 5 key stages that NSW Health services must follow for all admitted patients. The patient journey is similar for a person's engagement with outpatient or community-based health settings and the same stages are to be followed.

Examples of key tasks for care coordination for people with disability have been included below for each of the 5 stages. These activities are in addition to providing information and communicating with the person with disability and their carers and family (see Section 3.2), partnering in care planning (see Section 3.4.1) and clarifying the roles of services partners (see Section 4).

5.1.1. Pre-Admission/Admission to a hospital or service

- Offer pre-admission meetings for all planned hospital admissions to ensure optimal supports are in place for the person with disability and their carers and family (see Section 2.2 and Section 3). Additional time may be required for these meetings to support communication and comprehensive care planning. For example, pre-admission meetings can be used to identify triggering and protective factors for the person; their likes/dislikes that can be reasonably accommodated; preparation required prior to arrival and on arrival; how and where the person will be greeted and by whom; and a behaviour management plan if needed.
- If multiple appointments, tests and/or procedures are required, wherever possible, schedule these to support optimal outcomes for the person.
- Collect all relevant information to support the person's healthcare journey, such as referrals, health assessments, disability care plans (information about communication or behaviour support needs) and communication plans.
- Identify and ensure close liaison with service partners such as General Practitioners, NDIS providers and other partners listed in Section 5.2. This will support a person's transition into hospital, their access to community supports while in hospital (as appropriate) and their transition back to community living. This is also important for effective care coordination for people in outpatient and community-based health settings.

- Identify a person with disability's transition support needs early and collaboratively plan for them, such as when young people are transitioning to adult services. Recognise that transition periods can hold uncertainty and disruption for people, their carers and family members, such as during a change of service providers. It can also be an opportunity to re-evaluate their needs.
- Complete a locally developed Discharge/Transfer of Care Risk Assessment or equivalent to identify a person's needs that require further assessment and follow-up prior to discharge/transfer of care. This may include health and social care needs such as a change in accommodation or community based health and social services.
- Offer information about the service's Patient Representative, consumer feedback mechanisms and Health Care Complaints Commission.

5.1.2. Multidisciplinary Team (MDT) Review

All members of the MDT must work collaboratively to improve outcomes for the person. They must have defined roles and responsibilities in assisting in the care coordination process [10].

A key contact/coordinator from the multidisciplinary treating team must be identified to ensure that each step of the discharge planning process is completed [11].

5.1.3. Estimated Date of Discharge (EDD)

The EDD predicts the likely date that an admitted patient will be clinically ready to leave the hospital. It is defined as the date agreed by all members of the treating MDT for when active care is completed, and the person will be safe to transition to their next phase of care or discharge home. It provides everyone involved in the person's care, including the patient and their family/carers, with a date to coordinate the patient's needs and discharge planning.

The EDD must be reviewed and updated as required during the electronic patient journey board rapid multidisciplinary team huddle or equivalent, and communicated to the person with disability, family and carers, and relevant community service providers [10].

Outpatient and community-based health teams must communicate early about any time frames that apply to a person's engagement with the service and transfer of care.

5.1.4. Referral and Liaison for patient transfer of care

Once a patient's needs are identified, discussions with the appropriate providers must occur using the EDD as the start date. Discussions with providers must occur early to provide enough time to make the appropriate arrangements. Each NSW Health service is required to develop referral structures to enable staff to easily contact the relevant service providers [10]. See Section 5.2 for common partners in care.

Consider opportunities to refer the person to community-based services to enable them to receive care closer to home and remain in their usual routines. Examples include Hospital in the Home (HITH) and community nursing and allied health services.

Consider arrangements which support the person's transition to other services such as inviting community teams or transition support services to engage with the person and

participate in their care planning while they are in hospital or engaged with the outpatient/community-based service.

Ensure appropriate handovers to support continuity of care.

5.1.5. Transfer of care out of hospital/service

NSW Health is the lead agency for coordinating a collaborative discharge/transfer of care of a patient from a health service.

