

Disability Alliance

www.disabilityalliance.org.au

19 November 2009

The Hospital Reform Commission
Health Consumers Queensland

Dear Sir / Madam

Re: Further Consultation around the Recommendations from the Health of Hospitals Reform Report

“When we get it right for people with disability, we get it right for everyone”

On behalf of Disability Alliance Queensland, I thank you for the invitation to provide feedback to assist in the policy development emerging from the recommendations from the Health of Hospitals Report.

The Disability Alliance gives permission for this submission to be posted on your website.

Should you have any enquiries please do not hesitate to contact us via the details outlined below.

Yours sincerely

Contact:

Disability Alliance
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Submission

Hospital Reform Commission

November 2009

Disability Alliance

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SUBMISSION Consultation around the Health of Hospital Reform Recommendations November 2009

DISABILITY ALLIANCE

"When we get it right for people with disability, we get it right for everyone"

Who are we?

The Disability Alliance represents a broad network of Queenslanders concerned about the ongoing neglect and social exclusion of Queenslanders with disabilities.

The Disability Alliance is not affiliated with any political party or level of government. The Campaign is not a structural entity, as such, and seeks to represent the broader sector in its pursuit of Government action (at State, Commonwealth and Local levels) in addressing neglect and social exclusion faced by people with a disability and families living with disability in Queensland (and Australia).

The purpose of the Disability Alliance campaign is to position Disability as a mainstream issue for political parties and the wider community within the State and Commonwealth electorate. We are seeking political support for three early intervention outcomes (personal care, equipment and aids, and health issues), all of which will make a huge difference in the lives of Queenslanders with a disability.

History of the Disability Alliance

The Disability Alliance grew out of the Unmet Needs Campaign, a successful grassroots campaign which sought government action to address the unmet needs for support faced by people with a disability and families living with disability in Queensland and Australia.

In 2007 the Disability Alliance ran a campaign in the lead up to the federal election calling for a 20% increase in Commonwealth funding and a commitment to full annual indexation. The key messages for the Federal election campaign included: National leadership, funding for individuals and families, income support, workforce development for the disability sector, advocacy, human rights and social participation.

In 2009 the Disability Alliance ran a State election campaign seeking appropriate outcomes for: (1) personal care support; (2) equipment and aids; (3) appropriate care in hospitals and health systems.

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The evidence for this submission has been gathered by:

- Consultation with the Disability Alliance members which is made up of client and service representation across Queensland;
- Stories provided by people with disability and their carers;
- Further Disability Alliance consultation on the final draft submission;
- Conversation feedback; and
- Research identifying international benchmarks.

1.0

1.1 HOSPITAL AND HEALTH SYSTEMS

Hospitals patient care policies and procedures must be reformed to explicitly include people with a disability and their families. This requires an attitudinal shift from seeing people with disability as an inconvenience to an informed health concern. *“When we get it right for people with disability, we get it right for everyone.”* Additionally, the Disability Alliance recommends the government (both State and Commonwealth):

- Act as intermediaries
- Advise on patient safety
- Ensure access to communication, equipment and patient facilities; and
- Ensure timely, appropriate and communicated discharge planning.

The Disability Alliance would also like to see action taken to address the Public Advocate’s report recommendations around the health needs of people with disability *“In sickness and in health”*

1.2 AIDS AND EQUIPMENT

- Make medical aids and equipment free of charge;
- Loosen restrictions on eligibility;
- Implement a more responsive system for repair and/or replacement that recognises the essential role equipment plays in mobility; and
- Begin planning for equipment on admission rather than on discharge from hospital.

1.3 PERSONAL CARE

- Provide experienced carers for people with disability in the hospital and health systems
- Personal care impacts directly on the person’s health status. If the person is not receiving adequate personal care they will be subjected to more frequent and more severe hospital admissions.

1.4 EXPLICITLY OUTLINE RECOMMENDATIONS FOR PEOPLE WITH DISABILITY IN THE HEALTH REFORM AGENDA

- Develop specific recommendations
- Development specific measureable performance indicators
- Establish measurements to establish progress;
- Consult with the Disability Community to ensure their needs are met; and
- Maintain dialogue as the recommendations are implemented and evaluated.

- 2.1 The Disability Alliance urges the Health Reform Commission to consider more explicitly the plight of our most vulnerable Australians – those people with disability.

United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)

The Australian Government in 2008 ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The UN CRPD is a powerful document. The Convention enables a strong anti-discrimination mandate and creates an opportunity to promote participation, empowerment and independence for people with disability. It is now timely for the Australian Government to review all Public Policy in light of the UNCRPD and incorporate the underpinning principles. Human rights are protected as a fundamental cornerstone of government policy and practice.

The way we treat our most vulnerable in the health system can be seen as a barometer of how well we are doing as a society. Stories emerging from people with disability, their carers and the community service delivery sector that serves them, indicate strongly an entrenched culture of fear, distrust and disbelief in the hospital system and how it has let them down in the majority of cases. The stories in [Appendix A](#) demonstrate a system that is failing to meet its obligations when it comes to people who have disability and who are requiring health care. The stories indicate structural¹ and cultural violence² in hospitals and health systems at a level of extreme concern.

- 3.1 The Disability Alliance strongly urges the Hospital Reform Commission to reconsider their existing recommendations for reform in light of the Australian Institute of Health and Welfare (AIHW) Report on the Welfare of Australia released **November 19 2009**. It states:

- According to the Australian Bureau of Statistics (ABS), the number of people with disability doubled between 1981 and 2003, to reach an estimated 3.9 million Australians.
- The rate of growth in the number of people with profound or severe core activity limitation, that is, people who need help with core daily activities, was even higher (173% increase). Estimated to be around 1.5 million Australians by 2010, the number of people with this high level of disability is projected to increase to almost 2.3 million by 2030 – roughly equivalent to the entire population of Western Australia in 2009.
- Aboriginal and Torres Strait Islander people are more than twice as likely as non-

¹ **Structural violence**, a term which was first used in the 1960s and which has commonly been ascribed to [Johan Galtung](#), denotes a form of violence which corresponds with the systematic ways in which a given [social structure](#) or [social institution](#) kills people slowly by preventing them from meeting their basic needs. Institutionalized [elitism](#), [ethnocentrism](#), [classism](#), [racism](#), [sexism](#), [adultism](#), [nationalism](#), [heterosexism](#) and [ageism](#) are just some examples of structural violence. Life spans are reduced when people are socially dominated, politically oppressed, or economically exploited. Structural violence and direct violence are highly interdependent.

