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Disability Liaison Officer (DLO) Project

Final Project Report
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Delivering a **Healthy WA**

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CONTENTS

EXECUTIVE SUMMARY

This report provides an analysis and evaluation of the introduction of Disability Liaison Officers (DLO) into the WA Health system, Perth. It provides the basis for a proposed trial of this role.

The Disability Liaison Officer Project (Phase 1) was conducted over a six month period from April to October 2013. The aim of Phase 1 was to scope the needs in North Metropolitan Health Service (NMHS) and South Metropolitan Health Service (SMHS) adult tertiary and secondary hospitals for people aged 18-65 years with complex disability and how services that support these consumers can be improved, enhanced or newly implemented.

An extensive stakeholder consultation process was conducted to gain insight into the current service challenges and demands pertaining to inpatient care of patients with complex disability. This was achieved via individual interviews, group interviews, questionnaires, focus groups and open group consultation sessions. The key issues that were raised were: no access to one central point of patient information; poor awareness of and attitude towards disability; fragmented and poorly coordinated disability services across NMHS, SMHS and the community; resource limitations which impact on hospital service delivery; lack of disability education and training; and absence of disability service delivery models.

In addition, data was obtained from sources including; WA Health Epidemiology, Disability Services Commission Community Aids and Equipment (DSC CAEP), and ABF analysis, in order to analyse current service delivery and provide a baseline which describes the current experience of people with disability entering the hospital system.

This report describes the potential role of a Disability Liaison Officer based on the evidence presented by consumers, stakeholders, Epidemiology data, health reform initiatives and potential ABF cost savings. This report presents a number of options for the introduction of DLO's into NMHS and SMHS. The preferred options for a pilot are:

1. **NMHS** - place the DLO at SCGH within the inpatient complex care team (SWAT).
2. **SMHS** - place the DLO at Armadale Health Service (AHS) supported by the Complex Needs Coordination Team (CoNeCT).

It is imperative that disability service delivery is seen as a priority in NMHS and SMHS and funded accordingly. The summary recommendations include; endorsement of a 12 month pilot of a DLO in both NMHS and SMHS; establishing governance for these positions; identifying methods to evaluate the success of the DLO positions; ensuring that the DLO

positions work collaboratively across NMHS and SMHS and across the health and disability sectors.

1.0 PURPOSE

The DLO Project report describes the process and outcome of the investigation, data analysis, stakeholder liaison and consultation which was undertaken to scope the potential need for DLOs in NMHS and SMHS.

The Department of Health (DoH) WA and the Disability Services Commission (DSC) partnered to jointly fund two Project Officers (one based in NMHS and one based in SMHS) for 6-months (from April 2013) to scope and map the demand and potential role of a DLO and build capacity to improve the inpatient stay for people with complex disability in the hospital system. This paper will present the service challenges and proposed options for DoH WA and DSC to consider in the planning of disability health service delivery.

1.1 Disability Liaison Officer Project

The aim of the DLO project was to scope the needs in NMHS and SMHS adult tertiary and secondary hospitals for people aged 18-65 years with complex disability and how services that support consumers with a disability can be improved, enhanced or newly implemented. Excluded were: adults aged over 65 with disability (i.e. older adult); mental health as the primary diagnosis; children with disability; transition stages (i.e. from child to adult care, adult to older adult); emergency department presentations and primary health care.

Phase 1 of the project has focused on *inpatients* with *complexity* of need related to disability, with consideration of outpatient and ambulatory care services. Phase 2 of the project anticipates implementation of a pilot trial DLO in NMHS and SMHS.

2.0 BACKGROUND & DRIVERS FOR CHANGE

2.1 Clinical Senate

The DLO Project originated from the Clinical Senate report recommendations of the Health and Disability senate debate in June 2011 titled ‘Clinicians – Do you see me?’. The mandate for senators was to consider what they could do to improve the acute-care experience for people with a disability who interface with the Western Australian health system.

From this debate nine recommendations were made to the State Health Executive Forum (SHEF) of the Department of Health. In December 2011 the Director General of Health announced that three recommendations were endorsed by the SHEF:

- **Recommendation 1**: *The Department of Health will work in collaboration with the Disability Services Commission and other relevant agencies to establish a Disability Health Network;*
- **Recommendation 2**: *The Department of Health introduces Disability Liaison Officers in all adult tertiary/secondary health services. (the recommendation pertaining to this document);*
- **Recommendation 3**: *SHEF to direct the DOH to develop a living with disability awareness and training program for all DOH staff to change the service model to one of partnership with people with disabilities and their carers.*

The remaining six recommendations were referred to the newly formed Disability Health Network (DHN). See Appendix 1 for the Clinical Senate report.

2.2 Disability Health Consultative Group Launch

The Disability Health Consultative Group (DHCG) was launched in July 2012. It attracted representatives from the DSC, DoH, Health Consumers Council, disability sector organisations, advocacy agencies, and people with disability, families and carers. The participants examined the nine recommendations from the Clinical Senate Debate of 2011 and provided input into their implementation. Work that had already been undertaken in the WA health system was recognised and incorporated where appropriate. The DHCG Launch Paper (2012) summarises the contributions of over 70 stakeholders, including people with disability, carers, families, support workers, advocates, peak disability bodies, and health and disability professionals. The recommendations made by this group (Appendix 4) form one of the guiding resources for the DLO project. They highlight the wide range of issues arising when health care is considered from the perspective of the health system, clinicians, individuals and carers. Other guiding documents are listed in the additional bibliography (Appendix 15).

2.3 DLO Project Advisory Committee

The NMHS / SMHS Project Advisory Committee (PAC) was established to operate as an advisory committee to support the project officers in achieving the project goals. The PAC was made up of clinicians from NMHS and SMHS, representatives from the Aged and Continuing Care Directorate DoH and a consumer representative. The PAC met monthly

with the project officers to discuss progress of the project and provide advice and support. In addition, two focus groups were held with the PAC to inform the options paper. Members were presented with summaries from all of the available data sources and invited to discuss and prioritise the issues arising and problem-solve solutions. The PAC supported Phase 1 of the DLO Project, and its role in supporting Phase 2 (implementation of Pilot DLO) is pending the outcome of this report.

2.4 DLO Project Steering Group

The DLO Project Steering Group (PSG) was established to support and guide the project. Membership of the PSG included representatives from the DHN, DSC and project managers from WA Health who had line management responsibility of the project officers and overall carriage of the DLO project. The PSG met with the project officers approximately every two months. This group reports to the DHN Executive Advisory Group and provides a decision making and advisory forum which supports the DLO project.

2.5 Literature Review & Disability Complaints

"The current disability support system in Australia is considered to be very poor." [1]

Approximately one in every five Australians has a disability.[2] People with disability are a highly diverse group and their health conditions can be visible or invisible; temporary or long term; static, episodic or degenerating; painful or inconsequential.[3, 4] However what they have in common is a recognised unequal access to health care services and therefore unmet health care needs compared with the general population.[2, 3, 4]

Despite relatively limited data regarding the health of people with disabilities in Australia,[2, 3] it is known that their health is generally lower than that of their non-disabled peers [2, 5] and that they will require more inpatient and outpatient care than people without disabilities.[4] People with disability and their carers often report that their experience of the health care system is negative, and patients state that they encounter stigmatization and discrimination.[4] They also report coming into contact with health care workers who have negative attitudes towards, little knowledge of and little experience working with, people with disability.[4, 6]

These issues are starting to be addressed in WA and nationally. The National Disability Strategy sets out a ten-year national plan for improving the life for Australians with disability,

including a commitment that "people with disability attain highest possible health and wellbeing outcomes throughout their lives".[5, p59] Locally, the 'Count Me In' consultative paper[7] recommends that access to health and mainstream services be a priority area in Western Australian policy and development. The Clinical Senate Debate, Disability Health Consultative Group Launch, Disability Health Network and Disability Liaison Officer Project are examples of some of the work undertaken in WA around the issue of improving health access and outcomes for people with disability.

Some disability complaints from the Patient Liaison Service in 2012/13 are presented below to set the scene for this report;

A few examples of Disability Complaints from 2012/2013:

- Concern regarding **communicatio**n of the Doctor (Dr) assessing patient.
- Patient alleges Dr was dismissive of the interpreter and patient's support person.
- Inadequate **communication** re: late **cancellation of surgical procedure** & length of time to wait to be booked in for alternative procedure.
- Concern regarding **communication from treating team with family** re: patient's ongoing management plan.
- Patient had a shunt, was **denied pain medication. Not informed regarding results** of scan, nor asked regarding shunt before MRI.
- **Long Length of Stay (LOS)** - refusal by community agencies and kept on ward for 19-days when medically fit.
- Patient with Intellectual Disability (ID) - refusal of x-rays on 3x admissions when foot was broken. **Did not understand the needs of the patient**.
- **Infrastructure** - parking, cost of parking, walking distance of parking, meter locations, signage, no ceiling hoists on wards, no room on wards for essential equipment.

2.6 Definition of Disability

From a review of the literature surrounding national and international definitions of disability, the disability definition for the DLO Project, as endorsed by the DLO Steering Group and agreed between Department of Health WA and DSC on the 15th May 2013 was based on World Health Organisation International Classification of Functioning, Disability and Health (WHO ICF). This was to ensure that the DLO project would align with national and international definitions of disability and furthermore, this definition was more inclusive to the hospital system. A full definition of disability is outlined in Appendix 2.

2.7 Policy & Planning Context

Clinical Services Framework 2010

The WA Health Clinical Services Framework 2010-2020 (CSF 2010) is the state-wide structured plan for clinical services over the next 10 years. The role of the CSF is to provide a breakdown of clinical service levels across the state and projections of future service needs to guide service planning delivery. The publication of the CSF 2010 reinforces efforts to ensure openness and transparency in the WA public health system to meet the needs of the community. Please refer to the WA Health website for more information: http://www.health.wa.gov.au/publications/documents/CLINICAL_SERVICES_FRAMEWORK_WEB.pdf

Models of Care

Models of care provide an overarching framework to improve the care and flow of patients in the acute inpatient setting and across the patient continuum. They are underpinned by evidence-based practice and can provide guidance and shared understanding to clinicians, frontline staff, managers and Executives. WA Health does not currently have an over-arching model of care for disability, but relevant models of care to the disability cohort developed by the WA Health Networks include:

- The Stroke Model of Care (2012)
- Chronic Lung Conditions (2012)
- Motor Neurone disease (2008)
- Morbid Obesity (2008)

National Health Reform and Activity-based Funding

Western Australia agreed to sign the National Health Reform Agreement (NHRA) in November 2011. The NHRA is a nationwide agreement which will improve the transparency, governance and financing of Australia's health care system. Operational since July 2012, Activity Based Funding and Management (ABF/M) is the way that the WA health system is funded and managed for public hospital services. ABF/M facilitates a more efficient delivery of health services by measuring activity, application of a determined efficient price and

classification system (e.g. Diagnostic Related Group DRG for inpatient services). For more information about Activity Based Funding – please refer to the Independent Hospital Pricing Authority (IHPA) website: www.ihpa.gov.au/. Activity Based Funding allocation is based on: *price*, *activity levels* and *Weighted Activity Units* (WAU's) as per the equation below:

Further discussion of the benefits of the proposed DLO roles with regards to ABF is outlined in section 5.4 below.

Admission, Readmission, Discharge & Transfer Policy

The Admission, Readmission, Discharge and Transfer (ARDT) Policy provides a set of clear and consistent rules around criteria for counting and classing activity. An *admitted* patient is defined as a person who meets admission criteria to an admission category and care-type to undergo treatment and/or care over a period of time, for a minimum of four hours. A *readmitted* patient is defined as an admission of a patient either for the same condition or related one to the same establishment, within 28-days. This Policy also defines same day admissions, changes to care type, patient leave, Hospital and Rehabilitation in the Home (HITH, RITH), subacute care assessment and planning, Non Acute -Maintenance - Nursing home type patients and transfers. The ARDT Policy can be found here: http://activity/post/2013/01/29/Revised-Admission-Readmission-Discharge-and-Transfer-(ARDT)-Policy-Information-Session-19-November-2012.aspx

3.0 HEALTH REFORM & SERVICE OVERVIEW

3.1 NMHS Health Reform

NMHS is implementing a number of service reforms. Some of the key policies and systems underpinning NMHS major reform initiatives include: *NMHS Strategic Plan 2012-2015*, *NMHS Stakeholder Engagement Framework*, *NMHS Telehealth Plan*, *NMHS Workforce models and planning*, *NMHS Workforce Transition Services*, local site Clinical Service Plans (CSP's) the *NMHS Framework for Reform 2013.* Some of the key focus areas for NMHS include:

- Transition to the new Midland Public Hospital
- Interface with the New Children's Hospital

- Decommissioning and reconfiguration of services at Swan and Kalamunda Health Service
- Expansion of Joondalup Health Campus
- Mental Health reform partnership with WA Health Office of Mental Health and the Mental Health Commission
- Metropolitan medical credentialing database

These reform initiatives may influence decisions regarding the introduction of a DLO in NMHS. A summary of some of the proposed changes is provided in Table 1 below:

Table 1: NMHS Key Site/Service Changes

NMHS Site/Service	Proposed Reform	Implication
Joondalup Health Campus (JHC)	Expansion of JHC due to growth trends in admissions & population placing increasing demands on the hospital.	Growth
Osborne Park Hospital (OPH)	OPH will move to providing more speciality services (Maternity/Obstetrics, Rehabilitation). Outpatient redesign and elective surgery planning are also a focus (one service across SCGH & OPH).	Focus moves to specialties that are out-of-scope for DLO project.
Sir Charles Gairdner Hospital (SCGH) * *Tertiary*	Speciality service planning (respiratory, palliative care, rehabilitation, neurology), mental health inpatient unit planning, outpatient service redesign and elective surgery planning (one service across SCGH & OPH).	Growth
Swan and Kalamunda Health Service (SKHS)	Swan Districts Hospital - decommissioning of the facility and services, as well as associated workforce transition (including supporting staff affected by the closure). Kalamunda District Community Hospital (KDCH) – speciality planning, governance planning, redesign and community linkages (e.g. allied health, primary care). KDCH will continue to provide mainly subacute care.	Decommissioning/ Reconfiguration
Midland Public Hospital (MHC)	Preparing for the opening of the new MPH, workforce transition planning, review of service profile and contract negotiations between St John of God Hospital and WA Department of Health.	Redevelopment

3.2 SMHS Health Reform

SMHS is implementing an unprecedented level of clinical service reform and infrastructure development to meet the growing and changing needs of the community. A key focus is the development of area-wide service models which aim to co-ordinate and streamline patient

care. The location and delivery of public health services in SMHS is changing and will include:

- Opening of Fiona Stanley Hospital (FSH) in 2014
- Reconfiguration of services at Royal Perth Hospital (RPH)
- Relocation of components of the State rehabilitation services from RPH Shenton Park Campus (SPC) to FSH
- Transition of Bentley Hospital (BH) to a specialist hospital
- Reconfiguration of Fremantle Hospital and Health Services (FHHS)
- Continued growth and development at Armadale Health Service (AHS) and Rockingham General Hospital (RGH)

This reform has the potential to influence decisions regarding the introduction of a DLO in SMHS. A summary of some of the proposed changes is provided in Table 2 below.

