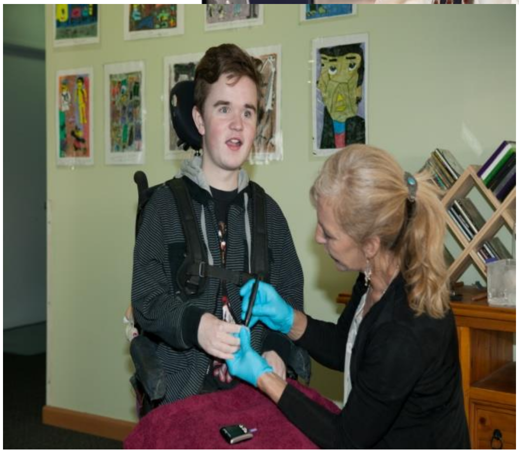
Tasmanian NDIS
Disability Health Advi



Policy proposal for the operational interface between the National Disability Insurance Scheme (NDIS), disability and health in Tasmania for:

adult NDIS participants with intellectual disability during hospitalisation

The Problem- Death by Indifference


Ted, RIP 61, after discharge


Tom RIP 20, aspiration pneumonia and esophagitis


Mark, RIP 30 fractured leg and pneumonia, severe pain


Warren RIP 25 ruptured appendix, not recognised


Martin RIP 43, stroke, not treated, starvation


Emma, RIP 26, cancer, not treated

Policy proposal for the operational interface between the National Disability Insurance Scheme (NDIS), disability and health in Tasmania for:

adult NDIS participants with intellectual disability during hospitalisation

Tasmanian NDIS-Disability-Health Advisory Group, October 2017

Tasmanian NDIS-Disability-Health Advisory Group representation:

National Disability Insurance Agency, National Disability Services, Advocacy, NDIS registered allied health and nursing providers, Minister's Disability Advisory Council and Educator, Consumer representative, NDIS registered Service Providers, Department of Health and Human Services, interested community experts, hospital health professional

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Disclaimer:

Although this paper was developed from above individuals representing stakeholder contributions, it must be acknowledged that not all agreement by all parties was obtained for all recommendations, and there are no accepted obligations of bodies for which the representatives stand to accept any of the recommendations. However, there was general consensus in approval of the final version of the documentation for forwarding to all the stakeholder parties to be individually considered by their own organisation.

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Abbreviations

CEO Chief Executive Officer

COAG Council of Australian Governments

COO Chief Operating Officer

NDIA National Disability Insurance Agency

NDIS National Disability Insurance Scheme

NDS National Disability Services

Preamble

Good health is fundamental to wellbeing for all people, including those living with disability. It helps individuals with a disability to participate in, engage with, and contribute to their society and community, to cope with life's adversities, have fun, to tackle challenges and to set and achieve goals. Achieving good health care for people with intellectual disability entails individualised, dedicated liaison between such consumers, their disability service providers, health providers and their family carer unit. The National Disability Insurance Scheme (NDIS, the Scheme) does not fund or replace mainstream healthcare services but is focused on providing and funding personalised supports related to people's disability support needs. Embedded in the principles of the NDIS is a recognition that both the NDIS and health systems need to work together at the local level to plan and coordinate streamlined care for individuals requiring both health and disability services, recognising that both inputs may be required at the same time and that there is a need to ensure a smooth transition from one to the other. Successful implementation of the NDIS therefore requires the establishment of a robust interface between the NDIS, and the disability and mainstream health sectors.

Although the Council of Australian Governments (COAG) has agreed to principles that determine the nature of the NDIS interaction with other mainstream service systems such as health, the practical protocols of such an interface, and the subsequent responsibilities of the NDIS, disability and health sector interactions for people with disability are not well defined yet. The COAG documents do however suggest that for NDIS participants with complex communication and behavioural needs (common in the majority of adult NDIS participants with intellectual disability) NDIS funding could apply for functional supports for the inpatient hospital setting. Clarity and timely resolution of these operational interface issues is necessary to enable people with disability to get the most effective support from their disability supports to access health, to know the funding source of this functional support, and to access quality healthcare provided by various elements of the health sector.

The Tasmanian NDIS-Disability-Health Advisory group comprising senior representatives from The National Disability Insurance Agency (NDIA, the Agency) and the disability and health sectors was established in 2016 to analyse and consider possible solutions to specific practical problems relating to the NDIS-disability-health interface operations.

