

Responding to Needs of People with Disability during Hospitalisation

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Functional Sub group Clinical/ Patient Services - Medical Treatment
Clinical/ Patient Services - Governance and Service Delivery
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Summary The Policy Directive sets out guiding principles for responding to needs of people with disability including inclusion, person-centred services, accessibility, communication, and reasonable adjustment. This policy is to be implemented in conjunction with other NSW Health policies relevant to, treatment in, and transfer out of hospital as referenced in the policy.

Replaces Doc. No. Disability - People with a Disability: Responding to Needs During Hospitalisation (revised Jan 08) [PD2008_010]

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Applies to Local Health Districts, Board Governed Statutory Health Corporations, Chief Executive Governed Statutory Health Corporations, Specialty Network Governed Statutory Health Corporations, Affiliated Health Organisations, Public Health System Support Division, Community Health Centres, Dental Schools and Clinics, NSW Ambulance Service, Ministry of Health, Private Hospitals and Day Procedure Centres, Public Hospitals, Cancer Institute (NSW)

Audience All staff

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

Review date 09-Jan-2022

Policy Manual Not applicable

File No. 13/2143

Director-General **Status** Active

This Policy Directive may be varied, withdrawn or replaced at any time.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.

RESPONDING TO THE NEEDS OF PEOPLE WITH DISABILITY DURING HOSPITALISATION

PURPOSE

This Policy Directive has been updated and replaces PD2008_010 *Disability – People with a Disability: Responding to Needs during Hospitalisation*.

This policy describes the responsibilities of all staff working in hospitals caring for people with disability. The scope of the policy includes: pre-admission planning, admission to hospital, care planning during the hospital stay and planning for the transfer of the patient back to the community; planned and emergency admissions; and in-hospital patient care settings (including Hospital in the Home), hospital emergency departments, and hospital outpatient departments.

MANDATORY REQUIREMENTS

This Policy Directive applies to all NSW Health services, which are required to have local policies, protocols and procedures in place based on the attached Procedures in all hospitals that provide admitted patient services to people with disability.

This policy requires NSW Health organisations and staff to provide services to people with disability that are:

- Inclusive
- Person-centred
- Accessible.

Health service staff must:

- Make reasonable adjustments according to needs of the individual
- Communicate with and provide information to the person with disability in a way they understand
- Involve the person with disability, and where appropriate, consult their carer, family, guardian and / or disability support staff as outlined in the attached policy directive
- Implement this policy in conjunction with other NSW Health policies relevant to admission to, treatment in, and transfer out of hospital as referenced in this policy.

IMPLEMENTATION

The following NSW Health organisations have responsibilities in relation to this policy:

- Local Health Districts (LHDs)
- Statutory health corporations – network governed (Specialty Health Networks)
- Statutory health corporations – chief executive governed
- Statutory health corporations – board governed
- Affiliated Health Organisations

- Statewide health services.

These organisations and their staff will:

- Treat people with disability, their carers and families equitably, with respect and use a person-centred approach in line with the guiding principles outlined in the attached Procedures
- Aim to keep people with disability healthy and out of hospital
- Allocate responsibility for implementing this policy in hospital facilities to an executive role
- Review their systems for meeting needs of people with disability in line with this Policy Directive, including but not limited to use of the Implementation Checklist in Appendix 3
- Use existing patient safety and quality monitoring processes to identify and address issues in the quality of health care provided to patients with disability and associated outcomes
- Monitor length of stay and unplanned hospital re-admission rate for people with disability and develop mechanisms to determine if there is a difference in outcomes for people with disability when compared to the general population
- Use this policy in the development of LHD / SHN local policies, protocols and procedures related to improving health care provided to people with disability when they are hospitalised (from admission to transfer to care).

Under this Policy Directive the NSW Ministry of Health will:

- Monitor and provide guidance and policy support to relevant health organisations to implement this policy
- Promote awareness of this policy across the NSW Health system
- Encourage LHDs, SHNs and other relevant health organisations to involve people with disability in the development of local policies, protocols and procedures
- Encourage LHDs, SHNs and other relevant health organisations to adopt the principles outlined in this policy.

REVISION HISTORY

Version	Approved by	Amendment notes
January 2017 (PD2017_001)	Deputy Secretary, Strategy and Resources	Replaces PD2008_010 Policy updated and title changed to <i>Responding to the Needs of People with Disability during Hospitalisation</i>
February 2008 (PD2008_010)	Deputy General, NSW Health	Replaces PD2005_625 Policy updated and title changed to <i>Disability- People with a Disability: Responding to Needs During Hospitalisation</i>
October 2005 (PD2005_625)	Deputy General, NSW Health	New policy

ATTACHMENTS

1. Responding to Needs of People with Disability During Hospitalisation:
Procedures

Responding to Needs of People with Disability during Hospitalisation



Issue date: January-2017

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1. BACKGROUND TO THIS DOCUMENT

This Policy Directive is an update of and replaces PD2008_010 Disability – People with a Disability: Responding to Needs during Hospitalisation.

The purpose of this policy is to improve the experience of people with disability accessing the State Health system, providing a safe and responsive stay during hospitalisation. This policy sets out the requirements of effective communication with the person with disability and where relevant their carer, family, guardian and disability support staff. It also sets out requirements to make reasonable adjustment during the patient journey to ensure people with disability access equitable, effective and safe health care.

Disability for the purpose of this policy is defined as “a long-term physical, psychiatric, intellectual or sensory impairment that, in interaction with various barriers, may hinder the person’s full and effective participation in the community on an equal basis with others.”¹ Disability itself is not an illness but people with disability may have long-term illnesses, chronic diseases, or co-morbidities that require ongoing attention and management.

People with disability have the right to the highest attainable standard of health. This is achieved through being able to access health services on an equitable basis, receive care that meets individual assessed health needs and through appropriate supports that ensure that high quality health care services are received prior to, during, and after hospitalisation; that barriers are not created due to a person’s disability.

The NSW Disability Inclusion Act (2014) commits the NSW Government to making communities more inclusive and accessible for people with disability. This will be achieved by, among other things, promoting the independence of people with disability and enabling choice and control.

This policy, in alignment with the Act, requires staff to provide services that are inclusive, person-centred and accessible.

¹ NSW Disability Inclusion Act 2014 No 41
<http://www.legislation.nsw.gov.au/maintop/view/inforce/act+41+2014+cd+0+N>

2. KEY PRINCIPLES

2.1 Inclusion

The NSW Government is committed to supporting the fundamental right of people with disability to “have the same right to choose the way to live their lives, to access the same opportunities and enjoy the benefits of living and working in our society”, and that the state and community have a responsibility to facilitate the exercise of those rights.²

For more information on how NSW Health is working to improve access and inclusion for people with disability see the *NSW Health Disability Inclusion Action Plan (DIAP) 2016-2019*.

2.2 Person-centred services

A person-centred approach places the person at the centre of decision making, and works with the carer, family, guardian, natural networks of support, and service providers as partners.

For the person to be at the centre of care he or she needs to be well informed about the hospital experience and involved at the centre of decision-making through all the stages of: planning for admission, during hospital stay, and transfer back to the community.

The treating practitioner is responsible for determining the capacity of the person with disability to participate in developing person-centred care plans, or what type of assistance the person needs to support their participation.

2.3 Accessibility

Accessibility includes access to the full range of hospital services and hospital amenities, and information about hospital services including complaints mechanisms. NSW Health organisations should ensure that facilities, services and information are accessible to both the person with disability and those who support them.

Ways to improve access to facilities include:

- Ensuring there is adequate space for wheelchairs and other equipment, and assistance animals
- Ensuring staff are aware that assistance animals are allowed in hospital buildings, including awareness of the Guideline on GL2012_007 - *Animal Visits and Interventions in Public and Private Health Services in NSW*

² p.5, NSW Disability Inclusion Action Planning Guidelines 2015,
http://www.facs.nsw.gov.au/_data/assets/file/0004/322366/NSW-DIAP-Guidelines.PDF

- Ensuring call systems, diagnostic equipment, toileting facilities, emergency / evacuation procedures and examination tables are fully accessible
- Having an alternative call system in place for patients who are unable to reach or use the call bell
- Providing any information available to patients, and their families, in an accessible format, for example signage, labels, directions and instructions.

Accessibility of information for patients

Health professionals have an obligation to ensure that information is provided to patients in a way that they can understand. This obligation could include the provision of communication aids, including interpreters or translators.

Information should be given in advance of admission to hospital, where possible, to the person, and to their carer and / or their support network as this will enable them to explain the information and prepare the person prior to the hospital stay.

Written information can be made more accessible when it is supported by verbal information given in an explanation. During hospitalisation, from pre-admission to transfer out of hospital, appropriately trained staff should take the time to go through written material with the person with disability, then check whether the person has understood the information, and answer any questions they may have.

2.4 Communication

The most significant factor associated with both a positive and a negative patient experience is the existence and degree of effective communication between health staff and the patient.

It is important there is effective communication between health staff, the person with disability and where relevant their carer, family, guardian and / or disability support staff to understand the person's health and support needs, to understand expectations and feelings, and respective roles and responsibilities.

People with significant and permanent disability living in both residential care and the community are a particularly vulnerable population. Many people often require assistance with activities of daily living, including communication. It is important that the communication support required is identified, documented and used.

All communication should always be addressed in the first instance to the person with disability in matters including treatment, comfort, services, supports, amenities and needs relating to their disability. Health professionals should consult the person with disability for advice on the most effective method of communication.

If the person is unable to advise hospital staff of the most effective method of communication, health professionals should then consult the carer, family, guardian

and / or disability support staff for information about what is 'usual behaviour', how the person communicates and whether they use any particular Augmentative and Alternate Communication (AAC) methods.

