

People with disability and hospitalisation: Challenges and opportunities in NSW

NDS Background Paper

NATIONAL DISABILITY SERVICES, NSW

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National Disability Services

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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.

Executive summary

Internationally and in NSW, firm commitments have been made to the human rights of people with disability. It is well established that people with disability have the right to universal and equitable health services. These obligations have been articulated through national strategies, NSW-based disability action plans, and several policy documents.

Yet, people with disability, their families and carers experience much poorer outcomes across the spectrum of health and wellbeing than the general population. For this population there are particular challenges presented by the hospital system. Today's public and private hospitals have been described by people with disability and the service providers that support them as disabling, uncoordinated, inadequate and inequitable.

National Disability Services (NDS), as the peak body for disability service providers, has engaged and consulted with member organisations across NSW on these concerns. Through a comparison of NDS member experiences with research and policy documents, particular problems have come to light. NSW is facing a reality where people with disability are being exposed to mistreatment and discrimination. The consultation and research undertaken in composing this paper has indicated that this arises from:

- a lack of clarity surrounding the responsibilities of universal health services in supporting needs and providing resources;
- the oversight in policy concerning people with other than intellectual disability; and
- inconsistency in approaches to supporting people with disability in hospital.

Case studies supplied by service providers in various NSW locations give some harrowing examples of the impact of these realities on people with disability, their families and carers. The case studies illustrate that there are key opportunities for improvement in the areas of work health and safety, disability awareness, role division and communication. Individual organisations have delivered strategies which have improved their local circumstances, but have not had broader success. The emergency department, transfer of care and primary health are key areas where the health and disability sectors need to work better together.

Fortunately, many opportunities for transformation lie ahead. Nationally and in NSW, we are in the midst of change in the ways people with disability access their communities and make choices about how they live their lives. The implementation of activity-based funding in hospitals, the National Disability Insurance Scheme and reforms to disability service provision in NSW are providing an ideal context for health services to enable accessible and equitable hospital outcomes.

At present, NSW Health is spending more than it should on the health and hospitalisation of people with disability due to longer hospital stays, poorer outcomes, and repeated, unnecessary admissions. In addition, disability service providers are often footing the bill for the hospital support NSW Health has been unable to provide – despite not being funded to do so. There are strategies which can and must undo this doubling-up of spending.

The national and NSW-based reforms will see significant implications for the financial resources of disability support providers. Block funding via a contractual arrangement with government will be replaced by services paid in arrears by the service user. While the impact on providers of this transition is yet to be fully understood, it may be assumed that providers will no longer be able to find the resources to fill the gaps left by the inadequate policies described above.

The NDIS also heralds implications for all universal service sectors. The Council of Australian Government's 'Principles to determine the responsibilities of the NDIS and other service systems', agreed in April 2013 and to be applied to the full rollout of the NDIS, highlight the

interaction between the NDIS and health services. These Principles set up the expectation that NSW Health will be able to provide people with disability with high-quality health services in a way which is consistent with the requirements of all of its national and state commitments.

Summary of recommendations

These recommendations will contribute to the creation of health services focused on the needs of the patient, the establishment of better links with other service sectors, and the development of greater disability awareness and practical skills across the health and disability workforce, as well as the broader community.

These recommendations are not new or groundbreaking; they are already recognised by NSW Health as strategies that address inequities in access and contribute to better outcomes.

Strategy 1: People with disability are identified as a priority group in health policy.

Strategy 2: A state-wide agreement defining a minimum standard of support provision which:

- Resources support provision.
- Sets minimum standards of knowledge and care expected of hospital staff.
- Clarifies how the roles of health and disability support staff can be decided upon in a person centred manner.

Strategy 3: Disability expertise, education and awareness are introduced to hospitals and all health services, addressing both:

- Hospital-wide staff training and awareness.
- Leadership and specialised disability support in hospitals.

Setting the scene

Despite an overall improvement in population health, the health gap between Australians with disability and those without disability remains¹. In 2007–08, 46 per cent of people aged 15-64 years with severe or profound disability reported poor or fair health, compared to only 5 per cent for those without disability². The average person with disability has more than three long-term or chronic health conditions that may not be directly associated with their disability³. People with disability aged 35 to 64 have the highest health cost of any NSW citizen⁴. The growing economic burden of chronic disease is well documented in Australia⁵.

Additionally, a recent report shows that service users of the Department of Family and Community Services (FaCS), specifically Ageing, Disability and Home Care (ADHC), have a rate of hospitalisation significantly higher than the rest of the NSW population, particularly those aged over 65 years⁶. People with disability using ADHC and/or HACC services were found in 2012 to be consistently over-represented in admissions for conditions such as diseases and disorders of the nervous system, the respiratory system and the kidneys and urinary tract⁷. People with disability who have a mental illness are also over-represented in NSW in hospital use⁸. In fact, the 2012 report by ADHC showed that those using disability and HACC services together account for nearly 20 per cent of the total hospital cost in NSW,⁹ yet make up only 12 percent of the total NSW population¹⁰.

The public hospital system has, however, long presented many obstacles and difficulties for people with disability and those who support them. This is despite the rhetoric in strategic commitments, plans and policy documents that espouse the rights of people with disability to equal access to health outcomes. NDS intends this paper to shed light on the reality of hospitalisation for people with disability, and drive the implementation of change beyond the written commentary.

This paper will highlight current opportunities and the context for change and innovation in policies and practices around the hospitalisation of people with disability.

Case studies presented throughout the paper are real-life examples submitted by NDS members, with the names changed.

A background paper, this document supports the NDS policy paper 'Creating inclusive NSW hospitals'¹¹.

This paper is mainly concerned with the period between the entry to hospital of a person with disability, either through a planned admission or the emergency department (ED), and their

1 Australian Institute of Health and Welfare. Australia's Health 2010, Canberra, 2010

2 Australian Institute of Health and Welfare. Australia's Health 2010, Canberra, 2010

3 Australian Institute of Health and Welfare, Australia's Health 2012, Canberra, 2012, p 6

4 NSW Government Department of Family and Community Services. Use of Emergency and inpatient hospital services by ADHC clients – Final Report, Sydney, 2012, p 105

5 Commonwealth of Australia, The National Primary Health Care Strategic Framework, Canberra, 2013

6 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

7 Ibid, p 13

8 Ibid, p 13

9 Ibid, p 11

10 Ibid, p 9

11 NDS, Creating Inclusive NSW Hospitals, Sydney, 2014

discharge. Community health care is certainly an area of policy and practice where difficulties have been identified, and these aspects of health services for people with disability are touched on in this document. Primary and community health care are addressed in detail in a report published by NDS Queensland, 'Health project – Improving access to health services for people with disability'¹². NDS also acknowledges the significance of the barriers and challenges faced by people with disability who have a mental illness. These challenges and the NDS position on systemic improvement of access to mental health services are addressed in the NDS submission to the Mental Health Commission Strategic Plan, 'Standing Together'¹³.

12 NDS Queensland and Metro North Brisbane Medicare Local Health project – Improving access to health services for people with disability, Brisbane, 2013

13 NDS, Standing Together: Mental Health and Disability Services, Sydney, 2013

Part one: the context for reform

International, national and state human rights obligations

NSW is subject to a number of obligations through which it supports the rights of people with disability to full social and economic participation in the community. Most broadly, all Australian service sectors must adhere to the UN convention on the Rights of People with Disability (UNCRPD). The UNCRPD affirms the importance of equitable access to quality health services and health outcomes.

In Australia, the National Disability Agreement (NDA) is underpinned by these human rights principles. The NDA aims to ensure people with disability enjoy choice, wellbeing and the opportunity to live as independently as possible. The Commonwealth Disability Discrimination Act (1992) makes it unlawful to discriminate against people with disability.

The National Disability Strategy 2010 – 2020 (the Strategy) commits all Australian governments, industries and communities to work towards creating inclusive communities which address justice and legislation; economic security; personal and community support; learning and skills; health and wellbeing. Its aim is that by 2020, people with disability will enjoy the best possible health and wellbeing across their lifespan, and have full and equitable access to universal health care¹⁴.

Sitting beneath the Strategy, the NSW Implementation Plan (NIP) aims to remove barriers to people with disability exercising their rights as equal and valued members of the community across all service systems¹⁵. The NIP identifies key actions to improve the health and wellbeing of people with disability and carers when they attend, are admitted to, or leave hospital¹⁶.

The health system also has specific obligations. For example, the Australian Charter of Health Care Rights identifies that all people have the right to access, safety, respect, communication, participation, privacy and consent in their health care¹⁷. The NSW Health Disability Action Plan commits NSW Health's policies and programs to effectively meet the diverse needs of people with disability¹⁸.

Evidently, there is collective acknowledgement that people with disability have the right to equality of access to health and hospital services, and that it is the role of universal services such as NSW Health to enable this. Australian and NSW-specific statements on the rights of people with disability evince a genuine desire for the health service system to enable equity.

NSW policy documents and their role in implementing our goals and obligations

The NSW Government policies and directives concerning people with disability and their access to health services originate from the NSW Department of Family and Community Services – Ageing, Disability and Home Care (ADHC), and the NSW Ministry of Health.

'Addressing the Needs of People with Disabilities in Hospital' ('the Directive'), published in 2008, is the only document to specifically address hospitalisation and acknowledges that people with disability other than intellectual disability have support needs. It acknowledges physical, intellectual, psychiatric and sensory disability, and affirms that all groups have a right to

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

15 NSW Government, National Disability Strategy, NSW Implementation Plan, Sydney, 2012, p 4.

16 Ibid, p 45

17 Australian Commission on Safety and Quality in Health Care, Australian Charter on Health Care Rights, Canberra, 2008

18 NSW Department of Health, Disability Action Plan 2009 – 2014. North Sydney, 2009, p 8

appropriate care¹⁹. The document does not compel services to behave in any particular way or implement particular policies. Consultation with NDS members has identified that the Directive has not been effective in ensuring people with disability are appropriately supported or resourced in hospitals. The Directive is currently under review by NSW Health.

In 2012, the Service Framework to Improve the Health Care of People with Intellectual Disability was released. This framework aims to improve the quality, range, consistency, accessibility and integration of services necessary to meet the health needs of people with intellectual disability²⁰. It does not acknowledge people with other disabilities, nor does it specifically address the needs of people with disability while in hospital.

Most recently, in April 2013, a joint guideline from NSW Health and ADHC was issued ('the Guideline'). The underpinning principles of the Guideline lay the foundation for an effective agreement which respects the human rights of people with intellectual disability. However, the Guideline applies only to those who are residents of ADHC-operated accommodation services. Sector consultation on the Guideline took place in 2011. Since then there have been major changes in the disability sector. Through NDS's consultation with members, it is clear that the aims of the Guideline - to describe roles and responsibilities and inform best practice²¹ - are not translating to the reality of hospital experiences.

