Creating Inclusive NSW Hospitals

NATIONAL DISABILITY SERVICES, NSW

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National Disability Services

Contact

Scott Holz
State Manager, NSW

Ph: 02 9256 3118
M: 0412 020 478
E: scott.holz@nds.org.au
Web: www.nds.org.au

Jacquelyn Johnson
Senior Sector Development Officer

Ph: 02 9256 3161
Mob: 0448 076 987
Email: jacquelyn.johnson@nds.org.au
Web: www.nds.org.au

About National Disability Services

National Disability Services is the peak industry body for non-government disability services. Its purpose is to promote and advance services for people with disability. Its Australia-wide membership includes more than 950 non-government organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.

Creating inclusive NSW Hospitals - Synopsis

The growing economic burden of chronic disease is well documented in NSW and Australia[1]. It is less widely acknowledged that aged 35 to 64, people with disability cost the health system more than other NSW citizens[2]. People with disability have a significantly higher rate of hospitalisation than the rest of the NSW population[3]. In fact, those using disability and Home and Community Care services together account for nearly 20% of the total hospital cost in NSW[4], yet make up only 12% of the population[5].

Despite this, the hospital system (public and private) presents many obstacles for people with disability and those who support them. From pre-admission through to transfer of care, people with disability are consistently denied their right to equal access to health care. The result is longer and repeated hospital admissions, unsatisfactory health outcomes and unnecessarily high costs to our health system[6].

The time to make changes is now. Reform in the disability sector has significant implications for service providers' funding arrangements. They will no longer be able to fill gaps in hospital capabilities. NDS recommends four actions that will empower health and hospital services to fulfil their responsibilities while accommodating and resourcing specialist support and expertise:

1. Identify people with disability as a priority group in health policy
2. Improve awareness and expertise
3. Define expectations of support provision and provide appropriate funding
4. Collect more comprehensive data for an accurate appreciation of costs.

1 Commonwealth of Australia, The National Primary Health Care Strategic Framework, Canberra, 2013
2 NSW Government Department of Family and Community Services. Use of Emergency and inpatient hospital services by ADHC clients – Final Report, Sydney, 2012, p 105
3 NSW Government Department of Family and Community Services. Use of Emergency and inpatient hospital services by ADHC service users – Final Report, Sydney, 2012, pp 4 & 9
4 Ibid, p 11
5 Ibid, p 9
6 NDS, People with disability and hospitalisation: challenges and opportunities in NSW, 2014, p 22-23

Creating inclusive NSW hospitals

"All health service providers (including hospitals… population health programs and ambulance services) have the capabilities to meet the needs of people with disability."[7]
- The National Disability Strategy.

Case study: Martin

Martin lives independently in a Housing NSW unit where he receives drop-in support six days a week. He has an intellectual disability, diabetes, heart and vascular disease and high cholesterol. During a visit, Martin's support worker found that his left foot was red and purple. She made an immediate appointment with Martin's GP who told them he needed to go to hospital straight away. At the hospital, Martin and his support worker were told to go home, to follow up with the GP next week and make an appointment to see a vascular surgeon as soon as possible.

Ten days later at the appointment with a vascular specialist, Martin was in considerable pain. The doctor was very concerned about Martin's foot. He was sent for an angiogram and again sent immediately to the hospital ED, where he was admitted. Two days later Martin's foot was amputated. He had gangrene, which was spreading up his leg.

During his stay in the hospital, disability support workers gave significant support to hospital staff. They worked far longer than on his usual drop-in service. Martin's workers knew him well and were aware of his reactions to certain medications. They were frustrated when they felt nursing staff were not listening to them.

Martin was often alone in hospital. He was not confident talking with nursing staff. At times his support workers were concerned that he was not receiving sufficient pain medication. When support staff visited he would tell them immediately that he was in considerable pain.

Martin was transferred to a rehabilitation hospital for physiotherapy. Staff at the rehabilitation hospital didn't consider Martin to be 'cooperative'. A visiting support worker noted that his speech had deteriorated, his right eye was different and he could not hold his cup. The support worker suggested to staff that he may have had a stroke. A brain scan revealed he had in fact suffered a stroke.

What's not working?

The hospital system frequently fails to recognise or respond to the support needs of people with disability.

