

Disability - People with a Disability: Responding to Needs During Hospitalisation (revised Jan 08)

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Personnel/Workforce - Learning and Development

Summary This document describes the responsibilities of all staff working in hospitals when caring for people with a disability and provides a framework for the provision of care during hospitalisation. This policy directive should be used in the development of local policies and procedures relating to improving the care provided to people with disabilities when they are hospitalised and in the review, monitoring and evaluation of Disability Action Plans. The revised policy emphasises the importance of discharge planning, the role of carers, the use of local protocols between hospitals and disability service providers, patient consent and the use of various communication tools to ensure people with a disability have better experiences with health services.

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Applies to Area Health Services/Chief Executive Governed Statutory Health Corporation, Affiliated Health Organisations - Non Declared, Community Health Centres, NSW Ambulance Service, NSW Dept of Health, Public Hospitals

Audience All staff

Distributed to Public Health System, Community Health Centres, Divisions of General Practice, Government Medical Officers, Health Professional Associations and Related Organisations, NSW Ambulance Service, NSW Department of Health, Public Hospitals, Private Hospitals and Day Procedure Centres, Tertiary Education Institutes

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This Policy Directive may be varied, withdrawn or replaced at any time.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

PEOPLE WITH DISABILITIES: RESPONDING TO THEIR NEEDS DURING HOSPITALISATION

Introduction

The NSW State Plan: A New Direction for NSW not only commits the NSW government to the achievement of key social objectives for people with disabilities but also prioritises increased customer satisfaction with Government Services.

One of the strategic directions outlined in the NSW Health State Plan is the aim to create better experiences for people using health services that is making sure that these services continue to be of high quality, appropriate, safe, available when and where needed, and coordinated to meet each individual's needs, including those from Aboriginal or other culturally and linguistically diverse backgrounds. What we are striving for is a health system that provides patients of NSW Health with ready access to satisfactory journeys through health services and ensures patients and their carers are informed and involved in health care decisions and treated with respect.

Every resident of New South Wales has access to a range of public hospital and community based health services. They will receive health care on the basis of assessed health need regardless of their financial situation. Staff look after patients with care and skill in keeping with recognised standards, practices and ethics. NSW Health is committed to providing equitable access to quality health care for people with disabilities who are hospitalised for any reason.

The goal of this policy is to improve healthcare provision and outcomes for people with disabilities by increasing the sensitivity and adaptability of the public health system to the needs of all people with a disability during hospitalisation. Most Area Health Services have mechanisms in place to improve access to health care and outcomes for people with disabilities. Thus this policy is seen to support and reinforce what is already taking place.

This document describes the responsibilities of all staff working in hospitals when caring for people with a disability and provides a framework for the provision of care during hospitalisation.

The NSW Disability Policy Framework sets down the parameters within which NSW Government agencies will undertake planning and adjust their programs to better meet the needs of people with disabilities. This approach is underpinned by the *Anti-Discrimination Act 1977*, *Commonwealth Disability Discrimination Act 1992 (DDA)* and the *NSW Disability Services Act 1993 (DSA)*.

Approximately one in 5 people (17.9%) in NSW have a disability¹. Disability itself is not an illness but may encompass people who have a disease or illness. A disability is an intellectual, psychiatric, sensory, physical or other impairment

¹ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers: Summary of Findings, 2003, NSW Tables, (Cat No 4430.0).

that results in a reduced capacity for communication, learning, mobility, decision-making or self-care. Examples may include Alzheimer's and Parkinson's diseases. Some people with disabilities may experience chronic illness associated with their disability. Others have infrequent contact with health services. People with disabilities are not homogenous in terms of their needs or preferences. They have unique needs depending on their age, gender, cultural background, economic circumstances, health status and access to support systems. They may be children, young people, adults, or parents and have frequent contact with health services. Their disability may include physical, sensory, developmental, psychiatric, cognitive, age related physical disabilities, or dementia.

Some people with disabilities may experience additional disadvantage. These include, for example, people from an Aboriginal background, those who live in remote or rural areas, those living with HIV/AIDS, people who identify as transgender and people from culturally and linguistically diverse backgrounds. Services provided by NSW Health including hospitals, need to identify and to respond appropriately to the needs of people with disabilities.