NDS members have identified two significant issues in their interaction with the hospital system under these policy frameworks. First, the Guideline aims to identify areas of risk that could compromise a person's safety, dignity and capacity to achieve their best health outcomes during a hospital stay. This paper will show that people with disability are often not afforded dignity or respect. Further, it will show that the safety of people with disability is often put at significant risk.

Second, the Guideline and the Directive purport to establish what additional supports are required to reduce these identified risks in hospitalisation, and designate responsibility for them. Indeed, the Directive indicates it is important that people with disability have additional, appropriate support to minimise the known negative effects of a hospital stay²². In reality, there is no additional resourcing, and responsibility for extra supports is frequently wrongfully placed on the person with disability and their networks.

It is well acknowledged that the issue of equality of access and outcomes for people with disability in hospital needs respectful articulation and action. Yet attempts by NSW Health and ADHC to address this obligation have been haphazard and incomplete. The lived experiences of people with disability in public hospitals do not equate to the vision of any of the above documents. Their sentiments have not translated into enabling resources and practices in hospitals.

This paper will show that the status quo poses current and ongoing risks to people with disability, their families, carers and indeed to disability and hospital staff. This should be sufficient reason to implement change, although time is of the essence. The current period of change is an opportunity that health services should grasp to make real reforms to cross-sector cooperation and resourcing.

19 NSW Department of Health. People with a Disability: Responding to Needs During Hospitalisation. North Sydney, 2008, pp 1-2

20 NSW Department of Health. Service Framework to improve the health care of people with intellectual disability. North Sydney, 2012, p 1

21 ADHC and NSW Health, 2013, NSW Health and Ageing, Disability and Home Care Joint Guideline, Sydney, p 1

22 NSW Department of Health, People with a Disability: Responding to Needs During Hospitalisation, North Sydney, 2011, p 3

Part two: why reform now?

Case study 1: Geoff

Geoff is thirty-five and lives in a group home. He is legally blind, is nonverbal, has epilepsy and severe intellectual disability. Geoff attended an emergency department (ED) after suffering four significant seizures within an hour. He was transported to the hospital via ambulance with group home staff travelling with him.

After six hours in emergency Geoff was still waiting to be transferred to a ward. His support staff left as instructed by their Operations Manager, with the intention of returning in the morning around 7am to assist with his personal care and breakfast. The support staff communicated this plan to the nursing staff in the ED.

Not long after the support staff had left, a phone call received at the group home from the hospital asking where Geoff's support staff were. After being told that staff had left, the group home was informed that the hospital wouldn't be able to give any extra care to Geoff overnight because they were understaffed. Staff from Geoff's home phoned the hospital at 5am to enquire about how he was. They were told he was comfortable and had slept throughout the night. Geoff was still waiting to be transferred to a ward.

Support staff arrived at 7am as planned. They found that Geoff had not slept at all and was very unsettled, lying in urine soaked bedding and clothing. The morning shift staff seemed to be unaware of Geoff's disability. A letter of complaint was sent to the hospital from the group home. Three weeks later a response was received saying that the issues that were noted were under investigation. The outcome, if any, is unknown.

The wave of change in disability service provision

Many are lauding the transition to the National Disability Insurance Scheme (NDIS) as the dawning of a better world for people with disability. Launched in July 2013, the scheme will evolve into a system that provides an estimated 460,000 eligible people individualised funding packages and choice and control over their support. The NDIS will work in tandem with the National Disability Strategy towards a community without barriers for people with disability.

In NSW, an increasing range of government services are being transferred to non-government organisations. This is also the case across Australia²³. By July 2018, Family and Community Services (FaCS) will have completely withdrawn from the provision of disability support services.

In the meantime, FaCS aims to realign planned reforms and expenditure to facilitate the transition to the NDIS in 2018-19. The strategy, 'Ready Together', will drive person-centred and flexible service provision through increased access to individualised funding. From July 2014, it is intended that people with disability will be able to choose their services and manage their own support funds.

At time of writing, the draft NSW Disability Inclusion Bill has been released for public consultation. Included in the draft principles are:

- People with disability have an inherent right to respect for their worth and dignity as individuals.
- People with disability have the same rights as other members of the community to participate in decisions that affect their lives.
- The right to privacy and confidentiality for people with disability is to be respected.

23 Shergold, P. Service Sector Reform, 2013, p.5

- People with disability have the right to access information in a way that is appropriate for their disability and cultural background, and enables them to make informed choices.

In exercising any functions of the Act, NSW Health will be obliged to uphold these and all other principles.

Under the proposed legislation, NSW Health will be obliged to develop and implement regular Disability Action Plans. These plans will need to describe:

- How NSW Health has consulted with people with disability in development of the Plan;
- How NSW Health will implement the principles of the Act;
- How NSW Health will support the inclusion of people with disability through:
 - Making information accessible;
 - Making buildings and facilities physically accessible;
 - Responding to the needs of people with disability as customers;
 - Making employment opportunities available to people with disability;
 - Creating opportunities for access to the full range of services and activities available in the community. This includes all health services normally available to people in NSW.

While the Bill has yet to be enacted, there is a clear indication of the nature of the obligations NSW Health will face under the Disability Inclusion Act 2014.

The NDIS and NSW-based reforms herald significant implications for service providers' funding arrangements. The impact on providers' cash flow of the move from block funding in advance to individual payment in arrears is yet to be fully comprehended and is being monitored in the NDIS trial sites. It can be assumed, however, that providers will no longer be able to move their resources from "one bucket to another" in response to crisis or unplanned extra expenditure, such as the need for extra support while a client is in hospital.

The Council of Australian Governments (COAG) Principles to determine the responsibilities of the NDIS and other service systems, agreed in April 2013 and to be applied to the full rollout of the NDIS highlight the interaction between the NDIS and health and hospital services. The Principles illustrate some of the activities that are inherent in the obligations of public health services to people with disability. These Principles should be used as the basis for better liaison between disability support providers and hospitals in the delivery of the more responsive services that will be required under the NDIS.

COAG Applied Principles to determine the responsibilities of the NDIS and other service systems

1. Commonwealth and State and Territory health systems have a commitment to improve health outcomes for all Australians by **providing access to quality health services** based on their needs consistent with the requirements of the National Healthcare Agreement and other national agreements and in line with reasonable adjustment requirements (as required under the Commonwealth Disability Discrimination Act or similar legislation in jurisdictions).
2. The above **health system will remain responsible for the diagnosis and clinical treatment of health conditions, including ongoing or chronic health conditions, and other activities that aim to improve the health status of Australians**, including general practitioner services, medical specialist services, dental care, nursing, allied health services (including acute/post-acute), preventive health, care in public and private hospitals, pharmaceuticals, and other universal health entitlements.
3. The above health system will also be responsible for **funding time limited, goal-oriented**

services and therapies where the predominant purpose is treatment directly related to the person's health status or after a recent medical or surgical event, with the aim of improving the person's functional status including rehabilitation, palliative care, or post-acute care.

4. The NDIS will be responsible for supports related to a person's ongoing functional impairment and that enable the person to undertake activities of daily living, including "maintenance" supports delivered or supervised by clinically trained or qualified health practitioners where this is directly related to a functional impairment and integrally linked to the care and support a person requires to live in the community and participate in education and employment.

Highlighting the implications of this COAG agreement, the NDIS Operational Guideline addressing the interface with health states that:

The NDIS will not be responsible for... care in public and private hospitals.²⁴

Developments in health service provision: activity-based funding

COAG has agreed that over 2014–2015, an activity-based funding (ABF) model will be gradually implemented in hospitals nationally. Under this model, hospitals will be consistently funded per activity carried out. Each activity undertaken is classified and given an 'efficient' price. Activities will be classified and priced to reflect the broad range of work that staff engage in. The financial incentive of an ABF model is to minimise the cost of each episode of care, which inevitably rewards the shortest length of stay in a hospital be²⁵.

The need for universal health reforms in Australia to be mindful of and meet the needs of people with disability is articulated in the Strategy's sixth outcome on health and wellbeing²⁶. To be a positive development for the health of Australians with disability and meet the obligations of the Strategy, ABF is an opportunity to take into account the importance of activities required for hospital staff to appropriately support people with disability. Developing nationally agreed classifications for all types of care, particularly the activity requirements of supporting people with disability in hospital will be a complex but important exercise²⁷. Activities such as professional education, learning and relationship-building can be acknowledged for their role in driving efficiency. Cross-sectoral awareness and partnerships are imperative in this task.

Collectively, these reforms present not only an opportunity but a necessity that the longstanding systemic and system interface issues between health, hospitals and disability support services are addressed in the short and long terms. All changes in partner sectors, particularly the health sector, should be consistent with the moral underpinnings of the Strategy and the national framework the NDIS creates: truly fair and equitable access to all the rights of the community. Nationally, the move toward ABF must dovetail with the arrangements of the NDIS to allow for more efficient use of government-funded services.

NSW must accommodate and respond to the changes occurring on a national level. The separation of people with disability who live in ADHC-operated services from others with disability will soon be obsolete. NSW Health must consider how it will work alongside the NDIS and the broader community in appropriately supporting people with disability through change and into the future.

The window of opportunity to establish and embed a mechanism for people with disability to access hospital services in a truly equitable way is now open.

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

25 K Eagar. ABF Series No.1 What is Activity based Funding?, Centre for Health Services Development, University of Wollongong, 2010 p 1

26 FAHCSIA. National Disability Strategy 2010 – 2020. Canberra, 2011, p 61

27 K Eagar, What is activity based funding? 2010, p 3

Part three: where are we at?

Case study 2: 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 rang his doctor who made an immediate appointment. Martin's GP told Martin and his support worker that he needed to go to hospital straight away. The GP provided a referral. On arrival at the hospital Martin was seen by a doctor but advised that there were no specialists available. He was told to go home, to follow up with his GP next week and to 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 said he 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, his 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, but were frustrated when they felt nursing staff were not listening to them.

Martin was often alone in hospital. He was not confident in talking with nursing staff and at times his support workers were very 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 where he started physiotherapy. During this time Martin did not eat well and was not considered 'cooperative'. During a visit his support worker noted that his speech had deteriorated, his right eye was different and he could not hold his cup at all. The support worker approached staff suggesting he may have had a stroke. A brain scan revealed he had in fact suffered a stroke.

Case study 3: Anne

Anne is quadriplegic. Anne 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?"

It is a failure of the NSW community and all social services that today people with disability must tolerate such breaches of their rights and dignity. Living independently, Martin would not need a hospital support plan. The Guideline does not apply to him. If Martin's support workers had not been involved in his hospital care, significant medical events could have been missed and his life endangered, yet his disability support service was not resourced to be involved in this way. The support service would have expended more resources than they usually would for Martin, with no remuneration. Anne's doctor showed a shocking lack of insight and is a prime example of the attitudinal and educational deficiencies reported by members by many health professionals.