Table 2: SMHS Key Site/Service Changes

SMHS Site/Service	Proposed Reform	Implication
Armadale Health Service (AHS)	Medical/surgical services will be enhanced, requiring enhanced clinical cover for a number of specialty areas.	Growth
Bentley Hospital (BH)	From 2014 BH will be reconfigured to focus on mental health, aged care and rehabilitation services, and elective surgical services.	Focus moves to specialties that are out-of-scope for DLO project.
Fremantle Hospital and Health Service (FHHS) * *Tertiary*	By 2014 FHS will reduce in size and provide limited general hospital services with a primary focus on MH, aged care, rehab services and elective surgery.	Focus moves to specialties that are out-of-scope for DLO project.
Rockingham General Hospital (RGH)	Clinical services will be significantly enhanced; requiring enhanced clinical cover for the majority of specialty areas.	Growth
Royal Perth Hospital Wellington Street Campus (RPH WSC) * *Tertiary*	RPH WSC will downsize but remain a tertiary hospital. It will continue to provide an extensive range of tertiary, quaternary and secondary-level services.	Reconfiguration
Royal Perth Hospital Shenton Park Campus (RPH SPC) * *Tertiary*	RPH SPC will close and the tertiary rehabilitation services will transition to FSH State Rehabilitation Centre, with the remaining services being redistributed to other hospitals in both NMHS and SMHS.	Relocation

3.3 Disability Sector Reform

The disability sector is currently facing a number of changes and reforms at a State and national level. Some of the changes include:

Disability Services Act and Regulations Amendments

The amendments include greater alignment with contemporary polices (including the United Nations Convention on the Rights of Persons with Disabilities), improved complaints processes, improved readability and increasing employment opportunities for people with disability.

Self-Directed Supports and Services

Nationally and internationally, there is a growing interest from people using services to have greater control over the design, planning and delivery of their supports and services. People also seek more personalised approaches to their supports and services that are tailored to and responsive to their individual requirements. There is also broad acknowledgement that better outcomes for people are achieved when they have genuine choice and the level of control they desire over their supports and services.

Procurement Reform

Procurement is undergoing a period of major change as part of the State Government's Delivering Community Services in Partnership Policy. Procurement will move away from an input/output model to an outcomes-based approach. This will provide people with disability more choice and flexibility in the way they purchase services and supports.

My Way

From 1 July 2013 the Commission accelerated the rollout of My Way in the Lower South West to explore the full potential and strengths of the model. The Lower South West area will focus on best practice in WA, whilst aligning with the emerging national system. My Way enables people with disability, their families and carers to design, plan and implement their own supports and services. It includes relationship-based support, local decision-making and early engagement in good planning processes.

National Disability Insurance Scheme

WA will join the National Disability Insurance Scheme (NDIS) from July 2014. There will be two national launch sites in WA, one using the Western Australia approach, My Way and the other following the DisabilityCare Australia model. The My Way locations are in the Lower South West region and the Cockburn-Kwinana area, while the DisabilityCare Australia model will be used in the Perth Hills. The launch sites will be jointly funded by the Commonwealth and State Governments. Other features include the use of a local advisory panel, local area coordinators and WA's quality assurance system for service providers. Information arising

out of each launch site will be shared between the State and the Commonwealth which will use the same data and IT systems.

4.0 METHOD FOR IDENTIFYING DISABILITY GAPS & SERVICE ISSUES

Extensive NMHS and SMHS stakeholder meetings, workshops and consultation were undertaken between April and August 2013 to ascertain the challenges facing disability health service delivery and the need for DLOs'. Comprehensive data requests and analysis were also used to identify the main areas of need, as detailed below.

4.1 Stakeholder Consultation

It was considered vital to engage stakeholders from across the health and disability sectors to inform this project. Stakeholder consultation was considered in three broad groups:

Consumers	Disability Agencies	WA Health
▪ People with disability, their families, carers and support workers.	▪ Representatives from the Disability Services Commission ▪ Representatives from specialist disability agencies, for example Nulsen, The Centre for Cerebral Palsy (TCCP), Ethnic Disability Advocacy Centre (EDAC) & others.	▪ Clinicians from tertiary and secondary hospitals ▪ Representatives from the Department of Health

Consultation was undertaken for a period of two and a half months and took the form of face-to-face interviews, telephone interviews, two open group consultation sessions, eight focus group sessions and questionnaires via Survey Monkey (clinicians and carers). In total, approximately 300 people were consulted via the consultation process. Please see Appendix 5 for the stakeholder list, Appendix 6 for a summary of the consultation process and Appendix 7 for a detailed summary of the open group consultation process.

4.2 Data

One of the key deliverables for this project was to provide baseline data regarding disability for NMHS and SMHS tertiary and secondary hospitals. In order to achieve this data requests were submitted to:

- Epidemiology Branch, WA Department of Health
- Allied Health Statistics (AHS)
- DSC Community Aids and Equipment Program (CAEP)

- DSC Disability and Aged Care Co-ordinator (DACC)
- Aged Care Assessment Program
- Long Stay Younger People Program

Relevant results are summarised and presented in section 5.2 below for Epidemiology and DSC CAEP, as these were deemed to be the most robust. Additional results will be presented in a separate data report.

5.0 RESULTS

5.1 Stakeholder Consultation – Current Disability Service Challenges

As described in section 4.1, a series of face-to-face meetings, open consultation sessions, site focus groups and phone meetings were held to determine the key service issues. Furthermore, mapping documents using Clinical Service Framework (CSF) headings (refer to template in Appendix 8) and Survey Monkey Questionnaires were completed by clinicians and carers. All issues were transcribed and tallied according to frequency. From this process, the following key themes were identified.

No access to one central point of patient information

The need for access to one central point for adequate patient information poses significant challenges. This was the number one issue identified. The lack of timely access to patient information creates bed blocking in the acute care setting, patient frustration with having to repeat information and incorrect clinical management. This issue was identified as a gap by consumers, hospital staff and staff from disability specialist agencies.

Currently, from a hospital staff perspective there are several inefficiencies and time wastages created due to not having access to current patient information, patient profile summaries and no central database that holds this information. This includes information such as next of kin, carer, General Practitioner (GP), therapists and disability agencies involved, accommodation, essential specialist equipment, other medical conditions, current medications, recent hospital admissions and functional requirements (e.g. meal-time management, mobility, night-time positioning, seating, communication, transport, hygiene & personal care). From a consumer and carer perspective they feel that they have to repeat the same information over and over again to several staff, which can lead to feelings of frustration and not being listened to.

> *"Not having the full story about a patient limits appropriate services being provided and can actually facilitate readmissions"* (State Head Injury Unit clinician)
>
> *"The right hand doesn't talk to the left'"* (person with disability about the hospital system)

Furthermore, specialist disability agencies reported that they often provide care plans for their clients for hospital admissions, but these are not being utilised by the frontline and hospital staff in some wards. This has key information to the patient care. Some examples of not using care plans provided included; a patient requiring thickened fluids for meal-times who was at risk of aspiration was not given thickened fluids nor positioned in her wheelchair for meal-times; alternative augmented communication (AAC) devices not used on the wards for numerous patients with complex communication needs and not utilising specialised pressure equipment for positioning for a patient who is at risk of pressure sores.

There are also gaps in transfers of information extra-hospital. Extra-hospital transfers pose a problem as often the information is not transferred to the treating hospital or if transferred, not in a timely manner for the acute admission.

DLO Outcome Measure(s) 1

- The DLO consider developing a hardcopy template of a 'Profile Summary' (patient passport) as a collation point of patient information, as an interim solution until an electronic options is available. Linking in with current systems and processes will reduce a siloed approach.
- The DLO considers creating a disability checklist (screening) to understand disability patient cohort complexity to better manage inpatient admission (this was identified as a strong need by consumers & clinicians alike).
- The DLO work in partnership with the Disability Health Network to achieve outcome measure(s) 1.

Disability Profile

Clinicians and consumers perceived that the profile of disability is still relatively low in the hospital system. Disability awareness, attitudes to people with disability and disability-specific education are still limited. This clinical area was deemed to be quite specialist in nature due to the complexity of the patient cohort, yet is often viewed as secondary to emergency department and other acute care services, which are better resourced. The hospital system was not perceived to be person-centric and family-centric, but focused on achieving key performance indicators (KPI's) or funding drivers. People with disability had a more positive view of some aspects of community disability services than hospital services. For example, they perceived community services as providing a more person-centred and timely service, as opposed to the hospital experience, in which they felt their needs were less of a priority and that staff did not always have enough time for them.

"*Many patients are stigmatised by their diagnosis and miss out on appropriate care – particularly those with mental health issues. Expectation levels drop if a patient is perceived to be multiply impaired*" (SWAT Team SCGH)

- The DLO will evaluate consumer satisfaction. This may be in the form of satisfaction surveys, interviews, incidence of complaints, receipt of qualitative positive feedback or other. This information will be reported informally **bi-monthly** and formally **bi-annually**.

Service Integration

Disability health services across NMHS and SMHS are reported to be fragmented and poorly coordinated which has led to numerous hospital service delivery issues including:

- Lack of early identification of patients with complex disability requirements within the acute inpatient setting.
- Poor pre-admission planning for elective admissions. See readmissions data Appendix 11.
- Poor discharge planning for disability (i.e. discharge planning not starting early enough, not involving external agencies in discharge planning and not comprehensive enough for the patient complexity).

"Limited & inappropriate discharge planning for service user to return home & do not include agency staff directly involved" (The Centre for Cerebral Palsy)

- Poor communication between hospital and community services.
- Limited case management (e.g. not using patient care plans on the ward, not involving external service providers in case conferences/discharge planning, not starting discharge planning early enough, poor handover to patient/family/key service providers involved, poor discharge plans, poor follow-up, poor community linkages).

"*There is a strong need for care coordination*" (CEO of a Disability Specialist Agency)

- People with disability with no external agency involved - currently a big gap. This cohort is more vulnerable particularly if there is no follow-up care or increased follow-up care required post discharge.
- Lack of clinical pathways, processes and mechanisms for this patient cohort resulting in fragmented and poor coordination of care.
- Poorly integrated care across the continuum for complex disability with co-morbidity. Particular co-morbidities reported to be poorly managed included; intellectual disability, cognitive issues, complex communication, English second language (ESL)

and Culturally and Linguistically Diverse backgrounds (CALD), alcoholism, drug-dependence, homelessness and morbid obesity (bariatric patients).

- Poorly integrated mental health care with complex disability. Often mental health care is siloed or not received in a timely manner for this patient cohort. The complex health of the patient includes their mental health, so better integrated mental health is required.
- Lack of safe discharge options and long length of stay due to issues when patient is medically stable e.g. Guardianship, lack of access to Neuropsychology for functional cognitive assessments, lack of community accommodation services for young people with disability and not enough transition or step down units available.

A summary of the main service integration gaps and issues across the patient continuum from emergency department, to inpatients and through to community are provided in Appendix 9.

"This results in fragmented care, when the primary issue is 'Disability" (DSC Nursing)

"The interface between Disability and Health is currently not a partnership for the benefit of the patient. They are not communicating well with each other and information and funding is siloed. There needs to be better links between the two and overarching frameworks which guide them to work together" (CEO of a Disability Specialist Agency)

"Poor discharge planning. Patients with complex disability needs are often fast-tracked for discharge without proper planning. Our agency is often not contacted when discharge occurs so timely follow up cannot always be guaranteed. Even when we have been consulted inappropriate discharge plans are often made. Despite our protestations one of our clients was discharged into the care of his son – the person who assaulted him and was responsible for him being admitted to hospital. No attempt was made to explore alternative discharge options" (State Head Injury Unit)

DLO Outcome Measure(s) 3

- Develop an early identification 'red flag' system in Emergency Department (ED) to flag complex disability.
- Improved holistic health care for the complex disability cohort, including integrated medical and mental health care. This will be achieved by the DLO working in alignment with multidisciplinary teams, mental health and medical teams (i.e. complex health includes complex co-morbidity and the mental health of the patient).
- Develop a pre-admission pathway (**quarter 1**), discharge planning pathway (**quarter 2**) and contribute to a multidisciplinary care plan for the disability cohort (**quarter 2**) of the pilot project in collaboration with other stakeholders.

Resource Limitations

The stakeholders identified a number of resource limitations which impacted on hospital disability service delivery, as summarised below:

- Lack of room on the wards for patients with complex disability: lack of room/ for patient essential/specialised equipment/wheelchairs; lack of space for family to stay alongside patient; lack of space for treatment and lack of storage for complex equipment. For example if a patient's wheelchair is not available, because it cannot be stored on the ward, this can have serious implications. This can impact on swallowing (due to inappropriate positioning at mealtime), respiratory management (due to insufficient upright positioning) and pressure care (due to prolonged rest-in-bed). Stakeholders reported that not allowing adequate access to a patient's wheelchair or complex equipment was unethical.
- Consumers with disabilities and stakeholders across the disability sector indicated that this patient cohort requires a more time-intensive, slower pace, specialist model of service delivery. It was acknowledged by consumers, hospital staff and community staff that hospital staff are busy. A lack of time of Nursing frontline staff was identified as a major barrier, as was a lack of Medical Consult time.
- Poorly developed or limited resources for people with vision and hearing impairment.
- Poorly developed information, resources, and handouts in layman terms for the disability patient cohort. It was perceived that while there is a lot available for carers/families, there is not much for the actual patient.
- Physical Infrastructure & accessibility - physical infrastructure, accessibility, lift lag time too fast for people with physical disability, fire exits do not have buttons at wheelchair access level, parking, cost of parking, walking distance of parking, meter locations, poor signage and no ceiling hoists on some wards. This issue formed a large source of patient complaints at the tertiary Hospital, SCGH in 2012/2013.

"*Not allowing access to a patient's wheelchair is equivalent to cutting off someone's legs*"
(The Centre for Cerebral Palsy, Adult Living Programme)

"Patients may bring in wheelchairs and equipment from home and often space is limited on the ward for these things" (SCGH Nursing Neurology & Neurosurgery).

"Time constraints within the hospital and on nursing staff can make it difficult to promote independence of patients" (SCGH Nursing Neurology & Neurosurgery)

"Lack of education on the resources available to patients with a disability on discharge"
(DSC Nursing)

DLO Outcome Measure(s) 4
▪ The DLO will work collaboratively with DAIP to identify hospital wards with the majority of the disability cohort and work collaboratively with the multidisciplinary team to consider one room on each of these wards is set-up to be as disability-friendly as possible e.g. ceiling hoist, sufficient room for wheelchair/essential equipment (this is a prime DAIP role that the DLO can assist with). ▪ The DLO will work collaboratively with hospital ward staff to audit the wards with biggest volumes of the disability cohort (see Appendix 3) and prioritise wards with greatest area of need.