Information on the person's communication needs and preferences must be documented in communication profiles in care plans, records and the Transfer of Care Referral form. Documentation should include any communication aids used by the patient, interpreting gestures, signs and behaviours which they may use to convey their needs and responses.

Ways to improve communication:

- Recognise that some patients may be unfamiliar with healthcare information and address each person's level of understanding
- Identify methods a person may use to communicate such as signs and gestures and use these methods when communicating with them such as pointing to objects
- Always speak directly to the person and not through the interpreter or the person's carer, family member or companion
- Allow sufficient time and be patient when communicating
- Listen attentively when talking with a person who has difficulty speaking and let them finish
- Keep sentences short, be specific and talk about one step at a time
- If you are not understood, repeat or rephrase the information, reduce the amount of information, use visual supports, or seek help from someone who knows the person well
- Confirm that the person (or carer / family member / disability support staff) has understood all the information provided, encourage questions
- If you do not understand the person, do not pretend to understand, clarify and confirm what the person is saying, ask the person to say it in a different way, ask the person to show you what they mean, check if the person's non-verbal communication supports what they are saying³
- People with a cognitive and / or psychiatric disability may require key information to be communicated more than once - using reminders and reassurance can improve communication.

Additional training may be required for health care workers to optimise their ability to effectively communicate with people with disability.

Health professionals may need to access information from other parties to assist in providing appropriate care to a person with disability. The person with disability should be actively involved as much as possible in providing information to health

³ Complex communication needs. Department of Communities (Disability Services), QLD. 2011
<https://www.qld.gov.au/disability/documents/community/complex-communication-needs.pdf>

professionals, being informed about their care in hospital, and making decisions about their care.

Health Care Interpreting and Translating Services

The Policy Directive, PD2006_053 - *Interpreters - Standard Procedures for Working with Health Care Interpreters* is a mandatory policy. This Policy Directive requires the use of professional health care interpreters (Australian Sign Language (Auslan) and / or spoken languages) to facilitate communication between staff and people who are not fluent in English, or people who are deaf.

- Health care interpreters are professionally accredited by the National Accreditation Authority for Translators and Interpreters (NAATI) or similar accreditation agencies
- Staff are not to be used as interpreters unless they are NAATI accredited at least at paraprofessional level
- NAATI accredited interpreters (AUSLAN and spoken languages) must be booked, as necessary and as requested, to communicate with people with disability and/or their carer and family
- Services are available 24 hours per day, 7 days per week. The service is available either face-to-face, by telephone or via videoconference if available.
- Interpreters are also available to provide 'sight translation' of documents such as consent documents. Sight translations should always occur in the presence of health service providers so questions can be addressed
- Subject to the requirements of the NSW Health Privacy Manual for Health Information carer, family, guardian, advocates, and / or disability support staff may be consulted using an interpreter for information that may affect the care or treatment of the person with disability
- It should not be assumed that because a person has good spoken language they have equal understanding of written language
- It should not be assumed a person whose first language is Auslan has English literacy skills.

2.5 Reasonable adjustment

In order for health care services to be accessible and safe for people with disability, adjustments need to be made. Making reasonable adjustments means doing things differently to ensure people are not disadvantaged or harmed.

In practice reasonable adjustment means "removing barriers people with disabilities experience in accessing services. This includes changing the ways services are delivered, ensuring that protocols and procedures work equally well for people with disabilities, and ensuring that staff are equipped with the necessary training and

resources to deliver effective, timely and quality healthcare to people with disabilities”.

In the context of anti-discrimination legislation, a person-centred approach to individualised-planning, the requirements of the *Disability Inclusion Act 2014*, and the National Disability Insurance Scheme (NDIS) there is growing expectation and increasing demand for accommodating the needs of people with disability through mainstream services.

The *Disability Discrimination Act 1992*⁴ (Cth) (the Act) recognises the rights of people with disability to equality before the law and makes discrimination based on disability unlawful. The Act defines both direct and indirect disability⁵ discrimination. A failure to make reasonable adjustments⁶ is an explicit feature of the definitions of direct and indirect discrimination.⁷

Local Health Districts (LHDs) / Specialist Health Networks (SHNs) must make reasonable adjustments to respond to the needs of people with disability during hospitalisation. Health staff should consult with the patient and where relevant their carer, family member, guardian and / or disability support staff and acknowledge and act on the advice provided.

Examples of reasonable adjustment include:

- Adjusting communication methods by taking into account the patient’s communication needs
- Addressing the patient’s ability to cope with different environments, changes in routines, unfamiliar procedures and unfamiliar staff
- Addressing the patient’s need to change the ways in which care or treatment is provided
- Allowing extra time to provide the support that is required
- Including and supporting the patient’s carer, family member, guardian or disability support staff as expert care partners
- Providing patient information in alternate formats such as ‘easy read’ documents.

LHDs / SHNs must consider:

- The barriers a person with disability may experience within their hospital’s facilities, processes and systems
- The individual person’s specific needs
- Supports the NDIS can or is providing for the patient and how they complement Health interventions.

⁴ https://www.comlaw.gov.au/Details/C2015C00252/Html/Text#_Toc422301339

⁵ Sections 5 and 6 https://www.comlaw.gov.au/Details/C2015C00252/Html/Text#_Toc422301340

⁶ Definition of reasonable adjustment is defined in section 4(1); definition is copied in the Glossary.

⁷ See section 5(2) direct discrimination and section 6(2) indirect discrimination.

3. THE PATIENT JOURNEY

Hospital can be a daunting experience for patients, in particular for people with disability due to unfamiliar environments, routines and care arrangements.

A hospital stay can have a significant negative or destabilising effect on people with disability as well as their carer, family, guardian and support networks. It can result in a loss of living skills, depression, and poor adjustment to school, employment and relationships. Some children, young people and adults with disability spend significant amounts of time in hospital.

For people with physical disability, hospitalisation can result in deterioration in their general physical and mental condition such as: loss of joint range, muscle strength and tone, functional independence, and ability in activities of daily living. Similarly, the patient's previous confidence in mobility may deteriorate unless this is noted on admission and reinforced daily within the limits of the patient's presenting diagnosis or condition. The patient's confidence in their ability to perform all functional tasks within the limits of their disability may also deteriorate unless health professionals continue to encourage maintenance of, or improvement on pre-hospitalisation independence.

Where appropriate, Hospital in the Home (HITH) should be considered for people with disability to enable them to receive the hospital care they need in their home environment allowing for the maintenance of routines and care arrangements.

Where hospitalisation is needed, it is important that people with disability receive flexible service delivery, where the health service adapts to meet their particular needs. Ensuring the patient is at the centre of their care, involved in pre-admission planning and supported with information will lead to a good hospital experience for people with disability.

While communication, consultation, consent and planning are essential elements of a good hospital experience for all people, these elements can be particularly important for people with disability.

3.1 Privacy

The collection, use, exchange, or disclosure personal information about the patient must be undertaken in accordance with the *NSW Health Privacy Manual for Health Information* (the Manual) which can be found at:

<http://www.health.nsw.gov.au/policies/manuals/Pages/privacy-manual-for-health-information.aspx>

The NSW Privacy Commission has issued a Direction for permitting an exception to the Health Privacy Principles to enable the exchange of health information to assist in the transition of funded individuals to the NDIS.⁸

The link to the Direction is

http://www.ipc.nsw.gov.au/sites/default/files/file_manager/NDIS_s62_HRIPA_Direction_Approved_by_Min_of_Health.pdf

The direction will enable Family and Community Services (FACS) (and other NSW public sector agencies including Health and Education) to collect, use and disclose personal health information about individuals and their carers, who receive disability supports funded by FACS, Health, NSW public sector agencies or an allied agency for the purposes of transitioning funded individuals to the NDIS.

The National Disability Insurance Authority (NDIA) will use this information to contact those individuals and commence their entry into the NDIS.

Guidance should be sought from LHD / SHN Privacy Contact Officers in relation to any external requests to release patient information under the Direction:

<http://www.health.nsw.gov.au/patients/privacy/Pages/privacy-contact.aspx>

Resource: Privacy Information Leaflet for Patients

<http://www.health.nsw.gov.au/policies/manuals/Documents/privacy-appendix-5.pdf>

3.2 Consent

The NSW Health Policy Directive PD 2005_406 - *Consent to Medical Treatment – Patient Information* sets the legal requirements for obtaining a valid consent from patients and advising patients of material risks associated with any proposed medical or dental treatment.

The policy also outlines how the law is to be applied when obtaining consent from a person who lacks capacity, is a minor, or is a patient who is being treated under the *Mental Health Act*. The Consent Policy can be found at:

http://www0.health.nsw.gov.au/policies/PD/2005/pdf/PD2005_406.pdf

Treating practitioners should assume that an adult patient has capacity to consent unless there is evidence to contradict this assumption. The patient must have capacity to give consent to medical or dental treatment. A person has decision making capacity if they can:

- Understand the facts and choices involved
- Weigh up the consequences, and
- Communicate their decision.

For information on obtaining consent for people who lack capacity see Appendix 2.

⁸ This Direction has effect until 28/10/2017

3.3 People with disability and their support networks

People with disability may have a range of support needs and may access these supports from a range of sources, and have multiple parties involved in providing care or support to have those needs met.

It is important that health professionals find out if the person with disability has a support network and whether the person will need the support network's involvement during their hospital stay.

Developing a plan for disability support while in hospital should be part of pre-admission planning.

Health staff should communicate with the carer, family, guardian, and / or disability support staff, about ways to provide safe and personalised care for people whose disability could result in significant risk of harm to themselves, the carer or hospital staff e.g. due to fear, anxiety, absconding, challenging behaviours, difficulties with communication.