In planning for the EDD, review the Discharge Risk Assessment and complete a locally developed Transfer of Care Readiness Checklist or equivalent. Consider the person's capacity to consent and decision-making arrangements, NDIS status and involved supports, mobility and transport requirements.

For transfer of care from inpatient or community settings, ensure that referrals have been made to relevant services and follow-up appointments have been negotiated and communicated in accessible ways to the person, their family/carers and other supports.

Provide information and relevant education and training to the person and where appropriate, their carer, family and disability support staff. This may include for example, changes in medication/s or treatments as a result of the hospitalisation or treatment provided and how to use new equipment (such as completing safe transfers using a hoist).

Collaboratively develop and explain the transfer of care plan to the patient, and where appropriate, to their carer, family, guardian and disability support staff. Provide the information in an accessible format appropriate for the person with disability.

Appendix 1 provides additional suggestions for tailoring care coordination for people with disability through making adjustments.

5.2. Mental health service consumers

NSW Health Policy Directive *Discharge Planning and Transfer of Care for Consumers of NSW Health Mental Health Services* (PD2019_045) guides discharge planning and transfer of care for consumers of admitted and non-admitted mental health services. It emphasises the need for partnership, trauma-informed and recovery-oriented principles and practices in care coordination and discharge planning. Key tasks to complete for mental health consumers are outlined in this Policy Directive.

5.3. Common partners in care

Key external service partners are to be identified as early in the person's healthcare journey as possible and involved as appropriate throughout the 5 phases of care coordination. Along with carers and family, examples of other common partners in care include:

- Guardians including the NSW Public Guardian
- Disability Advocates
- the National Disability Insurance Agency (NDIA)
- insurance based schemes such as the State Insurance Regulatory Authority (SIRA)

- National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission
- NDIS funded service providers and other disability service providers including Local Area Coordinator and Early Childhood Approach providers
- non-government service providers (such as housing, employment, out of home care)
- primary health networks (PHNs) and PHN funded services
- General Practitioners (GPs) and other private health service providers (such as Paediatricians, Physicians)
- health and hospital services such as dental, mental health and Justice Health and Forensic Mental Health
- Aboriginal Community Controlled Health Services, Aboriginal Medical Services
- NSW Police
- aged care services
- NSW Ageing and Disability Commission
- Prevention of Violence Abuse and Neglect services
- Department of Communities and Justice.

6. Enabling a Capable Workforce

NSW Health staff must be adequately skilled and equipped to respond to the needs of people with disability and their families, carers and supports. This includes recognising the needs of particular groups, including:

- Aboriginal and Torres Strait Islander people
- people from culturally and linguistically diverse (CALD) backgrounds
- people from refugee backgrounds
- LGBTIQ+ people
- children
- women
- older people, and
- people from rural and remote areas.

NSW Health staff must be culturally responsive to these priority groups.

Managers are to ensure there are adequate staff available to provide specialist consultation for people with disability particularly when they present to the emergency department or are admitted for an inpatient stay.

Managers must also ensure that the workforce is appropriate to support the cultural and diversity needs of people with disability and their carers and family members. Aboriginal

people must be offered support by being linked with Aboriginal Liaison Officers or Aboriginal Health Workers/Practitioners.

Building capability in health services for people with intellectual disability: the Essentials (Essentials) guides NSW Health services in meeting the needs of people with disability and in particular, the needs of people with intellectual disability. The Essentials contains links to resources and includes tools to support capability development and strategy implementation.

People with lived experience of disability and lived experience of caring for a person with disability must be consulted in the development of training and may participate in the delivery of training. Other subject matter experts and peak bodies such as the NSW Ageing and Disability Commission, NSW Public Guardian and disability and carer peak organisations can also provide advice on the development of training. In addition, these organisations may have training, education and resources suitable for use by NSW Health services and can provide specialist advice on topics within their remit.