Disability Education

Lack of general disability awareness and specialist education and training of frontline hospital staff was consistently identified as a major issue. The following areas were identified by consumers and hospital clinical staff as areas of limitation regarding education. Lack of the following:

- Disability Awareness training
- Education on 24-hour postural care & positioning for patients
- Training in meal-time management (MMT)
- Training in manual handling for complex physical disability
- Education on the resources available to patients with a disability on discharge
- Information and education on the facilities available to patients with disability.
- Education for managing challenging and escalating behaviours.
- Education on disability with co-morbid mental health issues.
- Education for specialist areas e.g. cognitive and sensory impairment.
- Knowledge of DSC inclusion/exclusion criteria.
- Education on other Disability Services, policies & contact details.
- Education in use of alternative augmented communication (AAC) devices
- Simulated learning for managing complex disability with tracheostomy
- Education on developing 'counselling skills' necessary to deal with patients & family members who have longer term complex disabilities
- Training and support in completing funding applications

*"Staff would like a better understanding of disability services /policies / inclusion / exclusion criteria and contact details- e.g. DSC exclusion criteria" (*Nursing G61 SCGH, Nursing DRAC SCGH, Nursing Gen Med SCGH, Nursing Neurology FHHS, SW RPH WSC, SW RGH)

DLO Outcome Measure(s) 5
▪ The DLO will aim to provide education and training for health care professionals, consumers and families to raise awareness of people with disabilty and their special needs in the health care setting – this may include specialist disability education for staff, general disability awareness training, bed-side education for consumers/families, information pamphlets in layman terms & resource packages.

Disability Service Delivery Models

The absence of an over-arching Disability Model of Care, clinical governance frameworks, clinical pathways and policy were highlighted as a strong stakeholder issue. This was identified as an issue by consumers, hospital staff and the disability sector alike. It was reported that there was no shared understanding and no accountability in the hospital sector for this patient cohort. Therefore fragmented services, silos, duplication, inefficiencies, poor patient flow and poor patient outcomes exist.

""We need a Policy change and Clinical Governance Framework for disability"
(CEO of a Disability Specialist Agency)

Stakeholders referred to the Stroke Model of Care and Fractured Neck of Femur hospital services as being well coordinated, patient-centred with good patient outcomes. Chief Executive Officer (CEO), Alan Lilly of Eastern Health Victoria talks about models of care as key for driving change (ABF/M Presentation 9 April 2013 WA).

""""An over-arching disability Model of care will create more integrated Services between Hospital and DSC, better patient flow and eliminate the fragmented care we are seeing" (DSC Nursing)

DLO Outcome Measure(s) 6
▪ The DLO will aim to develop a clinical pathway for the complex disability patient cohort (see Appendix 3) within **second quarter** of DLO pilot project. ▪ Work in partnership with the Disability Health Network to contribute to developing a overarching 'Disability Model of Care' (or overarching framework with principles) and Clinical Governance framework which will help support service delivery in the hospital system. ▪ Build strong working partnerships with Disability Services Commission (DSC) – particularly Hospital Eligibility Coordinator, My WAY Coordinators, DSC Hospital Eligibility and DSC Nursing. Aim to have **bi-monthly** or **quarterly** meetings. ▪ Build working partnerships with Specialist Disability Agencies and non-government

organisations (NGO's) e.g. TCCP, Nulsen, ILC, PwD WA, DDC, National Disability Services WA, Headwest, Brightwater, Mental Health Advisory Council (see stakeholder list for full complement). Aim to have **quarterly** service-wide disability sector meetings which include department of health WA.

- Work in collaboration & partnership with the Disability Health Network and Disability Access and Inclusion Plan (DAIP) hospital staff to help the DLO guide strategic direction and service planning requirements (i.e. eliminate siloed & fragmented services), with **bi-monthly** meetings.

5.2 Epidemiology Data

A summary of the Epidemiology Branch WA Department of Health data will be utilised to give a representation of Disability in the hospital system, as this data is deemed to be the most robust. Please see Appendix 10 for an explanation of the data definitions.

Data methodology:

- To understand the data analysis presented, refer to the Disability Cohort List (Appendix 3) agreed upon between WA Health and Disability Services Commission (DSC). This splits the cohort into *principle* diagnosis (of disability) and *additional* diagnoses (indicators of complexity/risk factors for this patient cohort which make them complex to manage within the hospital system).
- Data has been presented by *any disability* category (see definition Appendix 10). This has been utilised to capture all episodes for people with disability within the selected cohort entering the hospital system, regardless of their principal diagnosis. This will ensure that we would not under-represent the actual patient cohort utilising the hospital system.
- Data for Royal Perth Hospital combines Wellington Street Campus (WSC) and Shenton Park Campus for SMHS totals, but only RPH WSC for site level breakdown.
- The Median and Quartiles were used to describe the distribution of the length of stay because of skewed data.

Epidemiology Key findings:

The key findings from the Epidemiology Data are presented below. For a more detailed analysis see Appendix 11.

By disability category

- The disability categories with the highest number of people admitted to hospital for any diagnosis of disability between 2003 and 2011 were Cerebral Palsy (6,991), Stroke (6,784), Complex Communication (4,449) and Traumatic Brian Injury (3,520).
- The disability categories which had the highest number of hospital separations during the same time period were Cerebral Palsy (14,544), Multiple Sclerosis (12,229), Amputee (10,190), Stroke (7,739) and Complex Communication (5,241).
- People admitted with Multiple Sclerosis and Amputee had the highest likelihood of readmission within 5 years of their first identified separation.
- Spinal injury, Huntington's and Amputee had the highest median length of stay.
- The most expensive disability categories per admission were Spinal Injury, Amputee and Cerebral Palsy.
- The disability categories which had the highest number of people with co-morbidities were Stroke, TBI and Cerebral Palsy. Common co morbidities included communication problems, alcoholism, reduced mobility and mental health.

By Area Health Service

- Between 2003 and 2012 there were 67,014 public hospital separations for any diagnosis of disability in WA. Of those, 37,578 separations or 56% occurred at SMHS hospitals, and 18,917 or 28% occurred at NMHS hospitals.
- The disability categories which had the highest number of separations at NMHS hospitals in 2012 were Multiple Sclerosis (873), Stroke (617), Cerebral Palsy (582), Complex Communication (482), and Amputee (190).
- The disability categories which had the highest number of separations at SMHS hospitals in 2012 were Cerebral Palsy (1258), Stroke (939), Multiple Sclerosis (738), Traumatic Brain Injury (591) and Complex Communication (576).

By Hospital Site

- NMHS and SMHS tertiary hospitals had the highest volume of public hospital separations for any diagnosis of disability in 2012.
- SCGH experienced an increase of 170.4% over the 10 year period, from 821 separations in 2003 to 2220 in 2012. The highest volume disability categories were Cerebral Palsy, Stroke, TBI, Complex Communication and Multiple Sclerosis.
- RPH experienced an increase of 51.4% from 1377 in 2003 to 2085 in 2012. The highest volume disability categories were Cerebral Palsy, Stroke, Amputee, TBI and Complex Communication.

5.2 DSC Community Aids and Equipment (CAEP) Data

NMHS

Between 1 January 2011 and 1 January 2012 $450,123.16 was spent by CAEP DSC in NMHS on people with disability aged 17-59 years. This was relating to the purchase of new equipment, purchase of sub-components, maintenance, hire, modification, repair, transport, refurbishment and installation. Of a total of 898 equipment actions 369 (41%) were related to new purchases of equipment with five most frequent diagnoses (from most to least frequent) being other physical, other neurological, para/quadri/hemiplegia, Acquired Brain Injury (ABI) and Multiple Sclerosis (MS). See Table 3 below.

Table 3: NMHS CAEP DSC Summary of Costs by Age Group Jan 1 2011 - Jan 1 2012.

Action Type ID	Action Count	Cost
Purchase	369	$306,230.15
Maintenance	157	$43,015.13
Hire	4	$910.00
Modifications	35	$18,032.29
Repair	219	$55,548.85
Transport	6	$692.86
Refurbishment	16	$9,635.95
Purchase Sub-component	65	$12,401.43
Installation	27	$3,656.50
Total for Ages 17-59	**898**	**$450,123.16**

SMHS

Between 1 January 2011 and 1 January 2012 $978, 742.20 was spent by CAEP DSC in SMHS on people with disability aged 17-59 years. See

Table 4 below. Of a total of 1574 equipment actions 831 (53%) were related to new purchases of equipment with the five most frequent diagnoses (from most to least frequent) being other physical; paraplegia/tetraplegia/hemiplegia; other; acquired brain injury; and other neurological.

Table 4: SMHS CAEP DSC Summary of Costs by Age Group Jan 1 2011 – Jan 1 2012 Paid

Action Type ID	Action Count	Cost
Purchase	831	$743,218.89
Maintenance	176	$43,406.42
Hire	14	$7,984.00
Modifications	70	$66,177.12

Repair	324	$81,287.35
Transport	10	$2,839.55
Refurbishment	7	$2,725.90
Purchase Sub-component	98	$20,495.56
Installation	44	$10,607.41
Total for Ages 17-59	**1574**	**$978,742,20**

DLO Outcome Measure 7

The DLO will work collaboratively with the hospital CAEP co-coordinator to review DSC CAEP data **quarterly** to monitor equipment costs and patient need/unmet need for the disability cohort.

5.4 Example Activity Based Funding Case

In a system which is re-calibrating into an Activity Based Funding (ABF) model, there are a number of ways that the proposed DLO role may improve the service that the hospital provides to patients with a disability, and also to support the treating teams to achieve LOS targets. The cost of providing hospital health care continues to rise beyond ABF growth and it will be important to meet clear activity targets whilst ensuring patient safety and service quality for the disability cohort. A complex case has been presented to show an example of a patient with disability and multiple co-morbidities. This is to demonstrate the types of complex patients that are using the hospital system and how much they cost, particularly as WA has now moved into an ABF model.

Mrs A, 57years

CASE STUDY SPOTLIGHT

- Admitted for stroke
- **Co-morbidities:** Bipolar disorder, depressive episodes, dementia, incontinent, neuropathic pain, behavioural issues.
- **Other history of note:** previous hypoxic brain injury, bowel cancer, tooth ache.
- **Not accepted:** from RPH SPC rehabilitation**,** returning to Graylands accommodation, Selby lodge, Bright water Discovery Way.

  Length of Stay: 88 days, could have potentially been 7 days (i.e. medically stable at 7 days but not accepted from various services and placed on waitlist for Brightwater YPWD accommodation Oaks Street).
- **Outcome:** 88 day LoS, currently in Nursing Home placement on waitlist for Brightwater accommodation.
- **Gaps:** Fragmented services, poor coordinated care, lack of integrated mental health, eligibility criteria barriers, long LoS & bed-blocking due to community accommodation issues, no one central point of patient information, hospital staff not using behavioural care plan until week 2 of patient stay, coding.

Table 5: ABF revenue for disability case Mrs A with 88 day length of stay for 2012/13 period

Activity	Class	LOS	sWAU	SEP 12/13	ABF Revenue 12/13	DRG Cost 11/12	Gap
Emergency Department (ED)	URG 07	1 day	0.22126	$5135	$1,136.17	$748	+$388.17
Acute Admitted	DRG B70A Stoke other cerebrovascular disorders with catastrophic CC	23 days	4.23	$5135	$21,720.65	$40,742	-$19,021.35
						~12/13 = $42,575.39	-$20,855.39
Acute Admitted	DRG Z60A Rehabilitation (non-acute) with catastrophic CC	66 days	7.12	$5135	$36,543.26	$49,587	-$13,043.74
						~12/13 = $51,818.415	-$15,275.15
TOTAL					**$58,263.21**	**$91,077**	**-$32,065.79**

						~12/13= $95,141.81	-$36,878.60

Mrs A's LOS of 88 days comprised of one day in the ED, 23 days as an inpatient admission for stroke (DRG B70A) and 66 days for an inpatient admission for rehabilitation (DRG Z60A). To calculate the ABF revenue to the area health service, the state efficient price (SEP 2012/13) of $5135 was multiplied by the three state weighted activity unit (sWAU) for the Diagnostic Related Groups (DRG). The DRG cost was then provided by hospital Finance. The DRG costing information was only available for 2011/12 period, so 4.5% was applied to give us the 2012/13 costing. This enabled comparison with the 2012/13 ABF revenue to determine the gaps between the cost to the hospital and funding allocation received from ABF. There was a deficit to the area health service of approximately $36,878.60 for Mrs A's hospital admission, as demonstrated in Table 5.

Mrs A	LoS	Lower Bound	Upper Bound	Outcome (below, within, above)
DRG B70A	23	4	44	Within boundary
DRG Z60A	88	5	52	Above upper boundary (by 36-days)

Figure 1: ABF Upper & Lower Boundary

The ABF funding model encourages area health services and sites to focus on how they can reduce the numbers of patients who stay in hospital longer than average i.e. aims to reduce the number of patients who stay over the high boundary unnecessarily. As shown in Figure 1 it is evident that Mrs A was *within boundary* for her inpatient stroke admission (DRGB70A), however she was *above boundary* for the inpatient rehabilitation component (DRGZ60A) by 36 days. Episodes with an *above average* length of stay will tend to be more costly than the average patient within that DRG, and tend to be more costly than the activity based funding allocation (as demonstrated in Figure 1). If a length of stay of 7 days had been achieved (i.e. when Mrs A was medically stable but unable to be discharged due to not being accepted for rehabilitation at RPH SPC and due to lack of accommodation options), a cost saving of approximately $44, 668.08 would have been realised.

By improving the quality of care of disability health service delivery through implementation of a DLO, it is likely that costs will be reduced which aligns with the Area Health Service ABF activity targets. Executives have indicated that the DLO role must align with ABF.

DLO Outcome Measure(s) 8
▪ The DLO will support long stay patients with complex disability and support current health service initiatives. ▪ The DLO should report on LoS **monthly** for each category of disability in the cohort, the associated ABF revenue & those patients over the high boundary. ▪ Reduction in LOS for the complex disabled patient. Report **quarterly**. - 10% reduction of waiting time for discharge transport - 10% reduction in waiting time in discharge lounge ▪ The DLO work collaboratively with hospital Executives on a gap regarding transition/step-down unit options to manage the issue when patients are medically stable but stay in hospital due to lack of access to accommodation or community options. Executives have been made aware of this issue.

6.0 PROPOSED DLO OPTIONS FOR WA HEALTH

As outlined above, the challenges for the hospital system, clinicians, people with disability and their carers are great and require a strategic, multi-agency approach. The DHN has begun to progress a number of projects which will bring agencies together and actively start to address the gaps in coordination, training, data collection and processes.

The DLO role has been scoped with measurable and achievable outcome aims. This role will be of great advantage to the hospital system to ensure improvements to the acute-care experience for people with a disability who interface with the DoH WA health system is well informed and appropriate.