The first practical problem of interface the group looked at involved one of the largest subsets of NDIS participants, adults with intellectual disability, and their functional supports in relation to accessing mainstream healthcare in a hospital. Clarity of the operational relationships between NDIS, health and disability for this subset of NDIS participants in this particular health setting was considered of high priority locally, at a state level and nationally. It is recognised and well reported in the literature that adults with intellectual disability have much poorer outcomes in the hospital setting compared with peers without disability. These outcomes are not inevitable, and have been attributed to remedial deficiencies in both health- and disability- related supports. The group presents in this document specific policy and procedural recommendations and responsibilities relating to this particular operational interface relevant for NDIA and in NDIS planning, for disability service providers, for health service providers, for when adult NDIS participants with intellectual disability require inpatient hospital level care.

This position paper is relevant reading for representatives of people with intellectual disability and their families, and all NDIA, disability and health professionals, administrators and sectors, relevant government departmental leaders, and health and disability interested stakeholders. The Executive Statement contains the Advisory Group's overarching policy statement, with background values, beliefs which underpin the policy, then policy and procedural implications and recommendations. Subsequent chapters provide focused information from health, disability and NDIS spheres on aspects of health and functional supports for adults with intellectual disability requiring hospitalisation and upon which the proposed policy derives. The appendices provide some practical resources related to the NDIS, disability, and health interface in relation to adults with intellectual disability accessing hospital level care in the era of NDIS.

The balanced contributions from the diverse Advisory Group membership make this Position Statement unique and powerful within the realm of the developing operational interface of NDIS, Health (specifically hospitalisation), Disability (specifically intellectual disability) thereby ensuring greater prediction of indemnity for adults with intellectual disability.

Executive Summary

Main policy statement

Adults with intellectual disability with illness requiring hospitalisation endure very poor, but not inevitable, health outcomes compared to peers without disability. Causes are attributable to both inadequacies in care from mainstream health and disability support sectors, and the absence of satisfactory communication between them and people with intellectual disability to address the causes all together. Interactions of the National Disability Insurance Scheme with adult participants with intellectual disability and the hospital and disability services they access will ensure the presence of:

1. quality person centred healthcare plans from hospital based health professionals, fully funded by health, and taking into account the implications of living with intellectual disability

2. quality person centred functional supports plans specifically designed, including estimated requirements for daily hours of functional supports and roles of supports , pre-prepared for hospitalisation situations, and being prepared during usual NDIS planning

3. pre-defined fiscal responsibility for the funding of such functional supports required during hospitalisation, that responsibility being shared between disability and health in a pre-determined manner

4. a general understanding that such participants' NDIS plans will include provision for funding of up to 6 hours daily for required maintenance, core, functional disability supports and the remaining required daily hours of functional support required during hospitalisation events will be funded by health

5. established local, state and national routine, formal communication opportunities between adults with intellectual disability and their representatives, health and disability professionals and their sector representatives, other relevant stakeholder representation, and the National Disability Insurance Agency to secure the establishment of such quality health and functional supports, and their funding arrangements.

Our Values and beliefs

In development of the position paper to achieving optimal hospital level healthcare for adults with intellectual disability the Tasmanian NDIS-Disability-Advisory Group asserts the following core principles:

6. their strong support for the NDIS and its underlying values and principles, including individual autonomy, non-discrimination, and full and effective participation and inclusion in society

7. their belief that further enhancement of NDIS, disability and health engagement is a key approach to achieve the very best strategic, systematic, clinical, evidence based, economic, ethical, practical, sensible and fair approaches to clarifying the practical interconnections between NDIS, disability and health, ultimately to minimise the health disparity endured by adults with intellectual disability

8. intellectual disability is characterised by significantly sub average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skills areas: communication, self-care, home-living, social skills, community use, self-direction, health and safety, functional academics, leisure, work, and manifests before the age of 18 years

9. “functional”, “disability” or “core” supports are synonyms all used to describe the types of assistance provided by others to adults with intellectual disability to cater for their limitations in specific adaptive skills in accessing mainstream health services, and must be understood by health and disability professionals.

The Group membership acknowledges:

10 there is a distinction between
- (a) healthcare plans (eg diagnosis and treatment of health problems) as provided by health professionals and systems to individuals with intellectual disability, and funded by health *versus*
- (b) the functional supports plans (eg assistance in communication, understanding diagnosis, and undertaking treatments) as provided by disability supports and services required by individuals with intellectual disability to access that healthcare
- (c) and furthermore such person centred functional and healthcare plans are likely to vary depending on the type of healthcare setting

11 that the implications of living with intellectual disability include

- (a) the presence of multiple medical problems as the norm

- (b) high use of the hospital system compared with peers without disability

- (c) the experience of unacceptable, not inevitable, excessive preventable suffering, morbidity and mortality especially in the hospital setting,

- (d) a requirement for, as for peers without disability, patient-centred healthcare plans by health professionals in all health settings,