Drawing 'the line' on what is a health need

In theory, Australia's system of universal health care has primary responsibility for meeting the needs of all hospital inpatients²⁸. It is therefore fair to say the current system expects the health

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

needs of hospitalised people with disability to be met by hospital resources²⁹. This begs the question though, how does one define ‘health needs’?

A recent KPMG report has attempted to isolate NSW Health’s responsibilities as the treatment and management of health conditions which may or may not be associated with the person’s disability³⁰. Disability services are defined as having the role of maintaining and improving functional capacity, with a focus on daily living and participation in the community³¹. This aligns with the COAG Applied Principles but it is far from straightforward to draw this line in practice.

During hospitalisation, a person with disability is truly in a grey area: where the need for support with daily living is inextricable from the management of their health conditions. And every case is different.

The place we are at in articulating the support needs of people with disability in policy documents does not meet our obligations. The COAG Principles provide high-level guidance. Current NSW policy documents attempt, unsuccessfully, to delineate, when in fact a rigid division may not be possible or helpful. Instead, NSW must continue its work towards its stated goal of eliminating differences in outcomes and experiences resulting from factors that are avoidable and unfair³². While the current discourse in NSW focuses on who should perform what support function for people with disability in hospital to make their outcome equitable, a more productive conversation would be how to support individuals with disability in hospital and ensure that resources are available and appropriate.

Additional resources are necessary, but at whose expense?

At present, there is no consistent practice across the state to decide where additional resources should come from to support a person with disability in hospital.

The NSW Health 2010 Disability Action Plan states that “people with disability whose support needs cannot be met through mainstream services [i.e. hospital staff] are supported by specialist/ adaptive services funded through the [Health] department”³³. The Guideline contains explicit support for a funding model or protocol between intellectual disability service providers and hospitals. Yet the Directive states that it is important to establish “who pays” while support workers are providing care in hospitals. Actual resourcing and responsibility for covering costs are left to a process of negotiation in both the Guideline and Directive. In essence, current policy documents imply at once that NSW Health will cover the costs of extra resourcing, and that each case is open to negotiation.

Disability support providers do not have a fund to draw on for extra resources for the people they support. As far as can be discerned, nor do individual hospitals. Asking hospitals and disability providers to negotiate “who pays” from a non-existent source of funds is not fair or adequate and

29 Tracey, Jane “Improving Healthcare Provided to People with Intellectual Disability: The Role of Mainstream and Specialist Services” in Seventh Annual Roundtable on Intellectual Disability Policy, 2012, p 37

30 KPMG and NSW Department of Health Analysis of costs and benefits of specialised intellectual disability health services and enhanced clinical leadership. North Sydney, 2009, p 12

31 Ibid, p 12

32 NSW Department of Health. NSW Health and Equity Statement. In All Fairness, Increasing equity in health across NSW, North Sydney, 2004, p 1

33 NSW Department of Health, Disability Action Plan 2009 – 2014, North Sydney, 2009, p 3 & NSW Department of Health, Memorandum of Understanding between Ageing Disability and Home Care, Department of Human Services and NSW Health In the Provision of Services to People with an Intellectual Disability and a Mental Illness. North Sydney, 2010, p 3

is an obstacle to the achievement of health outcomes.

In most cases known to NDS, providers have been called on to make available and fund extra support and care. The costs to be considered are extensive. Support worker wages can vary from \$17 to \$37 per hour, plus superannuation, casual or leave loading, shift penalties, workers compensation and other insurance. Where a staff member is assisting a person in hospital, their usual position in the drop-in, accommodation, respite or community participation service needs to be backfilled by additional staff. A service user in hospital may need one-on-one support, when within the usual service setting that staff member may have been supporting a number of individuals at once. Accommodation service staff may not be required during residents' work hours, but they may well need to support their resident in hospital throughout the day.

Disability service providers operate on lean budgets, even now under predominantly block-funding. During consultation, providers reported quarterly deficits of up to \$200,000 after supporting a service user in hospital where there were no clear arrangements for the coverage of the additional costs.

At present, where disability providers cover costs there is an unsustainable financial impact and a knock-on effect on other service users as resources are stretched. Where only a hospital can provide increased support to people with disability, this may simply not happen due to a lack of time, understanding or knowledge (see part four of this paper). Such a fracture in policy is contrary to the principles of the Strategy and its NSW Implementation Plan.

NDS members report that efforts over many years by community groups and organisations to build local solutions have been largely unsuccessful. Establishing resourcing agreements to improve outcomes relies on proactive individuals in local health districts and the relationships they form. As workers move on in a high-turnover industry, agreements evaporate. This simply cannot continue. At present, service providers large and small struggle under the financial burden. In the absence of an all-encompassing agreement on how to meet resourcing requirements under individualised funding, providers are concerned they will not be able to ensure the safety of the people they support, or maintain their own financial viability.

At present, individual circumstances dictate whether a person with disability may expect appropriate support in hospital. The place we are at in resourcing is not bringing to life the rhetoric that people with disability have the right to equality of access to health and hospital services.

People with disability other than intellectual disability are left out of research and policy

About one third of disability service users in Australia have an intellectual disability³⁴. ADHC-operated services apply only to people with intellectual disability. ADHC-funded, non-government organisations provide services to other disability groups. People with physical disability comprise about 30 per cent of the disability service user population³⁵. Other disability groups using support services in NSW include acquired brain injury, vision, hearing and speech-related conditions as well as neurological and psychiatric disabilities. All groups rely on hospitals to understand and accommodate their support needs.

The needs and resourcing requirements of ADHC-operated services for people with intellectual disability tend to be included in government research and articulated in government policy. Non-government disability service providers and other disability types often are not. This is neither ethical nor reasonable.

34 National Disability Services, NDS Disability Data Snapshot, Canberra, 2013, p 2

35 Ibid, p 2

For example, recent research produced for ADHC on the ‘Use of emergency and inpatient hospital services by ADHC service users’³⁶ explored in great detail hospital use data for ADHC-operated services. It failed, though, to explore the use and experience of hospital services for a large number of people with disability. It completely excluded people with disability who are not in receipt of HACC or ADHC direct services. Those outside this group are identified in this study only inasmuch as it was acknowledged that they do engage with health services³⁷. The Guideline, for example, addresses only residents of ADHC-operated accommodation services when hospitalised.

A significant financial issue for NSW Health

People with disability who are service users of ADHC have a rate of hospitalisation that is significantly higher than the rest of the NSW population, particularly for those aged over 65 years³⁸. There is limited quantification of the cost of this higher rate of hospitalisation and longer periods of admission experienced by people with disability. However, an AIHW study analysing the additional costs associated with the hospitalisation of people with dementia provides some relevant data. Dementia is also associated with higher rates of hospitalisation and longer admissions, for similar health issues to those experienced at higher rates by people with disability. These include respiratory infections and kidney and urinary tract infections, which occur at a much higher rate than in the general NSW population³⁹.

The AIHW study indicates that where additional health and communication issues exist, the costs to the health system are significantly increased⁴⁰. The AIHW paper found that for respiratory, urinary or kidney infections and inflammations, where a person with dementia is in hospital longer than the general population, the costs are between \$800 and \$920 per day⁴¹.

The AIHW study concludes that the average cost of hospital care for people with dementia was \$7,720, compared with \$5,010 for someone without dementia per hospital episode⁴². This is in stark contrast to the 2011–12 estimated expenditure on health per person over 12 months averaging \$6,230⁴³. The high cost was attributed at least in part to communication and engagement difficulties. These difficulties were related to delays in recovery, extended lengths of stay in hospital, an increased risk of complications and ultimately a much higher cost⁴⁴. It stands to reason then, that appropriate support and resources to facilitate communication and ensure suitable care is available, would minimise these costs and improve outcomes.

It is not rational that NSW Health should go on spending so much more than necessary on the hospitalisation of people with disability when there are strategies which would provide care that is equitable, responsive to the human rights of people with disability, and would save unnecessary hospitalisation costs.

36 NSW Government Department of Family and Community Services. Use of Emergency and inpatient hospital services by ADHC clients – Final Report. Sydney, 2012, p 8

37 Ibid, p 8

38 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

39 AIHW, Dementia care in hospitals costs and strategies. Canberra, 2013, p 16 & NSW Government Department of Family and Community Services. Use of Emergency and inpatient hospital services by ADHC clients – Final Report, Op. Cit. p 17

40 AIHW, Dementia care in hospitals costs and strategies, 2013, Op. cit. p 77

41 Ibid, p.77

42 Ibid, p.77

43 AIHW, Health Expenditure Australia 2011 – 12, Canberra, 2013, p 18

44 Ibid, p 18

Relying solely on local initiatives leads to inequity

All over the world, studies are emerging calling for increased coordination and consistency in support and services to people with disability⁴⁵. Yet NSW policies and procedures effectively condone significant disparities in service provision. The Directive indicates that most local health districts have mechanisms in place to improve access to health care and outcomes for people with disability⁴⁶. This statement shows worrying complacency towards the inconsistency in approach of various local health districts.

At present, Disability Action Plans are unique to their health district of origin. They are dependent on what priority is placed on them and the resources available to the district, and restricted by the district's time and availability to implement them. There is no minimum standard for addressing the needs of people with disability in hospital⁴⁷.

Such resourcing concerns are not common to every local health district: NDS is aware of some practices and individual hospital–organisation agreements that have been working to overcome some of the challenges described. However, this inconsistency is precisely the issue that needs addressing.

It is not acceptable that where you live, what type of disability you have and which disability support services you are involved with, if any, dictate the type of treatment you receive in hospital. Nor is it reasonable that, depending on the location of a disability support service, it may or may not be expected to invest well beyond its means in the care of a service user. That there is no policy framework which obliges all districts to make local decisions within minimum requirements and responsibilities that exist across the state has resulted in inequity.

45 Krahn, GL & Hammond, AT, 'A cascade of disparities: Health and health care access for people with intellectual disability' in *Mental Retardation and Developmental Disability Research Reviews*. 2006, 12:1, p 78

46 NSW Department of Health, *People with a Disability: Responding to Needs During Hospitalisation*, Op. Cit. p 1

47 NSW Government Department of Family and Community Services, *Health Care Policy and Procedures*, 2012, p 30

Part four: opportunities for improvement in practice

Case study 4: Bob

Bob was transferred to an emergency department from his group home following several episodes of vomiting. After assessment and a diagnosis of suspected aspiration pneumonia, he was admitted to the renal ward. Disability support staff remained with Bob throughout admission. They felt that nursing staff were not familiar with the management and care of a person with multiple disabilities presenting with aspiration pneumonia.

During his time in the renal ward, several issues significant to Bob's care and support arose. There were delays in acquiring an Alpha mattress, affecting his comfort. Bob's feed had been ceased when he entered emergency. It is protocol for hospital staff to consult with a dietician before resuming feeding in such a case. It was the weekend when Bob was admitted and he wasn't able to see a dietician until Monday. Bob waited two days for his feed to be resumed and when the dietician did attend, Bob's support people were informed that there had been an on-call dietician who should have been summoned by hospital staff.