The following questions guided the development of the options for NMHS and SMHS. See summarised in Appendix 12.

i. Who will the DLO service? (all Disability cohort or specific Disability groups)
ii. What will the DLO role do? (Consumer support; Clinician support; Organisational support; a combination of any of these).
iii. At which hospital site will the DLO work?
iv. Where should the DLO sit in the hospital community?
v. Where will the DLO be positioned (stand alone role or aligned with a team)

Please see table 6.1 and 6.2 for NMHS and 6.3 and 6.4 for SMHS proposed options and validation for the DLO position. Each option has been explained in full in the DLO options paper.

6.1 NMHS Proposed DLO Options

Option	Hospital Site:	Patient Cohort:	What will the DLO role do:	Where will the role sit:	Where will DLO be positioned - team or stand alone:
Option 1: **SCGH SWAT** **Inpatient complex care team**	Sir Charles Gairdner Hospital (SCGH)	All Disability Cohort	Combined (organisational & consumer)	Hospital, acute in-reach team	SWAT
Option 2: **SCGH CoNeCT** **Community complex needs co-ordination team**	Sir Charles Gairdner Hospital	All Disability Cohort	Combined (organisational & consumer)	Hospital, ambulatory care team	CoNeCT
Option 3: **Standalone role**	Sir Charles Gairdner Hospital	All Disability Cohort	Combined (organisational & consumer)	SCGH – to be advised	Team to be advised
Option 4: **Joondalup Health Campus**	Joondalup Health Campus (JHC)	All Disability Cohort	Combined (organisational & consumer)	Hospital, acute in-reach team	Team to be advised due to contract arrangements
Option 5: **Organisational only**	NMHS Hospital Planning or Policy	All Disability Cohort	Organisational only	Potentially Policy & Planning	Team to be advised as this would need to be negotiated
Option 6: **Consumer only**	Sir Charles Gairdner Hospital	All Disability Cohort	Consumer only	Potentially Patient Liaison, Consumer Advocacy	Team to be advised as this would need to be negotiated
Option 7: **RITH/Homelink**	Sir Charles Gairdner Hospital	All Disability Cohort	Combined (organisational & consumer)	Hospital, ambulatory care team	Rehabilitation in the Home(RITH)/Homelink

6.2 Validation of NMHS DLO Options

Option	Meets Project Scope	Data or evidence-base	Stakeholder Perspective	Stakeholder Motivation	Shortlisted	Prioritisation
Option 1: SCGH SWAT Inpatient complex care team	Yes	▪ Largest NMHS data volumes	16 votes	Yes	**Yes**	**1**
Option 2: SCGH CoNeCT Community complex needs co-ordination team	No (50:50)	▪ Largest NMHS data volumes ▪ CoNeCT model well evidenced	6 votes	Yes (stakeholders felt not enough inpatient authority)	**Yes**	**2**
Option 3: Standalone role	Yes	▪ Literature (pros/cons)	10 votes	Yes (some stakeholders indicated that a DLO will be a duplication)	**Yes**	**3**
Option 4: Joondalup Health Campus	Yes	▪ One of busiest ED NMHS ▪ 2nd largest data volumes NMHS. Big growth projections, including 18-65.	3 votes	Yes (Identified need for DLO)	**Yes**	**4**
Option 5: Organisational only	No	▪ Qualitative need identified ++ consumer & clinician groups	0 votes	Mixed response (strong support from clinicians, less from consumers)	**No**	**5**
Option 6: Consumer only	Yes	▪ Literature ▪ Qualitative need identified +++	0 votes	Mixed response (strong support from consumers, less from clinicians & hospital leaders who feel systemic-change needed)	**No**	**6**
Option 7: RITH/Homelink	Yes	▪ Qualitative need identified	2 votes	Mixed response (stakeholders felt not enough inpatient authority)	**No**	**7**

6.3 SMHS Proposed DLO Options

Option	Hospital Site:	Patient Cohort:	What will the DLO role do:	Where will the role sit:	Where will DLO be positioned - team or stand alone:
Option 1 AHS	Armadale Health Service	All patients	Combination (consumer, clinician & organisational)	Hospital, inpatients	CoNeCT Complex Needs Coordination Team
Option 2 RPH WSC	Royal Perth Hospital WSC	Select patients	Combination (consumer, clinician & organisational)	Hospital, inpatients	Social Work
Option 3 RPH WSC	Royal Perth Hospital WSC	Organisation	Organisation (policy, procedures, systemic change)	Hospital, policy and planning	Clinical Safety and Quality Team
Option 4 RGH	Rockingham General Hospital	All patients	Combination (consumer, clinician & organisational)	Hospital inpatients	Allied Health

6.4 Validation of SMHS draft options

Option	Meets Project Scope	Data or evidence-base	Stakeholder Perspective	Stakeholder Motivation	Shortlisted	Prioritisation
Option 1 Armadale Health Service	Yes	Somewhat (& predicted growth)	Yes	Yes	**Yes**	**1**
Option 2 RPH WSC	In part (does not service all of project disability cohort list)	Yes	Yes	Some internal resistance (e.g. experienced clinicians confident in their management of this group of patients: "we don't need another person telling us what to do.")	**Yes**	**3**
Option 3 RPH WSC	In part (organisational support only)	Yes	Some (does not meet needs identified by patients, families, carers)	Mixed response (some stakeholders can see benefit of this role but would prefer that the DLO have more direct involvement with patients)	**Yes**	**4**
Option 4 Rockingham General Hospital	Yes	Less so (but predicted growth)	Yes	Yes	**Yes**	**2**

6.5 RECOMMENDED OPTIONS

6.5.1 NMHS DLO Recommendation

The recommendation is to implement option 1 and place the DLO pilot position at Sir Charles Gairdner Hospital within the *inpatient complex care team,* SWAT*.* This option is strongly supported by the Epidemiology data, with this tertiary hospital having the highest volumes of the disability patient cohort for NMHS. Furthermore it meets the aims of the inpatient project scope and is endorsed by both NMHS clinicians and consumers alike.

This option is further supported by the draft NMHS Rehabilitation Plan which includes recommendations to improve and enhance the SWAT team for complex inpatients, including added medical governance to better support the team. Proposed governance for this option would include daily management by the SWAT team lead, with an Executive sponsor and an advisory team (see Appendix 14).

Recommended name change: Stakeholders felt that SWAT was not a disability friendly title as it has connotations with army force. It is suggested to change the name to 'Inpatient Complex Care Coordination Team' (ICCT) which aligns with the naming of the Emergency Department Care Co-ordination Team and outreach Care Co-ordination Teams. This name change recommendation is further supported by the draft NMHS Rehabilitation Plan.

Recommended logistic location: the SWAT team and CoNeCT team be logistically located together to ensure a more streamlined and collaborative service for the disability cohort.

Additional resources proposed (discretionary): to support the DLO pilot position and for sustainable disability service delivery, additional resources have been proposed. Please note that these are *discretionary* and the DLO role can still proceed without these;

i. 0.5FTE Project Administration (to collect data, measure KPI's, provide information for patients with complex disability, prepare resource packages and project support).
ii. Enhance the SWAT team with mental health input and medical governance, which is further supported by the draft NMHS Rehabilitation Plan.
    - 0.4 FTE Neuropsychology
    - 0.4FTE Clinical Psychology
    - Medical Governance (Rehabilitation Physician Consultation)
iii. Increase DAIP to 0.5 FTE (currently 0.1 FTE DAIP is too limited to influence sustainable change for disability). See Appendix 13.

6.5.2 SMHS DLO Recommendation

The recommendation is to implement Option 1 and place the DLO pilot position at Armadale Health Service. This option meets the aims of the project scope, is supported by Epidemiology data and stakeholder consultation, and is endorsed by AHS clinicians.

The DLO will be supported by the CoNeCT team, however will need to have clearly defined boundaries to distinguish its role, aims and objectives from that of CoNeCT, which has a greater focus on supporting people in the community to prevent readmissions. Aligning with CoNeCT has the advantages of linking the DLO with an established multi-disciplinary team, and also creating stronger links between inpatient and community management of patients with complex disability.

Proposed governance for this option would include daily management by the CoNeCT team lead, with an Executive sponsor and an advisory team (see Appendix 14).

7.0 FINAL RECOMMENDATIONS

It is recommended that NMHS and SMHS endorse the proposed options based on the evidence presented by consumers, stakeholders, Epidemiology data and potential ABF cost savings. In a system which is shifting into an Activity Based Funding model, there are a number of ways that the proposed DLO role may improve the services that the hospital provides to patients with disability, and also support the treating teams to achieve LOS targets and quality patient outcomes. By implementing a DLO, proposed benefits include;

- Improved quality of care for patients and families.
- Supporting earlier identification of complex disability patients.
- Identifying gaps in knowledge and resources to support service improvements.
- Sharing successful strategies and outcomes across clinical areas and wards.
- Facilitation of staff education both formal and on an “as needed” basis.
- Improved patient satisfaction with the hospital experience.
- Reduce complaints.
- Improved length of stay.
- Potential cost savings.
- Reduced readmissions (improving and supporting complex discharge planning to prevent same-diagnosis readmissions).
- Better partnerships with the disability sector.
- Better patient flow across the continuum of care.

Key recommendations to support the NMHS & SMHS options for phase 2:

Recommendation 1
Endorsement & Funding: ▪ WA Health and DSC endorse and appropriately fund NMHS and SMHS DLO pilot roles for phase 2 based on the options detailed in section 6.5.1 and 6.5.2 ▪ Different options may be chosen for NMHS and SMHS to meet the individual needs of the area health services, however it is recommended that the two parties work together collaboratively to support the DLO pilot positions, particularly to measure data and the success of these roles. ▪ Consideration of recurrent funding and justification of continuation of the DLO roles in adult tertiary and secondary NMHS/SMHS hospitals under ABF management be evaluated.
Recommendation 2
Governance: ▪ Establish governance across NMHS and SMHS for the DLO positions including an Executive Sponsor, steering group and links with the DHN (see example in Appendix 14).
Recommendation 3
Evaluation: ▪ Identify methods to evaluate the success of the DLO positions. ▪ Suggested outcome measures throughout this report.
Recommendation 4
Collaboration & Partnerships: ▪ Ensure that the DLO positions work collaboratively across NMHS and SMHS. ▪ Form partnerships between the health and disability sectors. ▪ Consideration of memorandum of understanding(s).
Recommendation 5
Parked Issues: ▪ Issued that were deemed to be out-of-scope to the Disability Liaison Officer role project, but important for disability health care are highlighted in Appendix 15 for future consideration in disability service delivery.

8.0 CONCLUSION

It is a well documented concern that people with disability often have poor experiences in the hospital system, and these sentiments were clearly echoed in the Clinical Senate report in June 2011 which mandated the need to investigate a potential option for making improvements.

The Disability Liaison Officers (DLO) Project (phase 1) was conducted from April to October 2013 to explore whether this was a suitable option. After extensive consultation with stakeholders, and in conjunction with data obtained from Epidemiology and other sources, this report endorses the introduction of DLOs in area health services in Western Australia.

It is imperative that disability service delivery is seen as a priority in NMHS and SMHS and funded accordingly. The DLO role will provide great benefits to the hospital system and staff and ensure improvements to the acute-care experience for people with a disability who interface with the DoH WA health system.

"People with disability and their families and carers want to build a relationship with someone like a DLO who can assist them through the healthcare system" (CEO of a Disability Specialist Agency).

"Patients need to be empowered to let the hospital know what they need – they need to be advocated for, potentially by the DLO..." (SWAT SCGH).

9.0 REFERENCES

1. Productivity Commission. Disability care and support: productivity commission inquiry report, overview and recommendations. Canberra: Commonwealth of Australia; 2011. 101p. Report no.: 54
2. VicHealth. Disability and health inequalities in Australia: research summary. Victoria: VicHealth; 2012. Publication no.: P-053-HI
3. Australian Institute of Health and Welfare. Health of Australians with disability: health status and risk factors. Canberra: AIHW; 2010. 32p. Bulletin no. 83. Cat. no. AUS 132
4. World Health Organisation & World Bank Group. World report on disability. Geneva: WHO; 2011. 350p.
5. Commonwealth of Australia. National Disability Strategy 2010 – 2020; an initiative of the Council of Australian Governments. Canberra: Commonwealth of Australia; 2011.
6. Webber R, Bowers B & Bigby C. Hospital experiences of older people with intellectual disability: responses of group home staff and family members. J Intellect Dev Disabil. 2010; 35(3):155-64.
7. Disability Services Commission . Count Me In: disability future directions. Perth: Government of Western Australia; 2012.
8. Australian Bureau of Statistics. Disability, Australia, 2009. Canberra: ABS; 2011. Cat no.: 4446.0

APPENDICES

APPENDIX 1: The Clinical Senate Report 'Clinicians – do you see me?'

Can be accessed at the following link:

http://www.clinicalsenate.health.wa.gov.au/debates/docs/Final_Report_June2011.pdf <Current as of 12 August 2013>.

APPENDIX 2: Disability Definition – World Health Organisation (WHO)

The agreed Disability definition for the DLO Project, as endorsed by the DLO Steering Group on 15th May 2013 is as follows:

World Health Organisation, International Classification of Functioning, Disability and Health (ICF).

The Disability definition is based on the World Health Organisation's International Classification of Functioning, Disability and Health (ICF):

(a) *The person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and*

(b) *the impairment or impairments are, or are likely to be, permanent; and*

(c) *the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:*

(i) *communication;*

(ii) *social interaction;*

(iii) *learning;*

(iv) *mobility;*

(v) *self care;*

(vi) *self management; and*

(d) *the impairment or impairments affect the person's capacity for social and economic participation*

(e) *the person's support needs in relation to his or her impairment or impairments are likely to continue for the person's lifetime.*

Considerations for Disability within the Hospital system will include factors or circumstances where impairments may be considered permanent, whether impairments result in substantially reduced functional capacity or psychosocial functioning, and the criteria to determine or circumstances where impairments may affect a person's social and economic participation.