6.1. Building workforce capability

Local health districts (districts) and specialty health networks (networks) are responsible for ensuring staff are adequately trained and supported to meet the needs of people with disability and their carers and family. Clinical staff must also be provided opportunities to gain experience in working with people with disability as relevant to their role.

All staff (clinical and non-clinical) should attend disability awareness training that includes a values and attitudes component and builds capabilities in:

- offering an inclusive, person-centred approach
- respecting the privacy[3] and promoting the human rights, choice and control of people with disability
- understanding the rights of carers under the *Carers (Recognition) Act 2010* (NSW) and *Mental Health Act 2007* (NSW)
- promoting people with disability's access to mainstream services
- making adjustments
- providing and creating accessible information (such as Easy Read resources)
- communicating with people with disability and their carers, family and supports
- working with National Disability Insurance Scheme (NDIS) funded supports
- promoting the inclusion of assistance animals (where relevant and appropriate).

All clinical staff should complete relevant training and education to ensure they have core capabilities in responding to the needs of people with disability, including:

- using common signs, communication aids and methods to communicate[4]

[3] HETI courses include – Privacy - It's Yours to Keep, Let's Talk Disability
[4] For example CEC resources - Safety fundamentals for person centred communication

- using supported decision making strategies[5]
- applying NSW Health privacy and consent policies and guidance
- understanding the roles of carers and family[6]
- understanding guardianship and the scope of various guardian roles[7]
- understanding the role of the NDIS Quality and Safeguards Commission
- understanding the NDIS and where to access local advice on the NDIS
- recovery-oriented practice for people with psychosocial disability
- accessing local pathways for specialist disability consultation and escalation of issues
- accessing resources for people with disability and their carers and family[8].

As relevant to their role, clinical staff should also complete training and education to ensure they are capable in:

- supporting transitions of young people with disability from paediatric to adult services[9]
- providing comprehensive, holistic and trauma-informed assessment and treatment that responds to a person with disability's presenting issues and avoids diagnostic overshadowing[10]
- developing integrated care plans with a person, carers, families, supports and other service partners (such as general practitioners, NDIS providers, other health service providers)
- partnering with the National Disability Insurance Agency (NDIA), NDIS providers and other disability providers (such as housing, employment)
- supporting the delivery of health care and facilitating the transitions of people with disability who have complex health and social needs.

6.2. Specialist advice, specialist services and capacity building

NSW Health services are to access specialist disability advice and services, and training and education provided locally or through networked arrangements. These include but are not limited to:

[5] Resource - NSW Trustee & Guardian Supported decision-making and capacity
[6] HETI My Health Learning courses include – Partnering with Carers
[7] HETI has various My Health Learning training modules available on guardianship such as. Understanding Guardianship, Implementation of Guardianship Guidelines
[8] Example of resources - ACI - Intellectual disability health network resources
[9] Examples of transition supports and guidelines – Transition Care Network, Trapeze, Trapeze transition practice guidelines
[10] Example of available My Health Learning training - HETI Let's Talk Disability, HETI Enabling person centred end of life care for people living with dementia, mental illness or intellectual disability, HETI Cognitive Disability and the Criminal Justice System UNSW ID Health Education

- District/network disability units/teams and roles (such as NDIS leads, Disability Strategy managers, Intellectual Disability clinicians)
- Statewide Intellectual Disability Health Service
- Statewide Intellectual Disability Mental Health Hubs
- NSW Health Carer Support Service
- Agency for Clinical Innovation Clinical Networks.

Specialist disability health worker/coordinator roles and teams provide advice, capacity building and consultation for mainstream health staff. They are also to provide support and promote resources for a person, their carer and family. This may include for example:

- providing advice on complex matters (such as consent, working with the NDIA and other supports while a person with disability is in hospital)
- contributing to case conferences for patients with complex needs
- sourcing specialist information needed for decision making and care planning
- developing pathways for people with complex needs to access the NDIS or alternate supports
- monitoring safe, high-quality care for people with disability.