With the consent of the person with disability, health professionals should ensure that appropriate information is effectively communicated to the relevant members of the person's support network, in both the admission and the transfer of care planning stages.

Refer to section 4.2 Protocols between key agencies on LHD / SHN responsibility for negotiating and establishing frameworks and protocols with local disability support service providers for the provision of disability support services to the person with disability while they are in hospital.

Carers, family members, and disability support staff may assist with basic needs at the request of the person with disability and in consultation with health professionals, but are not obliged to assist with individual or medical care needs.

Carers

A carer⁹ provides ongoing, unpaid¹⁰ support to a family member, neighbour, or friend who needs help because of disability, chronic, terminal or mental illness or frail ageing.

The patient, their carers, hospital staff and the health care system all benefit from involving carers as a partner in the health care team. The work carers do is essential to the wellbeing of the person with disability and it is essential that they are listened to and consulted with through all stages of a person's hospitalisation.

⁹ As defined in the NSW Carers (Recognition) Act 2010, refer to the Glossary for definition.

¹⁰ Carers may receive the Carer Payment or Carer Allowance

<http://www.humanservices.gov.au/customer/services/centrelink/carers-allowance>

The level of carer involvement may vary. Regardless of whether the carer chooses to remain with the person, or not, carers should be consulted at all stages of the patient's hospitalisation.

LHDs / SHNs should develop local policies which outline the level of support that is available for the carer while the person with disability is in hospital e.g. bedside accommodation for the carer or family are providing support to the patient.

When a person the disability has a paid carer or disability support worker, due consideration will need to be paid to their status on the wards as an employee of the person with disability. Please refer to section 4.2 for more specific advice.

3.4 Care coordination

Care coordination and transfer of care arrangements for people with disability should be made in accordance with NSW Health Policy Directive PD2011_015 - *Care Coordination: Planning from Admission to Transfer of Care in NSW Public Hospitals*^{11 12}, which sets out five stages of care coordination:

1. Pre Admission / Admission
2. Multidisciplinary Team Meetings
3. Estimated Date of Discharge (EDD)
4. Referrals and Liaison for patient transfer of care
5. Transfer of care out of the hospital.

LHDs / SHNs are responsible for establishing mechanisms to ensure that the essential stages of care coordination are undertaken in each facility and are sustained as part of normal care coordination and transfer of care planning.

Preparing for planned admission

Health services should ensure that as part of their pre-admission screening process, people with disability are offered pre-admission meetings for all planned episodes of hospitalisation. A relatively simple procedure can become unnecessarily complicated if there is insufficient pre-admission planning to ensure optimal supports are in place for the person with disability.

¹¹ http://www0.health.nsw.gov.au/policies/pd/2011/PD2011_015.html

¹² Care Coordination. The following links to three documents that were developed to support staff with implementation of the Policy Directive PD2011_015 *Care Coordination; Planning from Admission to Transfer of Care in NSW Public Hospitals*:

<http://www.health.nsw.gov.au/pfs/Pages/carecoordination.aspx> . The three documents are:

1. Care Coordination Policy Directive Reference Manual
2. Care Coordination Policy Directive Staff Booklet
3. Planning your hospital stay patient brochure

If the person requires multiple tests and / or procedures, consideration should be given to scheduling these in a way to maximise outcomes for the person during their admission to hospital.

Close liaison with the person's General Practitioner (GP) or other community based health professionals will support safe, quality, smooth admission into hospital and subsequent transfer back to the community.

Hospital staff should inform and involve the person's carer, family, guardian and / or disability support staff in planning for the admission as appropriate and with the agreement of the patient.

Should there be an expectation that during the patient's admission their accommodation needs will change, discussing these with the patient and their carer or family as early as possible will facilitate a smoother discharge.

Information about the facility's Patient Representative and consumer feedback mechanisms as well as the Inquiry Service of the Health Care Complaints Commission should be provided as part of pre-admission planning.

Pre-admission meeting

A pre-admission meeting should be arranged with the person, and when relevant, involve the carer, family, guardian, disability support staff and relevant hospital staff. Reference should be made to GL2013_001 section 4.3.1, Pre admission meeting (pp.10-11), of the *NSW Health and Ageing, Disability and Home Care (ADHC) Joint Guideline: Supporting residents of ADHC operated and funded accommodation supported services who present to a NSW Public Hospital*, NSW Health.¹³

Staff should be aware that additional time may be needed to develop a pre-admission plan with people who use augmentative and alternative communication methods.

Hospital staff should ensure that information about the hospital admission, hospital routines, and procedures are communicated to the person in the person's preferred communication style.

Transfer of Care Risk Assessment Tool

The person conducting the Transfer of Care Risk Assessment (TCRA) is responsible for communicating any identified risk to the relevant members of the multidisciplinary team. When a transfer of care risk is identified it must be documented and managed.¹⁴

¹³ http://www0.health.nsw.gov.au/policies/gl/2013/pdf/GL2013_001.pdf

¹⁴ p. 1, Policy Directive PD2011_015 *Care Coordination; Planning from Admission to Transfer of Care in NSW Public Hospitals*, http://www0.health.nsw.gov.au/policies/pd/2011/pdf/PD2011_015.pdf

A TCRA should be conducted at pre-admission and patients with an identified risk should be referred early to the appropriate community teams so planning for transfer back to the community can begin. Completion and actioning of the TCRA within the first contact with the patient, or within 24 hours will expedite this process.

Planned day-only admission

Transfer of care planning must also occur for patients having day-only procedures. Hospital facilities may nominate their own processes to ensure the Transfer of Care Risk Assessment is completed. Ideally this should occur prior to the day of the patient's procedure.

Pre-admission plan

The following issues may need to be addressed in order to complete a pre-admission plan for a person with disability:

- Disclosure of information and the inclusion of others from the person's support networks in the pre-admission and discharge planning process in line with the *NSW Health Privacy Manual for Health Information*
- Identification of whether the person is a participant of the NDIS or in the process of making an application to the Scheme
- Procedures for determining informed consent
- Information regarding medical history, social and functional skills
- Clarification of the role of parties involved in care of a person with disability during the hospital stay, including the role of hospital staff, carer / family and disability support staff
- Key community resource contacts, where community or disability service agencies are involved or may be available
- Transportation and mobility requirements
- Physical support needs including appropriate lifting and positioning
- Nutrition and diet requirements; eating and drinking techniques
- Hygiene assistance needs
- The person's specific communication requirements. Hospital staff responsible for planning the admission should ensure that if required a person with disability can bring to hospital their communication resources or equipment such as augmentative communication devices, mobility or functional aids
- Management strategies for difficult or challenging behaviours. Consider involving Dementia Specialists e.g. Clinical Nurse Consultant Aged Care in a suitable management plan
- Consideration of usual care and activity routines to ensure that any medical intervention causes the minimal amount of disruption, confusion and stress to them

- Specific information on equipment that patients must bring to the hospital e.g. for pressure care, respiratory support, should also be discussed. Consider involving Occupational Therapy and Physiotherapy in discussions regarding required equipment
- Hospital staff should ensure that space is provided for comfortable operation and safe storage of equipment, and that the equipment is readily available for use
- Patients who use an assistance animal, such as a guide dog, should not be separated unnecessarily from the animal, and space and care for the animal should be planned and made available
- Conflict resolution mechanisms
- Hospital complaints mechanisms and processes.

Planning for an extended hospital stay may need to include strategies to assist the person to maintain their skills and capacities such as:

- Hospital day passes to access day program and community services can assist in sustaining pre-hospital functional capacity
- Patients, their carer and family, where the patient is an NDIS participant, should be consulted to acquire details of any education, home or day programs that they receive funding for and how those may be accessed.
- Where the patient is not an NDIS participant, they should be consulted to determine whether they are involved in any Information Linkages and Capacity Building (ILC), state / Commonwealth provided education, respite or day supports and how these are accessed
- Where the patient is a long stay resident, the NDIA will need to be informed that the Hospital will temporarily assume the status as the clients' place of residence and that all correspondence should be sent there
- Patients with intellectual disability who underutilise their skills will risk losing those skills. In extended admissions, where possible, hospitals should seek input from their current disability supports and education services for their day-to-day care.
- Where practicable, enable children to continue their school education activities and have access to play therapy.

Engage with the National Disability Insurance Agency (NDIA)

When the person with disability has identified themselves as a participant of the NDIS, identify on what basis their plan is being managed:

- Self-managed – the person with disability will be able to discuss their plan components and, as the coordinator of supports, work with hospital staff to incorporate discharge and ongoing service needs into their budget
- Plan Management Provider – appropriate client consent needs to be gathered and contact made with the plan management provider to ascertain the types

of disability supports the client is funded by the NDIS for and discuss their future discharge needs.

Where the person with disability is not an NDIS participant, consideration should be given at the pre-admission stage as to whether they may be eligible for the NDIS. If the person with disability is understood to satisfy the access requirements then they should be supported with an application to the NDIA as early as possible. However this should not delay the planned hospitalisation unnecessarily.

3.5 Admission

When a person with disability is admitted to hospital, health staff should ask the patient, what communication needs they have, whether they are in the NDIS, what existing home support networks they have in place and how their supports and care are coordinated at home. It should always be assumed that the patient is capable of providing consent unless there is evidence (legal or other) otherwise. See Appendix 2: Obtaining consent from a person who lacks capacity.

Planned admission

All planned admission patients should have their Transfer of Care Risk Assessment completed at presentation or before admission to hospital, such as at a pre-admission clinic or meeting. Completion of this assessment will allow the identification of transfer of care risks. Necessary referrals should be made before admission, where possible, and confirmed during the acute phase of care.

Emergency or direct admission

An emergency admission for a person with disability may result in a lack of optimal supports being readily available because of the absence of pre-admission planning.