² (Galtung, 1969). 'Cultural violence' is defined here as any aspect of a culture that can be used to legitimize violence in its direct or structural form. Symbolic violence built into a culture does not kill or maim like direct violence or the violence built into the structure.

- Indigenous Australians to need help with core daily activities because of disability.
- Disability shows an uneven geographic distribution, not always linked to remoteness. Census data on capital cities show that higher levels of disability tend to be more prevalent in areas of relevant economic disadvantage.
- Many people with disability rely on government income support as a sole or main source of income. In 2006, almost one in three people aged 18 to 64 years with specific activity limitations or participation restrictions lived in jobless households, compared with one in 13 people without limitations or restrictions.
- Respite services registered the highest rate of growth of any of the six broad service groups funded under the Commonwealth State Territory Disability Agreement: from 96 service users per 1,000 people in the target population in 2003-04 to 137 per 1,000 in 2007/08.
- Within generic employment assistance programs, people with disability have been less likely than average jobseekers to achieve positive employment or training outcomes.

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4.0

BARRIERS TO RECEIVING ADEQUATE HEALTH CARE

- 4.1** Evidence shows that a majority of people with disability often lack opportunities to engage meaningfully with the health system to enhance health outcomes. For example people with disability:
- Are not provided with the opportunity to engage in screening and preventive health care activities;
 - Do not have adequate access to primary healthcare, hospital care and long-term care services;
 - Report a high prevalence of theoretically preventable secondary conditions;
 - Report fair/poor general health and a high number of days;
 - Have difficulty obtaining a family doctor’s services;
 - Have been refused medical treatment by a family doctor because of their disability;
 - Report they have difficulty in physically accessing their family doctors office, equipment and washroom;
 - Report they were receiving inadequate primary health care because of their disability.
 - Report they must spend considerable effort educating their primary care providers about their disability and they feel that physicians sometimes focus inappropriately on their disability, per se, rather than on the secondary health problems with which they present (Eastgate, Lennox 2003; Veltman et.al 2001(1 and 2); Branigan 2001; Wilber et al 2002);
 - Report they have poor dental health and are subjected to long waiting times to receive routine dental care;
 - Report they do not receive discharge plans to provide to their community service delivery organisation;
 - Experience re-admission more times than the rest of the population;
 - Are high users of the health system usually because of their disability;
 - Report that staff in hospitals generally do not know how to use a hoist to execute a transfer with minimum risk;
 - Report that staff do not know the importance of their communication devices and keep them separate to the presenting patient who is trying to communicate in a new environment;
 - Report that they are discriminated by staff who do not wish to acknowledge them as human beings;

- Are communicated with via the carer instead of person to person;
- Report that they need to take their carer into the hospital in order to feel safe and this then depletes the face-to-face contact hours they require to get out of bed each day when discharged.

Additionally:

- Physicians find it difficult to examine individuals with physical disability and stated that it took more time;
- Physicians received minimal training in medical school, or in residencies, yet acknowledged the need for such training (Larson et al. 2002);
- Invariably, overseas trained staff in hospitals had different cultural perceptions of people with disability that sometimes led to discriminatory practices and who required further training to ensure high level health service delivery in the Australian hospital context.

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- 4.2** Moreover, the onset of an acquired disability has an impact, not only on the person directly affected, but also on other family members. A spouse may find he or she wishes to, or is obliged to, reduce hours of paid work in order to care for the newly disabled person. Conversely, pressure on household finances as a result of the disability may be such that they must increase their earnings. Children in the family will be affected by the changes in the allocation of their parents’ time, possibly by taking on new responsibilities, and by changes in household income.

Medical technology and advances have increased the rates of survivors with severe trauma or chronic conditions. Survivors face long rehabilitation, yet health care systems compress treatment and recovery times.

- 4.3** There are a number of **implications** for the hospital and health system. These include:
- People with physical disability have greater health risks and health problems than those without disabilities;
 - They have greater health disparities compared to non-disabled people;
 - There are strong associations between being poor, being out of work, having low educational qualifications, having a disability and the risk of developing a long-term health problem or impairment (Eastgate, Lennox 2003; Veltman et al 2001(1 and 2); Branigan 2001; Wilber et al 2002).

- 4.4** It is clear that the hospital system is failing to deliver equitable and adequate service to people with disability. This is problematic given the rate at which the disability population is growing.

Therefore it is vital that the Hospital Reform Recommendations proactively incorporate this vulnerable group as a specific and explicit category with specific targets and measurable outcomes. Not to do so would be a missed opportunity to address the inequitable access to adequate health systems for people with disability.

- 4.5** Although there has been limited research in Australia on the health concerns of people with disabilities, we know that people with disabilities experience major inequalities in health status, and that they experience significant disadvantage in the social determinants of those inequalities. For example: compared to non-disabled people they:

- are less likely to be in paid work;
- are in the lowest income earning bracket;
- spend more of their income on medical care and health related expenses;
- are less likely to receive appropriate health services;
- are substantially over represented in public housing and more likely to be institutionalised;
- are often forced to live in situations in which they experience, or are at risk of experiencing,

- violence, abuse and neglect;
- are more likely to be unlawfully sterilised; and
- are more likely to be assaulted, raped and abused.