Nursing staff were not experienced in connecting feeding tubes to the peg and incorrect tubing was used when introducing routine medications into the peg. The feeding tube was mistakenly used for medication, despite clear instructions to the contrary. Disability support staff from Bob's group home were called upon to remedy the confusion. Despite instructions, Bob's accommodation service reports that health staff did not change feed bottles as prescribed.

Bob was tended to without any verbal interaction or attempt at explanation of what was happening.

There were two known instances of Bob being laid flat for pad changes and personal care despite clear instructions that Bob required elevation in his folder and on instructions displayed above his bed. The instructions emphasised that Bob must not be placed lower than thirty degrees because of the high risk of aspiration. When Bob was laid flat, support staff corrected the health staff, however the error was made twice. Bob's condition deteriorated following the second incident. He started coughing and his chest was audibly congested.

Following an ICU admission, Bob was placed in a medical ward where he was managed well. Ward staff were familiar with his management needs and there was good communication between Bob, his family, group home staff, consultants, dieticians and nursing staff.

This case study touches on a number of areas where improvement in practice is necessary. The roles and responsibilities of support workers were unclear. Support staff felt that hospital employees lacked awareness of Bob's needs, and that they depended on Bob's support workers in some aspects of his care. Mistakes in Bob's care were made, despite information being provided to the hospital that should have prevented these mistakes. Bob's health suffered considerably as a result of inconsistent communication. Upsettingly, Bob's care was carried out without any attempt at interaction with him. This indicates a serious lack of disability awareness, or a lack of time or desire to find out about patients under their supervision and care. Probably inadvertently, hospital staff treating patients in this way have made value judgments on the right of people with disability to be treated equitably and participate in their own care and support.

Most significantly, when Bob transferred to a different ward, the picture was completely different. In the same hospital, the variability in knowledge and approach to supporting a person with disability is staggering.

Work Health and Safety, professional indemnity and public liability

The requirement of a Work Health and Safety (WHS) induction for ADHC employees supporting

a person in hospital is a positive inclusion in the Guideline. NDS is concerned, however, that the WHS requirements outlined in the Guideline are not being consistently implemented. Consultation with NDS members revealed that not one of the 35 organisations consulted had experienced a support worker, allied health worker or interpreter undergoing orientation or induction to a hospital site. This is attributed to a lack of time and resources, particularly where admission is unplanned.

Similarly, where a support worker has provided support on hospital premises, no organisation recalled an occasion where their workers compensation, professional indemnity and public liability certificates of currency were requested by NSW Health.

What works?

Members who deal often with their local hospital reported that where they have asked the hospital to educate their staff en masse, for example an entire social work department, this has had demonstrable success. NDS suggests a similar approach to inducting disability support staff to hospital WHS procedures. Disability support organisations and hospitals that frequently work together would benefit from regular group induction sessions to hospital WHS. This is more realistic and efficient than the current expectation of case-by-case induction. Sharing of other WHS-related documentation could more reliably occur systematically through local agreements between disability providers and district hospitals.

Disability awareness

Case study 5: Jenny

A spinal cord nurse from an NGO provider attended hospital with Jenny, who was suffering Autonomic Dysreflexia (AD). Though Jenny displayed all the symptoms of AD, the treating doctor told the nurse he thought there was nothing wrong with the client as her blood pressure was in the normal range. The nurse asked the doctor if he knew what the normal range for a person with a spinal cord injury should be. The doctor admitted not knowing what AD was, nor the symptoms, nor that Jenny's normal blood pressure range should be much lower than the standard.

Clinical understanding: The Directive states that hospitals are required to exercise reasonable care and skill in the provision of professional advice and treatment to people with disability⁴⁸. Consultation with service providers and other evidence has highlighted that in practice, a lack of education and knowledge can preclude such care and skill.

In Bob's story, support staff were concerned about the level of understanding ICU ward staff had of his care and support needs. For Jenny above, the doctor would not have understood the patient's situation without the disability support nurse.

In another case, a lack of understanding of the implications of disability in an ED presentation, combined with other factors, had tragic results. A recent report by the Coroner's Court found that a young woman with intellectual disability died shortly after being discharged from Bankstown Hospital from meningitis related to a middle ear infection. In this incident (known as 'Michelle's Case'), there appears to have been an assumption that her agitation arose from her developmental disability and was due to a "temper tantrum" rather than illness. This diagnosis is a matter of significant concern⁴⁹. Policy changes have been made at Bankstown Hospital since this incident in 2009, but the account of this night shows clearly how a busy ED environment, missed opportunities in communication with the young woman's carers and assumptions about her disability contributed to tragic consequences⁵⁰.

Case study 6: Susan

Susan, who has profound intellectual disability went to hospital for a planned surgical procedure and was staying three nights. Susan was non-verbal, so the hospital felt she would best be supported by staff from her accommodation service. When the nursing staff or the doctors tended her, none would speak with her directly but directed questions to staff. She was not given choices for her food or drinks.

Judgments and attitudes: It would appear from the case studies collected by NDS, such as Martin, Bob and Susan's stories, that some hospital staff operate on certain assumptions about people with disability⁵¹. This can lead to vital information and cues being missed and the exposure of people with disability to discrimination.

Disability service providers describe a variety of prejudiced and discriminatory hospital staff attitudes. In one alarming case, medical staff confronted support staff of a very unwell patient with the question "Why is there not a Do Not Resuscitate order?", based on the patient having complex disabilities and significant needs.

48 NSW Department of Health. People with a Disability: Responding to Needs During Hospitalisation, Op. Cit.

49 H C B Dillon, Inquest into the death of Michelle McIlquham, 2012, Glebe p 7

50 Ibid p 7

51 H C B Dillon, Op. Cit., p 39

NDS members say they feel medical staff perceive people with disability to have a lower quality of life and therefore require less diligence on treatment decisions. For example, a support worker was asked by a doctor in a public hospital if they would give permission to refuse medical intervention for a client in palliative care. The doctor knew they were a paid employee, not a family member. It has also been recorded that medical staff can be unwilling to accept a person with disability consenting to treatment themselves, even where this is entirely appropriate⁵². It is the law to assume that every person has capacity to make their own decisions.

What works?

Clinical knowledge and appropriate perceptions and attitudes are critical if people with disability are to have equality of access to hospital services and care. Educating employees equips them with the appropriate skills to manage scenarios they will come across in their work⁵³. Extensive workforce training leads to shared understandings and shifting attitudes.

To address this, the Illawarra Disability Health Group brings local providers together to advocate for health management for a range of people with disability. The network includes 10 local service providers. Using connections with local health districts, the group has been instrumental in coordinating health education forums. Most recently, a training day called 'Partnering with Consumers – A Disability Perspective' was held in October 2013. The forum aimed to educate health employees on disability awareness and discuss systemic and specific issues facing people with disability in hospital.

Similarly, St George Hospital has developed a partnership with the Sylvanvale Foundation. New hospital staff visit Sylvanvale as part of their orientation. The visits include learning about appropriate approaches to supporting and treating people with disability, communication and planning for hospital admissions.

The CRAM Foundation has also taken a proactive approach to educating staff in their local hospitals. CRAM's client group have profound disability and are medically frail. As a result, they have a lot of contact with health services, including the local hospitals via planned and emergency admissions. CRAM staff regularly make educational presentations to the hospital social work department. The social workers practise throughout the hospital, and are expected to educate others in turn. CRAM provides educational resources to the hospital for this purpose.

While these examples have been successful in engaging NSW health districts, members often encounter frustration. Without consistent expectations or a framework for educating hospital staff, members rely on supportive individuals in NSW Health getting on board and promoting the cause. If key health employees move on, projects easily lose traction.

Less dependent on enthusiastic individuals, the approach of online education is increasingly being taken up to inform the disability workforce. For example, ADHC's 'Good to Great' program of online learning now includes a module familiarising staff with the Guideline. This tool is accessible to all ADHC staff, but it only applies to a small proportion of those concerned with hospitalisation, and within a few years will be irrelevant.

More broadly applicable, as part of its health project, NDS Queensland developed two online modules with the goal of improving access to health services for people with disability. Freely accessible, one module outlines the role of disability support workers in health care⁵⁴; the other is for general practitioners and other health professionals, to increase their awareness of disability

52 NSW Attorney General's Department. Capacity Toolkit. Sydney, 2008, p 10

53 Australian Institute of Health and Welfare, Dementia care in hospitals costs and strategies, Op. Cit., p 56

54 Available online at: <http://ndshealthandwellbeing.avana.com/>

types and their impact on health⁵⁵.

Resourcing and dividing roles and responsibilities

Case study 7: Finau

A support worker was asked by hospital staff to attend the hospital every day while Finau was an inpatient. She was required to assist the hospital with Finau's care and support. As a support worker at a day program, the worker's provider was only funded to provide a defined staff to participant ratio so could not afford to roster any additional staff. The only way the worker could meet the hospital's request was by bringing other participants in the day program along to the hospital.

Case study 8: Tom

Following a dental procedure Tom, who has a mild/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 the hospital to accommodate him and for his care needs to be met. He 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.

The cost to Tom's group home of paying a support worker to stay with him was more than \$2,500, excluding the cost of a substitute worker at Tom's house. The thousands of dollars the provider spent on Tom's hospital care came out of the limited budget for the needs of all three people living in the group home.

Confusion about the extent and limitations of the roles of disability support workers in a hospital setting, as illustrated in the cases above, was a prominent theme in consultation. These case studies also indicate practical and financial consequences of this role ambiguity.

The Directive, which applies to all people with disability, states that family members, carers and support workers may assist with meeting service users' basic support needs. If disability support workers are required to assist with basic needs, this must happen under an individual agreement between the hospital and service provider⁵⁶. The Guideline more stringently commits ADHC and NSW Health staff to implementing agreed support arrangements throughout a person's hospital stay. The Guideline delineates the roles of disability support workers and hospital staff⁵⁷.

The Hospital Support Plan provided in the Guideline, if well implemented, could facilitate cooperation and the sharing of clinical and disability support expertise. However, undermining any sense of order laid out in the Hospital Support Plan are some considerable implementation issues.

Resourcing responsibilities: The Guideline expects that an agreement will be reached between the hospital and accommodation service about resourcing supports. Yet there is no source of funding attached to this expectation. In the experience of many service providers, hospitals will depend on the 'goodwill' of support services to meet additional needs, as in both case studies above. Furthermore, as identified, the Guideline and its plans only apply to a minority of people with disability, and will no longer apply at all in five years.

In Finau's case, the Guideline and Hospital Support Plan were irrelevant. Her support was at

55 Available online at: <http://www.qcidd.com.au/gps>

56 NSW Department of Health. People with a Disability: Responding to Needs During Hospitalisation, Op. Cit., p 4

57 NSW Health and ADHC, Joint Guideline: Supporting residents of ADHC operated and funded accommodation support services who present to a public hospital, 2013, Sydney

the expense of the provider, the other people using the service, and her privacy and dignity. Resources were required that were not agreed upon and the outcome was not person- or patient-centred. This case demonstrates clearly where improvement can be made to implementing the key principles of the Guideline⁵⁸, a responsibility under the NSW Implementation plan of the NDS⁵⁹.