Non-planned admissions through the Emergency Department or through direct admission should have a Transfer of Care Risk Assessment completed on the inpatient ward within the first 24 hours of admission.¹⁵ This will ensure that all risks to the safety and wellbeing of the person while in hospital are identified, and appropriate arrangements made for the availability of supports needed by the person while they are in hospital. The risks identified and arrangements made should be documented in care plans, records and Transfer of Care Risk Assessment. This should be done as soon as practical either prior to transfer to the ward or once the person is settled in the ward.

¹⁵ p.2, Policy Directive PD2011_015 *Care Coordination; Planning from Admission to Transfer of Care in NSW Public Hospitals*, http://www0.health.nsw.gov.au/policies/pd/2011/pdf/PD2011_015.pdf

People with disability admitted through the Emergency Department should be asked whether they are a NDIS participant. Refer to discussion under *Engage with the National Disability Insurance Agency* above for reasons and suggested action.

Where the patient has a known intellectual disability, the presence of a known person may reduce stress, reduce the risk of escalating challenging behaviours and improve overall health and safety outcomes for the health service and the person with disability alike.

Emergency admission to hospital from an Ageing, Disability and Home Care (ADHC) operated or funded supported accommodation

Reference should be made to *NSW Health and Ageing, Disability and Home Care (ADHC) Joint Guideline supporting residents of ADHC operated and funded accommodation supported services who present to a NSW Public Hospital*¹⁶ NSW Health GL2013_001 (pages 9-10), which sets out what the disability support staff member who accompanies the person to hospital will do at presentation to the Emergency Department.

Emergency admission from non-government supported accommodation facilities and contracted accommodation providers under the NDIS.

LHDs / SHNs should consult with clients and their local non-government (NGO) supported accommodation providers, for example assisted boarding houses, to develop frameworks and protocols to establish arrangements for patients to be admitted through the Emergency Department from those facilities. Reference should be made to the Joint Guidelines for examples of issues for which there should be agreed frameworks and protocols between the LHD / SHN and the NGO. Refer to section 4.1 on NGO's.

3.6 During the hospital stay

All staff providing care must ensure that they are familiar with the specific care and communication needs of the person with disability throughout the duration of their hospitalisation.

Staff will need to recognise the individual needs that some patients with complex impairments may have and make additional time is available for discussion and treatment.

Staff and other resources may need to be available to enable patients to access usual care in activities such as eating, drinking, toileting and personal hygiene. Some patients with disability may also require frequent checks on their safety.

¹⁶ http://www0.health.nsw.gov.au/policies/gl/2013/GL2013_001.html

In some cases, simple techniques can be used to enable patients to access usual care – for example, letting a patient who is blind know that their meal has arrived, where it is, and where different parts of the meal are on a plate, acknowledging the patient when entering or leaving the room; obtaining the visual attention of a person who is deaf or hard of hearing prior to addressing or approaching them.

Additional staffing resources may be required to meet these needs. Refer to section 2.5 Reasonable adjustment.

Multidisciplinary Team meeting

Refer to Policy Directive PD2011_015 - *Care Coordination: Planning from Admission to Transfer of Care in NSW Public Hospitals* for policy requirements on:

- Conducting multi-disciplinary team meetings
- Estimated Date of Discharge (EDD).

Referrals and Liaison

In consultation with the patient, their carer, family, guardian and/or disability support staff, it is important to agree what services are required after transfer from hospital following an acute episode of care. Where the supports are not chronic or disease focused, the patient may be able to acquire supports through NDIS funding.

Each hospital is required to develop a referral structure to enable staff to easily contact relevant chronic condition or disease service providers. When the patient is in the NDIS, they will need to provide details of their current relevant service providers as well as their plan management provider and be ready to contact the NDIA about their plan.

Involvement of NDIA planners, during discharge planning by multidisciplinary teams, should be considered to ensure that health related components are represented in NDIS applicant's plans and that a proper discharge timetable can be constructed.

Details for referrals should be recorded in one place in the patient's medical record and on any relevant individual referrals, for example to the patient's General Practitioner (GP) and other community based services.¹⁷

Where a patient has given permission for Health staff to contact their community service provider, Community based staff who will be involved in providing out of hospital care and support should be encouraged to visit the patient while they are in hospital to assess their ongoing needs at home and discuss the patient's needs with the Multidisciplinary Team.

Examples of out of hospital programs or services (non-NDIS) that may support transfer of patients from hospital, or patients in the community, are:

¹⁷ p.5, Op.cit.

- Community Packages (ComPacks)
- Hospital outpatient department services
- Community nursing
- General Practitioners.

3.7 Transfer of care out of hospital

Clear communication between the patient, carer, family, guardian, hospital staff, community-based services and the person with disability's support network is vital to an effective transfer of care process.

Special information that should be noted and will assist in the completion of the Transfer of Care Risk Assessment and Transfer of Care Readiness Checklist, and identification of the Estimated Date of Transfer includes:

- Whether the person has capacity to consent to medical treatment, and, if not, what arrangements have been made for someone to make decisions on behalf of the person
- Clarification of the patients' NDIS status and of the role of people already involved in providing supports and their contact details
- Mobility and transport requirements.

Information provided to patients, and where appropriate, to carers, family, and disability support staff who will be involved in their ongoing care should be in plain English and explained to the patient and those who will be involved in their care.

The transfer of care process for the person with disability must include:

- Determination of the suitability of existing home support systems or the patient's NDIS plan components (if an NDIS client), when completing a Transfer of Care Risk Assessment. This should involve consultation with the patient, and, where appropriate, their carer, family, guardian, their advocate, and provider of supports to establish the level of care and support needs required. Environmental adjustments should be made as needed
- Referral to out of hospital, community-based health services, or specialist services as required by the patient:
 - Arrange appointments for post hospital services as required, examples:
 - Follow up appointments with medical specialists related to acute episode of care, and if needed, referrals for management of chronic conditions or disease
 - Allied Health services
 - Hospital outpatient department.
 - Refer the patient, if needed, to post hospital home visits by nursing services. For surgical admissions, post-surgery links with community health services

- (e.g. community nursing services). Referrals are to be made before transfer of care and service/s negotiated, including consideration if the patient's care needs can be met on a short or long-term basis
- Provide information about the appointments and arrangements to the patient and where appropriate to their carer and or family. If the person's home is in supported accommodation this information should be provided to the disability support staff that provide support to the person
 - Medication education / medical reconciliation: if the Multidisciplinary Team identifies the patient has a medication risk (as per Transfer of Care Risk Assessment) the patient should be prioritised for the pharmacist's review over non-urgent cases
 - Provide information and relevant education and training to the patient, and, where appropriate, their carer, family, guardian, and disability support staff. The information should include: post-hospital care and support the person needs, including: changes to or new medication/s or treatments reflecting any changes in care required as a result of the hospitalisation or treatment provided
 - Explain the transfer of care plan to the patient, and where appropriate, to their carer, family, guardian, and disability support staff
 - In the case of a patient living in supported accommodation, the transfer of care plan needs to be developed in collaboration with the patient, and where appropriate their carer, family, guardian, and disability service provider/ staff in a case conference
 - Notify, advise and confirm transfer date and time with carer, family, guardian and disability support staff.

It may not be feasible for the patient to return to their previous accommodation on leaving hospital, including people who were admitted from supported accommodation. For example, if a clinical event has changed their ongoing care needs the patient's support arrangements may need to be altered. Early identification of the person's care needs after the hospital stay and timely referrals to establish appropriate arrangements may minimise delay in transfer of care out of hospital. The person, their carer, family, and guardian should be involved in these discussions and supported while arrangements are made for alternative residential accommodation.

Progressively from June 2016 where a person with disability requires functional supports to be put in place in order to be safely transferred back to the community and they are not an NDIS participant, consideration should be given to an application being made to the NDIA. This should be done as soon as practical, ideally as a part of pre-admission planning or shortly after admission, in order for the NDIA to make a decision about eligibility and for an appropriate plan to be put in place.

Transfer of care referral (known as transfer of care summary or discharge summary)

The patient's General Practitioner (GP) or Aboriginal Community Controlled Health Service (ACCHS), and community nurse (where required) should receive a written transfer of care referral when the patient is transferred out of hospital or within 48 hours of the transfer.

The transfer of care referral should include:

- A summary of the person's clinical episode of care
 - A list of medications with information about changes to medications
 - Follow up advice for the GP or ACCHS
 - Details of community services involved or residential care arrangements
 - Information on the person's communication needs and preferences.
- Documentation should include: communication aids used by the patient, interpreting gestures, signs and behaviours which people may use to convey their needs and responses.

The transfer of care plan should be explained to the patient, and where appropriate, to their carer, family, guardian, and disability support staff.

In short stay services such as emergency departments, day only or planned day only services, a short stay referral summary may be utilised instead of a full transfer of care referral summary; as clinically appropriate.

4. IMPLEMENTATION AND MONITORING

4.1 Local working relationships

LHDs / SHNs should establish effective working relationships with local community based health and disability service providers to improve transfer of care for people with disability between public health facilities and community based service providers.

Examples of types of organisations include:

- National Disability Insurance Agency (NDIA)
- Plan Management Providers funded by the NDIA
- Community based medical practitioners, includes specialists and General Practitioners
- Community based allied health services (private; non-government)
- Disability service providers
- Community organisations
- Supported accommodation providers
- Aged care providers

- Aboriginal Medical Service (AMS)
- Aboriginal Community Controlled Health Service (ACCHS).

LHDs / SHNs should work collaboratively with community based service providers to establish effective referral pathways to ensure coordination of care around the needs of the person with disability.

Stakeholders

The phased implementation of the NDIS across NSW from July 2016 is likely to increase the number and diversity of non-government disability support services.