This deep-rooted exclusion experienced by people with disabilities is further neglected because little information is available on its extent or impact in them seeking appropriate health treatment in the hospital system.

5.0

THE SHUT OUT REPORT- Recommendations around personal care, health systems, aids and equipment.

- 5.1** Of importance to the Health of Hospitals Report and subsequent Recommendations is the “*Shut Out*” report. This first report was based around the consultations on the National Disability Strategy which is available on the FAHCSIA web site. Of specific concern to the Department of Health and Ageing are the following:

Personal Care:

A system that truly places people with disabilities and their families, friends and carers at the centre and looks for creative, innovative solutions to meet their needs.

- Personal care that aids in the prevention of entry into the hospital and health system;
- Adequate health support infrastructure in the community service sector to provide for early discharge, management of preventive health strategies, and clinical competency for the more complex cases this sector has to provide support to.

Aids and Equipment:

Elsewhere in the world, people with disabilities have a legislated right to the aids, equipment and technology they require for daily living. Proposed solutions included:

- Nationally coordinated and funded equipment scheme;
- Equipment made available through Medicare;
- Improving tax concessions and rebates for those purchasing their own equipment;
- Broadening the existing communications allowance into a utilities allowance.

Health Support

- Increase funding for health care to ensure their health care needs are met
- Expand the health care card system to improve access and affordability;
- Increase subsidies for essential medications;
- Improve the training of health and allied health professionals; and
- Increase funding for early intervention for children with disabilities.

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- 6.1** In light of the various government documents outlined above it is necessary to outline the political campaign that the Disability Alliance has been running for the past twelve months. Of specific importance to the health of hospitals and health systems of Australia are the three current areas of focus. A more comprehensive outline of the problem/solutions/benefits is provided in [Appendix B](#). Briefly, the three campaign issues include:

6.2 1. Queensland Hospitals and Community Health Care

Reform of Queensland Hospitals' patient care to better include people with a disability and their families.

Download the [Disability Alliance - Position Statement - Community Health Care \(PDF\)](#)

We propose:

- A state-wide program to be developed to constructively engage people with disability and their family and support staff during treatment periods in Queensland hospitals including admission, treatment and discharge.
- Disability and Health Liaison positions be established in all Metropolitan and Regional Hospitals in Queensland. These positions will be responsible for coordinating admissions and discharge planning for persons with disability receiving patient care in Queensland Hospitals.
- Action be taken to address health issues highlighted in the Office of the Public Advocate Issue Paper "In Sickness and in Health: Addressing the health care needs of adults with a decision-making disability".

6.3 2. Medical Aids and Equipment

The Medical Aids Subsidy Scheme be reformed to deliver Aids and Equipment in an affordable, equitable and timely manner.

Download the [Disability Alliance - Position Statement - Medical Aids and Equipment \(PDF\)](#)

We call for:

- A comprehensive review of the provision of aids and equipment in Queensland.
- Eligibility guidelines to be broadened in order to remove barriers to accessing equipment services.
- Access to appropriate aids and equipment to enable people with disability to live with dignity.

6.4 3. Personal Care

All people with disability living in Queensland are fully supported to live the same life as any other Queenslanders.

Download the [Disability Alliance - Position Statement - Personal Care \(PDF\)](#)

We need:

- Increased State funding to provide personal care support for the estimated 3500 people with

disability living in Queensland that are not currently supported.

- Reform of funding structures to provide more support for people with disability.
- Commitment to the introduction and ongoing research into flexible funding options that will provide better outcomes for people with disability.

7.0

OTHER AREAS OF CONCERN FOR MEMBERS OF THE DISABILITY ALLIANCE

7.1

Health Promotion

1. Meaningful inclusion of key disability peak groups in the further dialogue and development;
2. Reduction of environmental barriers to enable people with disability/ies access to a broader range of general and specialised public health programs that focus on preventing secondary conditions;

Health Prevention

3. Inclusion of routine screening for people with a disability. Examples include: osteoporosis, breast, cervical, prostate, and colorectal cancers;
4. Establishment of a comprehensive flexible case management system that goes beyond a GP centered approach to incorporate the person's disability support service provider.

Health Maintenance

5. Improvement in access to affordable aids and equipment through a nationally consistent program;
6. Improvement in capacity of hospitals to meet the needs of people with disability around hospital services and discharge planning.

Health Outcomes

7. Improving health outcomes for people across the major health priorities (e.g. cancer, asthma, diabetes, arthritis, mental health, occupational health and safety).
8. Improving the health of people who have disability.

7.2 Despite making headway in recent times people with disability face common lifelong barriers to full participation in Australian society and more specifically the health system.

- One in five Australian people still experience disability;
- There is much diversity across Australians who have a disability and so one size does not fit all;
- Explicit and implicit stigma, prejudice, attitudes and discrimination still prevail in the health system;
- Health systems and organisations can sometimes act as barriers to inclusion and rights.

7.3 In light of the evidence, the Disability Alliance cannot stress to the Health Reform Commission enough that people with disability require a specific set of reform recommendations that address the barriers to adequate health care services including performance indicators and measurements.

8.1 HOSPITAL AND HEALTH SYSTEMS

Hospitals patient care policies and procedures must be reformed to explicitly include people with a disability and their families. This requires an attitudinal shift from seeing people with disability as an inconvenience to an informed health concern. *“If we get it right for people with disability, we get it right for everyone.”* Additionally, the Disability Alliance would like the Queensland Government employ a network of disability liaison staff to:

- Act as intermediaries
- Advise on patient safety
- Ensure access to communication, equipment and patient facilities; and
- Ensure timely, appropriate and communicated discharge planning.

The Disability Alliance would also like to see action taken to address the Public Advocate’s report recommendations around the health needs of people with disability *“In sickness and in health”*

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8.2 AIDS AND EQUIPMENT

- Make medical aids and equipment free of charge;
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- Implement a more responsive system for repair and/or replacement that recognises the essential role equipment plays in mobility; and
- Begin planning for equipment on admission rather than on discharge from hospital.