Many people with disabilities experience disadvantage and discrimination, heightened vulnerability and a higher level and longer term of dependence on service systems. People with disabilities may come into the hospital system for emergency admissions or for planned admissions. It is crucial that the public health system makes particular efforts to ensure that people with disabilities have access to health care, which meets their needs.

People with disabilities may be living independently, residing with families and/or carers, be living in licence boarding houses, nursing homes or group homes and may rely on regular paid or unpaid support and care.

The *NSW Carers Action Plan* aims to ensure carers are recognised, respected and valued. More than one in ten members of the NSW community are unpaid carers and evidence suggests that the involvement of carers in the hospitalisation process improves patient outcomes and reduces re-admissions. It is important that carers of people with a disability are listened to and consulted about care management and discharge planning.

Good health care for people with disabilities requires an understanding of all these issues, an awareness of the needs of people with disabilities and a commitment to improving health services and health outcomes.

While communication, consultation, consent and planning are essential elements of a good hospital experience for all people; these elements take on additional importance for people who are more dependent on services including many people with disabilities.

Continuity of care between hospitals, community health services, general practitioners and other support can be achieved through well co-ordinated

systems and a holistic approach to care planning, referral and admission, inpatient care, clinical care, discharge and intake processes.

Under Section 9 of the *NSW Disability Services Act 1993* all NSW Government agencies are obliged to prepare a disability action plan specifically showing how they will meet the needs of people with a disability, periodically review and report progress in implementing the plan and making the plan available to the public. Under the *NSW Annual Report (Statutory Bodies) Regulation 2005* agencies are required to report on implementation of disability action plans in each Annual Report.

The NSW Department of Health, all Area Health Services, the Ambulance Service of NSW, The Children's Hospital at Westmead and Justice Health have each developed and implemented Disability Action Plans to address their commitment to improving the quality of health services provided to people with disabilities in NSW.

This policy directive should be used in the development of local policies and procedures relating to improving the care provided to people with disabilities when they are hospitalised and in the review, monitoring and evaluation of Disability Action Plans.

The Hospital Experience

For some people with disabilities, unfamiliar environments, routines and care arrangements can be a daunting experience and a risk to their health.

Some children and young people with disabilities spend significant amounts of time in hospital during their childhood. It is important to recognise that a hospital stay can have a significant negative/destabilising effect on children, their family and support networks.

Hospitalisation can also result in a loss of living skills, depression, and poor adjustment to school, employment and relationships. It is important that people with disabilities are provided with information and appropriate assistance to minimise the negative impact of an inpatient stay in hospital and to facilitate successful re-integration to a non-hospital environment. The general approach ought to be one of flexible service delivery – adapting the service to meet the particular needs of the person with a disability.

Some hospitals are developing aids such as web site virtual tools to assist children familiarise themselves with hospital prior to admission. This type of resource could be accessed by the general community and may assist people with disabilities in the same way.

Access to appropriate maternity care for women with disabilities is essential. This involves assessment and provision of appropriate support throughout pregnancy and the neonatal period. Planning needs to be undertaken well in advance of delivery. For people with disabilities including partners and support

people, planning needs to include how to communicate effectively during labour.

People with disabilities require access to the same range of hospital services as any other member of the community. This includes palliative care services. It is important that pain management support and palliative care services are provided to children and adults with disabilities as required.

Roles and Responsibilities in Caring for People With Disabilities in Hospitals

People with disabilities and their support networks

It is important that health professionals familiarise themselves with the support network of the child, young person or adult with a disability, preferably before they enter hospital, if this is feasible.

People with disabilities have a range of support needs. They may access support from a range of sources including from general community services, disability services, family, friends and neighbours. In some instances, a person with a disability will have multiple parties involved in their care. Sometimes they will have paid support workers, as well as family, advocate(s), a guardian and friends. Disability support staff may include 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 with the care of the person with a disability at the time of hospitalisation.

During the hospitalisation of people with disabilities, hospitals are required to exercise reasonable care and skill in the provision of professional advice and treatment.

Family members, carers and disability support staff may assist with basic needs at the request of the person with a disability and in consultation with health professionals, but are not obliged to assist with individual or medical care needs. 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 agency and the hospital, with the respective roles clarified at pre-admission planning.