1. Knowledge and attitudes

Case study: Anne

Anne, who is quadriplegic, was admitted to hospital for pneumonia. The attendant doctor assumed that she did not talk and could not understand him. The doctor spoke to the support nurse who had accompanied Anne to hospital. When questioned by the nurse about why he wasn't addressing his patient directly, the doctor replied, "Does she talk?"

7 Australian Department of Families, Housing, Community Services and Indigenous Affairs (FAHCSIA). National Disability Strategy 2010 – 2020. Canberra, 2011

A lack of knowledge about disability pervades the hospital system. Anecdotal evidence indicates that some hospital staff operate on assumptions about disability[8], undermining their ability to provide rights-based, informed and appropriate support[9].

Clinical knowledge and appropriate perceptions and attitudes are critical if people with disability are to access sufficient support in hospital. Without these attributes, vital information and cues can be missed. Poor treatment and negative outcomes may result.

2. Drawing the line between health needs and disability support

Case study: Amynta

Amynta has motor neurone disease. She was taken to a regional hospital due to ongoing pressure sores. She had no voluntary movement below the neck. Repeatedly, hospital staff attempted to transfer her using a standing hoist despite statements by Amynta and her support workers that she was unable to complete a standing transfer and required full body support when being transferred. Contrary to instructions she was also repeatedly left to feed herself. Meals were removed uneaten despite her requests for assistance. Amynta arranged for her support staff to visit at meal times so that she could be fed.

During hospitalisation the need for support with daily living is inextricable from the management of one's health conditions. Drawing the line between health needs and disability support is far from straightforward, and is different in every case.

Established communication and role division protocols between hospital staff and families, carers and support workers are failing[10]. For example, a current guideline states that disability support staff should not provide support with feeding, bathing or showering[11]. Yet, case studies gathered by NDS describe toileting, oral care, hygiene and nutritional support being left to support workers when and if they are able to visit. Support workers have also been asked to administer medication via gastrostomy and enemas.

Paradoxically, families, carers and disability support workers are feeling unreasonably depended upon by hospital staff who lack knowledge and resources, while at other times feeling ignored and devalued by hospital staff who do not appreciate their knowledge.

Current policy in NSW attempts, unsuccessfully, to standardise delegation of tasks for all people to whom the documents apply. Instead, negotiating arrangements for individuals with disability must involve families, carers and service providers in defining support that is preferred by, and most suited to, each individual.

8 Dillon, H. C. B., Inquest into the death of Michelle McIlquham, Glebe , 2012, p 39
9 NDS, People with disability and hospitalisation: challenges and opportunities in NSW, 2014, Sydney pp 28-30
10 For example, the NSW Health and ADHC Joint Guideline leaves out two thirds of people with disability (those with disability other than intellectual disability): NSW Health and ADHC, Joint Guideline: Supporting residents of ADHC operated and funded accommodation support services who present to a public hospital, 2013, Sydney
11 ADHC and NSW Health, Joint Guideline, Op. Cit., p 5

3. Support is costly, but no support costs more

Case study: Tom

Following a dental procedure Tom, who has a moderate intellectual disability, fainted and recorded a low blood pressure reading. He was admitted from his group home to hospital without a hospital support plan. His support service provided as much information about Tom's needs as they could. The hospital indicated that a support worker must remain with Tom for the duration of his two-night stay for his care needs to be met. Tom is mobile, verbal and able to carry out his own personal care. Three people live in Tom's group home and it is funded only to employ one staff member at any given time.

There is no question that throughout a hospital journey, people with disability are entitled to support with personal care, eating, oral care, communication, and emotional support. It is also clear that nursing staff feel unfamiliar with the processes or don't have the time to be effective in these roles[12]. The evidence gathered through consultation indicates that without the intervention of disability support providers, hospital stays may end up causing harm[13]. As a result, disability service providers are providing support in hospitals at a cost that far outweighs expenditure on regular service delivery[14].

Current policy documents imply contradicting positions. NSW Health will cover the costs of extra resourcing, according to one, while another states that in each case it is important to establish 'who pays' for disability support workers to provide care in hospitals[15]. There is no funding attached to either of these expectations.

Often, though not always, it is most appropriate for family, carers or familiar support staff to accompany and support a person with disability throughout their hospital stay. However, without necessary funds being made available, support workers and service providers find themselves in a difficult position. They want to support their service users, but lack the resources to do so. The individual in hospital, other service users, staff and the organisation all suffer as a result.