8.3 PERSONAL CARE

- Provide experienced carers for people with disability in the hospital and health systems
- Personal care impacts directly on the person’s health status. If the person is not receiving adequate personal care they will be subjected to more frequent and more severe hospital admissions.

8.4 EXPLICITLY OUTLINE RECOMMENDATIONS FOR PEOPLE WITH DISABILITY IN THE HEALTH REFORM AGENDA

- Develop specific recommendations
- Development specific measureable performance indicators
- Establish measurements to establish progress;
- Consult with the Disability Community to ensure their needs are met; and
- Maintain dialogue as the recommendations are implemented and evaluated.

8.4 EXPLICITLY OUTLINE RECOMMENDATIONS FOR PEOPLE WITH DISABILITY

- Develop specific recommendations
- Development specific performance indicators
- Establish measurements to establish progress;
- Consult with the Disability Community to ensure their needs are met; and
- Maintain dialogue as the recommendations are implemented and evaluated.

APPENDIX A –

DOCUMENTED EXPERIENCES OF PEOPLE WITH DISABILITY WHO ENTER THE HEALTH SYSTEM

CASE STUDY ONE

Media Release

8 November 2006

Townsville Hospital Disgrace

“I will only enter this hospital again if I am in
a coma or dead”.

“A hospital prepared to risk my life because they claim a physio is not on call is not fit to be deemed a health service provider – and breaks all the assurances by the Queensland government about hospital care. And the people of North Queensland need to know.”

This is Kirwan resident Michael Dagan talking about The Townsville Hospital after he had to check himself out because he could get better care at home.

Mr. Dagan, a member of this Association, entered hospital last Friday with a chest infection. Physios are trained in assisting people with spinal cord injury to cough and the physio attending in the Emergency Department and later in the Ward told Mr. Dagan to have Ward staff contact her if he needed assistance because she was on call.

That night, he was in dire need of that assistance but hospital staff claimed it was the weekend and no physios were available.

Question: how can North Queenslanders have any faith in a hospital that treats a patient this way?

CONTACT:

John Mayo

Manager – Community Relations 3391 2044 or 041 888 4806

Mr. Dagan is available for interview

CASE STUDY TWO

Mr. Phil Cammish
District Manager
Cairns Base Hospital
Fax 4050 6599
Dear Mr. Cammish,

25 September 2003

Re: Treatment of patient, Mr. Bob Snell at Cairns Base Hospital

We have now secured further information concerning the above.

As we both know, Mr. Bob Snell has died in hospital since our first correspondence to your office on 29 August.

In addition to the content of our letter of 29 August, we now write to identify further information about what happened which gives us cause for serious questioning and alarm. The key elements are as follows:

Atherton Hospital talked with Dr. Goldstraw of the FIRST team and elected to transfer Mr. Snell to Cairns Base Hospital because "Cairns has better treatment facilities" and Mr. Snell was advised to anticipate a 48 hour stay at Cairns Base Hospital before release.

Atherton Hospital took x-rays of Mr. Snell prior to his transfer to Cairns Base Hospital and these showed no acute difficulty with his lungs.

Once at Cairns Base Hospital, Mr. Snell waited 12 hours for a Registrar to sign him in, during which time he shivered in emergency and his lungs commenced to collapse.

Mr. Snell arrived in Emergency at 2-30pm. The Registrar was in Emergency when Mrs. Shirley Snell arrived at 3-30pm but he left to attend other patients. At 10pm he returned to advise Mr. & Mrs. Snell that the next shift Registrar commencing duty at 10-30pm would sign Mr. Snell in.

The next shift Registrar was there at 10-30pm, talked to Mr. Snell, got a phone call, said he had to go to another part of the hospital and only returned to admit Mr. Snell at 2.30am, a full 12 hours after Mr. Snell's arrival at hospital.

We are in receipt of a letter dated 2 September from Dr. Jill Newland, Cairns Health Service District acknowledging our concerns but stating that confidentiality precludes provision of patient information to a third party such as ourselves. On that advice, we are asking Mrs. Snell to take the matter up with Dr. Newland.

However, from our own perspective, you will understand our enormous concern and anxiety over the treatment to our member, Mr. Snell, a recent State Government award recipient for excellence acknowledging his continuous service to the Tablelands community.

Yours sincerely,

Mark Henley
CC
The Hon. Wendy Edmond, MP
Dr. Goldstraw, FIRST, Townsville
Dr. Jill Newland, Cairns Health Services District
Mr. Bruce Picard, Queensland Health

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CASE STUDY THREE

Name: George Dougherty (member)
Address: 70 Whynot St West End QLD 4101
Ph: 07 3844 2949 or 0418 769 397
Email: georgedou@optusnet.com.au

Complaint 1

Admittance: 27 July 2009

Discharge: 07 August 2009

Hospital: Princess Alexandra Hospital – Infectious Diseases Ward (5D)

Bowl Evacuation Procedure (lack of):

- Staff operating in the Infectious Diseases Ward 5D, where George was admitted, would not perform a digital stimulation to evacuate George's bowels while he was admitted. The staff claim they were not allowed to perform such a procedure.
- In order to have this procedure, George had to contact his carers and ask that they come to the hospital and perform the procedure.
- On 31 July, George went to the Spinal Unit at the hospital to ask if one of the nurses could be available the following day to perform the bowl evacuation procedure, as none of his carers were going to be available that day. George spoke to a male nurse called Mick and Mick agreed to come the following day to the Infectious Diseases Ward and perform the procedure.
- On 01 August, after the male nurse Mick had assisted George with the procedure, Mick made it clear to George that coming and performing the procedure for him was a one off favour and that he would not be able to assist George with such a request on a regular basis.
- Question: What if someone with similar care needs was in the same position as George, but was not as capable or proactive as George with their ability to find themselves adequate care? What would happen? – The bowl evacuation procedure would simply not take place and this has obvious health risks and implications.