LHDs / SHNs should ensure that organisations representing people with disability, such as disability advocacy and carers organisations are consulted in implementing changes to health service systems to interface with the new disability service system that will result from the reforms.

4.2 Protocols between key agencies

LHDs / SHNs should develop and establish agreements and protocols with local disability support providers to apply in situations where disability support staff or disability support nurses provide disability supports in the hospital or acute care setting.

Section 2.5 Reasonable adjustment is relevant to this section.

Ageing, Disability and Home Care (ADHC) operated and funded accommodation support services

The NSW Health and Ageing, Disability and Home Care (ADHC) Joint Guideline: Supporting Residents of ADHC Operated and Funded Accommodation Support Services Who Present to a NSW Public Hospital, NSW Health GL2013_001¹⁸ (Joint Guideline) aims to ensure staff in hospitals and disability accommodation services operated and funded by ADHC are aware of their respective roles and responsibilities for people with disability before, during and after transfer of care from hospital.

Reference should be made to the Joint Guideline in situations when a person with disability is admitted to hospital from an ADHC operated or funded facility, for guidance on:

¹⁸ http://www0.health.nsw.gov.au/policies/gl/2013/GL2013_001.html The Joint Guideline was endorsed by ADHC and NSW Health, and was developed in consultation with key stakeholders across health and disability sectors. The Joint Guidelines notes some Local Health Districts and ADHC Regions have developed local protocols which provide the framework for effective support of ADHC clients during a hospital stay, and the Guideline aimed to facilitate a higher level of compliance with NSW Health and ADHC policies.

- Roles and responsibilities of staff in hospitals, and disability accommodation support services before, during and after transfer of care from hospital
- Identifying areas of risk that could compromise a person with disability's capacity to achieve the best health outcome and their safety and/ or dignity during their hospital stay
- Agreeing on what additional supports will be required to reduce identified risks
- Negotiating responsibility and resources for the provision of agreed additional support.

Non-government supported accommodation

People with disability living in non-government organisation (NGO) supported accommodation may receive support from disability support staff, which includes any of the following: residential care workers, assistants, physiotherapists, occupational therapists, speech pathologists, psychologists, social workers, nurses, case managers, and other support staff who are involved in the care or support of the person at the time of hospitalisation. Residential care workers are most likely support providers.

LHDs / SHNs should develop frameworks and protocols with NGO service providers in their district for the provision of supports and care to people with disability before, during and after transfer of care from hospital for people who live in supported accommodation settings.

In some instances, disability support staff may assist with basic needs, but this should happen within the context of a protocol or agreement between the disability support provider and the hospital, with the respective roles clarified at pre-admission planning.

It is important at pre-admission that the expectations, roles and responsibilities of disability support staff are clarified within the context of a protocol or agreement between the disability agency and the LHDs / SHNs including who pays while disability support staff are providing support in hospitals.

The frameworks between the LHDs / SHNs and NGO service providers should address effective partnerships and provide a structure for protocols between local hospitals and the local community and/or disability services. Local protocols should:

- Address roles and responsibilities of disability support staff in the hospital or acute care setting including, work health and safety arrangements, workers compensation, professional indemnity, and public liability insurance
- Address what the disability support staff will do when accompanying a person to the Emergency Department. Refer to section 3.4.2 Admission

- Include a decision making escalation process for issues that cannot be negotiated at the level of Nurse Unit Manager with their counter-part representing the NGO service provider
- Include general principles and procedures to ensure that transfer of care between the hospital, community and disability services is articulated and coordinated clearly around the needs of people with disability. Section 3.4.3 on Transfer of care out of hospital is relevant here.

LHDs / SHNs may wish to use the Joint Guidelines as a reference for the range or types of issues that need to be jointly agreed across stages in the patient's journey.

4.3 Existing resources

In addition to patient safety and quality monitoring systems, a range of resources are available to support staff to meet the needs of people with disability during hospitalisation.

- Aboriginal Hospital Liaison Officers are an important resource for patients who identify as Aboriginal
- LHD / SHN Carer Support Services are available to provide staff with development and training, information, resources and advice on support for carers.¹⁹
- Courses and programs are offered by Health Education and Training Institute and Intellectual Disability Mental Health e-learning²⁰
- The NSW Health and Ageing, Disability and Home Care Joint Guideline supporting residents of ADHC operated and funded accommodation supported services who present to a NSW Public Hospital, NSW Health GL2013_001²¹
- TOP 5 Model is a simple process that encourages health professionals to engage with carers to gain valuable non-clinical information to help personalise care²²
- Health Care Interpreting and Translating Services – Patients, carers, and family who do not speak English as a first language or who are deaf have a right to free confidential and professional interpreters when they use public health services. Policy Directive 2006_053 - *Interpreters – Standard Procedures for Working with Health Care Interpreters* is mandatory.²³ Information about the five Health Care Interpreter Services in NSW – three metropolitan and two rural, and three

¹⁹ Information on:

- NSW Health support for carers can be found here:
<http://www.health.nsw.gov.au/carers/Pages/default.aspx>
- Local Health District Carer Support Services can be found here:
<http://www.health.nsw.gov.au/carers/Pages/resources.aspx>

²⁰ <http://www.heti.nsw.gov.au/heti-online-modules/>

²¹ http://www0.health.nsw.gov.au/policies/gl/2013/GL2013_001.html

²² <http://www.cec.health.nsw.gov.au/programs/partnering-with-patients/top5>

²³ http://www0.health.nsw.gov.au/policies/pd/2006/PD2006_053.html

Translation Services can be found on the Health Care Interpreting and Translating Services website.²⁴

- Agency for Clinical Innovation (ACI) has developed resources that “relate to the care and health of people with intellectual disability across all ages, including acquired brain injuries by enhancing the capacity of primary and secondary health services.” The link to these resources is:
<http://www.aci.health.nsw.gov.au/networks/intellectual-disability/resources>²⁵
- *NSW Health Carers (Recognition) Act and Carers Strategy Implementation Plan 2013-2016*²⁶
- *NSW Carers 3 2014-2019*²⁷; factsheet²⁸ on NSW Health website has actions that Health staff can undertake to reflect the strategy.

4.4 In-service, education and training

It is important that hospital staff are familiar with developments including contemporary practice in the support of people with disability in the community.

Training must include information about appropriate communication with people from culturally and linguistically diverse backgrounds (including people who are deaf) and people from an Aboriginal and / or Torres Strait Islander background.

LHDs / SHNs should support health staff to access to education and training on:

- Values and attitudes towards people with disability, their families and carer
- Skill development (e.g. communication and disability etiquette)
- Best practice in health provision for people with disability.

Organisations representing people with disability should also be consulted in the development of disability awareness training for staff.

4.5 Monitoring

An Implementation Checklist (Appendix 3) has been developed for use by LHDs / SHNs to assess their compliance with this policy directive. LHDs / SHNs can also use the checklist to monitor their implementation of the policy by undertaking assessments in different time periods or at stages of an implementation plan.

²⁴ <http://www.health.nsw.gov.au/multicultural/Pages/Health-Care-Interpreting-and-Translating-Services.aspx>

²⁵ The ACI Intellectual Disability Network works to improve the care and health of people with intellectual disability across all ages by providing clinical leadership, research and education to enhance the capacity of primary and secondary health services. Information about the network including on becoming a member can be found here:

<http://www.aci.health.nsw.gov.au/networks/intellectual-disability/about>

²⁶ <http://www.health.nsw.gov.au/carers/pages/default.aspx>

²⁷ https://www.adhc.nsw.gov.au/_data/assets/file/0017/300077/NSW_Carers_Strategy_2014-19.pdf

²⁸ <http://www.health.nsw.gov.au/carers/Documents/carers-strat-fact-sheet-final.pdf>

Safety and quality systems

In most LHDs / SHNs there are existing patient safety and quality monitoring processes that can be used to identify issues in the quality of health care provided to patients with disability and associated outcomes. These include:

- Incident Information Management System (IIMS)
- Complaints mechanisms
- Consumer, carer and patient satisfaction surveys and interviews
- Accreditation processes
- Periodic health record audits
- Length of stay reporting
- Monitoring of hospital readmissions.

Performance indicators, outcomes measures and patient experience

LHDs / SHNs should develop mechanisms to determine if there is a difference in outcomes for people with disability when compared to the general population. This information should be disaggregated by age, gender, type of disability, place of residence and cultural background.²⁹ See Appendix 1 for examples of performance indicators and outcome measures.

The type of assessment described above could be undertaken in targeted projects or reviews of specific areas or service types of interest.

Systematic monitoring of people with disability's access to health services, and comparing their outcomes against those of the general population requires data items to identify people with disability in data collection systems.

NSW Health is committed to enhancing services and building greater accountability by improving data collection and reporting on disability inclusion in Strategy 8 of the *Disability Inclusion Action Plan 2016-2019* (DIAP):

- Action 8.1 The DIAP Governance Group to work closely with relevant partners to consider appropriate systems to identify people with disability to improve equity in access and measure health outcomes compared to the general population.

The NSW Ministry of Health will monitor changes in the sensitivity and adaptability of LHDs / SHNs staff to the needs of people with disability during hospitalisation through an annual report which will be prepared by the Bureau of Health Information and made publically available:

- Action 8.2 Produce a disability focused report on an annual basis of patient perspectives on the care people with disability receive through NSW Health.

²⁹ United Nations *Convention on the Rights of Persons with Disabilities*, Article 31 – Statistics and data collection <http://www.un.org/disabilities/convention/conventionfull.shtml>

APPENDIX 1: POTENTIAL PERFORMANCE INDICATORS AND OUTCOMES MEASURES

The following are examples of performance indicators and outcomes measures that LHDs / SHNs may use to assess whether there is a difference in outcomes for people with disability when compared to the general population. Refer to *section 4.5 Monitoring*.