Dividing roles: Those close to people with disability, including families and informal carers, have experienced a frustrating lack of appreciation for their strengths and skills by hospital staff. At the other end of the spectrum, families, carers and disability support workers have also experienced a lack of boundaries and inappropriate assumptions about or reliance on their skills and knowledge, as was the case in the examples of Bob and Tom. This feedback is echoed in a recent research project on dementia care, which found that carers feel a paradox in their role in hospital. At once they reported feeling that their presence was required as a familiar person and to support basic requirements of hygiene, diet and toileting, yet recalled feeling ignored and disregarded by hospital staff⁶⁰.

Consultation has shown that hospital staff may tend to see the presence of disability support workers or carers as an opportunity to shift caring responsibilities. The Guideline states that disability support staff should not provide support with feeding, bathing or showering⁶¹. Yet, several examples have been given where the toileting, oral care, hygiene and nutrition or eating requirements have been simply ignored or left to support workers when and if they are able to visit. Support workers have been asked to administer medication via gastrostomy and administer enemas. Nursing staff feel unfamiliar with the processes or don't have the time to spend carrying them out⁶². Not only does this present complex WHS issues for employees of disability service providers, as identified earlier in the paper, but in hospital, only hospital staff are suitably qualified and indemnified to respond to any medical issues arising from such procedures.

Overall, an important message emerged from consultation. It is often (but not always) most appropriate for familiar disability support staff to accompany a person with disability on their hospital journey. Their admission and stay would be greatly improved if workers were able to approach their role in hospital with flexibility. However, the provision of this support has a cost, and without necessary resources being made available, support workers and service providers find themselves in a difficult position. They have a moral compulsion and a duty of care (which, it must be noted, hospital staff also have) to support service users as fully as possible, but lack the resources to do so. Either way, the individual in hospital, other service users or staff of the support service will suffer as resources are directed elsewhere.

What works?

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

At the commencement of any hospital event, 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 which accompanies them to hospital, signed by the CEO.

58 ADHC and NSW Health, The Joint Guideline, 2013, p.2 & NSW Health, People with Disabilities: responding to their needs during hospitalisation, 2008, Sydney

59 NSW Government, National Disability Strategy, NSW Implementation Plan. Sydney, 2012, p.9

60 Grealish, L., Jamieson, M., Brown, J., Moore, B., Proctor, M. & Gibson, D. The interaction between hospital and community-based services for people with dementia and their carers. Sydney, 2013

61 ADHC and NSW Health, Joint Guideline, Op. Cit., p 5

62 NDS NSW, NDS Member Consultations, 2010 to 2013

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 by the disability support worker. CRAM staff are registered nurses and in this particular case the ‘likeness’ of the professions has had a positive impact on their middle ground and ability to understand each other. The hospital must sign off a form that describes exactly what they want in terms of bedside support from CRAM, if any, and confirms agreement to pay for it. Over time, the hospital has learned when they need extra support from CRAM, and 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.

CRAM is the only service to NDS’ knowledge that has successfully made an agreement with a local hospital which includes a commitment of payment for the disability provider’s support. Yet, the applicability of this model of agreement across the board, where specialist support cannot be provided for by the Health system, is clear. The accessibility of hospitals for people with disability would be significantly improved by a state-wide commitment to resourcing the flexible and person centred support of people with disability.

Communicating as a team

Case study 9: 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. Hospital staff attempted to transfer her using a standing hoist despite repeated statements by Amynta and her support workers that she was unable to complete a standing transfer and required full body support when being transferred. Despite instructions she was repeatedly left to feed herself with meals removed uneaten despite her requests for assistance. She eventually arranged for her support staff to visit at meal times so that she could be fed.

The positive or negative experiences of time spent in hospital for people with disability largely depend upon effective communication and partnership between the person, their carers and/or support workers and their medical practitioners. However, it is often the case that support workers have had little or no training in health services, and medical practitioners have had little or no training in disability support⁶³. Furthermore, health and disability staff approach their work from different paradigms, aiming for different outcomes⁶⁴. Gaps in understanding between disability and health professionals contribute to the poor communication and teamwork currently experienced by people with disability⁶⁵.

From admission planning to discharge, a workable level of communication between all involved in a patient’s journey can ensure patient centred, safe and adequate care. The Guideline appropriately emphasises the importance of careful planning for admission, including a pre-admission meeting to set expectations around communication and how best to support an individual with disability in hospital. The picture that emerged through consultation shows that there is much opportunity for improvement.

Communicating as a team obviously includes communicating appropriately with the person with disability. The Guideline identifies that if necessary it is the responsibility of disability support staff to ensure that hospital staff are aware of how an individual with disability communicates, via the

63 Tracey et al. Improving Healthcare Provided to People with Intellectual Disability: The Role of Mainstream and Specialist Services, Op. Cit., p 38

64 Evans, E, Howlett, S, Kremser, T, Simpson, J., Kayess, R & Trollor, J. ‘Service development for intellectual disability mental health: a human rights approach’, Journal of Intellectual Disability Research, 56:11, 2012, p 1102

65 Tracy et al, p 38

Hospital Support Plan⁶⁶. Yet, as described, this plan is not always applicable, and is rarely used. The Guideline also states that where significant communication difficulties exist and assessment of pain and responses to treatment may depend on picking up subtle changes, it is those familiar with the person that are best placed to provide that information to hospital staff⁶⁷. Such an expectation lends further weight to the importance of resourcing disability support services to play an appropriate role in the hospital journey.

Where possible, as part of admission planning, health professionals are expected to pre-empt and familiarise themselves with communication styles, aides or devices so they are enabled to communicate effectively and uphold the 'patient centred' principles of the Directive and Guideline. The NSW Health Policy on Transfer of Care instructs hospitals to initiate admission planning⁶⁸. Yet, NDS members report that service providers usually instigate pre-admission planning out of anxiety for what would happen if they didn't. Where information about care and communication needs has been shared with hospitals, the experience of members is that information isn't taken on board or is lost between shifts⁶⁹. Conflicted by competing priorities and a lack of time and resources, hospital staff are hampered in their ability to complete, commit to memory and implement complex support instructions and plans. Evidence of this can be read in many of the case studies throughout this paper.

In Amynta's case for example, failures of communication resulted in mistreatment and risk of significant harm. Bob, in case study 4, should have had a current hospital support plan. If he did, he was still subjected to wildly inappropriate care. Martin, in case study 2, lived independently so there were no concrete procedures designed to ensure that his support needs were known and being communicated. Not only are roles and responsibilities failing to be communicated, but basic information is failing to be shared and translated into practice.

The rights of people with disability are commensurate to the rights of all other citizens, so they should expect reasonable levels of care from hospital staff. Yet the Directive merely suggests that disability support staff 'remind' hospital staff to act on the information provided to them⁷⁰. Failing to communicate as a team is resulting in longer hospital stays, poor outcomes and, ultimately, higher costs and a heavier burden on hospital and community resources⁷¹. Most importantly, NSW is falling short of its human rights obligations.

What works?

It is well known that in any complex organisation, voluminous guidelines and protocols tend to sit unread in large folders or on organisational intranet servers, rarely referred to unless something goes wrong⁷². As previously stated, giving disability support staff sufficient resources to provide ongoing assistance would improve communication. However, they should not always be relied upon, as many people with disability have no or very little engagement with the formal service system. It is the responsibility of NSW Health to educate employees to meet the needs of people with disability.

There is a place for checklists, or short, accessible guidelines that share information efficiently,

66 ADHC and NSW Health, Joint Guideline, Op. Cit., p 2

67 ADHC and NSW Health, Joint Guideline, Op. Cit., p 3

68 NSW Health, Care Coordination: Planning from Admission to Transfer of Care in NSW Public

69 Hospitals, 2011, Sydney, p 1

70 NDS Member Consultations, NDS NSW, 2010 to 2013

71 Australian Institute of Health and Welfare, Dementia care in hospitals costs and strategies, Op. Cit., p 1 and KPMG and NSW Department of Health. Analysis of costs and benefits of specialised intellectual disability health services and enhanced clinical leadership, Op. Cit., p 33

72 Dillon, Inquest into the death of Michelle McIlquham, Op. Cit., p22

prompt memory and ensure that patients are communicated with and assessed appropriately⁷³. Disability support services have created numerous forms and procedures to this end.

The Mai Wel group has devised a 'hospital passport'. This has a simple 'traffic light' format. It lays out the things nursing staff must know such as important contacts and allergies, the things that are very important to the person with disability and important likes and dislikes of the person with disability. Space is given for any extra information and nursing staff are required to sign confirming they have read it all.

'Top 5' is another simple, quick reference communication tool. On admission, the person with disability, their informal networks and support workers are asked to identify the five best strategies hospital staff could use to support them. Top 5s include routines, objects or actions of significance, key words and tools for communicating. The Top 5 tool was piloted in 2007 in two Central Coast public hospitals across four acute-care wards. The Top 5 strategies were placed on the bed chart of the person with disability. Tags were used to identify the patient as a Top 5 user on the spine of their medical record and the top of the bed chart.

Evaluation found the Top 5 tool was helpful in building hospital staff confidence in communicating more effectively and relating better with patients. It was observed that people with disability using the Top 5 tool expressed less distress and frustration⁷⁴. Carers reported that hospital staff had an increased awareness of their role, tending to seek and acknowledge their advice more often⁷⁵. Overall, relationships between people with disability, their support networks and hospital staff improved through the use of 'Top 5'. The Top 5 tool is now used with positive results in dementia care⁷⁶ and has been encouraged in hospitals in South Western Sydney, West Sydney, Hunter New England, Northern NSW and the Mid North Coast. Including best practice examples of such forms in state-wide practice guidelines and policy directives could improve the take-up of information and confidence of hospital staff.

The emergency department (ED)

Case study 10: David

David lives independently in the community. He has drop-in accommodation support once a fortnight. David has mild to moderate intellectual disability and epilepsy.

David called his support worker one day to let her know that he was being taken to his doctor by his employer as he had severe pain in his head. Later that day, he called his support worker again to say that he was being transferred to hospital as a scan the doctor had taken showed possible fluid on the brain. The support worker discussed with David that he should expect them to keep him in overnight, but if they don't he should ask them for a taxi voucher. It would be unsafe for David to travel alone on the train at night.

At 9.45pm David called his support worker to say he was on a train, that he had been discharged and his request for a taxi voucher had been declined. The hospital was aware of his disability, epilepsy and independent living situation. He was sent home with a consult note and little understanding of the meaning of decisions that were made for him.