Emergency Call Button:

- In addition to the lack of care in regards to the bowl evacuation procedure, George claims he was totally unable to use the emergency call button near his bed.
- George claims he could not access the button due to the combination of its position and his disability.
- When George did in fact need to use the button in order to call a staff member, he was forced to ask the patient in the bed next to him to use their call button. However, later on this person was in fact moved and George was left with no ability to contact staff if he in fact needed to. He was in a room on his own with no ability to use the emergency call button.

Care Package:

- No care package for George was discussed on admittance.
- George is unsure whether this is hospital policy or not to provide this type of assessment?

- If the hospital had assessed what sort of patient George was in regards to his level of needs and care then perhaps dangerous situations, such as the emergency call button being out of George's capability to use, could have been avoided.

Complaint 2

Admittance: 25 August 2009

Discharge: (still a patient)

Hospital: Princess Alexandra Hospital – Infectious Diseases Ward (5D)

George was admitted again into the same ward as his last admission and is experiencing the exact same problems as before:

- No staff will perform a bowl evacuation procedure and staff will not contact someone from the Spinal Unit to come and perform this procedure for George.
- The emergency call button is still unavailable for George to use in case of emergency.
- It is obvious that upon George's second admission a care package was not drawn up – the hospital does not know what level of needs and care George requires as a patient.
- When George requested someone from the Spinal Unit to come to Ward 5D to perform the bowl evacuation procedure, he spoke to a nurse in Ward 5D who said she would contact the Spinal Unit and inquire if someone from there could come and perform the procedure. The nurse did so, and was told by the Spinal Unit that this was not possible.

Notes on emergency call button 28/08/09:

- Nurse Manager in Ward 5D (Kylie) is attempting to deal with the bedside emergency call button by instituting a regime whereby George is reviewed every hour 24/7.
- We have learnt that the emergency call button system in the Spinal Injuries Unit is not compatible with other hospital wards at the PA hospital. Therefore, this means that a patient with George's level of care needs cannot use the emergency call button in a ward such as Ward 5D because the system is not designed for a patient such as George (emergency button system does not cater for people with George's level of disability).

Complaint 3

Admittance: 01 September 2009

Discharge: (still a patient)

Hospital: Princess Alexandra Hospital – Infectious Diseases Ward (5D)

- George attempted to make contact with Dr. Tim Geraghty from the Spinal Unit at the PA Hospital today, in order to have the bowl evacuation procedure performed on George.

N.B. George was informed by the Association that Dr. Tim Geraghty would be able to help facilitate this procedure due to the fact no one at the hospital was willing to go to Ward 5D and perform it for George.

- George asked the nurse in Ward 5D to contact Dr. Geraghty at the Spinal Unit.
- The nurse returned and told George that staff at the Spinal Unit said there was no direct contact with Dr. Geraghty.
- The nurse also told George that the Spinal Unit once again refused to send staff over to Ward 5D to perform the bowl evacuation procedure.

N.B. George is adamant and very worried the bowl evacuation procedure will not take place and put his health at risk. The procedure needs to happen by tomorrow – 02 September 2009.

Complaint 4

13 October 2009

Hospital: Princess Alexandra Hospital – Ward (5C)

- George's wife Hazel phoned the Association to detail the concerns she has for George regarding the treatment he is receiving from staff in the hospital.
- Hazel states that George is being bullied by the hospital staff.
- An example of this is an issue regarding a recent hoisting procedure. George, Hazel and George's usual carer (Quinn) argued with hospital staff regarding the way they were performing this procedure, arguing that the hospital staff were performing the procedure incorrectly and that Hazel and George's carer could show them the right way to manage the hoist in order to best perform the procedure.

Hospital staff told Hazel and George's carer that they did not want advice on how to perform their job and that they knew what they were doing.

George suffered from this procedure and experienced markings on his body from hoist.

- Another example of the lack of professionalism in regards to the care George is receiving is when the hospital ran out of KY Jelly. Hazel had to travel to the pharmacist to purchase some for George due to the hospital not having any of its own.
- Further examples:

George's bed is positioned next to the toilet. The bed is so close to the toilet that in order to have the hoist positioned next to George's bed, the bed itself has to be moved every time.

George's bed also has a large rubbish bin positioned right next to it. This bin has various hospital rubbish placed in it, for example, dirty under sheets. The most worrying issue is that the bin is uncovered and situated so close to George's bed – this is not a sanitary situation.

No paper towel dispenser in bathroom.

Emergency call button at George's bed doesn't work, even after being replaced.

George has lost 3kgs in the last week – stress related as George is in fact eating quite well.

As well as having skin issues post hoist/sling incident due to the hoisting, George has other areas affected besides the areas effected from the hoist and these are making life difficult to perform tasks like sitting up.

Wound were absis is located was is now worse in last week.

- George is worried and frightened about his own physical well being and feels unsafe after judging the care he has received from the hospital. In his own words to his wife Hazel, he fears that “the only way I'll get out of this hospital is in a box.” He feels that hospital staff are going to hurt him simply because they refuse to listen to advice being given to them from himself, Hazel and George's various carers. His quality of life is decreasing because he feels the hospital staff are not treating him as a person.

14 October 2009

Hospital: Princess Alexandra Hospital – Ward (5C)

- George phoned the Association to detail his latest issue regarding his stay in the hospital.
- George states that hospital staff hassled his carer (Mohamed) on the 13.10.09 with regards to certain procedures Mohamed was attempting to perform on George.
- George states that when Mohamed attempted a procedure, such as bowl therapy or using the hoist, staff would hassle Mohamed by saying that he shouldn't be performing such a complex procedure due to the fact he isn't qualified.