Carers play a crucial role as care partners. They are often experts in the care of the person requiring care and can assist with care planning and delivery, with the agreement of the care recipient. Carers improve the quality of life for the person they care for and enable them to remain in the community and evidence shows that the involvement of carers in the hospitalisation process improves patient outcomes and reduces re-admission rates. The work of carers should be recognised, respected and valued in the hospitalisation process.²

² NSW Carers Action Plan 2007-2012

Health professionals may need to access information from other parties to assist in providing appropriate care to a person with a disability. However, it is essential that the person with a disability remains actively involved where possible in providing information to health professionals and in being informed about their care in hospital.

It is essential that in both the admission and the discharge planning stages, health professionals ensure that appropriate information is effectively communicated to the relevant members of the support network for the person with a disability. Any information sharing is subject to privacy legislation and NSW Health Privacy policies including Policy Directive PD2005_593: *NSW Health Privacy Manual*.

Pre-Admission and Discharge Planning

Pre-Admission Planning

Pre-Admission Planning must include anticipating any additional disability support requirements that are likely to be necessary during hospitalisation and the communication of this information to relevant staff. People with disabilities may require routine therapy services that they would normally access outside the hospital. It is essential that the role and expectation of carers and disability support workers are clarified at this time.

Pre-Admission planners should ensure that a person with a disability has access to communication resources or equipment such as augmentative communication devices, or mobility or functional aids that they may use in other settings or may require in hospital. Hospital staff should ensure that space is provided for comfortable operation and safe storage of equipment.

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

- Disclosure of information or the inclusion of others in the pre-admission planning process is subject to privacy legislation and NSW Health Privacy policies including Policy Directive PD2005_593: *NSW Health Privacy Manual*
- Procedures for determining informed consent (see section on Consent)
- Information regarding medical history, social and functional skills
- Information regarding current medication (Policy Directive PD2007_077: *Medication Handling in Public Hospitals*)
- Clarification of the role of parties involved in the care of a person with a disability and the role of hospital 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, positioning and feeding techniques
- Hygiene and nutritional needs

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- Medical, nursing and personal care requirements of the individual
- The person's specific communication requirements
- Management strategies for difficult or challenging behaviours
- Conflict resolution mechanisms
- Complaints mechanisms.

Discharge planning

Ideally, discharge planning should commence prior to admission, at a preadmission clinic or equivalent, with community based service providers to ensure optimal service availability following hospitalisation. Initiating discharge planning on admission enables patients, family members and carers the opportunity to plan and predict needs and outcomes ensuing from the hospitalisation. Clear communication between the patient, carer, hospital staff and community providers is vital to an effective discharge process.

Many people with a disability already have a range of support needs provided for them at home:

- By general community services
- By disability services – which can include residential care workers, assistants and therapy staff as well as health professionals (nurses, occupational therapists, physiotherapist, social workers, psychologist)
- By family, friends, legal guardian and neighbours.

When a person with a disability is admitted to hospital, health professionals need to gain an understanding of their existing home support network and how their care is coordinated at home.

Special information that should be noted and will assist in the development of a discharge plan includes:

- Who is providing consent for the patient's hospital treatment and their ongoing care arrangements (for example, a legally appointed substitute decision maker)
- Clarification of the role of people already involved in providing care, including contact details
- Mobility and transport requirements.

The discharge process for the patient with a disability must include:

- A determination (at the assessment phase) of the suitability of existing home support systems
- Consultation with the patient, their family/carer/legal guardian and provider of services to establish the level of care and support needs required
- Post-surgery links with community health services (eg community nursing services). A referral is to be made before discharge and a service

negotiated, including whether the patient's care needs can be met on a short or long-term basis.

- Links to a Palliative Care Service for patients with a life limiting illness. A referral is to be made and negotiations regarding the service to be provided are to occur prior to discharge.

For a patient with a disability who lives in a supported accommodation setting such as group homes or larger residential care facilities, both the pre-discharge assessment and the discharge planning process should:

- Include the patient, their family/carer/legal guardian, their advocate and disability support staff
- Ascertain whether the pre-admission support system can continue to meet the level of care required
- Prepare disability support staff with education and training (where possible and appropriate).
- Ensure staff and residents are prepared for the deterioration and ultimate death of the patient with a life limiting illness.

Discharge Planning for patients with dual diagnosis of a disability and mental illness and associated challenging behaviours can require additional consideration. The use of a mental health advocate in case management was cited as a good model of that could be extended to the area of disability.³

Hospital staff should not assume that the person is being discharged to an environment that provides nursing or allied health care when this may not be the case. In many cases, the person's arrival home needs to be co-ordinated with the availability of support workers to assist them into their home and provide necessary personal care.