73 Dillon, Inquest into the death of Michelle McIlquham, Op. Cit., p 22

74 Strudwick, M, 'Top 5 - A Win-Win Partnership for Carers and Staff in an Acute Hospital Setting' Carer Support Unit Central Coast, Carers in Action in NSW Conference, 2009

75 Ibid

76 Grealish, L., Jamieson, M., Brown, J., Moore, B., Proctor, M. & Gibson, D. The interaction between hospital and community-based services for people with dementia and their carers. Sydney, 2013, p 35

Everybody can find illness, injury and trips to the ED distressing. With the addition of mobility or communication differences, time in the ED provides particular barriers and challenges. David's challenge was advocating for himself when he didn't understand what was being said to him. ED staff did not respond to his needs and arguably put him at risk.

The Guideline suggests that in the event of a resident of an ADHC-operated accommodation service attending an ED, the necessary additional staff are to be located and brought in⁷⁷. In practice, this Guideline is expensive and impractical. In an emergency it is intuitively unwise to wait for additional staff members to be located and sent where needed. Delays are a failure of duty of care at best and at worst, risk significant harm. In such cases it must be within the capability of paramedics and ED staff to manage the immediate needs of a person with disability in health or injury crisis. This is a goal clearly identified in the Strategy.

Outside the Guideline, a significant proportion of people with all types of disability benefit from support in an ED, where advocating for oneself and clear communication are crucial. As argued above, where hospital staff are unable to respond to the needs of a person with disability, resourcing extra support would improve access to suitable and equitable emergency assessment and care.

Again, the intention is not to imply that the presence of a support worker is or should be integral to any health or hospital service providing support for all people with disability. Across the spectrum of disability there is also a spectrum of engagement with disability support services. In David's case, for example, a phone call to his support service could have kept him safer and allowed him more understanding, choice and control over his circumstances. The point is as identified above: a commitment to resourcing flexible, knowledgeable and person-centred support for people with disability, beginning with ED presentation through to transfer of care, would improve the experiences of people with disability.

What are the opportunities for improvement?

Members report that ED staff would benefit from a reliable source of information on important contacts and communication guidelines. As discussed above, it is not possible or appropriate for support workers to accompany people with disability at all times, and hospitals themselves must be accessible. There is a role for ongoing education of NSW Health employees about disability, and for specialised disability support services in hospitals.

The Disability Health Network has proposed that in addition to increased education and expertise, people with disability who live independently but with support from a service provider, and are likely to present to an ED, should have an identification card to give to hospital staff.

This ID card would link to a patient file (electronic or paper-based) provided to the hospital by disability services in the catchment area. Relevant information on that individual, details of the service involvement and appropriate contact numbers would be accessible if needed. This information would ensure ED staff are aware of the implications of presenting concerns and would influence their approach to treating them. As described by the Coroner in 'Michelle's Case';

"While signs and symptoms and other clues or indicators of serious illness may be ambiguous or unspecific, they will almost always be detectable during a patient's presentation to an emergency department. The key is ensuring that the signs are looked for... and picked up."⁷⁸

This system has not yet been introduced. However, it presents food for thought in defining an agreement between disability and health services that recognises the responsibilities of NSW

77 ADHC and NSW Health, Joint Guideline, Op. Cit., p 9

78 Dillon, Inquest into the death of Michelle McIlquham, Op. Cit., p 22

Health inherent in the community responsibility of EDs.

Discharge and transfer of care

Case study 11: Steve

Steve was recovering in hospital from a serious fracture to his leg as a result of a fall. An application for a guardian and financial manager were in process, as Steve needed support to make decisions. The hospital raised concerns with Steve's service provider that he was threatening staff and was verbally abusive. Shortly after raising their concerns, the hospital discharged Steve without planning or consultation and despite being advised by the occupational therapist that his home was unsafe for him. There was no time or discussion allowed for planning for supporting Steve in his home.

Case study 12: Mehmet

A young man with complex care needs experiencing a high temperature and vomiting was discharged from an emergency department and returned to his group home via ambulance. His group home was not notified in advance. The hospital's expectation was that as Mehmet had support staff at the group home, he would be safe and his health needs taken care of. His health deteriorated and he returned to hospital, requiring two weeks of intravenous antibiotics.

Case study 13: Fenyang

Fenyang, who lived independently, was hospitalised for a lengthy period. During her hospitalisation her living skills deteriorated significantly. It was determined she would not be able to look after herself on return to her home and extra supports would be required.

Fenyang was deemed ineligible for post-hospital support because she already had in-home care in place. Her support staff explained that her two hours of support per week – limited to budgeting, shopping, transport and doctors' appointments – was insufficient for the home care and personal care she would now need. Nevertheless, Fenyang was discharged with a community nurse visiting once a week. The nurse reported to the hospital and community health service that Fenyang was not coping alone and required additional support. She was soon readmitted to hospital.

During this stay Fenyang was reassessed and it was determined she was eligible for home care. This assistance is now in place and is vital for her ongoing independent living.

The Guideline stipulates that transfer of care is to be carried out in accordance with the NSW Health Policy Directive 'Care Coordination: Planning for Admission to Transfer of Care in Public Hospitals'.⁷⁹ A plan addressing potential risks of transfer of care should be completed and all referrals, appointments and follow-up information, including medication advice, communicated to the patient, their family or carers.

However, a major concern identified by service providers is the timing and planning of hospital discharge, as in all three case examples above. Connected to this is a lack of understanding among hospital staff of the resources of disability services and the disability workforce in post-hospital care, as in the second and third case examples. Such cases directly contravene the NSW Health Policy 'Your Health Rights and Responsibilities',⁸⁰ the Directive, the Guideline, and the

79 ADHC and NSW Health, The Joint guideline, Op. Cit., p 11 & NSW Health, Care Coordination: Planning from Admission to Transfer of Care in NSW Public hospitals, North Sydney, 2011

80 NSW Health, Your Health Rights and Responsibilities, 2011, NSW

principles of the Strategy,⁸¹ – and put people with disability at risk.

The Directive explains: “Hospital staff should not assume that the person is being discharged into an environment that provides nursing or allied health care when this may not be the case.”⁸² Yet it is assumed that disability support staff will be able to take on responsibility for ongoing clinical care and/or rehabilitation following a hospital visit, with little or no support from the hospital or public health services. Some ADHC-operated services have access to clinical staff, but most NGO disability service providers do not. Unannounced and improperly organised discharge can result in basic care needs such as fluid intake or other follow-up not being monitored. Ultimately, a lack of planning increases the likelihood that a person will ‘ping-pong’ back into emergency and repeat the whole experience, as in Mehmet’s case. Service providers reported that workers feel ill-equipped, stressed, guilty and confused upon the discharge of people they support.⁸³

These experiences demonstrate the impact of a lack of knowledge, inconsistently implemented procedures and inadequate resources. This finding is supported by research reporting on discharge planning for patients with dementia and their carers.⁸⁴ This research found that while discharge planning commencing at the point of admission is considered best practice, this did not happen with most people with dementia or their carers.⁸⁵ These examples add to the picture of confusion existing around the extent and limitations of the roles in hospital of disability support workers and carers explored earlier. These challenges are opportunities for improvement. These stories illustrate strongly the need for support people, no matter their employer, to communicate effectively with the care team and for the education and resourcing of hospital staff to work in the way that the policy directives prescribe.

What are the opportunities for improvement?

Specific training and specialised support and coordination services would facilitate timely and effective discharge planning,⁸⁶ ensuring the respective roles of disability support and community health services are appreciated.

Reforms such as the NDIS and policy frameworks such as the Strategy are opportunities for Australia to move closer to an inclusive society where people are not discriminated against based on disability. NSW Health has a responsibility to ensure that people with disability are discharged into a safe environment in the same way that this responsibility exists for the whole population. An underlying explanation for discharge and post hospital care remaining such a concern in NSW is that in accessing discharge planning and services such as ComPacks, people with disability are being treated differently. Disability support services are being seen as substitute health services. Disability support services and health support services are not mutually exclusive and should not be confused as such. Both have roles for a person with disability transferring out of hospital.

As identified throughout part four of this paper, communication, planning, identifying the lines of responsibility, and resourcing appropriately are important in implementing existing policies

81 Australian Department of Families, Housing, Community Services and Indigenous Affairs (FACSlA). National Disability Strategy 2010 – 2020, Op. Cit., p 60

82 NSW Department of Health, People with a Disability: Responding to Needs During Hospitalisation, Op. Cit., p 7

83 NDS Member Consultations, NDS NSW, 2010 to 2013

84 Grealish, L., Jamieson, M., Brown, J., Moore, B., Proctor, M. & Gibson, D. The interaction between hospital and community-based services for people with dementia and their carers. Sydney, 2013, p. 23

85 Ibid, p 38

86 Ibid, p 7

and procedures that should facilitate successful transfer of care. Initiatives such as the NSW Electronic Medical Record program (eMR), if appropriately attuned to being inclusive of people with disability, will have a significant role to play in addressing planning, communication and service coordination.

Primary health care

It is generally agreed that hospitalisations can be reduced by better managing community health and wellbeing⁸⁷. Australia as a whole has to address population ageing and the increasing burdens of chronic and complex health issues. Solutions cannot lie in hospital care, but in preventive and more cost-effective primary health care⁸⁸. Yet people with disability can be excluded from mainstream community health initiatives.

NDS Queensland has identified three main barriers.⁸⁹ First, people with disability are more likely to be disadvantaged in the social determinants of health, resulting in a reduced access to community resources. Social and economic disadvantage is a major contributor to poor health⁹⁰. Second, the shift in disability support away from a medical model has reduced health literacy in the disability workforce and disability literacy in the health workforce. Last, people with disability need genuinely accessible health promotion resources and activities to help them become involved in their own health care⁹¹. This includes accessible forms of communication⁹² and cross-sector communication.

The planning and delivery of services continues to be heavily segmented, with government departments and their funding streams operating autonomously as 'silos'. This makes joint, inclusive planning difficult. Yet connecting medical and other health providers and community sectors to each other, to hospitals and to patients, will improve the coordination of high-quality, inclusive primary health care in the community⁹³.

Connecting the 'silos' can be seen as a job for Medicare Locals, assuming its function remains unchanged*. This 61-strong nationwide network has responsibility for population health planning and needs assessment for their regions, identifying gaps in primary health care services, and developing and implementing strategies, in collaboration with communities, population groups and service providers that address these service gaps.

What are the opportunities for improvement?

A greater integration of health and hospital services through strong transfer of care planning and engagement of primary care can improve patient outcomes and the efficiency of care⁹⁴. It is widely acknowledged that for people to participate actively in their own health care leads to improved health outcomes⁹⁵. Federally funded Medicare Locals, working with state-funded

87 GP NSW, Primary Health Care – an idea whose time has come, Sydney, 2013, p 2

88 GP NSW, Primary Health Care – an idea whose time has come, Op. Cit., p 2

89 NDS Qld, Improving Access to Health Services for People with Disability, Op. Cit., p 3

*The structure of Medicare Locals is currently under review.