George believes that this indicates lack of knowledge on hospital staff's behalf regarding the role and competency of personal carers.

To add to this, the hospital staff are perfectly happy to let Mohamed perform less complex tasks so that they themselves don't have to perform these 'simple' tasks.

15 October 2009

Hospital: Princess Alexandra Hospital – Ward (5C)

- George phoned the Association to detail his latest issue regarding his stay in the hospital.
- A staff member came to George on the 14.10.09 and advised George to run shower water over wound on back of George's neck, without any bandaging covering the wound, as well as advising George to sit in the toilet with the wound uncovered.

- George was later advised by other staff that this shouldn't have taken place and that the wound needed kept sealed in the shower and toilet area.
- John Mayo queried as to whether any staff from the Spinal Unit had come to visit George today. George, as of 4:30pm, advised that this had not taken place.

CASE STUDY FOUR

30 April 2009

Dear Sir/Madam,

Complaint against Townsville General Hospital (Psychiatric Unit)

I, Leanne Dawn Holland, wish to complain about the Townsville General Hospital – Psychiatric Unit. My complaint refers to my admission to the hospital during the dates of 10 February 2009 and 16 February 2009.

I am a person with quadriplegia (T7) who has a schizophrenic effective disorder. I started to become mentally unwell on the 23 January 2009.

10 February 2009

On the 10 February my mental condition caused me to burn myself intentionally due to the fact I hear voices telling me to do so. I inflicted burns to my fingers and lip. After this occurred my mother, Dawn Holland, accompanied me to the Townsville General Hospital Emergency Department at about 3:30pm. Upon arrival my mother was told by a nurse from the Intake and Assessment Team they could do nothing for me as I was not communicating correctly. My mental condition at that particular time caused me to be paranoid and highly untrusting of anyone, thus rendering me unable to communicate effectively. The nurse tried again to talk to me, this time with my mother in the room. My mother was then told that I would be admitted.

At 4:55pm, my mother and I were then told to wait in the Emergency Department until I could be taken to the Psychiatric Unit. At about 9:45pm we were escorted to the Unit by a female staff member. Upon entering the Psychiatric Unit another female staff member walked past my mother and I and, in a very unfriendly manner, said that we were an admission she did not know about and that we were to wait until someone could proceed with the admission.

My mother then got me into bed and realized I had had an accident (bowel movement) while waiting to be admitted. Due to my state at the time I did not mention this to my mother. My mother then proceeded to clean me up on her own. There was nothing available for my urine bag to be attached to for drainage throughout the night (upon admission my mother had explained to staff that I would have to have the bag emptied throughout the night). A nurse, Mary, said she would put this in the notes and that someone would check on the situation. This did not happen, and as a result I was forced to empty the urine bag into the waste paper basket which was not fully reachable and the contents of the bag spilt everywhere.

My mother advised staff that I was on a medication (Resperidal, Effexor and Warfarin) and that I needed to be receiving this medication at a certain time. The hospital staff advised my mother that the hospital could not take the medication from her and that they would have to administer their own supply of that medication. This did not happen that night or the next morning I was in the hospital. I therefore did not receive my regular medicine intake.

The evening of the 10 February 2009 was a very restless one. I was up all night and frightened with no one there to assist me to get out of bed if I needed to. This resulted in me propping myself up on my elbows for extended periods of time which caused the skin on my elbows to be removed. I would wake up

between 4:00am and 5:00am every night while I was admitted to the hospital. The first 3 mornings I was given assistance to get out of bed at 7:30am, the rest of my stay at the hospital I was only given assistance to get out of bed at 10:00am. This resulted in my missing breakfast on a number of occasions.

11 February 2009

On the 11 February, I phoned my mother to ask if she would please bring my shower chair from home to the hospital as the shower chair provided at the hospital was not appropriate (flat, hard and not padded). My mother arrived at the hospital at around 10:00am and dropped the chair off at the main desk and requested it be delivered to me. At about lunch time the chair had still not arrived. I advised staff that my chair had been delivered to the front desk. I eventually received my chair in order to have a shower at about 2:00pm.

The burns I had inflicted on myself prior to my admission to the hospital were reported to the nurse from the Intake and Assessment Team on my arrival to the Emergency Department on the 10 February 2009.

12 February 2009

On the 12 February, I rang my mother to inform her that nothing had been done about these burns. My mother, fearing the hospital would not attend to this, contacted the Spinal Injuries Association in Townsville for advice and spoke to the Manager Mary Langdon. Ms Langdon gave my mother the number for the North Queensland Spinal Service at the hospital. My mother spoke to a female person by the name of Kathie, who said she would come to see me but she never did.

My mother came to visit me on the 12 February 2009 at about 2:15pm. A nurse accompanied my mother to my room and upon entry to the room the nurse asked me if I had been "complaining?" My mother told the nurse that in fact it was her who had made the enquiries and not me. By this stage I had received some dressings on my elbows (from where they had rubbed raw from propping myself up) and on my finger (from the burns I had inflicted on myself). Later that day a nurse by the name of Sue from the Wound Clinic came to look at my burns. She informed my mother and me that Kathie from the North Queensland Spinal Service had telephoned her.

I had also spilt hot coffee on myself on the 12 February 2009 and didn't realize I had burned myself. When I was either being showered or being dressed, one of the nurses had noticed the burns due to the coffee spill on my backside near the crease of my leg and noted that this needed treatment. I would like to note that this is an important area of skin for wheelchair users as there is a lot of pressure placed on this spot, the skin becomes thin and susceptible to pressure sores. My mother got the wound nurse, Sue, to check the burns and she said that it would need to be monitored. Sue, the wound nurse then dressed the wounds and said she would try to get back the next day to check on them. Sue also said that the dressing on the burn on my finger needed to be moistened to make the ointment work. None of this happened.