- Access by people with disability to health services (including hospitals) — how many seen; in what services; for what reasons
- Adherence to adjustments to meet the needs of people with disability — including audits of identified support needs/adjustments required and the adjustments made (and type of adjustment)
- Rates and trends over time for emergency department presentations, including:
 - Pathways to and from emergency department
 - Rates of ambulatory care sensitive presentations to emergency department for people with disability, disaggregated by disability type.
- Rates and trends over time for admitted patient data for people with disability, disaggregated by disability type and admission facility, including
 - Admission pathways
 - Diagnoses
 - Potentially avoidable admissions
 - Length of stay
 - Separation mode
 - 30-day readmission rates.
- Rates and trends over time for ambulatory care for people with disability, disaggregated by disability type and ambulatory care setting.
- Error rates for people with and without disability, disaggregated by disability type.
- Use of restraints (with examination of the identified support needs and the support provided)
- Inclusion in chronic disease management and other out-of-hospital programs.
- Inclusion in preventative health programs.

APPENDIX 2: OBTAINING CONSENT FROM A PERSON WHO LACKS CAPACITY

If a health care practitioner has doubts or concerns about whether their patient has capacity to make a particular decision, then a capacity assessment may be needed.

Capacity is specific to the particular decision that needs to be made. In some circumstances, the law sets out what tests must be met for capacity to make the decision, for example in relation to medical treatment. The NSW Capacity Toolkit produced by the NSW Department Justice aims to assist people in correctly identifying whether an individual has the capacity to make their own decisions. It provides information generally about capacity, capacity assessments and the various legal tests of capacity in NSW although it does not specifically address the assessment of capacity in regard to consent to medical treatment. For further information refer:

http://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf

Where a patient lacks capacity to consent – substitute decision makers

In circumstances where a patient lacks capacity to consent to medical or dental treatment, there are legislative and policy frameworks to assist health professionals identify a person who can make decisions on behalf of that patient.

The Responsible Person

The *Guardianship Act 1987* requires the health care practitioner to seek consent from the patient's 'Person Responsible' if the patient is not capable of consenting to their own treatment.

A Person Responsible may not necessarily be the patient's next of kin or carer. Section 33A(4) of the *Guardianship Act 1987* sets out a hierarchy of people who can be the Person Responsible.

NSW Civil and Administrative Tribunal (NCAT) Guardian Division Fact Sheet Person Responsible (April 2016)

http://www.ncat.nsw.gov.au/Documents/gd_factsheet_person_responsible.pdf

Enduring Guardian

An adult can appoint an Enduring Guardian to make personal and lifestyle decisions on their behalf if they lose capacity to make such decisions. If a person appoints an Enduring Guardian with authority to make medical treatment decisions then they will be their Person Responsible.

In addition to the usual authority of a Person Responsible, an Enduring Guardian may also have the authority to make decisions about a range of personal/lifestyle areas on behalf of the appointee, not just medical treatment decisions. Find out more

about how to appoint an Enduring Guardian at

<http://planningaheadtools.com.au/appoint-an-enduring-guardian/>

For more information see the Guardianship Division of the NSW Civil and Administrative Tribunal at

<http://www.ncat.nsw.gov.au/Pages/guardianship/guardianship.aspx>

Mental Health Act 2007

Under the Mental Health Act 2007, a patient who is either mentally ill or mentally disordered will be admitted or treated in a declared mental health facility as a voluntary or detained patient (including assessable patients, involuntary patients, correctional patients and forensic patients). This status determines how decisions should be made about their mental and physical health treatments and who has the legal authority to make them.

The *Mental Health Act* establishes obligations for health care practitioners to inform carers of patients being treated under the *Mental Health Act* depending on the category of patient and the medical treatment involved.

The two types of carers are designated carers and principal care providers.

A *designated carer* of a person (the patient) is defined in the Act to be:

- (a) *the guardian of the patient; or*
- (b) *the parent of a patient who is a child (subject to any nomination by a patient referred to in paragraph (c)); or*
- (c) *if the patient is over the age of 14 years and is not a person under guardianship, a person nominated by the patient as a designated carer under the Act under a nomination that is in force; or*
- (d) *if the patient is not a patient referred to in paragraph (a) or (b) or there is no nomination in force as referred to in paragraph (c);*
 - a. *the spouse of the patient, if any, if the relationship between the patient and the spouse is close and continuing; or*
 - b. *any individual who is primarily responsible for providing support or care to the patient (other than wholly or substantially on a commercial basis); or*
 - c. *a close friend or relative of the patient.*

A person may nominate up to two persons to be their designated carers.

A *principal care provider* of a person is defined in the Act to be the individual who is primarily responsible for providing support or care to the person (other than wholly or substantially on a commercial basis).

A principal care provider may also be the designated carer of a person.

Voluntary patients without capacity under the Mental Health Act

If a voluntary patient lacks capacity to consent (due to mental illness or otherwise) and requires medical treatment, the substitute decision making provisions of the *Guardianship Act* will generally apply (see above).

Refer to NSW Health Policy Directive PD2005_406 - *Consent to Medical Treatment – Patient Information*.

Assessable patients, involuntary patients, correctional patients and forensic patients

The *Mental Health Act* provides for a substitute decision to be made for detained patients without capacity. The decision maker may vary according to the category of patient and the type of medical treatment required as well as the urgency of the need for such treatment. These decision makers include:

- The Secretary of NSW Health
- Senior Officers within NSW Health who have been designated as authorised medical officers by the Secretary of NSW Health
- The Mental Health Review Tribunal.

Refer to:

- The NSW Health Policy Directive *Consent to Medical Treatment – Patient Information*, PD2005_406

The Mental Health Review Tribunal: <http://www.mhrt.nsw.gov.au/the-tribunal/>

APPENDIX 3: IMPLEMENTATION CHECKLIST

IMPLEMENTATION REQUIREMENTS			
Assessed by:		Date of Assessment:	
	Not commenced	Partial compliance	Full compliance
IMPLEMENTATION LEADER 1. An executive role is allocated responsibility for implementing this policy in all hospital facilities in the organisation. 2. Progress on implementation is discussed annually at leadership meetings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes:			
PRINCIPLES			
INCLUSION 3. Disability inclusion is a standing item on leadership meeting annual agendas to discuss actions and/or detail progress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes:			
PERSON CENTRED SERVICES 4. Promote a patient based care model in service delivery organisations, and this is supported by a range of programs that support coordinated care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes:			
ACCESSIBILITY 5. Principles of disability inclusion are embedded within the design and functional brief for all capital projects, including the critical importance of consulting with stakeholders from commencement of the planning and design process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes:			
COMMUNICATION 6. LHDs/SHNs websites comply with W3C Web Content Accessibility Guidelines (WCAG) level 'AA'. 7. LHDs/SHNs feedback and complaints mechanisms are accessible to people with disability. This may include a range of formats and alternative avenues. 8. Essential information for patients is in easily accessible formats. 9. Patients with disability have access to NAATI-accredited interpreters (PD2005_053) if relevant. 10. Information about the person's communication needs and preferences is documented in care plans and records. Documentation includes any communication aids used by the patient, interpreting gestures, signs and behaviours they may use in communication.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes:			

IMPLEMENTATION REQUIREMENTS			
Assessed by:	Date of Assessment:		
	Not commenced	Partial compliance	Full compliance
REASONABLE ADJUSTMENT 11. LHDs/SHNs review systems and policies to ensure frontline staff are supported and able to implement reasonable adjustments as required according to specific needs of individual patients. 12. Establish local agreements and protocols with local disability support providers to apply in situations where disability support staff or disability support nurses provide disability supports in the hospital or acute care setting.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes:			
PATIENT JOURNEY THROUGH HOSPITALISATION			
PRE-ADMISSION PLANNING 13. Ensure Pre-Admission planning includes, but is not limited to: <ul style="list-style-type: none"> Anticipate any specific disability support requirements that the person will need during hospitalisation. All people with disability are offered a meeting to plan their admission to hospital, and upon their invitation people from their support network are involved in developing the plan to provide disability supports during their stay in hospital. 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes:			
ADMISSION 14. Information obtained during Pre-Admission about the person's home support network and how their disability supports and care is provided and coordinated is confirmed, or is collected and documented upon Admission. This information is used in planning and providing disability support services to the person during their stay in hospital.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes:			
DURING THE HOSPITAL STAY 15. Reasonable adjustments are made in the patient's accommodation and care environment, as needed, to meet their specific needs during their stay in hospital.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes:			
TRANSFER OF CARE OUT OF HOSPITAL 16. Transfer of care risk assessment reflects consideration of the suitability of existing home support systems to meet the person's post-hospital support needs and appropriate arrangements made to ensure these are established before they are transferred home. 17. The transfer of care plan is explained to all people with disability, and where appropriate, to their carer, family, guardian and disability support staff where relevant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Notes:			

APPENDIX 4: GLOSSARY

Term	Definition
Accessible web design	<p>The philosophy and practice of designing web content so that it can be navigated and read by everyone, regardless of location, experience, or the type of computer technology used. https://www.humanrights.gov.au/our-work/disability-rights/standards/world-wide-web-access-disability-discrimination-act-advisory#whatis</p> <p>All NSW Government websites were required to conform to the World Wide Web Consortium's (W3C) Web Content Accessibility Guidelines (WCAG) 2.0 at Level A by 31 December 2012 and at Level AA by 31 December 2014. http://arp.nsw.gov.au/c2012-08-nsw-government-website-management</p>
Accessibility	<p>Access by people with disability, on an equal basis with others, to:</p> <ul style="list-style-type: none"> • The physical environment (e.g. buildings and grounds) • Transportation, and • Information and communications, including information technology and emergency communications. <p>““Universal design” means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.”</p> <p>http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf</p>
Assistance animal	<p>A dog or other animal accredited and/or trained to assist a person with disability to alleviate the effect of the disability, and to meet standards of hygiene and behaviour that are appropriate for an animal in a public place. http://www.austlii.edu.au/au/legis/cth/consol_act/dda1992264/s9.html</p>