APPENDIX 3: Disability Cohort List

Primary Diagnoses	Secondary Diagnoses - other Indicators of Complexity/Risk Factors for the Disability Patient Cohort
Acquired Brain Injury (ABI)	Alcoholism
Amputee - arm(s) and/or leg(s)	Behavioural Problems
Autism	Cognitive
Blind/Vision Impairment	Communication Problems - Aphasia, Apraxia, Dysarthria, Dysphonia, Laryngectomy
Cerebral Palsy	Dementia
Deaf/Hearing Impairment - Conductive Sensoneurial, Bilateral, other hearing loss	Disability
Down Syndrome	Dysphagia - swallowing problem
Huntington Disease	Falls Risk
Intellectual Disability	Malnutrition
Motor Neurone Disease (MND)	Mental Health - Anxiety, Bipolar Disorder, Depression, Personality Disorder, Schizophrenia
Multiple Sclerosis (MS)	Obesity
Muscular Dystrophy	Prolonged Hospital Stay
Parkinson's	Psychosocial - problems social, lack of support systems, lack of accommodation, homelessness
Post-polio Syndrome	Reduced Mobility
Specific Learning Difficulty	Respiratory problems - Cystic Fibrosis, COPD, Emphysema, Bronchiectasis, Dyspnoea, Asbestosis, Pulmonary Fibrosis, CRF
Communication Problems - Aphasia, Apraxia,Dysarthria, Dysphonia, Laryngectomy	Tracheostomy
Spina Bifida	
Spinal Injury - Para/quadri/tetra/hemiplegia	
Stroke/Hemiplegia/CVA	
Traumatic Brain Injury (TBI)	
Wheelchair bound	

APPENDIX 4: Disability Health Consultative Group Launch Recommendations – July 2012

Consultation Report Recommendations
Preventative Strategies
Health Promotion/Education for Clinicians & Staff "holistic" approach
Undergraduates to work with people with disabilities (link with Universities?)
Policies & Resources
Opening communication between silos
Specialists services or is this institutionalising?
Transition stages
Activity Based Funding (ABF) & longer length of stay (LoS) for people with disabilities
No data collected for when Services are refused (complex disabilities)
Clinical Handover
Discharge summary & link to community services
Communication Service-Service e.g. Hospital to community
Preventative Screening in care plans
Peer/Sibling inclusion
GP Incentives to complete care plans for people with disabilities
Medicare locals to fill gaps to assist people with disabilities to access services (treating & preventative)
GP Incentives to complete care plans for people with disabilities
Medicare locals to fill gaps to assist people with disabilities to access services (treating & preventative)
Freedom of Information requests
Public Accountability (UK model)
Models of Care & Care Planning
Care plans - implemented, modified, reviewed, reported.
Care plans - individualised, flexible, accountability (review care plans for best EBP & consistency across the sector)
Disability Fact Sheets (NSW Intellectual Disability Council)
Health Diaries for patients (Nick Lennox)
eHealth records - GP's & Health practitioners need to opt in (raise awareness to Clinicians & families)
Support Disability staff/workers (pay, resources, equipment) - staff turnover and burnout an issue. Training & stability key for outcomes of people with disabilities.

Travel - increase taxi subsidy
Group home rules/arrangements
Improved discharge planning
Include client in decision making, treatment plans, care, treatment.
Preventative Strategies
A key service provider / case manager
Increased communication & coordination between Services
Medicare locals to facilitate sharing of preventative health information & linkage to services.
Target the biggest need/gaps of preventative Health for peoplewith disabilities.
Consider co-morbidity with chronic illness
Key risk areas - messages targeted towards these at risk groups.
Social Inclusion
Care plans should include an 'inclusion plan'
Social inclusion at University & Tafe facilities e.g. Midland Tafe
Scandinavian Model
Breakfast clubs in schools successful
Audit of activities/facilities to determine what is 'disability friendly'
GP annual check
Aim for 'social connectedness'
Build capacity of generic/mainstream Services for people with disabilities & balance with some specialist services
Palliative care nurses within the Commission
Medical School Dr's training - embed cultural attitudinal change in Universities, education, increase awareness, social role valorisation.
Health Indicators - drugs, alcohol, exercise
Social determinants to well-being
Ambassadors to involve community e.g. AFL, Cricket Australia, Rugby
Community Model - whole community approach to promote inclusion
Universal access e.g. new buildings old buildings
Attitudinal Change
Medical Students - Universities

GP's
Consultants'/Doctors'/Clinicians'
Community
Key Messages
"The right access to the same services"
"You need to have your heart in disability & your head in health…"
"Wellness"
"Disability friendly"
"Social inclusion"
"See the person, not the disability"
"Care plans need to be individualised, flexible, define or clarify accountability and liability"

Taken & summarised from 'Disability Health Consultative Group Launch Report' Disability Services Commission State-wide Specialist Services – 10 July 2012

APPENDIX 5: DLO Stakeholder List

Name	Title	Phone	Email
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Ministerial Advisory Council on Disaiblity			

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Disabled people and their carers, family			
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APPENDIX 6: Stakeholder Consultation Snapshot

Consultation	Number Conducted	Stakeholders involved		How was this information used?
Face-to-face interviews	More than 100 **combined NMHS & SMHS*	1. Clinicians 2. Consumers 3. DSC & Disability Agencies	**55%*** **22%*** **23%***	Forms the majority of consultation to identify key issues and themes. Reported in mapping spreadsheets.
Open Group Consultation Sessions	2	1. Department of Health 2. Consumers 3. DSC & Disability Agencies	**17%** **23%** **60%**	Forms part of prioritisation of issues and problem solving to identify solutions. Reported in mapping spreadsheets.
Focus Groups	8	1. Allied Health 2. Nursing 3. Medical 4. Consumer (carers)	**2** **3** **2** **1**	Focus groups were used towards the end of the stakeholder consultation to problem-solve solutions and inform decision making regarding the DLO role, site and recommendations. This involved facilitation, brainstorming & a voting process.
Survey Monkey Questionnaires	2	1. Clinicians 2. Carers / Support workers	**n=121** **n=24**	To provide additional data to inform the data report – a key deliverable of this project.

APPENDIX 7: Stakeholder Consultation - Summary of Open Group Consultation Sessions

As part of the stakeholder consultation process two separate open group consultation sessions were held on 26th July and 2nd August 2013. Invitations were sent to all those who had previously attended the Disability Health Consultative Group Launch, as well as others who were part of the DLO Stakeholder list. A total of 31 people attended the sessions. There were representatives from the Department of Health, DSC, community organisations, people with disability, their families and their carers.

After an update about the DLO project, the attendees were presented with a list of the top eleven issues that had arisen from the consultation process thus far. These issues were displayed on large sheets of butchers paper around the room. Each person was given three sticky dots and asked to place one on each of the three most important issues. These were then tallied and prioritised.

PRIORITISED LIST OF DLO ISSUES (across the Clinical Service Framework areas):

Prioritisation of Issues	26.07.13	02.08.13	Total	Rank
Clinical				
Long stay in hospital	0	0	0	9
Fragmented services (across health & disability sectors)	12	6	18	1
Poor communication between facilities and services	4	10	14	2
Lack of co-ordinated DC planning	2	8	10	4
Access				
Limited access to integrated mental health	2	2	4	7
Limited access to specialist assessment and services	6	3	9	5
No one central point to access patient information	3	8	11	3
Education / Resources				
Disability education / awareness	5	9	14	2
Time constraints	0	1	1	8
Facilities (parked)				
Other				

Lack of advocacy	2	2	4	7
No disability model of care and care planning	5	2	7	6

At this point, the top five or six issues were identified, and a 'World Café' format was used to discuss each issue. The group divided into 3 small groups and each discussed two issues for between ten and twenty minutes. They then moved to another table, and discussed another two issues, and so on. The aim of these discussions was to problem-solve and seek solutions for the issues.

KEY DISCUSSION POINTS AROUND TOP ISSUES

Fragmented Services & Poor Communication:
▪ creating a central repository of information ▪ encouraging use of Personally Controlled Electronic Health Records ▪ patient passport / profile summary ▪ creating a database for disability ▪ improved case management and care planning across health & disability ▪ improving clinical handover
Disability Education & Awareness
▪ provide targeted training and staff education ▪ increase exposure to disability education at university ▪ provide incentives for training ▪ share educational opportunities between hospital & community organisations
No Access to Central Point of Information
▪ use of electronic health resources ▪ utilise technology, share between health & disability sectors ▪ use DLO as central point of communication
Discharge Planning
▪ needs to start early in admission

- hospital DC plan needs to better integrate with community plan
- hospital staff need a better understanding of each patient's home environment and services
- there is a lack of hospital follow-up services
- the DC plan needs to be timely and more accessible

Limited Access to Specialist Assessment & Services

- use the DLO to help navigate the system & broker-in specialist services
- increased FTE in specialist areas
- standardise services across hospitals
- provide comprehensive (not generic) disability assessments

No Disability Model of Care

- create and implement a model of care.

At the end of the small group discussions, the points were summarised and fed back to the group as a whole, for consensus discussion.

DLO SKILLS AND EXPERIENCE

The group were then asked to discuss the potential DLO role, and its roles and responsibilities, as well as qualifications and experience needed.

Summary of DLO Skills & Experience discussion:

- should be a health professional
- experienced in both the health & disability sectors
- understands both hospital and community systems
- with links and contacts throughout the disability sector
- need advanced communication, interpersonal, negotiation skills
- needs experience in delivering training & education
- is a limited resource so will need a strong support system
- needs to be in a 'position of clout' / have credibility / power / authority & recognition.

The open consultation groups were thanked for their input and informed that the information gained would be used to inform the DLO Project and the final report.

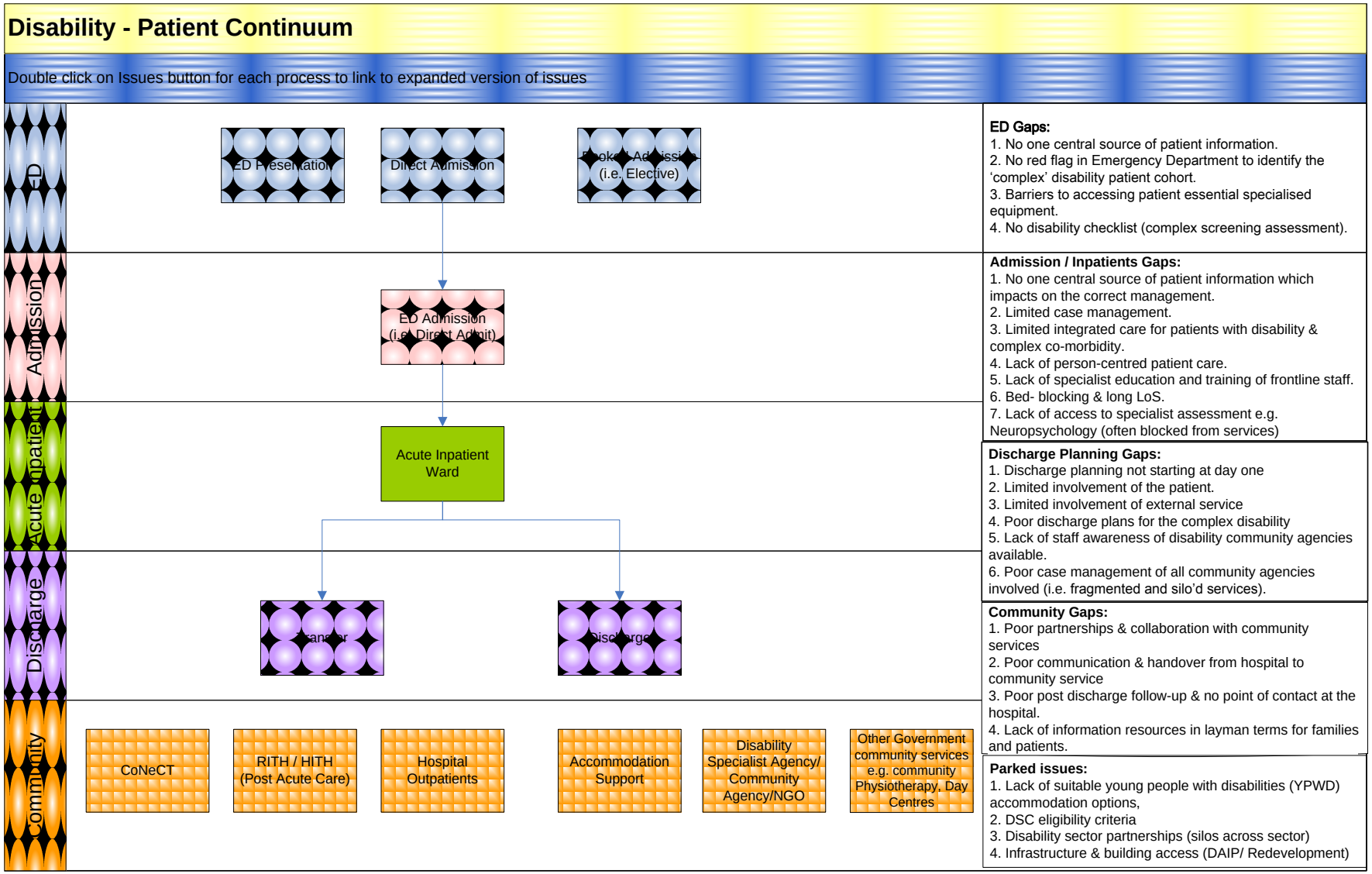
APPENDIX 8: Template Mapping Document across Clinical Service Framework (CSF) Areas

Disability - Main Issues/Gaps/Challenges in adult tertiary/secondary Hospitals NMHS

1. Clinical Issues	
2. Access Issues	
3. Resources/Workforce/Professional Development/Teaching & Training	
4. Facilities	
5. Other Issues/Gaps/Challenges	
6. Possible Recommendations/Solutions	

This was a 'mapping' document template used during the stakeholder consultation process to map gaps/issues in the hospital system

APPENDIX 9: Disability Gaps & Issues across the Patient Continuum



APPENDIX 10: Epidemiology Data Definitions

Data Term	Definition
Principal diagnosis	Refers to hospital separations where one of the specified disability codes was the principal diagnosis (the single diagnosis that is chiefly responsible for the admission). See Disability Cohort List appendix 2.
Any disability	Refers to hospital separations where one of the specified disability codes was recorded in any of the principal diagnosis, co-diagnosis or additional diagnoses fields (up to 22 in total – see Disability Cohort List appendix 2). E.g. the patient can have that disability but has been admitted for something else e.g. if a patient was admitted for Pneumonia, but also coded for Cerebral Palsy they would be captured in this category. Therefore the *any disability* category allows us to capture the patient with Pneumonia and Cerebral Palsy.
Length of stay and cost	Length of stay and cost information was summed across all separations for each individual (including all their single separation events, transfers between hospitals and readmissions) between 2003 and 2011. Descriptive statistics were then calculated for these summary values. The cost per separation represents the average total cost expected based on patients with similar clinical conditions requiring similar hospital services.

APPENDIX 11: Epidemiology Data Analysis

Number of People with Disability WA (2003-2012)

The disability categories which had the highest number of people admitted to hospital for *any* diagnosis of disability between 2003 and 2012 were Cerebral Palsy, Stroke, Complex Communication, Traumatic Brain Injury (TBI) and Intellectual Disability (ID). See Table 6.

Table 6: Number of people admitted to hospital for disability* 2003 - 2012 by category of disability

Disability Category	People with principal disability diagnosis only	People with additional disability diagnosis only	Total people with any disability diagnosis
Cerebral Palsy	622	7130	**7752**
Stroke	6415	1297	**7712**
Complex Communication	370	4741	**5111**
Traumatic Brain Injury	3080	968	**4048**
Intellectual Disability	131	2144	**2275**
Amputee	66	1594	**1660**
Multiple Sclerosis	1214	385	**1599**
Wheelchair bound	<5	1230	**1234**
Parkinsons	311	698	**1009**
Blind Vision Impaired	41	671	**712**
Spinal Injury	21	571	**592**
Down's Syndrome	<5	422	**426**
Autism	80	272	**352**
Motor Neuron Disease	237	114	**351**
Spina bifida	11	189	**200**
Muscular Dystrophy	32	108	**140**
Huntingtons	50	41	**91**
Post-polio Syndrome	0	0	**<5**

Number of People and Separations: By Disability Category (2003-2011)

Figure 2, demonstrates not only the amount of people admitted to hospital with a disability, but also the number of hospital separations those people were responsible for.