13 February 2009

During my mother's visit on the 13 February I told her that my finger was extremely sore, throbbing and very red. My mother contacted my nurse at the time and said something needed to be done about my finger. The nurse said that if the wound nurse (Sue) said she was coming back to look at the burns then that would do. As it was getting later in the afternoon and being a Friday, my mother asked the nurse if she would please check to make sure that Sue the wound nurse was coming. The nurse then checked and said that Sue wouldn't be able to make it as she was too busy. My mother then asked if a doctor could attend to the burn as nothing would be done over the weekend. A doctor did see it and took a swab, put me on antibiotics and dressed the finger. I would like to note at this stage I was still suffering from my mental condition and was still hearing voices.

16 February 2009

On 16 February my mother came to visit me at about 2:30pm. The wound nurse arrived to dress my burns. At this stage the burn on my lip was never seen to, my mother was the one who applied cream she had brought from home. This morning the staff did not get me up until 9:30am. When the nurses eventually got me out of bed I asked if they could please look at the burns on my backside. The nurse responded by saying that the burns would be ok. It was put in the notes that the burn had to be checked daily and when I raised this with the nurse she still refused to check it. Later, the wound nurse and my mother checked the burn. The wound itself was ok but welts had appeared where the plaster was. The wound nurse then went away to get the correct cream.

During this time the room I occupied was full of flies due to the fact the toilet had been soiled and not cleaned for a long time. My mother then cleaned the toilet herself and did not complain to staff. The wound nurse and my mother then got me out of bed with the hoist as there didn't seem to be any staff around in order to help with this procedure. Sue the wound nurse then said she was going to give Kathie from the North Queensland Spinal Service another phone call as the current situation I was in was not good enough.

I would like to note at this point that in regards to the nursing staff's ability to use the hoist they were totally unprepared and untrained to undertake such a task. On a number of occasions I was hurt by staff when it came time to using the hoist for moving me in and out of bed or in and out of the shower chair. On one occasion I was forced to move my bowels in bed as the nurses did not know how to operate the sling. Another point in relation to the hoist use is that staff used to take my pants off in the shower chair rather than in bed. This meant that they didn't have to put me into bed, take my pants off and then hoist me out again. This put me in an incorrect, highly uncomfortable and painful position which made my legs numb. I would also like to point out at this stage that I was still mentally unwell and so was therefore unable to voice my concerns or help myself at moments when ordinarily I would be able to do so.

My mother left the hospital on the 16 February at about 3:45pm. When my mother arrived home she received a message from the hospital via the Spinal Injuries Association that the hospital wanted my carers put in place so that I may be discharged. My mother did not agree at this stage that my mental state had improved enough for me to be discharged and that it was in fact too early for such a course of action.

My mother advised a nurse (Mary) that if I was well enough to be discharged, then the hospital should wait until the next day so that things may be put in place to organize the extra care that I needed upon my return home. If I had been discharged that day, I would have been without a carer until 10:00pm that evening. My regular carers, at this stage, were advised that they were not needed until further notice.

At about 5:00pm that day my mother spoke to Natalie from the Spinal Injuries Association Townsville Office, and was informed by Natalie that the hospital had said that they did not have the resources to take care of me and that they wanted me discharged. My mother advised Natalie that she did not agree with this as it was so late in the day and thus difficult to organize any sort of care for me upon arriving home. My mother tried 3 times to reach me at the hospital and was told to ring back in half an hour each time. At the same time my mother was trying to contact me in the hospital I was trying to contact her, however the staff at the hospital made it impossible for me to do this and thus appropriate care was not organized upon my arrival at home. My mother received a phone call from the hospital at about 7:00pm informing her that I had been discharged (even though they knew I did not have the appropriate care ready for my arrival home).

17 February 2009

On the 17 February, after I had been discharged, my carer noticed a burn to my stomach, in my navel and around it which was quite infected. An appointment had to be made with my GP to have this looked at and attended to. These burns were from when I spilt coffee on myself and were not noticed or attended to by hospital staff.

Conclusion

In conclusion, I would like to state that the general treatment I received from hospital staff was terrible. Not once was I asked by staff how I was feeling or if I wanted to discuss my problems. Once I needed help emptying my urine bag and the nurse replied "Do it yourself." I had to empty the bag into the sink as I obviously couldn't physically make it to the toilet.

I believe this is a situation where a person with a spinal cord injury enters a mental unit and staff are not trained to look after such a patient. If the Townsville Psychiatric Unit cannot provide this care, Queensland Health must put a facility in place that can.

Given my treatment by hospital staff was inappropriate, degrading, unprofessional and frankly inhumane, questions must be asked about the policies, procedures and behaviors of this hospital and of its management team.

Yours sincerely,

Leanne Holland

Leanne Holland
7 Pelorus Court, Wulguru, QLD 4811
Phone (07) 4729 0206
Email: hleanne@yahoo.com

Date of birth:

09/08/69

Complaint against:

Townsville General Hospital – Psychiatric Unit
100 Angus Smith Drive
Douglas
QLD 4814
Phone (07) 4796 1111

Dates: 10/02/09 – 16/02/09

CASE STUDY FIVE

July 2009 (name withheld at request)

Hospital – Prince Charles

This young woman has the disability of chronic arthritis and is unable to speak and so uses a computer to type messages and communicate. This woman had to have a hip replacement in Prince Charles. Upon admission staff took her communication device off her when they were asking her about her pain because they felt she was asking too many questions.

This caused an increased stress and distress experience for this woman. The fear and distress was so intense that the woman left too soon following the operation because she did not feel safe in the hospital and felt that she would die if she stayed.

Strong advocacy by the carer enabled communication although

CASE STUDY SIX

July 2009 (name withheld at request)

Hospital - Royal Brisbane and Women's Hospital

This woman has Cerebral Palsy (CP). In 2006 she had an intrathecal catheter inserted into her spine and attached to a pump for morphine managed pain relief. In 2007 the woman went to her doctor because the catheter had stopped working.