89 VicHealth, Disability and Health Inequalities in Australia Research Summary, 2011, Melbourne, p.4

90 VicHealth, Disability and Health Inequalities in Australia Research Summary, 2011, Melbourne, p.4

91 NDS Qld, Improving Access to Health Services for People with Disability, Op. Cit., p 4

92 VicHealth, p 4

93 GP NSW, p 2

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

95 NDS Qld, Improving Access to Health Services for People with Disability, Brisbane, 2013 p 3

community health services on primary health care, illness prevention and health promotion⁹⁶ are well placed to facilitate this.

NDS Queensland has engaged the Metro North Brisbane Medicare Local to create a framework in its catchment area. This is a good example of how connecting services and breaking down barriers to primary health care could be applied across the country. The project's activities included supplying information and awareness resources to disability service providers across the district. Health conversations were held with people with disability, and with a broad range of people with a shared interest in improving health and building empowerment of people with disability. Workshops focused on capacity building, and a range resource and engagement initiatives across sectors have resulted⁹⁷.

Two online learning modules that resulted from the project are particularly worth mentioning. One outlines the role of disability support workers in health care.⁹⁸ This module, developed with the Queensland Centre for Intellectual and Developmental Disability, equips disability support workers to assist people with disability with their primary healthcare needs. The other is for general practitioners and other health professionals, increasing their awareness of disability and health.⁹⁹ The overall result is a disability and health workforce that is better able to help people with disability to achieve better primary healthcare outcomes.

96 Commonwealth of Australia. National Primary Health Care Strategic Framework. Canberra, 2013

97 NDS Qld, Improving Access to Health Services for People with Disability, Brisbane, 2013, p 5

98 Available at: <http://ndshealthandwellbeing.avana.com/>

99 Available at: <http://www.qcidd.com.au/gps>

Part five: recommendations and conclusion

The Directive states:

“... [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”¹⁰⁰.

Economic imperatives for change

People with disability are some of the most disadvantaged members of our community, and intensive users of health and social services¹⁰¹. The quality of primary and acute health care has a significant impact¹⁰² under these circumstances, making this a great opportunity to improve outcomes and efficiency.

Change in the disability support sector through the NDIS may ease pressure on health systems through reducing disadvantage overall¹⁰³. The NDIS will ensure that people with disability have access to ‘reasonable and necessary’ support related to their disability, enabling them to move around, look after themselves, communicate, access the community and participate in all areas and at all stages of life. But the NDIS cannot be relied on as a panacea to solve all ills – and in fact it may well throw the shakiness of the interface between NSW Health and the disability service sector into even sharper relief.

As things stand, people with disability are experiencing discrimination. The evidence presented in this paper indicates that their health care, without the intervention of disability support providers, may pose a real and significant risk of harm, and can cause actual harm.

As the NDIS is implemented across the state, disability service providers will not be able keep on footing the bill for informed and appropriate support. As noted, service plans prepared under the NDIS will facilitate choice and control for people with disability but will not include making universal health services accessible. The Strategy has made this the responsibility of each universal service sector. Indeed, the COAG Applied Principles (see part one of this paper) also state that the health and hospital system will be responsible for reasonable adjustments to care¹⁰⁴. The cost to NSW Health of failing to resource such adjustments is dire¹⁰⁵.

Difficulties with communication, personal care, mobility and decision-making inevitably lead to mistreatment, inappropriate treatment decisions, longer hospital stays, repeated hospital admissions and a high risk of ongoing poor health.

On the other hand, the benefits to the state of investment in hospital services are real. Overcoming the barriers faced by people with disability in both acute and primary healthcare results in the right care being provided at the right time. Services that are not crisis-driven are more cost-efficient¹⁰⁶. Thorough preventive transfer of care planning and engagement with primary care also improve patient outcomes and care efficiency¹⁰⁷. This in turn leads

100 NSW Health, *People with Disabilities: responding to their needs during hospitalisation*, 2008, Sydney, p 2

101 C, Ham & N, Walsh, *Making integrated care happen at scale and pace*, London, 2013, p 4

102 Ibid, p 4

103 VicHealth, *Disability and Health Inequalities in Australia Research Summary*, Op. Cit., p 4

104 COAG, *Principles to Determine the Responsibilities of the NDIS and Other Service Systems*, Op. Cit., p 3

105 NDS NPRU, *Why the NDIS makes economic sense*, Canberra, 2013, p 5

106 Ham & Walsh, *Making integrated care happen at scale and pace*, Op. Cit., p 1

107 Ibid, p 1 & NDS NPRU, *Why the NDIS makes economic sense*, Op. Cit., p 3

to increased social capital and economic participation¹⁰⁸, wider social benefits that greatly outweigh the costs¹⁰⁹.

Through this paper, NDS asks that health services, and specifically hospital services, embrace the vision of the Strategy and NDIS and contribute to building an inclusive society that enables people with disability to fulfil their potential as equal citizens.

As noted, NSW Health should not continue spending more than necessary on crisis-based and repeated hospitalisations when there are strategies to make care more cost-effective, equitable and responsive. The health system has it in its power to ease the situation.

108 Shergold, *Service Sector Reform, A roadmap for community and human services reform*, 2013, Melbourne

109 NDS NPRU, *Why the NDIS makes economic sense*, p 3

Recommendations

The National Disability Strategy's sixth key outcome area is health and wellbeing. Its goal is that:

“All health service providers (including hospitals, general practices, specialist services, allied health, dental health, mental health, population health programs and ambulance services) have the capabilities to meet the needs of people with disability.”¹¹⁰

All policies discussed in this paper accept that people with disability have the right of equal access to health and hospital services, and that it is the role of universal services to facilitate this. Yet, as we have seen, hospital support of people with disability often at best falls short of ideal, and at worst exposes them to harm. This can be explained by factors based on education, expertise, resourcing and relationships, and so the recommendations following will centre on these themes.

It has also been clearly established that human rights obligations of universal services cannot and should not remain the default remit of the disability services sector. The vision of the NDIS and the Strategy is to create an inclusive society that enables people with disability to fulfil their potential as equal citizens. In this, all service systems have a role to play¹¹¹. Therefore, the recommendations presented will focus on the roles of NSW Health in realising equity of access and outcomes for people with disability.

All proposed solutions must remain mindful that the NDIS is four years away for the majority of Australians, and that people with disability who are not eligible for the NDIS will also have support needs. There is most certainly a role for immediate response from ADHC (with reference to all funded disability support services) and NSW Health, as well as longer term shifts to accommodate the NDIS. To achieve this, all recommendations will depend upon a balance between empowering health and hospital services to fulfil their responsibilities to people with disability with accommodating and resourcing specialist support and expertise. This need for balance is reflected in the Strategy:

“Some people with disability and their carers need specialist supports to be able to maintain everyday wellbeing at home, and to be involved in community life. It is important to have these specialist supports in place, and to work to improve their quality and accessibility. However, a key imperative is for the broader community and mainstream services and facilities that are part of ordinary Australian life to be available and fully accessible for people with disability.”¹¹²

Recommendations have been guided by the examples provided in part four of this paper.

Strategy 1: People with disability are identified as a priority group in health policy.

A major goal of the upcoming new NSW State Health Plan is to ‘deliver on health priorities’¹¹³. Priorities in health policy identify people with diverse needs with the intention that policies and services can be developed which concentrate on these populations. The focus on specific groups of health service users is particularly important where the group experiences health disadvantage and inequality in other areas of life. Such policies and programs aim to provide people with diverse needs equitable access. Many members of the community have been identified as having particular health needs such as children, Indigenous Australians, culturally and linguistically

110 FAHCSIA, National Disability Strategy 2010 - 2020, Op. Cit., p 60

111 COAG, Principles to Determine the Responsibilities of the NDIS and Other Service Systems, Op. Cit., p 1

112 FAHCSIA, 2010 – 2020 National Disability Strategy, Op. Cit., p 13

113 NSW Health, NSW State Health Plan 2013 - 2023 outline, viewed online <http://www.health.nsw.gov.au/statehealthplan/Pages/default.aspx>

diverse (CALD) people and older people.

It stands to reason that people with disability should be identified as a priority group. People with disability experience inequality and disadvantage in many areas of their lives and can have complex health needs. Yet they are not generally identified by NSW Health as a priority group or a group with different or more complex needs than the general community. NDS believes that NSW Health must identify adequately addressing the needs of people with disability as a priority to fulfil its human rights obligations.

The NSW Health Policy and Implementation Plan for Culturally Diverse Communities (2012 – 2016) points out that failing to respond appropriately to the specific needs of CALD groups can result in poor communication, misdiagnosis, inappropriate treatment and poor health outcomes¹¹⁴. NDS has identified similar consequences of failure to respond appropriately to the needs of people with disability in hospital. The provision of culturally safe care ensures that individuals have the right to have their beliefs and value systems responded to sensitively and have all aspects of their religion, food, prayer, dress, privacy and customs respected. Strategies that afford the same rights and respect to people with disability are necessary to achieve the aim of providing the best quality health care.

Among numerous strategies NSW Health has implemented to support CALD communities are:

- coordinating a consistent approach to multicultural health across NSW Health
- training and supporting NSW Health staff in working with people from CALD communities
- increasing access to interpreters and acknowledging the role of close family members in communication and understanding
- better engaging CALD people in health policy and practice development¹¹⁵.

Indeed, “it is reasonable that hospitals pay attention to [people with disability] in a way that reflects more complex needs¹¹⁶.” Yet, recognition as a priority group should not apply only to hospital settings, but also across the spectrum of NSW Health services: mainstream services, community health and nursing and allied health, among others. Addressing the needs of people with disability at a primary health level reduces the need for hospitalisations overall. The impacts of systemic and structural reform can flow into collective and individual ideologies and facilitate change at an individual and service level.

The role of the eMR project for electronic hospital records in NSW cannot be ignored or underestimated. NDS recommends thorough consultation with the disability service sector on how this innovation can be used to address some of the challenges outlined above.

Strategy 2: a state-wide agreement defining expectations of support provision

The inconsistency of hospital care and the inadequacy of current policies throughout NSW described in this paper make clear the need for a single agreement. Such an agreement must direct hospitals to address minimum standards of practice and the coordination of resources between people with disability, NSW hospitals, disability support services, families and carers. The result should be a binding commitment that can be realistically implemented at a local health district level, allowing flexibility for the circumstances and preferences of the individual concerned.

114 NSW Ministry of Health, NSW Health Policy & Implementation Plan for Culturally Diverse Communities 2012 – 2016, North Sydney, 2012, p 8

115 Ibid, p 21 - 23

116 Dillon, Inquest into the death of Michelle McIlquham, Op. Cit., p 26

This recommendation is reflected in the Productivity Commission's report on disability care and support¹¹⁷ and the recently published 'Ageing in Place' report which explored the impacts of the ageing population of people with disability. The Ageing in Place report argues for an agreement between ADHC and NSW Health to streamline provision and improve accessibility to services for people with disability who are ageing¹¹⁸.