All health professionals should familiarise themselves with Policy Directive PD2007_092 *Discharge Planning: Responsive Standards (Revised November 2007)*.

Communication

Any communication should always be addressed in the first instance to the person with a disability in matters including treatment, comfort, services, amenities and needs relating to their disability.

Communicating with some people who have a disability may require more time and effort. You may need to consider communicating in different ways, for instance, by using a communication board or device. People with communication difficulties do not necessarily have an intellectual disability. It is important not to make assumptions about someone's ability to understand based on whether or not they can speak.

³ Evaluation of the Policy Directive PD2005_625: People with Disabilities: Responding to their needs during hospitalisation", Julie MacDonald and Associates, April 2007

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For advice on the most effective method of communication health professionals should consult the family/carers/legal guardian and/or disability support worker.

Where necessary and subject to privacy legislation and NSW Health Privacy policies including Policy Directive PD2005_593 (if the person with a disability is unable to provide this information) it may be appropriate to communicate and consult with family members, advocates, friends, carers and or disability support staff involved in the person's care to ensure that the individual's needs are clearly identified and addressed.

Information, which patients need to know, should be available in a range of accessible formats – plain English, large print, on computer disk or audiotape. Other communication needs should be addressed, e.g. Auslan and community language interpreters.

Access to qualified interpreters should be available if necessary to communicate with people with disabilities and/or their carers.

Family members, advocates, friends, carers and/or disability support staff may be able to contribute information that may affect the care/treatment of the person with a disability subject to privacy legislation and NSW Health Privacy policies including Policy Directive PD2005_593. However, there may be a need to take reasonable steps to independently verify any discrepancy in information provided or assessment of need.

Substitute Decision Making and Patient Consent

Part 5 of the *NSW Guardianship Act 1987* and the Guardianship Regulations relate to anyone 16 years and over who is incapable of consenting to their own treatment.

This means that before medical or dental treatment is provided to a patient, the medical/dental practitioner has a professional and legal responsibility to obtain consent for the treatment. The consent is only valid if the health professional has told the patient about: the nature of the proposed treatment and its effects

- the risks associated with the proposed treatment
- alternative treatments (their nature, effects and risks) or the impact of undertaking no treatment.

The patient must be able to understand the treatment provided and agree to the proposed treatment before the treatment can be administered. The patient has a right to refuse or to withhold consent to the proposed treatment. If a patient is not able to comprehend the proposed treatment options or is unable to communicate their choice, the practitioner must seek lawful substitute consent.

“Person responsible”

When a person is unable to give valid consent to treatment, medical and dental professionals have a responsibility to obtain consent from the patient’s ‘person responsible’.

If there is no legally appointed substitute decision-maker, a spouse, de facto or same sex partner with whom the person has a close, continuing relationship can be determined a ‘person responsible’ and consent on behalf of the patient. If there is no guardian such spouse, defacto or same sex partner, an unpaid carer who is now providing support to the person or who provided this support before the person entered residential care can give consent. If there is neither a spouse, defacto or same sex partner nor an unpaid carer, a close friend or relative can give consent.

If there is no person responsible, the treatment is ‘special’ or the patient objects to the treatment an application to the Guardianship Tribunal for consent is needed. The person responsible cannot override the patient’s objection to the treatment unless the person responsible has been given specific authority from the Guardianship Tribunal.

Enduring Guardian

A patient may have appointed an enduring guardian or been appointed a guardian by the NSW Guardianship Tribunal. Enduring guardianship allows the patient to legally appoint a substitute decision-maker of their choice to make those lifestyle and health care decisions if the patient loses the capacity to make decisions at some time in the future. The appointment of the patient’s enduring guardian takes effect only if the patient loses the capacity to make personal or lifestyle decisions.

When treatment may be carried out without consent

If the health professional considers the treatment to be urgent and necessary to save the patient’s life, prevent serious damage to health or prevent or alleviate significant pain or distress (except if the treatment is special medical treatment), they may treat without consent.

For further details see <http://www.lawlink.nsw.gov.au/opg>.

All health professionals should familiarise themselves with Policy Directive PD2005_406: *Patient Information And Consent To Medical Treatment*.

In the case of a minor, the consent of a parent or guardian should be obtained.