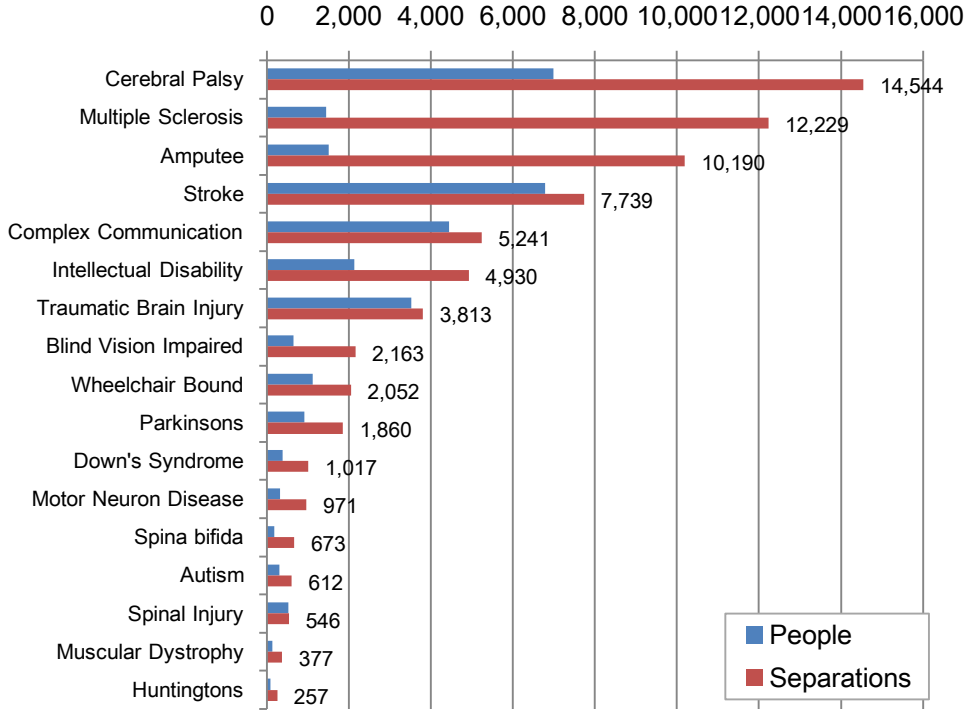


Figure 2: Number of hospital separations for people admitted to hospital for a disability diagnosis in any diagnosis field in WA between 2003 and 2011 by category of disability**

Highest number of people admitted

The disability categories with the highest number of people who were admitted to hospital between 2003 and 2011 for any disability diagnosis in any diagnosis field were Cerebral Palsy (6,991), Stroke (6,784), Complex Communication (4,449) and Traumatic Brian Injury (3,520).

Highest number of hospital separations

The disability categories which had the highest number of hospital separations for any diagnosis of disability were Cerebral Palsy (14,544), Multiple Sclerosis (12,229), Amputee (10,190), Stroke (7,739) and Complex Communication (5,241) (see Figure 2). While the number of people admitted to hospital for Multiple Sclerosis and Amputee did not appear in the top five disability categories, they were amongst the highest number of hospital separations during this time period.

Co morbidities: By Disability Category (2008-2012)

Between 2008 and 2012 there were a total of 18,950 disability related episodes[1]. Of these 15,708 or 83% had no co morbidities listed in any diagnosis field in any separation within the disability related episode. Please note that if the co-morbidity was not coded that the numbers below may be under-represented.

Table 7: Number of disability related episodes* in WA between 2008 and 2012 by number of co morbidities per episode

Number of Co morbidities per Episode	Number of Episodes
0	15708
1	2383
2	632
3	174
4	41
5	<10
6	<5
TOTAL	***18950***

[1] A disability related episode* was defined as including separations which were contiguous in time (i.e. back to back and likely to be transfers) and contained a principal diagnosis of disability anywhere in the episode.

The disability categories which had the highest number of co morbidities in WA between 2008 and 2012 were Stroke, TBI, Cerebral Palsy, Multiple Sclerosis, Parkinsons Disease, Cerebral Palsy, Motor Neuron Disease and Huntingtons. The common co-morbidities for each disability category are provided in Table 8.

Table 8: Count of co-morbidities for people admitted to hospital for principal diagnosis of disability in WA between 2008-2012

Disability Categories	Common Co- morbidities
Stroke	Alcoholism, behavioural problems, cognitive problems, communication problems, dementia, Disability, Falls risk, malnutrition, mental health, obesity, prolonged length of stay, psychosocial, reduced mobility, respiratory problems
Traumatic Brain Injury	Alcoholism, behavioural problems, cognitive problems, communication problems, dementia, Disability, Falls risk, malnutrition, mental health, obesity, prolonged length of stay, psychosocial, reduced mobility, respiratory problems
Multiple Sclerosis	Alcoholism, behavioural problems, cognitive problems, communication problems, dementia, Disability, Falls risk, malnutrition, mental health, obesity, prolonged length of stay, psychosocial, reduced mobility, respiratory problems
Parkinsons	Alcoholism, behavioural problems, cognitive problems, communication problems, dementia, Disability, Falls risk, malnutrition, mental health, prolonged length of stay, psychosocial, reduced mobility, respiratory problems
Cerebral Palsy	Alcoholism, behavioural problems, cognitive problems, communication problems, dementia, Disability, Falls risk, mental health, prolonged length of stay, psychosocial, reduced mobility, respiratory problems
Motor Neuron Disease	Alcoholism, communication problems, dementia, Disability, Falls risk, malnutrition,mental health, prolonged length of stay, psychosocial, reduced mobility, respiratory problems
Huntingtons	Alcoholism, cognitive problems, communication problems, dementia, Disability, Falls risk, malnutrition, mental health, prolonged length of stay, psychosocial, reduced mobility

Readmissions: By Disability Category (2003-2011)

Table 9 provides a breakdown of the likelihood of people readmitting to hospital for *any disability diagnosis* in WA between 2003 and 2011 by disability category[2].

Table 9: Readmissions* for people admitted to hospital for a disability diagnosis in any diagnosis field in WA between 2003 and 2011 by category of disability**

Category of Disability	Total People	Readmissions within 5 years of first event	% readmitted within 5 years
Multiple Sclerosis	1,454	927	**63.8%**
Amputee	1,509	891	**59.0%**
Huntington's	82	48	**58.5%**
Motor Neuron Disease	329	185	**56.2%**
Spina bifida	186	102	**54.8%**
Down's Syndrome	394	195	**49.5%**
Muscular Dystrophy	129	60	**46.5%**
Intellectual Disability	2,133	886	**41.5%**
Wheelchair Bound	1,113	408	**36.7%**
Autism	304	106	**34.9%**
Blind Vision Impaired	652	214	**32.8%**
Cerebral Palsy	6,991	2,250	**32.2%**
Parkinson's	918	288	**31.4%**
Complex Communication	4,449	596	**13.4%**
Stroke	6,784	851	**12.5%**
Traumatic Brain Injury	3,520	290	**8.2%**
Spinal Injury	524	31	**5.9%**

[2]Data does not identify the first ever admission for an individual but only the first admission that occurred after 01/01/2003

Highest likelihood of readmission

Between 2003 and 2011 the disability categories which had the highest likelihood of readmission within 5 years of the first identified separation were Multiple Sclerosis (63.8%), Amputee (59.0%), Huntington's (58.5%), Motor Neuron Disease (56.2%) and Spina Bifida (54.8%). This helps to explain why the number of people admitted to hospital with Multiple sclerosis and Amputee was low, but the number of separations was high.

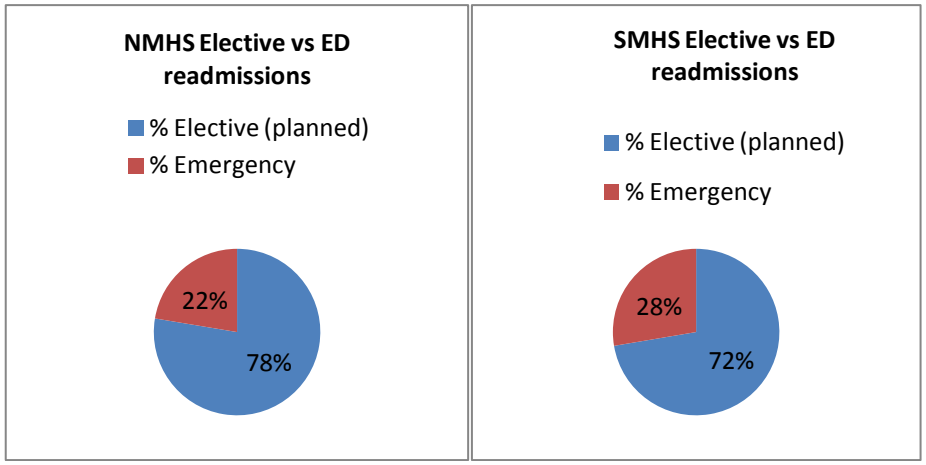


Figure 3: NMHS and SMHS Elective (planned) vs. Emergency readmissions 2003-2011

Of those people that readmitted at **NMHS** hospitals with a principal diagnosis of disability, within 5 years of the first event, approximately 78% were elective (planned) readmissions and 22% were emergency (non-planned) readmission. At **SMHS** hospitals approximately 72% were elective and 28% were emergency readmissions (see Figure 3). This highlights that the NMHS and SMHS could be better planning for elective admissions.

Length of Stay: By Disability Category (2003-2011)

Table 10 summarises the length of stay associated with separations for *any diagnosis* of disability. Length of stay information was summed across all separations for each individual (including all their single separation events, transfers between hospitals and readmissions).The Median and Quartiles are used to describe the distribution of the length of stay because of skewed data.

Table 10: Length of stay* for people admitted to hospital for a disability diagnosis in any diagnosis field WA between 2003 and 2011*** by category of disability**

Category of Disability	Lower Quartile Length of Stay	Median Length of Stay	Upper Quartile Length of Stay	Maximum Length of stay for an individual (outlier)
Spinal Injury	4	**37**	101.5	1232
Huntingtons	7	**35**	74	1736
Amputee	8	**31**	78	1247
Parkinsons	7	**19**	49	**5207**
Cerebral Palsy	4	**15**	47	**4351**
Motor Neuron Disease	6	**15**	38	1147
Complex Communication	3	**12**	37	**8478**
Muscular Dystrophy	2	**11**	28	368
Stroke	4	**11**	32	**6147**
Wheelchair	4	**11**	33	704
Multiple Sclerosis	4	**10**	36	750
Intellectual Disability	3	**9**	30	**4140**
Spina bifida	3	**8.5**	38	683
Autism	1	**8**	26.5	577
Traumatic Brain Injury	3	**8**	27.5	1442
Blind Vision Impaired	2	**7**	23.5	558
Down's Syndrome	1	**5**	18	2198

Highest Median Length of Stay

Between 2003 and 2011 the disability categories which had the highest median length of stay for people admitted with any disability diagnosis were Spinal Injury (37 days), Huntingtons (35 days), Amputee (31 days), Parkinsons (19 days) and Cerebral Palsy (15 days).

Maximum Length of Stay for an Individual

Over the 9 year period the disability categories which had the highest maximum length of stay for an individual were Complex Communication (8478 days), Stroke (6147 days) and Parkinsons (5207 days)[3].

[3] Please note that where disability is not the main reason for a separation (i.e. it is not the principal diagnosis), not all of the length of stay associated with the separation is likely to be attributable to disability.

Cost: By Disability Category (2003-2011)

Table 11 summarises the adjusted costs associated with separations for *any diagnosis* of disability. Cost information was summed across all separations for each individual (including all their single separation events, transfers between hospitals and readmissions). Descriptive statistics were then calculated for these summary values.

Table 11: Consumer Price Index (CPI) adjusted costs* for people admitted to hospital for a disability diagnosis in any diagnosis field in WA between 2003 and 2011*** by category of disability**

Category of Disability	Lower Quartile Cost	Median Cost	Upper Quartile Cost	Maximum Cost for an individual	Sum of Costs for all individuals
Spinal Injury	$10,701	**$34,623**	$79,860	$1,536,468	$35,347,655
Amputee	$10,810	**$30,429**	$81,415	$927,150	$92,428,521
Cerebral Palsy	$9,273	**$20,854**	$46,534	$3,893,610	$298,419,662
Muscular Dystrophy	$7,276	**$19,732**	$41,717	$508,378	$6,263,226
Huntington's	$6,089	**$19,228**	$41,167	$213,469	$2,350,555
Stroke	$7,748	**$19,002**	$36,766	$908,140	$221,324,773
Motor Neuron Disease	$7,914	**$18,916**	$36,768	$1,165,567	$11,844,048
Spina bifida	$7,695	**$17,934**	$46,195	$300,111	$7,424,488
Traumatic Brain Injury	$5,919	**$17,848**	$59,070	$1,006,129	$163,427,939
Parkinson's	$7,264	**$15,560**	$26,880	$400,634	$23,702,660
Multiple Sclerosis	$4,303	**$14,775**	$50,460	$482,130	$52,468,158
Complex Communication	$6,765	**$14,139**	$33,490	$625,616	$125,140,132
Wheelchair	$6,503	**$12,815**	$28,748	$1,035,110	$30,044,061
Intellectual Disability	$4,468	**$10,593**	$24,365	$1,090,751	$46,956,732
Autism	$4,972	**$10,541**	$22,503	$283,080	$6,285,482
Blind Vision Impaired	$4,805	**$9,768**	$22,828	$410,760	$14,666,980
Down's Syndrome	$3,248	**$8,241**	$21,059	$534,823	$8,813,074

Highest Median Cost

Between 2003 and 2011 the disability categories which had the highest median adjusted cost for people admitted with any disability diagnosis were Spinal Injury ($34,623), Amputee ($30,429) and Cerebral Palsy ($20,854).

Highest Sum of Costs for all Individuals

Over the 9 year period the disability categories which had the highest sum of costs for people admitted with any diagnosis of disability were Cerebral Palsy at greater than $298 million, Stroke (greater than $221 million) and Traumatic Brain Injury (greater than $163 million)[4].

[4] Please note that where disability is not the main reason for a separation (i.e. it is not the principal diagnosis), not all of the costs associated with the separation are likely to be attributable to disability.