In late 2007 the client had two hip replacements. In order to feel safe the client took her partner with her on a 24/7 basis to care for her because she felt unsafe in the hospital environment.

An IV was inserted into her left hand although staff did not stabilise the drip and the spasms from her CP rendered the IV useless. While this person was, on the whole, independent no thought by medical staff went into where the IV should be strategically placed in order to maintain her independence. Because the IV was inserted into the only useable arm the client had she had to rely on her partner when she needed to go to the toilet.

The recovery phase was made extremely difficult because of the client's addiction to morphine which was administered as a palliative treatment in the first instance instead of a normal route treatment of the hip replacement.

In July 2009 the client was admitted to hospital again to have the Morphine pump removed. While the client was supposed to remain in hospital for three days and lay flat she was conscious of the bad experiences of the previous admissions and so went home early.

CASE STUDY SEVEN

August 1 2009

Princess Alexandra Hospital – Brisbane

A mother with disability was booked into hospital for facio maxillary surgery. To follow through with the surgery, the mother had to arrange child care, organise a carer, and notify service providers of the pending surgery and though adjust times of support provision.

When she arrived at the hospital she was informed that the surgery could not go ahead because the hospital had lost the patient file and that she was to go home.

November 2009

APPENDIX B – FULL BRIEFS AROUND

- 1. HEALTH AND COMMUNITY HEALTH CARE FOR PEOPLE WITH DISABILITY**
- 2. AIDS AND EQUIPMENT**
- 3. PERSONAL CARE**

Our position on Queensland hospitals and community health care

Queensland hospitals' patient care policies and procedures must be reformed to explicitly include people with a disability and their families.

The problem

The problem with patient care policies and procedures in Queensland hospitals is that currently, they result in:

1. people with disabilities being neglected to the point that they are made vulnerable by the health system;
2. a reluctance from people with disability to enter the health system (which also makes them vulnerable);
3. disability support workers being required, in many places, to support their clients throughout every stage of contact with the hospital (which is a poor use of resources); and
4. people with disability experiencing poor health outcomes due to a lack of timely access to support (for things like communication and assistance to navigate the health system).

The solutions

Queensland hospitals' patient care policies and procedures must be reformed to explicitly include people with a disability and their families. Additionally, the Disability Alliance would like the Queensland Government to employ a network of Disability Liaison Staff to:

- act as intermediaries;
- advise on patient safety;
- ensure access to communication, equipment and patient facilities; and
- ensure timely, appropriate discharge plans.

The Disability Alliance would also like to see action taken to address the health issues highlighted in the Office of the Public Advocate's Issue Paper *In Sickness and in Health: Addressing the health care needs of adults with a decision-making disability*.

The benefits to Queensland

Funding Disability Liaison Staff in Queensland hospitals whose work was guided by patient care policies and procedures that included people with a disability and their families would:

1. create jobs;
2. freeing up hospital beds;
3. reduce the frequency of health complications for Queenslanders with disability; and
4. reduce subsequent readmissions into hospital.

Make a difference this election

Call on your local Member to publicly support reforms to patient care policies and procedures to include people with a disability and their families.

www.disabilityalliance.org.au

Our position on medical aids and equipment

The Medical Aids Subsidy Scheme must be reformed to deliver aids and equipment in an affordable, equitable and timely manner.

The problem

Queensland's Medical Aids Subsidy Scheme is the worst in the nation. People cannot afford the medical aids and equipment they need, which means that Queenslanders:

1. have less independence (relying more on family and service providers than they would otherwise need to);
2. have longer hospital stays than they need; and
3. can be re-admitted to hospital with complications and infections caused by inappropriate equipment.

The solution

The Disability Alliance believes the solutions to this shortfall simple and affordable. They are:

1. Make medical aids and equipment free of charge;
2. Loosen the restrictions on eligibility;
3. Implement a system for repair and/or replacement; and
4. Begin planning for equipment needs on admission rather than discharge.

The benefits to Queensland

With adequate access to medical aids and equipment available to Queenslanders who need them, Queenslanders with disability will have:

- shorter hospital stays (with fast and efficient discharge system);
- less health complications from poor handling, inappropriate medical aids or no equipment at all;
- a better quality of life;
- improved health;
- less reliance on carers and service providers; and
- greater participation in the workforce (and tax system).

Make a difference this election

Call on your local Member to publicly support reforms to the Medical Aids Subsidy Scheme that will deliver aids and equipment in an affordable, equitable and timely manner.

www.disabilityalliance.org.au

Our position on personal care

Queenslanders with disability should have adequate personal care to be supported to live the same life as any other Queenslander.

The problem

Thousands of Queenslanders who are eligible to receive personal care and/or support are unable to access the support they need, resulting in:

- a poor quality of life of thousands of Queenslanders;
- young people with disability being housed in aged care facilities and other inappropriate arrangements;
- Queenslanders with disability unable to work (and pay tax);
- family breakdowns across the state; and
- undue pressure on other areas of the community (including family and community services, and the criminal justice system).

The solutions

There are three clear course of action that the Disability Alliance would like to see the Queensland Government adopt:

1. Fund support services for the estimated 3500 people with disability who have applied for support.
2. Reform funding structures to reduce the compliance burden and free-up resources to provide more support for people with disability.
3. Commit to ongoing research into flexible, individualised funding options that will provide better outcomes for people with disability.

The benefits for Queensland

Queenslanders want to look out for each other. It would be more than a benefit — it is an honour — if we were able to say, "Queenslanders support our neighbours in need." Additionally, supporting Queenslanders with disability to live normal lives would:

- improve the quality of life of thousands of Queenslanders;
- create jobs;
- reduce the reliance on families and carers; and
- promote greater participation in the workforce (and tax system).

Make a difference this election

Call on your local Member to publicly support increasing the availability of personal care for Queenslanders with disability.

www.disabilityalliance.org.au