The *NSW Guardianship Act 1987*, divides medical and dental treatment into three categories – minor, major and special treatment. It is essential that health professionals are familiar with the three categories of treatment to ensure that the appropriate consent is obtained.

Accessibility

Accessibility includes access to the full range of hospital services and hospital amenities and information about hospital services including complaints mechanisms. Information about the facility's Patient Representative and consumer feedback mechanisms as well as the Patient Support Office of the Health Care Complaints Commission should be provided as part of pre-admission planning.

Ongoing efforts to improve accessibility to health services for people with disabilities should be documented and reported on in Area Health Service Disability Action Plans.

People with disabilities should be included in consumer participation processes.

In-service Education and Training

The Area Health Service will support health workers' access to in-service education and training on values and attitudes towards people with disabilities, their family and carers, skill development (eg communication) and best practice in health provision for people with disabilities. It is important that hospital staff are familiar with developments including contemporary practice in the support of people with disabilities in the community.

This training must include information about appropriate communication with people from culturally and linguistically diverse backgrounds and people from an Aboriginal background.

Education of staff regarding the particular needs of people with a disability should be a priority. This may best be achieved by having Disability Clinical Nurse Consultants or senior nurses who can advise on the specific needs of people with disability and suggest appropriate treatment, modification or other resources available to optimise patient outcomes. It is recommended that specific training is identified and incorporated in the Area level education timetable.

Protocols Between Key Agencies

Some people with a disability live in supported care settings and others are supported by specialist disability services.

Where Area Health Services encompass agencies involved in the provision of care and support to people with disabilities, protocols should be developed between the Area and key government and non-government agencies. Protocols between key agencies at an Area level will provide the framework for protocol development around service co-operation and addressing specific issues between local hospitals and local disability services.

Local protocols should be developed and maintained between local health services and disability services. Local protocols should address the general principles and procedures for effective agency partnerships. The aim of the protocol is to ensure that service provision between agencies is articulated and coordinated clearly around the needs of people with disabilities.

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

An example of good practice is a local agreement with the NSW Department of Ageing, Disability and Home Care for the provision of acute services at two hospitals for residents of local hostels whereby residents will be cared for by staff from those hostels while in hospital.⁴

Sharing Best Practice

It is recommended that opportunities for networking between hospitals to share resources and quality or performance monitoring systems is supported, in particular utilising existing governance forums in order to progress Area wide policies such as the Health Care Quality Executive Committee. The involvement of Consumer Advisory Committees could be used to assist in identifying those services, organisations and groups that requires the establishment of linkages.

An evaluation report has found that those services or hospitals which tend to see more patients with disabilities, for example rehabilitation, mental health, complex care and children's services have policies, procedures and practices that were most responsive. These included nursing and multidisciplinary assessments and management plans; the involvement of carers in case conferences; and early admissions for elective surgery to enable any communication and support needs to be assessed and addressed.⁵

Implementation and Monitoring

Implementation of this policy directive should be included in Area Health Service's disability action plans. It is suggested that a senior staff member of Area Health Service be allocated responsibility for leadership in coordinating disability issues and facilitating the development of ongoing staff education and training within the area or as stated in relevant disability action plans.

All Health professionals should familiarise themselves with relevant disability action plans.

⁴ " Evaluation of the Policy Directive PD2005_625: People with Disabilities: Responding to their needs during hospitalisation", Julie MacDonald and Associates, April 2007

⁵ Evaluation of the Policy Directive PD2005_625: People with Disabilities: Responding to their needs during hospitalisation", Julie MacDonald and Associates, April 2007

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In most Area Health Services there are existing patient safety and quality monitoring processes that can be used to identify any issues in the quality of health care provided to and received by patients with disabilities and associated outcomes. These include:

- Incident Information Management System (IMMS)
- Complaints mechanism
- Consumer/patient satisfaction surveys and interviews
- Accreditation processes
- Periodic medical record audits
- Length of stay reporting

Local examples of where consumer feedback has led to quality improvement includes the consultation mechanisms established between some hospitals and a large disability provider and improving access to food services for parents of children with disability who are unable to leave the child's bedside for meal breaks.⁶

Quality Improvement

These protocols should provide a framework for collating and communicating information about the specific needs of people with disabilities in the health system and statistics showing usage, length of visits, areas of need, feedback and complaints, consumer participation, use of guardianship/people responsible.

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Director-General

⁶ Julie MacDonald et al

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