Some local health districts are seeing the benefits of working in partnership with disability service providers. NDS is aware of individual hospital–organisation agreements that have overcome the challenge of 'who pays'.

Case study: The CRAM Foundation

The CRAM foundation has made an agreement with its local hospital, proving the benefits of a uniform system of resourcing and individualised role division that is consistently implemented.

At the commencement of any hospital admission, the CRAM worker presents a letter to the hospital describing who they are and why there is a support person at the hospital. The letter is placed at the very front of the CRAM client file that accompanies them to hospital, signed by the CEO. The document details what support CRAM will provide for the individual and why, and what the hospital needs to do to have that support provided. The consistency of the application of this policy means that the hospital is well versed in the value of the additional support which they, in effect, purchase from CRAM.

12 NDS NSW, NDS Member Consultations, 2010 to 2013
13 NDS, People with disability and hospitalisation: challenges and opportunities in NSW, 2014, Sydney
14 NDS, People with disability and hospitalisation: challenges and opportunities in NSW, 2014, Sydney, p 20
15 National Disability Services, 'People with disability and hospitalisation: challenges and opportunities in NSW', Sydney, 2014, p 20

Thorough care planning through engagement with disability services and primary health care can improve patient outcomes[16].

It is not acceptable that location, disability type or support service engagement dictate the nature of treatment received in hospital. This reality is contrary to several NSW and Australian policy documents that commit to equity and inclusion[17].

Now is the time for positive change

Public services that are not crisis-driven are more cost-efficient[18]. NSW Health can reduce spending on crisis-based and repeated hospitalisations by adopting strategies that make care more cost-effective, equitable and responsive. This is particularly so in the present reform environment.

Recently introduced to Parliament, the NSW Disability Inclusion Bill articulates that the inclusion of people with disability in our community is everyone's right and responsibility. When enacted, it will oblige NSW Health to publish a Disability Inclusion Action Plan identifying strategies undertaken to respond to the needs of people with disability as customers, and to provide access to the full range of services.

Additional NSW-based developments herald immediate implications for service providers' funding arrangements. Individualised planning under 'Ready Together' has commenced. Individual plans will facilitate choice and control in the delivery of disability support services but this will not include making universal health services accessible.

By 2018, people with permanent and significant disability will be supported by the NDIS. The National Disability Insurance Agency (NDIA) Operational Guideline addressing the interface of the NDIS with health services states that "the NDIS will not be responsible for… care in public and private hospitals."[19]

Providers will no longer be able to fill the gaps in the health system by moving portions of their block funds from "one bucket to another" to provide extra support while a client is in hospital. These individualised funding models simply will not allow it. In fact, they will throw the interface between the health and disability service sectors into sharper relief. NSW Health will be wholly responsible for providing and resourcing support for people with disability in hospital.

The health sector's own reforms must align with the NDIS and the Disability Inclusion Bill. Activity Based Funding, for example, must dovetail with NDIS activities to allow for the most efficient use of government-funded services.

16 Shergold, P., Service Sector Reform. A roadmap for community and human services reform, Independent Publication, Melbourne, 2013

17 For example, Australian Department of Families, Housing, Community Services and Indigenous Affairs, National Disability Strategy 2010 – 2020, Canberra, 2011 / NSW Government, National Disability Strategy, NSW Implementation Plan, Sydney, 2012 and NSW Department of Health, Disability Action Plan 2009 – 2014. North Sydney, 2009

18 Ham, C. & Walsh, N., Making integrated care happen at scale and pace, London, 2013, p 1

19 National Disability Insurance Agency, 'Operational Guideline – Planning and Assessment – Supports in the Plan – Interface with Health (v 1.0), Canberra, 2014, p 4

Simple measures exist that build on existing mechanisms and will have a broad impact. Strategies depend on a balance between empowering health and hospital services to fulfil their responsibilities and accommodating specialist support and expertise where appropriate.

NDS recommends the following:

1. People with disability can be identified as a priority group in health policy

It is reasonable for hospitals to have a focus on disability in a way that responds to the more complex needs of people with disability[20]. Policy may then develop accordingly.