Number and Percentage of Hospital Separations: By Area Health Service (2003-2012)

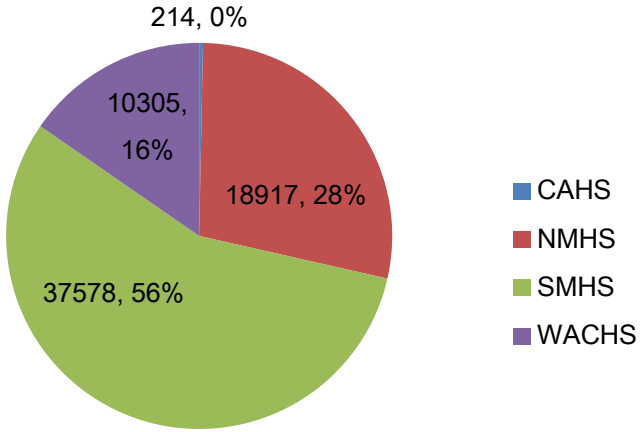
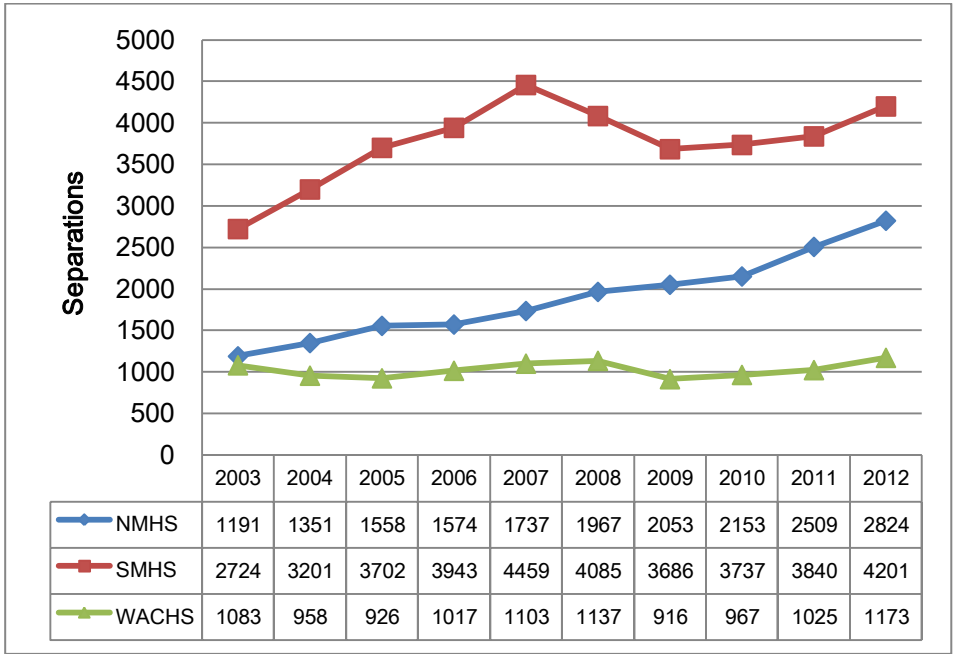


Figure 4: Percentage of hospital separations with any diagnosis of disability* from WA public hospitals by area health service from 2003-2012

Figure 4 illustrates the proportion of hospital separations for any diagnosis of disability in WA between 2003 and 2012 by Area Health Service. Between 2003 and 2012 there were 67,014 public hospital separations for any diagnosis of disability in WA. Of those, 37,578 separations or 56% occurred at SMHS hospitals, and 18,917 or 28% occurred at NMHS hospitals.

Hospital Separations over time by Area Health Service (2003-2012)



	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
NMHS	1191	1351	1558	1574	1737	1967	2053	2153	2509	2824
SMHS	2724	3201	3702	3943	4459	4085	3686	3737	3840	4201
WACHS	1083	958	926	1017	1103	1137	916	967	1025	1173

Figure 5: Number of hospital separations with any diagnosis of disability* from WA public hospitals between 2003 and 2012, by Health Service and separation year

Figure 5 illustrates the number of public hospital separations over time for any diagnosis of disability by area health service between 2003 and 2012. Since 2003 there has been a marked growth in hospital separations for any diagnosis of disability at NMHS hospitals. The total separations increased by 137.1% from 1191 in 2003, to 2824 in 2012. Between 2003 and 2012 SMHS hospitals experienced an overall increase of 54.2% in hospital separations for any diagnosis of disability. From 2007 to 2009 there was a reduction in the number of separations for any diagnosis of disability in SMHS hospitals. In 2012, there were a total of 2824 separations for any diagnosis of disability at NMHS hospitals and 4201 separations for any diagnosis of disability at SMHS hospitals.

Hospital Separations: By Disability Category and Area Health Service in 2012

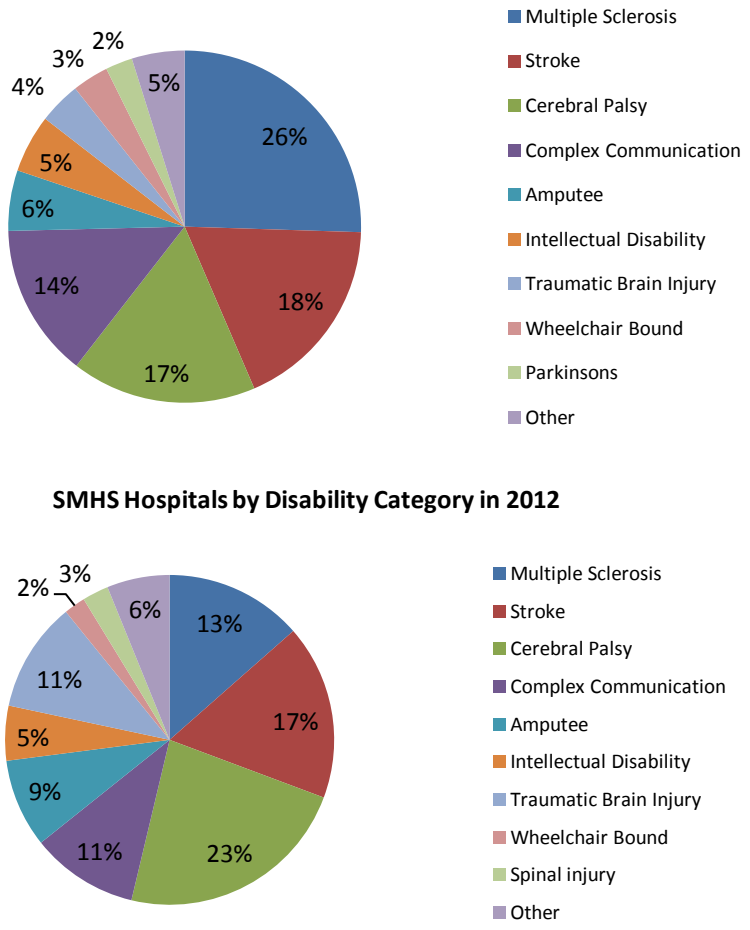


Figure 6: Percentage of hospital separations with any diagnosis of disability* from North Metropolitan and South Metropolitan Health Service hospitals by disability category in 2012 [5]

As shown in Figure 6, the disability categories which had the highest volume of separations in 2012 differed for NMHS and SMHS hospitals[6].

The disability categories which had the highest number of separations at NMHS hospitals in 2012 were Multiple Sclerosis (n= 873), Stroke (n=617), Cerebral Palsy (n=582), Complex Communication (n=482), and Amputee (n=190) (see figure 6).

The disability categories which had the highest number of separations at SMHS hospitals in 2012 were Cerebral Palsy (n=1258), Stroke (n=939), Multiple Sclerosis (n=738), Traumatic Brain Injury (n=591) and Complex Communication (n=576) (see figure 6).

Number of Hospital Separations over time by Site (2003-2012)

As shown in Table 12 the NMHS and SMHS tertiary hospitals had the highest volume of public hospital separations for any diagnosis of disability in 2012. SCGH experienced an increase of 170.4% over the 10 year period, from 821 separations in 2003 to 2220 in 2012. RPH experienced an increase of 51.4% from 1377 in 2003 to 2085 in 2012.

[5] Other includes disability categories <2% = Autism, Parkinson's, Down's Syndrome, Blind Vision Impaired, Spina Bifida, MND, Muscular Dystrophy and Post Polio

[6] Please note that some separations will be counted in multiple disability categories, as some separations had more than one disability diagnosis.

Table 12: Number of public hospital separations for any diagnosis of disability* in WA between 2003 and 2012 by selected hospitals and year *public patient only

Hospital Name	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	% change over 10 years
SCGH	821	977	1194	1186	1345	1563	1652	1730	1988	2220	**170.4%**
RPH	1377	1586	1828	1888	2271	1911	1953	1956	1884	2085	**51.4%**
FHHS	487	503	488	554	709	808	685	728	698	801	**64.5%**
SDH	98	102	74	93	81	84	111	133	232	256	**161.2%**
RGH	30	57	52	47	53	75	67	92	164	245	**716.7%**
JHC**	73	154	140	168	165	192	190	187	199	219	**200.0%**
AKMH	82	63	158	166	135	167	152	146	112	118	**43.9%**
BH	68	67	69	72	57	57	66	87	81	84	**23.5%**
OPH	65	33	40	35	38	31	27	22	17	28	**-56.9%**
KH	20	14	12	21	19	9	12	11	12	12	**-40.0%**

Number of Hospital Separations by Disability Category by Site (2003-2012)

Table 13**Error! Reference source not found.** provides a breakdown of the public hospital separations by disability categories at selected metropolitan hospitals between 2003 and 2012. The disability categories which experienced the highest number of hospital separations at RPH between 2003 and 2012 were Cerebral Palsy, Stroke, Amputee, TBI and Complex Communication. At SCGH the highest number of public hospital separations occurred in the disability categories of Cerebral Palsy, Stroke, TBI, Complex Communication and Multiple Sclerosis.

Table 13: Number of hospital separations with any diagnosis of disability* from selected metropolitan hospitals between 2003 and 2012, by disability category and hospital

	RPH	FHHS	SCGH	AKMH	OPH	SDH	BH	RGH	KH	JHC
Cerebral Palsy	5038	1565	3612	406	105	346	137	303	41	513
Stroke	3653	1334	3382	278	31	254	48	119	24	347
Amputee	3294	1097	1170	116	13	61	63	86	12	122
Traumatic Brain Injury	2970	150	1272	39	8	36	21	22	0	79
Complex Communication	2353	943	2130	102	44	173	58	94	6	276
Multiple Sclerosis	1809	1229	3810	126	34	79	12	146	9	313
Intellectual Disability	1760	566	788	229	22	374	291	89	41	149
Blind Vision Impaired	555	224	197	35	<5	21	15	26	<5	24
Wheelchair Bound	553	135	656	72	5	33	19	91	5	109
Spinal Injury	453	17	43	0	0	<5	0	<5	0	<5
Downs Syndrome	298	172	153	46	<5	66	9	31	<5	35
Spina bifida	232	51	62	8	<5	10	<5	8	<5	12
Parkinsons	225	284	424	92	132	52	114	29	<5	71
Motor Neuron Disease	184	66	224	12	5	14	<5	14	11	35
Autism	144	125	92	28	<5	41	21	16	0	34
Muscular Dystrophy	143	40	118	10	<5	18	<5	<5	<5	5
Huntingtons	66	27	56	9	0	7	7	7	<5	21
Post-Polio	0	0	0	0	0	0	0	0	0	0

APPENDIX 12: DLO Options Identification Questions

Who will the DLO service?	What will the DLO role do?	At which hospital site will the DLO work?	Where should the DLO sit in the hospital community?	Where will the DLO be positioned (stand alone role or aligned with a team)?
i. **All patients** within the DLO Project disability cohort (see appendix 2) OR ii. A **select group** of patients with specific disability diagnoses.	i. **Consumer support - patient/ family/ carers'** (e.g. advocacy, information packages, checklist screening, transport, pre-admission planning, post discharge planning, education, liaison with hospital team, linkages external agencies). ii. **Clinician support** (e.g. case management, equipment support, transport, discharge/care planning). iii. **Organisational support** (e.g. developing policies, clinical pathways, systems, processes & procedures to change service delivery for patients with disability at a hospital-wide level). iv. **A combination** of any of above.	The tertiary and secondary hospitals within NMHS and SMHS are: ▪ **NMHS** – SCGH, JHC, SDH, OPH ▪ **SMHS** – RPH, FHHS, AHS, BH, RGH	▪ Hospital, inpatients ▪ Hospital, stand-alone ▪ Hospital, outpatients ▪ Policy or planning teams ▪ Patient advocacy / liaison / complaints teams ▪ Community (in-reach to hospital, ambulatory)	Whether the DLO is a standalone role or aligned with a particular team is dependent on each hospital site.
Decision Criteria				
The decisions made in answer to this question are based on epidemiology data (for example number of patients seen at each hospital), stakeholder feedback (for example identified gaps in service delivery) and knowledge of existing services (for example specialist or well-resourced teams already providing a service to particular groups of patients).	*Decisions made in relation to this took into account stakeholder feedback (for example identified issues and recommendations for DLO role), stakeholder preference (voting at open group consultation sessions and focus group sessions).*	*Decisions took into account the data (e.g. the volume of patients seen at each hospital), health reform (e.g. projected expansion or reduction in services), stakeholder feedback (e.g. identified gaps in service delivery), knowledge of existing services (e.g. specialist or well-resourced teams already providing a service to particular groups of patients), and stakeholder enthusiasm (e.g. whether clinicians gave appositive, negative or mixed response to the idea of the DLO being positioned at a particular hospital).*	*In order to answer this question, consideration was given to the previous three questions, as well as stakeholder feedback (for example discussions with clinicians in similar roles in WA and inter-state, as well as clinician preference), and knowledge of the hospitals' organisational structures.*	*This question will be answered in the NMHS & SMHS options below.*

APPENDIX 13 – NMHS DLO Recommended Option 1 (DLO in SWAT team) Discretionary Additional Resources Proposed

DLO role proposed FTE breakdown:

- 0.7 FTE consumer support
- 0.3 FTE organisational support

Existing **(E)** Resources – the SWAT inpatient complex care team for patients 18-65 years currently includes the following FTE for a 7-day a week service:

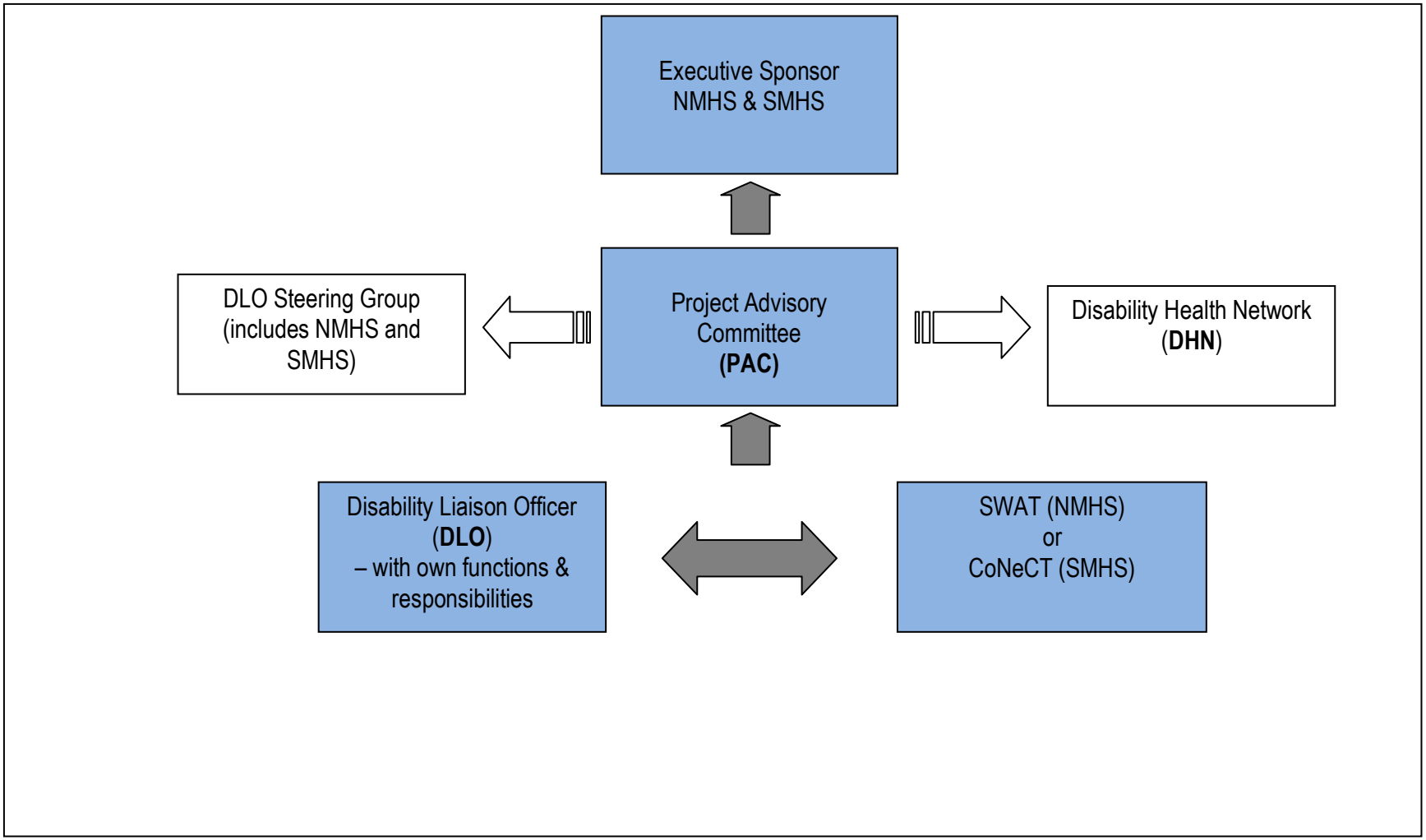
- 0.5FTE P2 (SWAT Team Lead) **E**
- 2.3FTE P2 (Occupational Therapy) **E**
- 2.3FTE P2 (Physiotherapy) **E**
- 2.3FTE P2 (Social Work) **E**
- 0.8FTE P2(Dietician) **E**
- 1.20FTEP2 (Speech Pathologist) **E**
- 1.0FTE (Therapy Assistant) **E**

Additional **(A)** resources proposed to support DLO position (discretionary):

- 0.5FTE Project Administration **A**
- 0.4 FTE Neuropsychology **A**
- 0.4FTE Clinical Psychology **A**
- 0.5FTE Disability Access and Inclusion Plan (DAIP- currently 0.1FTE, recommend increase to 0.5FTE) **A**
- Medical Governance (Rehabilitation Physician Consultation) **A**

E – Existing resources
A – Additional resources proposed to support DLO role (discretionary)
NB: *The DLO role can still go ahead without the additional resources, but these have been scoped as adding the most value and sustainability for complex disability health care.*

APPENDIX 14 – DLO Example Governance Reporting Structure for NMHS & SMHS



* *The above is a **proposed** governance structure for the DLO and open for discussion. This shows NMHS and SMHS, as it will be the same.*

Appendix 15: Clinical Service Framework (CSF) - Matrix of DLO Parked Issues & Recommendations

CSF AREA	ISSUE	DESCRIPTION / EVIDENCE	RECOMMENDATIONS
1. CLINICAL	Partnerships between health & disability sectors are siloed	▪ There is a lack of awareness within the hospital system of community services. ▪ Disability specialist agencies often have capacity, but because of protocols & procedures are unable to provide services ▪ Case example: a patient with an Acute Brain Injury had a long LoS in SCGH (6 months) and was waiting for CAP funding approval. A bed was available for this patient at Nulsen, but couldn't be accessed due to funding restrictions	▪ Increased awareness and education of hospital staff in order to make better use of the services that do currently exist. ▪ Streamlined funding process, eliminate eligibility criteria where possible to facilitate transfer of care.
	Liaison between hospital and group homes is limited	▪ "[We need]..greater understanding by the hospital regarding issues within the group home…it isn't a nursing home with wide hallways and big bedrooms." ▪ "[We need]…education to hospital staff that group homes supported by DSC do not have nursing staff on hand." ▪ Case example: a patient was discharged home and their medication was not made available in a Webster pack – a requirement of the group home, as their staff are not allowed to dispense medications.. The patient was unable to receive their medication until this issue was resolved. This led to the patient being in pain unnecessarily.	▪ Provide medical / health training for staff as required. ▪ Hospital staff need to have greater awareness of support worker skills / training etc and accommodate this in DC planning ▪ Resources (for example on hospital intranet, or DSC website) regarding group homes, support workers

	Lack of Community Resources (particularly accommodation options for young people with disability)	▪ There are exceptionally limited age-appropriate residential accommodation options for people with high-care needs, cognitive disabilities & physical. ▪ Strict eligibility criteria, excludes people with behavioural problems. Limited residential care facilities for young-disabled patients with behavioural issues and high functional needs. ▪ It was acknowledged that there is a lack of resources in the community for disability (funding, staffing, wait-time) which can contribute to longer waitlists, a lack of available services and delays discharging patients from hospital.	▪ More funding needs to be directed to young accommodation facilities and beds to address this ongoing issue. ▪ Residential care facilities for younger-disabled patients with high psychiatric, behavioural issues and functional needs. More flexible eligibility criteria. ▪ Hospital needs to consider transition/step-down unit so that when accommodation options are not available, the patient does not need to stay in hospital unnecessarily. ▪ Review of community funding and resources as appropriate. More of a focus on ambulatory care as per Victoria, Australia.
2. ACCESS	**Transport Barriers**	▪ Patient Transport Services outpatient eligibility criteria – minimum of monthly appointments and 48 hrs notice of appointment may exclude patients with complex health needs/disability. ▪ Hospital transport services do not currently cater for patients who are to be admitted either for day surgery or longer term admission ▪ Current criteria based on outpatient needs ▪ Issues include insufficient disabled parking spots, cost of parking, and distance of parking from hospital.	▪ Hospital review of inpatient and outpatient transport policy to include people with disability and their transport needs. ▪ Hospital review of parking policy and access. ▪ Greater number of disabled parking bays, at closer access to hospital entrance points.

		▪ "The cost of parking forces patients to decide between paying for parking to attend appointments or pay for medication / nutrition supplements." (Carers WA staff) ▪ "The distance the patient has to walk from his/her car park in the hospital parking lot can wear the patient out. Often patients would require a wheelchair just to get to the door of the hospital." (Clinician)	
3.RESOURCES / TEACHING & TRAINING	**University Curriculum (limited undergraduate education on disability)**	▪ Lack of disability education provided in university nursing, allied health and medical curricula ▪ Lack of professional development pathway in the clinical speciality of disability (for example, UK model of post-graduate training in intellectual disability)	▪ Liaison between University and Health staff. ▪ Consideration to be given to increasing university curricula content in disability ▪ Consideration be given to increasing disability-specific learning opportunities that can be provided within NMHS and SMHS e.g. clinical placements for students.
4. FACILITIES	**Infrastructure & DAIP**	▪ Signage and way-finding in hospitals is inadequate ▪ Doorways are too narrow in certain clinical areas for wheelchair access ▪ Toilet doors can be too heavy and patients with disability are not able to push them open. ▪ Not all wards have rooms with ceiling hoists. ▪ Hospitals rooms are too small to accommodate the patient's specialist equipment.	▪ Review via hospital DAIP committees.

		▪ DAIP Committee members feel under-resourced.	
5.OTHER	**Guardianship issues resulting in extended length of stay in hospital**	▪ Hospital staff, carers and families identified a lack of understanding of guardianship and informed consent. ▪ Presents barriers when staff between hospital and disability agencies cannot share information ▪ Group home staff feel pressured into signing consent on behalf of patients (but cannot) ▪ The organisation looking after the patient is not necessarily also the guardian. A support worker accompanied a patient to an outpatient appointment, and the guardian was unable to be present. Doctors are unable to share information with the support worker, however this information may be vital to the patient's care.	▪ Review of protocols and procedures re: guardianship. ▪ Strategy / process to address issues surrounding informed consent of patients. ▪ Increased awareness of 'Sharing Information of health Care Policy (no P08/0703). ▪ Consider opportunities to engage in pre-planning with LACs, to identify Power of Attorney, Advanced Health Care Directive prior to admission.

**The above matrix outlines the issues that were out-of-scope to the Disability Liaison Officer (DLO) role in the project, but important to consider for sustainable disability service delivery*

APPENDIX 16: Additional Bibliography

16.7.1 Western Australian Documents

- Department of Health, Western Australia. Clinicians - Do you see me? Final report. Perth: Clinical Senate of Western Australia, Department of Health WA; 2011.
- Department of Health and Disability Services Commission Joint Protocol to Guide the Assessment and Support of Younger People with a Disability. 2013.
- Disability Services Commission Statewide Specialist Services. Disability Health Consultative Group Launch. 2012.
- Ministerial Advisory Council on Disability and the Carers Advisory Council. Sharing healthy conversations: consultation report. Perth: MACD & CAC; 2013.
- Model of Care for Long Stay Younger People (LSYP) with Disabilities in Metropolitan Public Hospitals. 2013.
- NMHS and SMHS Clinical Service Framework 2010 – 2020.
- NMHS and SMHS Disability Access and Inclusion Plans.
- Somerford P, Katzenellenbogen J, Codde J. WA Burden of Disease Study: burden of disability in WA. Perth: Department of Health, Western Australia; 2004.
- Western Australian Council for Safety and Quality in Health Care. Western Australian Strategic Plan for Safety and Quality in Health Care 2008 – 2013: placing patients first. Perth: Office of Safety and Quality in Healthcare; 2008.
- WA Health Networks Models of Care [Internet]. [Cited 2013 July]. Available from http://www.healthnetworks.health.wa.gov.au/modelsofcare/
- Western Australia Disability Services Act [Internet] 1993 [Cited 2013 June 6]. Available from http://www.slp.wa.gov.au/pco/prod/FileStore.nsf/Documents/MRDocument:25180P/$FILE/Disability%20Services%20Act%201993%20-%20[04-a0-00].pdf?OpenElement

16.7.2 National and International Documents

- Australian Institute of Health and Welfare. Health of Australians with disability: health status and risk factors [Internet}. 2010. [Cited 2013 June 6.] Available from http://www.aihw.gov.au/publication-detail/?id=6442472401
- Australian Institute of Health and Welfare. Definition of disability [Internet]. Cited 30 April 2013. Available from http://www.aihw.gov.au/definition-of-disability/
- PWC. Disability expectations: investing in a better life, stronger Australia [Internet]. 2011 [Cited 2013 June 7]. Available from http://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf
- Madden R, Hogan T. The definition of disability in Australia: moving towards national consistency. Canberra: The Australian Institute of Health and Welfare; 1997. Report no.: DIS 5.
- MENCAP. Death by indifference: 74 deaths and counting; a progress report 5 years on [Internet]. 2012. [Cited 2013 May 23}. Available from http://www.mencap.org.uk/campaigns/take-action/death-indifference/74-deaths-and-counting-report
- National Disability Insurance Scheme Rules Consultation Paper. 2013.
- National People with Disabilities and Carers Council. Shut Out: the experience of people with disabilities and their families in Australia. Canberra: Commonwealth of Australia; 2009.
- World Health Organisation. ICIDH-2: International classification of functioning, disability and health [Internet]. 2002. [Cited 2013 April 30]. Available from: http://www.sustainable-design.ie/arch/ICIDH-2Final.pdf

16.7.3 Articles

- Brown M, MacArthur J, McKechanie A, Mack S, Hayes, M, Fletcher J. Learning disability liaison nursing services in south-east Scotland: a mixed-methods impact and outcome study. J Intellect Disabil Res. 2012;56(12):1161-74.
- Buzio A, Morgan J, Blount D. The experiences of adults with cerebral palsy during periods of hospitalisation. Aust J Adv Nurs. 2002;19(4):8-14.
- Castles A, Bailey C, Gates B, Sooben R. Experiences of the implementation of a learning disability nursing liaison service within an acute hospital setting: a service evaluation. Br J Intellect Disabil. 2013; accessed online prior to publication: DOI 10.1111/bld.12070.

- Gibbs S, Brown M, Muir W. The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study. J Intellect Disabil Res. 2008;52(12):1061-77.
- Hart S. Learning-disables people's experience of general hospitals. Br J Nurs. 1998;7(8):470-7.
- Hemsley B, Balandin S. Without AAC: the stories of unpaid carers of adults with cerebral palsy and complex communication needs in hospital. Augment Alternat Communicat. 2004;20(4):243-58.
- Leonardi M, Bickenbach J, Bedirhan Ustun T, Kostanjsek N, Chatterji S. The definition of disability: what is in a name? Lancet. 2006;368:1219-20.
- McNamara P, Bryant J, Forster J, Sharrock J, Happell B. Exploratory study of mental health consultation-liaison nursing in Australia: part 2 preparation support and role satisfaction. Int J Ment Health Nurs. 2008;17:189-96.
- Pointu A, Young J, Walsh K. Improving health with acute liaison nursing. Learn Disabil Pract. 2009;12(5):16-20.
- Sharrock J, Bryant J, McNamara P, Forster J, Happell B. Exploratory study of mental health consultation-liaison nursing in Australia: part 1 demographics and role characteristics. Int J Ment Health Nurs. 2008;17:180-88.

16.7.4 Other

- Australian Indigenous HealthInfoNet: what is disability? [Internet]. [Cited 2013 April 30]. Available from: http://www.healthinfonet.ecu.edu.au/related-issues/disability/reviews/background-information
- Disabled World: Definitions of disability [Internet]. [Cited 2013 April 30]. Available from: http://www.disabled-world.com/definitions/disability-definitions.php#ixzz2Rvkw6wFz
- Lily A. Managing in an ABF environment [Internet]. 2013 April 9 [cited 2013 September 2]. Available from: http://activity/post/2013/04/11/2013-Autumn-Staff-Forum-Presentations.aspx
- World Health Organisation: Disabilities [Internet]. [Cited 2013 April 30]. Available from: http://www.who.int/topics/disabilities/en/

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