NDS recommends that NSW Health and ADHC immediately establish such an agreement which will carry through until the full implementation of the NDIS in NSW in 2018-19. This agreement should as closely as possible mimic the COAG Principles¹¹⁹ and must include reference to all people with disability, not solely those in receipt of some types of ADHC-operated services.

In the longer term, the issue of the interface between health services, including hospitals, and disability supports will be a matter for the National Disability Insurance Agency (NDIA). One of the guiding principles of the NDIS is a nationally consistent approach to the basis on which it engages with other systems¹²⁰. The NDIA will apply the COAG Principles in NSW, as it will across the country, with the expectation that NSW Health will be able to provide access to quality health services based on need, in consistency with the requirements of all national and state commitments¹²¹.

As identified in part one of this paper, the draft Disability Inclusion Bill proposes to commit NSW Health to devising and implementing four-yearly Disability Action Plans and describing how health and hospital services are upholding the principles of inclusion.

The agreement NDS proposes must therefore set minimum standards of knowledge and care expected of hospital staff. Such an agreement must also provide for building relationships with local disability providers, and for local disability support staff to be trained, inducted and supported to respond to the preferences and needs of the people they support in hospital. Both measures will ensure that NSW Health functions in accordance with the COAG Principles upon the rollout of the NDIS.

Any such agreement must address also these two key areas for improvement identified in this paper: the adequate resources required to support people with disability in hospital and guidelines stating how to achieve clarity and understanding on the respective roles of disability service staff and hospital staff in each case.

Resourcing

NSW Health must provide health services for the whole community. The critical issue of funding varied levels of support for individuals with varying support needs is not addressed in any previous policy documents or directives. The proposed agreement must guarantee that adequate resources will be available and from where they will be sourced in order to enact necessary supports for people with disability.

In doing this, the assumption that the services disability support staff provide to a person with disability in hospital simply correlate directly to the support they would provide outside hospital must be abandoned. As we have seen, disability support services invest levels of support in their hospitalised clients that far outweigh the typical practical support provided and the usual cost of

117 Productivity Commission, Disability Care and Support Enquiry Report, Canberra, 2011

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

119 Productivity Commission, Disability Care and Support Enquiry Report, Canberra, 2011

120 Council of Australian Governments, p 1

121 COAG Applied Principles to determine the responsibilities of the NDIS and other service systems

running their services.

NDS recommends, too, that the access issues faced by people who require interpreters to access hospital services (as addressed in the Policy and Implementation Plan for CALD Communities) need consideration in light of the COAG principles.

Role clarity

NDS applauds the recognition in the Directive that expectations as to roles and responsibilities of hospital and support staff must be clarified and agreed upon. However, NDS does not advocate a strict division of roles to apply to all people with disability who receive support as exists in the current Guideline.

In any person-centred (and indeed patient-centred) system, there must be space for sensitivity and adaptability to individual differences. Within the proposed agreement, the individual must be at the centre of decisions made about support carried out by the disability provider and hospital staff. In this way, the detail provided in the current Guideline is not necessary. A higher-level agreement that compels the relevant service sectors to communicate effectively in order to discern and plan roles, at a local level, and in partnership with the person with disability would suffice.

Such local partnerships and local decision-making result in person-centred service provision, so long as this occurs in the context of local disability staff being appropriately trained and supported to act autonomously, and hospital staff being supported to meet certain minimum state-wide care standards. This would include admission planning, and mechanisms whereby planning and communication are triggered upon the emergency presentation of a person with disability who is engaged with support services.

Strategy 3: disability expertise, education and awareness are introduced to hospitals and all health services

To implement the above recommendations, increased awareness and skills among hospital staff are vital.

Hospital-wide staff training and awareness

This paper has presented a clear case for investment in professional education and training on understanding and supporting people with disability in hospital. Consistency is urgently required throughout the state on the minimum expertise required for a hospital to support people with disability, to prevent people with disability being exposed to risk and harm, discriminated against, ignored or discharged from hospital inappropriately.

Better information and access to training minimises risks for people with disability and for the professionals who support them. Shifts in understanding disability and attitudes toward disability, identified as key opportunities for improvement in this paper, are needed to enhance support of people with disability in hospital.

Training and education programs have been shown to improve the provision of care and support in the hospital setting.¹²² NSW Health acknowledges the benefits of staff training. It identifies the importance of hospital staff being familiar with contemporary practice in the support of people with disability, and that such education should be a priority.¹²³ The Directive states that

122 Australian Institute of Health and Welfare, Dementia care in hospitals costs and strategies, Op. Cit., p 56

NSW Department of Health. People with a Disability: Responding to Needs During Hospitalisation , Op. Cit., p 10

training should be incorporated into area-level education timetables.¹²⁴ The cost of this is not addressed, however, and evidence from NDS members indicate that adequate training is not yet taking place. As identified in part four of this paper, a consistent framework for educating hospital staff is needed, as individual projects easily lose traction.

There are arguments for the training of health industry students in disability, and for the training of currently practising professionals. Outside of NSW Health, teaching undergraduates has the advantage of being far-reaching and having an influence on large numbers of future health professionals.¹²⁵ For NSW Health, professional development has the advantage of having immediate applicability to and therefore impact on practice.¹²⁶ NDS advocates for training in both forums. The online training tools identified in part four of this paper provide good examples of training which has wide and varied applicability.

All health services at all times need awareness-raising to ensure that the service is accessible to and supportive of people with cognitive, communication, social, behavioural and physical differences¹²⁷.

Leadership and specialised disability support services in hospitals

NDS advocates two paths to developing and maintaining practice leadership in supporting people with disability in hospitals.

First, for whole-of-staff training and information to be effective, leadership will be necessary in both the health and disability sectors. Senior staff and organisational leaders must promote a culture where positive and informed attitudes toward people with disability prevail. Where leaders promote inclusion and the voice of people with disability, improved organisational awareness and culture will follow.

Second, expertise must be available and accessible to hospital staff in an ongoing way. NDS recommends implementing a model similar to that proposed in the service framework for the care of people with intellectual disabilities composed in 2009. This involves specialised disability support staff in hospitals, whose role would be to facilitate an equitable hospital experience. This recommendation addresses the key area for improvement of communicating as a team. At present, medical professionals and other health staff are simply unable to spread themselves and fill this role due to time and resource constraints. Communication has been shown to fail at several points. Specialist staff positions would ensure continuous and co-ordinated health care within hospitals. They would also facilitate collaboration and cooperation between their hospital, the community, people with disability in the community, mainstream health and disability support systems.¹²⁸

Expertise would be put towards coordinating and working to improve the practice implementation of those opportunities which have been identified as flawed in the current system:

- Communication and division of roles among people with disability, their support workers, family and carers;
- Coordinating support for the person with disability whether staff are sourced from within the

124 Ibid, p 10

125 Tracey, "Improving Healthcare Provided to People with Intellectual Disability: The Role of Mainstream and Specialist Services" Op. Cit., p 39

126 Ibid, p 39

127 Ibid, p 42

128 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

hospital or the relevant disability support service;

- Admission and discharge planning, linking with primary health care services;
- Other needs during hospital stay such as specialised equipment or aids;
- Evaluation and data collection to monitor service effectiveness and outcomes. Part of this role must include ongoing consultation with people with disability, their families and carers;

Training and advice of general hospital staff.¹²⁹

Enabling a group of professionals to focus on the unique needs of any group in such a way allows the development and maintenance of expertise and is known to influence outcomes for that group.¹³⁰ Indeed, sectors representing populations where there are communication challenges and involvement of several supports and services regularly advocate for a ‘key worker’ model of coordination.¹³¹ In such a way, patients receive adequate, informed and organised care which is otherwise unavailable.

Benefits have been found to include better coordination of health services and more effective management and treatment¹³². Indeed, specialised services similar to that described here have been found to reduce the average length of stay of people with dementia by 3.6 days, and improve the quality of care provided.¹³³ Better health outcomes for people with disability potentially lead to a reduction in repeat hospitalisations.¹³⁴

Awareness initiatives in primary health care

The example of NSW Queensland working in partnership with Metro North Brisbane Medicare Local shows that barriers can be broken down and services can be connected to improve primary health care for people with disability.¹³⁵

NDS recommends investment in primary health information. Awareness-raising and capacity-building strategies for people with disability, their families and carers as well as a range of medical and allied health professionals should use the network of Medicare Locals, if its function remains unchanged under the Coalition Government. Methods such as paper-based information, targeted engagement activities, workshops and online learning modules should be applied.

129 KPMG and NSW Department of Health, Analysis of costs and benefits of specialised intellectual disability health services and enhanced clinical leadership, Op. Cit., p 22

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

131 Grealish et al, The interaction between hospital and community-based services for people with dementia and their carers. Op. Cit., p 7

132 KPMG and NSW Department of Health, Analysis of costs and benefits of specialised intellectual disability health services and enhanced clinical leadership. Op. Cit., p 5

133 AIHW, Dementia care in hospitals costs and strategies, Op. Cit., p 51

134 NSW Department of Health. Disability Action Plan 2009 – 2014. North Sydney, 2009, p 27

135 NDS Qld, Improving Access to Health Services for People with Disability, Brisbane, 2013

Conclusion

This paper has shown that far from achieving equitable outcomes, people with disability can face actual risks to their safety in hospital. Through wide-ranging case studies, it has been demonstrated that their dignity is frequently not being observed or respected. If a hospitalised patient with disability needs additional supports, these are often forgone, or the responsibility for provision is wrongfully placed on the patient and their support networks.

The interface between the health and disability sectors is awkward and needs improvement. As the Strategy and NSW Implementation Plan are implemented statewide alongside the rollout of the NDIS, the clearest solution is for each sector to agree to acknowledge interdependencies and respond to them communicatively; for each sector to use each other; and for each to contribute relevant resources and expertise. The changes the disability sector is undergoing are a real opportunity for it and the health sector to collaborate to improve the quality of support and outcomes for people with disability.

NDS has recommended that people with disability be identified as a priority group for health policy. An agreement between NSW Health and ADHC has been suggested to incorporate consistency in care standards across the state, including space for local responses to individual needs and resourcing access to specialist support. Education of the health workforce and the broader health and disability community is vital in achieving the outcome of equity in accessing universal health services for people with disability. Implementing these recommendations will effectively prepare NSW for the rollout of the NDIS, which will expect NSW Health to provide person-centred support aligned to the COAG Principles for Health.

These recommendations are not ground-breaking. They are logical and align closely with the stated goals of the National Disability Strategy and the NSW Health Disability Action Plan. They reflect the human rights and equity grounds on which the NDIS has been designed. The recommendations in this paper are variously recognised by NSW Health as addressing inequities in access and contributing to better outcomes. This paper asks for universal services in NSW to seize this moment of historic reform. We are calling for action to realise the aspirational rhetoric of those documents in which our community and government have clearly and repeatedly articulated their responsibilities.

NBS