For example, appropriately prioritising accessibility and support needs through admission, stay and discharge in the design and implementation of Personally Controlled Electronic Health Records and Electronic Medical Records[21] in NSW would make a significant difference. Improving information access in a way that is inclusive of people with disability will be of great assistance to hospital staff. Thorough consultation with the disability sector on the application of electronic records will positively impact the current challenges. Relevant research is under way that can inform the evolution of electronic records[22].

Recognition as a priority group should apply not only to hospital settings, but across the spectrum of NSW Health services. Addressing the needs of people with disability at a primary health level can reduce hospitalisations overall.

2. Awareness and expertise can be significantly improved

Two changes are required to improve broad and specialised knowledge.

There is a clear case for investment in professional education and training on understanding and supporting people with disability in hospital across the workforce[23]. The importance of education and training is articulated in existing policy[24]; however, NDS members indicate that adequate training is not yet taking place and even a basic level of disability awareness is lacking.

There is also a need for specialist workers trained to manage and coordinate the support of people with disability in hospital[25]. NDS recommends implementing a model similar to one proposed for the support of people with intellectual disabilities developed in 2009. Specialists facilitate and coordinate hospital experiences through planning and cooperation between the hospital, people with disability, mainstream health and disability support systems[26]. Enabling a group of professionals to focus on the unique needs of any group in a 'key worker' mode of

20 Dillon, Inquest into the death of Michelle McIlquham, Op. Cit., p 26
21 http://www.hss.health.nsw.gov.au/programs/electronic-medical-record-emr Accessed 22 April 2014
22 Hemsley, B., Balandin, S., Giorgiou, A. & Hill, commencing in 2014, The Personally Controlled Electronic Health Record: Charting the Course for Successful Healthcare Transitions for Young Adults with Communication Disabilities, cited from http://safetycatchproject.net/2014/03/07/new-nhmrc-project-grant-awarded-on-the-pcehr-in-australia-communication-disability/
23 Australian Institute of Health and Welfare, Dementia care in hospitals costs and strategies, Op. Cit., p 56
24 NSW Ministry of Health, Policy Directive: People with disability, responding to their needs during hospitalisation, North Sydney, 2008, p 10
25 NSW Ministry of Health, NSW Health Professionals Workforce Plan 2012 – 2022, 2012, North Sydney, p 17
26 KPMG and NSW Department of Health, Analysis of costs and benefits of specialised intellectual disability health services and enhanced clinical leadership. Op. Cit., p 13

coordination is known to positively influence outcomes[27].

It would be unreasonable to expect, though, that specialist support can or should always be provided by the health system. It is often most appropriate that service providers who are familiar with the people they support should be meaningfully involved. The funding for their involvement needs to be resolved.

3. Expectations of support provision and funding can be defined

Current policy documents direct that if disability support workers are required to assist with basic needs, an individual agreement between the hospital and service provider must be made[28]. There are two ways to maximise the utility of agreements of this nature.

First, the critical issue of funding varied levels of support for individuals with varying support needs must be addressed. Funding arrangements are conspicuously absent from existing policy documents and directives. Adequate resources must be available through which necessary supports for people with disability can be implemented.

Second, inconsistency of hospital care throughout NSW makes clear the need for minimum standards for negotiating service provider assistance with communication, nutrition, personal care and other support, where people with disability desire and require it. Districts making locally tailored decisions should work within such defined practice standards to ensure statewide consistency. This approach is advocated in other sectors as a way to improve and streamline accessibility to services[29].

4. More comprehensive data can be collected to contribute to better understanding

There is a dearth of longitudinal and statistical information on the impact of hospitalisations on people with disability. NDS proposes specific research be commissioned to uncover the real costs of hospital care for people with disability and the services that support them.

NDS looks forward to further conversation with the NSW departments of Health and Family and Community Services in the resolution of current systemic inadequacies and future challenges. NDS's vast network will provide valuable insight into ways forward.

27 Tracy, "Improving Healthcare Provided to People with Intellectual Disability: The Role of Mainstream and Specialist Services" Op. Cit., p 45

28 NSW Department of Health. People with a Disability: Responding to Needs During Hospitalisation, Op. Cit., p 4 NSW Health and ADHC, Joint Guideline: Supporting residents of ADHC operated and funded accommodation support services who present to a public hospital, 2013, Sydney

29 O'Connell Advisory, Ageing in Place – Research project Report, Sydney, 2013, p 17