Term	Definition
Augmentative and Alternative Communication (AAC)	<p>Communication methods used by people with a range of conditions who have difficulties speaking. There are two main types of AAC – aided AAC and unaided AAC.</p> <p>“Aided AAC is any external item used to aid communication (e.g. object symbols, communication boards, books, key-ring mini-cards, wallets, speech generating device, computer, mobile phone, tablet). Aided AAC includes both high technology systems and low/light technology systems.</p> <p>Unaided AAC refers to communication techniques that do not require the use of an external aid. That is, the person uses whatever is available to them, generally their own body. Examples of unaided AAC include using eye contact, facial expression, body language, gestures and manual sign.” Speech Pathology Australia http://www.speechpathologyaustralia.org.au/library/2013Factsheets/Factsheet_AAC.pdf</p> <p>See also ‘communication board’ and ‘communication book’.</p>
Auslan	<p>The signed language used by the Australian Deaf community as a first or preferred language. It differs substantially in grammar and idiom from English. There is no written form. Also known as Australian Sign Language. http://www.deafau.org.au/info/auslan5.php</p>
Carer <i>Carers Recognition Act (NSW) 2010</i>	<p>An individual who provides ongoing personal care, support and assistance to any other individual who needs it because that other individual has a disability, has a medical condition (including a terminal or chronic illness), has a mental illness, or is frail and aged. Under the <i>NSW Carers (Recognition) Act 2010</i>, the definition does not include people providing care as an employee, contractor or volunteer. A person is not a carer merely because they are a family member, guardian or friend of a person with disability.</p> <p>http://www.legislation.nsw.gov.au/fullhtml/inforce/act+20+2010+cd+0+N#pt.1-sec.5</p> <p>The fact sheet for the NSW Carers Strategy 2014-2019 sets out actions NSW Health staff can undertake to support carers.</p>
Challenging behaviour	<p>“Challenging behaviour may be defined as:”</p> <p>“Behaviour...of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result</p>

Term	Definition
	<p>in exclusion.” p.14 Banks, R., Bush, A., Baker, P., Bradshaw, J., Carpenter, P., Deb, S., Joyce, T., Mansell, J. and Xenitidis, K. (2007). Challenging Behaviour- a unified approach: Clinical and service guidelines for supporting peoples with learning disabilities who are at risk of receiving abusive or restrictive practices. College Report CR144. Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists.</p> <p>“Any behaviour displayed by a person which is considered challenging or inappropriate by others, or which gives rise to reasonable concern, may be considered as challenging. However, the use of the term challenging should be understood in terms of the social context in which behaviour occurs, rather than a symptom of individual pathology.” (Emerson, E. (1995). Challenging Behaviour: Analysis and intervention in people with learning difficulties. Cambridge University Press. P5)</p> <p>in p.5 ADHC Behaviour Support Policy Revised March 2012 https://www.adhc.nsw.gov.au/_data/assets/file/0007/228364/Behaviour_Support_Policy_March2012_updated.pdf</p>
Cognitive impairment	<p>“Cognitive impairment is a broad term to describe a wide variety of impaired brain functions relating to the ability of a person to: concentrate; formulate ideas; problem solve; react to emotions; remember; reason; think.</p> <p>There can be a wide range of severity in impairment from mild through to severe.”</p> <p>Cognitive impairment can be associated with many disabilities and disorders for example: acquired brain injury, intellectual disability, and dementia.</p> <p>http://www.jobaccess.gov.au/workplace-adjustment/disability/cognitive-impairment</p>
Communication board, communication book	<p>Types of AAC which use sets of “photos, drawings, symbols or words that are used by an individual for communication”</p> <p>http://www.novita.org.au/Content.aspx?p=64#types_of_aac</p>

Term	Definition
Communication impairment	<p>People who have difficulty communicating may require assistance with speech, language, literacy, social communication, voice, and fluency.</p> <p>There are many causes of communication impairment. Examples include: neuro-developmental disorders; cleft palate, vocal nodules, hearing impairment, degenerative neurological conditions, or acquired brain damage.</p> <p>http://www.speechpathologyaustralia.org.au/library/2013Factsheets/Factsheet_Communication_Impairment_in_Australia.pdf</p>
Deaf	<p>Used (often with a capital 'D') to refer to members of the Australian Deaf community who identify as Deaf. Deaf people may use Auslan as a first or preferred language. Note that many Deaf people are not fluent in written or spoken English and use Auslan exclusively or usually. Other Deaf people are bilingual in Auslan and spoken and/or written English.</p> <p>People who are Deaf may or may not use devices such as hearing aids or cochlear implants. These devices do not restore normal hearing.</p>
Disability <i>NSW Disability Inclusion Act 2014</i>	<p>"... includes a long-term physical, psychiatric, intellectual or sensory impairment that, in interaction with various barriers, may hinder the person's full and effective participation in the community on an equal basis with others."</p> <p>http://www.legislation.nsw.gov.au/maintop/view/inforce/act+41+2014+cd+0+N</p>
Disability <i>Disability Discrimination Act 1992 (Cth)</i>	<p>Disability "in relation to a person, means:</p> <ul style="list-style-type: none"> (a) Total or partial loss of the person's bodily or mental functions; or (b) Total or partial loss of a part of the body; or (c) The presence in the body of organisms causing disease or illness; or (d) The presence in the body of organisms capable of causing disease or illness; or

Term	Definition
	<p>(e) The malfunction, malformation or disfigurement of a part of the person's body; or</p> <p>(f) A disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or</p> <p>(g) A disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;</p> <p>and includes a disability that:</p> <p>(h) Presently exists; or</p> <p>(i) Previously existed but no longer exists; or</p> <p>(j) May exist in the future (including because of a genetic predisposition to that disability); or</p> <p>(k) Is imputed to a person.</p> <p>To avoid doubt, a disability that is otherwise covered by this definition includes behaviour that is a symptom or manifestation of the disability."</p> <p>http://www.austlii.edu.au/au/legis/cth/consol_act/dda1992264/</p>
NSW Disability Inclusion Plan	<p>The NSW Disability Inclusion Plan is the NSW Government's commitment to identifying and breaking down the barriers which prevent those with disability from enjoying the same opportunities and choices as everyone else. It aligns with the Australian National Disability Strategy and our obligations under the United Nations Convention on the Rights of Persons with Disabilities.</p> <p>The plan has four focus areas that are aimed at creating long term change and require consistent efforts from government and the wider community. The focus areas are:</p> <ol style="list-style-type: none"> 1. Developing positive community attitudes and behaviours 2. Creating liveable communities 3. Supporting access to meaningful employment 4. Improving access to mainstream services through better systems and processes <p>A copy of the NSW Disability Inclusion Plan is available here:</p> <p>http://www.facs.nsw.gov.au/reforms/developing-the-nsw-disability-</p>

Term	Definition
	<p>inclusion-plan</p> <p>Under the <i>NSW Disability Inclusion Act 2014</i> all NSW Government departments are required to have a Disability Inclusion Plan.</p>
Disability support staff	<p>Refers to disability support staff employed by non-government disability support service providers who provide direct support to persons with disability.</p> <p>Ageing, Disability and Home Care (ADHC) part of Family and Community Services (FACS) also provides disability support services. Information about ADHC services can be found at this link:</p> <p>https://www.adhc.nsw.gov.au/about_us/what_we_do</p>
Easy English / easy language	<p>A way of writing, simpler than plain English, for people who have difficulty reading in English. It uses everyday words, simple sentence structure, clear formatting, and meaningful and clear images. Easy English is useful for people with intellectual disability and other cognitive disability but can also be useful for people with limited education or who are from language backgrounds other than English.</p> <p>http://www.scopevic.org.au/index.php/site/whatweoffer/communicationresourcecentre/accessibleinformation</p>
Hard of hearing / hearing-impaired	<p>Refers to people with a congenital or acquired hearing loss who prefer to communicate using speech, lipreading and residual hearing (as opposed to a signed language). The majority of people with a hearing loss are in this category. People who are hard of hearing or hearing-impaired may or may not use devices such as hearing aids or cochlear implants. These devices do not restore normal hearing.</p>
Hospital in the Home (HITH)	<p>Hospital in the Home services provide daily care to children and adults with acute or sub-acute conditions who reside outside hospital, as a substitution of in-hospital care.</p> <p>The most common conditions and treatments delivered by HITH to adults are intravenous antibiotic therapy for conditions such as cellulitis, urinary tract infections, respiratory tract or postoperative/post-traumatic infections, osteomyelitis and anticoagulant therapy for deep vein thrombosis or pulmonary embolism.</p> <p>The most common conditions and treatments delivered by HITH to children are complex wound dressings for eczema, intravenous</p>

Term	Definition
	<p>antibiotic therapy for cellulitis, osteomyelitis and cystic fibrosis</p> <p>http://www.health.nsw.gov.au/Performance/Pages/HITH.aspx</p>
<p>Intellectual disability NSW Health</p>	<p>“It is generally accepted that the definition of Intellectual disability refers to that cognitive impairment which arises at birth or in early childhood which continues into adulthood and which leads to the need for support from another person for aspects of higher functioning (eg advice on financial management) or for support for basic activities of daily living.</p> <p>A person with an intellectual disability will require lifelong support and assistance with basic living and / or functional activities at varying levels depending on individual needs, age, health, lifestyle preferences and living circumstances.”</p> <p>p.6, NSW Health Service Framework to Improve the Health Care of People with Intellectual Disability</p> <p>http://www.health.nsw.gov.au/disability/Publications/health-care-of-people-with-ID.pdf</p>
<p>Intellectual Disability American Psychiatric Association 2013, Intellectual Disability – DSM-5</p>	<p>Intellectual disability involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks:</p> <ul style="list-style-type: none"> • The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory. • The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities. • The practical domain centres on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks. <p>While intellectual disability does not have a specific age requirement, an individual's symptoms must begin during the developmental period and are diagnosed based on the severity of deficits in adaptive functioning. The disorder is considered chronic and often co-occurs with other mental conditions like depression, attention-deficit/hyperactivity disorder, and autism spectrum disorder.</p> <p>Name Change</p>