7. Monitoring High-quality Care

Local health districts (district), specialty health networks (network) and NSW Health organisations must monitor local compliance with this Policy Directive and ensure that related education and training is offered to staff. Implementation will form part of implementation of the NSW Health *Disability Inclusion Action Plan*. All NSW Health staff are to be familiar with relevant disability inclusion action plans and local implementation priorities.

Patient safety and quality monitoring processes are to be used to identify any issues in the quality of health care provided to people with disabilities and associated outcomes. Systems include but are not limited to:

- Incident management for NSW Health services and Serious Incident Response Scheme for multi-purpose services
- Compliments and complaints mechanisms
- Consumer/patient satisfaction surveys and interviews
- National Safety and Quality Health Service Standards
- Periodic medical record audits
- District/network performance reporting.

8. Appendix

1. Appendix 1: Examples of Adjustments

8.1. Appendix 1: Examples of Adjustments

Table 2 provides examples of common adjustments. It is an indicative list only and action should not be limited to these items.

Table 2. Examples of adjustments

Area	Adjustment
Communication and information	Refer to the person with disability's communication folder (or similar) and be guided by this information (such as Disability Care Plan, Admission 2 Discharge, Clinical Excellence Commission Top 5)
	Identify if Interpreters (such as Auslan) or translators are needed to improve accessible information and communication (such as sight translation of consent documents) and engage these supports
	Identify if communication aids and supports are needed and use these. For example, Say Less, Show More, My Care Board (to assist communication at the hospital bedside), hearing loops, Access Hub services
	Ensure people who use a communication device, mobile app, or similar, have ready access to it at all times
	Use methods like 'Teach Back' to check a person's understanding of the information given to them (refer to Safety fundamentals for person centred communication) and ask questions to clarify your own understanding of what the person says
	Meet with the person with disability face-to-face or by virtual care to explain written information, check they have understood the information and answer any questions (involve family, carers or supports with consent and if relevant)
	Facilitate access by patients, family, carers and supports to information via accessible websites, large print and Easy Read resources (such as brochures, medical appointment letters, service feedback forms) and apps (such as BindiMaps indoor navigation app)
	Provide health care plans and referral and discharge information in accessible formats for the person with disability and, with consent, their carers
	Provide accessible information in formats such as Easy Read (such as signs, labels, directions, health information and instructions in health facilities and on equipment)
Environments and equipment	Provide furniture and spaces for family, carers and supports where needed for admissions
	Provide spaces for wheelchairs, other mobility aids, equipment and assistance animals
	Provide access to information and communications technology such as large screens and screen magnification software
	Provide appropriate and safe lighting to enable lip reading, support vision or reduce sensory overload
	Manage noise if sound levels are of concern, particularly for people who are sensitive to their environment or behavioural support needs. For example, minimise noise or provide background white noise
	In hospital waiting areas assess environmental impact (including from other patients) and consider suitable alternative environmental options where possible
	Offer low sensory spaces to reduce pain or discomfort for people who experience sensory overload
	Provide call systems for people who are unable to reach or use the call bell

Area	Adjustment
	Provide accessible toileting and showering facilities and required equipment
	Provide accessible examination tables and diagnostic equipment
	Ensure appropriate lifting equipment is available prior to attendance at appointments (such as hoists)
	Assess the need for and organise equipment for the person to use in hospital or to safely leave hospital (such as wheelchair, volume increasing headsets)
	For admissions, ensure the bed location of a person with disability who has complex care needs including communication and self-care needs facilitates the delivery of safe, high-quality care (such as may need to be close to a nurse's station)
Service models and procedures	Involve the person and with their consent, involve their relevant family, carers and supports as expert partners in care. Discuss and describe the roles of each partner in care and share the document with all partners
	Facilitate contact and collaborate with the person's disability Support Coordinator or other relevant disability supports whilst the person is engaged with the health service
	With consent from the person with disability, allow family, carers and support people to attend appointments to facilitate communication with the person and assist their understanding of health information
	Ensure that a person who requires a substitute decision maker has that person present for conversations about decisions and where consent is required
	Consult specialist disability teams about how to optimise care for people with disability including where the use of disability support workers may be needed during a hospital admission
	Facilitate contact and collaborate with the person's carer and/or disability Support Coordinator or other relevant disability supports whilst the person is engaged with the health service
	Support the inclusion of assistance animals such as Assistance Dogs for people with mental health issues, sensory, emotional, cognitive and behavioural support needs
	Offer alternative models to hospital admission where possible (such as Hospital in the Home, outreach clinics, virtual care)
	Ensure service emergency/evacuation procedures cater for the needs of people with disability
	Minimise waiting times
	Adapt appointment times and lengths to most appropriately support a person with disability's needs (such as longer appointments to allow time for communication and understanding, appointments with breaks to assist with managing sensory overload)
	Ensure comprehensive and holistic assessments are conducted to avoid diagnostic overshadowing
	Offer pre-admission visits/clinics prior to a planned hospital stay
	Offer tours to familiarise a person with a hospital ward, theatre or X-ray department
	Manage upcoming investigations so each interaction can be used opportunistically (such as general anaesthetic also used for dental care and blood tests)
	Minimise changes in routines, procedures, environments and staff (where possible) for people who have difficulty adjusting to change

Area	Adjustment
	Offer assistance with toileting or feeding if a person cannot independently mobilise due to their disability
	Develop local policies and information for families/carers which describes the support available for the family/carers while a person with disability is in hospital (such as bedside accommodation for a family member/carer, how family/carers can partner with health services in providing support to the person with disability, extended visiting hours)
	Develop local policies covering the role of NSW Health services and how NSW Health staff are to discuss and document their role and the roles of other partners in care (such as disability support workers)

9. References

[1] NSW Health (2019). *IB2019_013 Identifying the Carer at Person Registration.* https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=IB2019_031 (accessed Feb. 23, 2023).

[2] Cho H L, 2019. *Can Intersectionality Help Lead To More Accurate Diagnosis?* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6383785/ (accessed Jun. 17, 2024)

[3] Australian Government. *Disability Discrimination Act 1992.* https://www.legislation.gov.au/Series/C2004A04426 (accessed Feb. 23, 2023).

[4] NSW Government. Disability Inclusion Act 2014 No 41 (accessed Feb 23 2023) https://legislation.nsw.gov.au/view/whole/html/inforce/current/act-2014-041

[5] NSW Health (2023). *NSW Regional Health Strategic plan 2022-2023*. https://www.health.nsw.gov.au/regional/Pages/regional-health-strategic-plan.aspx.

[6] Australian Government, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities (2022). *Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia*. https://disability.royalcommission.gov.au/publications/nature-and-extent-violence-abuse-neglect-and-exploitation-against-people-disability-australia

[7] Australian Government. *Australian Charter of Healthcare Rights* https://www.safetyandquality.gov.au/our-work/partnering-consumers/australian-charter-healthcare-rights (accessed Aug, 1, 2023).

[8] NSW Health (2020). *PD2020_013 Complaints Management.* https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2020_013.

[9] Australian Government, Department of Social Services. *The Applied Principles and Tables of Support to Determine the Responsibilities of the NDIS and other Service Systems* (current 12 April 2023). https://www.dss.gov.au/disability-and-carers-programs-services-government-international-disability-reform-ministerial-council-reports-and-publications/the-applied-principles-and-tables-of-support-to-determine-responsibilities-ndis-and-other-service.

[10] NSW Health (2022). *PD2022_012 Admission to Discharge Care Coordination.* https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2022_012

[11] NSW Health (2018). *NSW Health Strategic Framework for Integrating Care.* https://www.health.nsw.gov.au/integratedcare/Pages/strategic-framework-for-integrating-care.aspx