Term	Definition
	<p>Intellectual disability (intellectual developmental disorder) as a DSM-5 diagnostic term replaces “mental retardation” used in previous editions of the manuals. In addition, the parenthetical name “(intellectual developmental disorder)” is included in the text to reflect deficits in cognitive capacity beginning in the developmental period. Together, these revisions bring DSM into alignment with terminology used by the World Health Organization’s International Classification of Diseases, other professional disciplines and organizations, such as the American Association on Intellectual and Developmental Disabilities, and the U.S. Department of Education.”</p> <p>American Psychiatric Association 2013, Intellectual Disability – DSM-5,</p> <p>http://www.dsm5.org/documents/intellectual%20disability%20fact%20sheet.pdf</p>
NAATI	<p>The National Accreditation Authority for Translators and Interpreters, the body which accredits interpreters in over 60 languages.</p> <p>https://www.naati.com.au/</p>
NDIS (National Disability Insurance Scheme)	<p>The National Disability Insurance Scheme (NDIS) “supports people with permanent and significant disability that affects their ability to take part in everyday activities.”</p> <p>The NDIS will fund long-term high-quality care and support for people with significant disabilities, through a model that enables individual choice and control over the supports that are received. This model facilitates goal realisation and increased participation in the community.</p> <p>The NDIS is delivered through the National Disability Insurance Agency (NDIA)</p> <p>http://ndis.nsw.gov.au/</p>
Person-centred care	<p>The Australian Commission on Safety and Quality in Health Care (ACSQHC) defines Patient-Centred care as:</p> <p>“... an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. Patient- and family-centred care applies to patients of all ages, and it may be</p>

Term	Definition
	<p>practiced in any health care setting.”</p> <p>Source: Institute for Patient- and Family-Centred Care website. Institute for Patient- and Family-Centred Care, cited at p.14, <i>Patient-Centred Care: Improving Quality And Safety By Focusing Care On Patients And Consumers Discussion paper. Draft for public consultation. September 2010</i> http://www.safetyandquality.gov.au/wp-content/uploads/2012/01/PCCC-DiscussPaper.pdf</p> <p>The ACSQHC discussion paper overviews concepts of patient-centred care in Chapter 1 (pp.13-19), including that “[P]atient-centred care also has a focus on staff” and “[o]rganisation-specific concepts of ‘patient-centred care’ have also emerged”. (p.13)</p> <p>Gerteis M, Edgman-Levitan S, Daley J, Delbanco T. documented dimensions of patient-centred care in <i>Through the Patient’s Eyes: Understanding and Promoting Patient-Centred Care</i> (1993) as:</p> <ul style="list-style-type: none"> • respect for patients’ preferences and values • emotional support • physical comfort • information, communication and education • continuity and transition • coordination of care • the involvement of family and friends • access to care. <p>(Op. Cit. p.13)</p> <p>A health care based definition has been used rather than a definition that applies to the disability sector because this is policy directive is for NSW Health staff.</p>
Physical disability	<p>Total or partial loss of a person’s bodily functions (e.g. walking, gross motor skills, bladder control etc.) and total or partial loss of a part of the body (e.g. a person with an amputation)</p> <p>http://www.pdcnsw.org.au/index.php?option=com_content&id=49:what-is-physical-disability&Itemid=118</p>

Term	Definition
NSW Health Privacy Manual for Health Information	<p>The <i>NSW Health Privacy Manual for Health Information</i> provides a guide to the legislative obligations imposed on the health system by the <i>Health Records and Information Privacy Act 2002 (NSW)</i> and outlines procedures to support compliance with the Act in activities that involves health information.</p> <p>The <i>NSW Health Privacy Manual for Health Information</i> is available via the NSW Health Policy Manual webpage at: http://www.health.nsw.gov.au/policies/manuals/Pages/privacy-manual-for-health-information.aspx</p>
Psychiatric disability	<p>“Psychiatric disability is associated with clinically recognisable symptoms and behaviour patterns frequently associated with distress that may impair personal functioning in normal social activity. Impairments of global or specific mental functions may be experienced, with associated activity limitations and participation restrictions in a range of areas. Supports needed may vary in range, and may be required with intermittent intensity during the course of the condition. Change in level of supports tends to be related to changes in the extent of impairment and the environment. Psychiatric disability may be associated with schizophrenias, affective disorders, anxiety disorders, addictive behaviours, personality disorders, stress, psychosis, depression and adjustment disorders.”</p> <p>National Community Services Data Dictionary, version 3 (AIHW 2003b) in Table 4.1, p.33, <i>Disability prevalence and trends</i>, Australian Institute of Health and Welfare, December 2003, AIHW cat.no. DIS 34 http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442455756</p>
Public guardian	<p>The Public Guardian is a statutory official. The Public Guardian may be appointed by the Guardianship Division of NCAT or the <i>Supreme Court under the Guardianship Act 1987</i> to make decisions on behalf of a person.</p> <p>Information can be found at this link: http://www.publicguardian.justice.nsw.gov.au/</p>

Term	Definition
Reasonable Adjustment	<p>“Reasonable adjustment: an adjustment to be made by a person is a reasonable adjustment unless making the adjustment would impose an unjustifiable hardship on the person.”</p> <p>Section 4 <i>Disability Discrimination Act 1992 (Cth)</i></p> <p>https://www.comlaw.gov.au/Details/C2015C00252/Html/Text#_Toc422301339</p>
Sensory disability	<p>“A sensory disability refers to a disability of the senses” for example sight and hearing.</p> <p>Sensory disability includes:</p> <ul style="list-style-type: none"> • Vision impairment is also referred to as visual impairment. “The World Health Organisation (2010) identifies 3 categories of vision impairment (mild, moderate and severe impairment) and 3 categories of blindness based on visual acuity tests.” • “Hearing loss – may range from mild impairment to profound (deaf)” • “Deafblindness is a combination of vision and hearing loss. Individuals who have a combined vision and hearing loss have specific communication, learning, and mobility challenges due to their dual sensory loss. Deafblindness is a unique and diverse condition due to the wide range of sensory capabilities, possible presence of additional disabilities and the age of onset for the vision and hearing loss.” <p>Source: Disability Services Australia</p> <p>http://www.dsa.org.au/Pages/BeInformed/Sensory.aspx</p>
Supported decision-making	<p>“Supported Decision Making (SDM) is the process of assisting a person with disability to make their own decisions, so they can develop and pursue their own goals, make choices about their life and exercise some control over the things that are important to them.</p> <p>SDM empowers a person with disability and affirms their right to be in charge of their own life.</p> <p>Support for decision making is generally provided by those a person with disability trusts, and could involve assistance with communication, or providing information in accessible formats, among many other examples.</p> <p>SDM has a foundation in” Article 12 of the UN Convention on the</p>

Term	Definition
	<p>Rights of Persons with Disabilities.</p> <p>Core Principles of Supported Decision Making:</p> <ol style="list-style-type: none"> 1. Every person can express their will and preference 2. A person with disability has the right to make decisions 3. A person with disability can expect to have access to appropriate support to make decisions" <p>https://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/supported-decision-making</p>
Supported Decision Making NSW Public Guardian	<p>"UNCRPD stresses the concept of supported decision making as the model for people with decision making impairment rather than best interests or substitute decision making."</p> <p>p. 2 <i>Public Guardian Advocacy Report 2014</i></p> <p>The Public Guardian is "incorporating principles of supported decision making with people under public guardianship in an effort to further respect their will and preferences" and is "educating the community about supported decision making and will promote supported decision making principles in" their "work with private guardians." Op.Cit. p.1</p> <p>Information about a pilot project undertaken in 2012 by the Public Guardian, NSW Trustee & Guardian and Ageing, Disability and Home Care to support people with disability to make their own decisions can be found on page 12 of the report.</p> <p>http://www.publicguardian.justice.nsw.gov.au/Documents/advocacy%20rpt%202014final_for_web.pdf</p>
Transfer of care	<p>The term transfer of care is used rather than discharge because a patient's health care does not end when they leave hospital. 'Transfer of care' demonstrates that a patient's care continues beyond hospital as they receive care for another service / facility / or in the community. This care could be provided by the patient's General Practitioner; community health services, or other community based providers.</p> <p>PD2011_015 - <i>Care Coordination: Planning from Admission to Transfer of Care in NSW Public Hospitals</i></p> <p>http://www0.health.nsw.gov.au/policies/pd/2011/PD2011_015.html</p>

Term	Definition
Unjustifiable hardship	<p>Under the <i>Disability Discrimination Act</i>, a health provider needs to make reasonable adjustments to provide access to health services for people with disability, unless providing those adjustments would cause the health provider unjustifiable hardship.</p> <p>Determining unjustifiable hardship usually focuses on the cost and affordability of the adjustment, and its benefit to the person with disability.</p> <p>The burden of proving that something would impose unjustifiable hardship lies on the service provider.</p> <p>Section 11, <i>Disability Discrimination Act 1992 (Cth)</i> https://www.comlaw.gov.au/Details/C2015C00252/Html/Text#_Toc422301346</p>