- (e) a requirement for functional supports in health settings, because the presence of adaptive skills limitations impacts upon the ability to independently access and participate in optimal healthcare,

- (f) a possibility that usually required daily functional supports may be increased in the case of illness severe enough to be requiring hospitalisation

- (g) a need for healthcare services to implement reasonable adjustments to mainstream services to facilitate access;

12 that healthcare plans for adults with intellectual disability in inpatient, specialist outpatient situations provided by health professionals are often inadequate, and similarly the disability supports organisation of adults with intellectual disability in hospital settings is also frequently inadequate and haphazard, both contributing to the preventable morbidity, mortality and suffering in hospital;

13 the relevance of understanding the nature of individuals’ limitations in adaptive skills associated with their underlying intellectual disability when planning functional supports for social and community, including the health sector, mainstream access;

14 together the disability and health sectors have a currently unmet shared responsibility to address the barriers to provision of both optimal healthcare access and functional disability supports for adults with intellectual disability requiring hospitalisation; further, this now involves the NDIS;

15 the enhancement of NDIS, disability and health interconnections and engagement is a key approach by which the very best strategic, systematic, clinical, evidence based, economic, ethical, practical approaches to ensuring the necessary stakeholder partnerships are optimised to minimise the health disparity for adults with intellectual disability.

In the light of the above, the Advisory Group has made the following policy and procedural recommendations on improving the interconnections between NDIS, disability and health sectors for adult NDIS participants with intellectual disability who require hospitalisation.

Policy Recommendations

16 In consideration of NDIS-disability-health interface

(a) the NDIA, disability and health professionals will share a common biopsychosocial approach in their provision and design of services. This means that all parties recognise that living with intellectual disability has associated cognitive, health, psychological, social, economic, and environmental implications.

(b) opportunities will be made for hospital health services and front line clinicians to improve their working knowledge and values of the NDIS; similarly, opportunities will be made for NDIA and disability services to optimise their knowledge of hospital based health policy and processes; and all parties to appreciate the distinction between functional supports provided by carers required for access to mainstream healthcare, and healthcare itself provided by health professionals.

(c) forums by which NDIA, disability and health national, state and local representatives can engage in a formal way and problem solve aspects of the interface will be established. Furthermore, stakeholders will also include consumers with intellectual disability and advocacy representation.

(d) the NDIA, disability and health professionals and sectors will improve their knowledge of available data on health profile, the high hospital usage by adults with intellectual disability, the high rates of preventable suffering, deaths and adverse events in hospital experienced by this group. Theywill become familiar with the analyses of why these occur, and be prepared to address the causes as relevant in their own sector and in collaboration with others.

17 Adults with intellectual disability to have

(a) person centred healthcare plans from their health professionals relating to inpatient, outpatient, healthy living settings

(b) prepared individualised functional supports plans to clarify the nature of their disability and disability supports required to access healthcare in all settings, including in crises situations for hospital

(c) both their healthcare and functional supports plans considering their biopsychosocial situation

(d) an established pathway of communication of these health plans and functional supports plan for access to hospital health between themselves, their NDIS planners, family/primary carer, disability support and health professionals

(e) such individualised healthcare and functional supports plans even if they are not NDIS participants

(f) consideration of their family unit in making both these plans.

18 In consideration of functional supports required by adults with intellectual disability for hospitalisation

- (a) acknowledgement that such supports for adults with intellectual disability who are ill enough to be hospitalised are often greater than their usual daily functional supports for community participation and contribution
- (b) fiscal responsibility for functional supports in the hospital setting to be shared between NDIS and health
- (c) there is a requirement of pre-planning and documentation for such functional supports so that the disability service provider and carer unit know their roles
- (d) such precise pre-planning for the case of functional supports required for hospitalisation is to occur in the NDIS planning process and includes an estimated number of daily hours of functional support for hospitalisation
- (e) the scope of planned functional supports for in-hospital healthcare include assistance with:
  - i. communication of medical history of presenting problem, past history, complications, medications, allergies, usual health, mobility
  - ii. communication in relaying response to treatment and symptoms
  - iii. relaying the nature of usual adaptive skills limitations and cognitive understanding related to the intellectual disability
  - iv. emotional and behavioural support during the stay
  - v. filling out menus, hospital routines, daily ward rounds, hygiene and mobility
  - vi. undergoing tests
  - vii. understanding diagnoses and treatments
  - viii. admission, daily ward rounds and discharge planning
  - ix. relaying the usual home, family, social and environmental situation
  - x. relaying information about Person Responsible.

19 In consideration of the provision of healthcare by mainstream health professionals and hospitals for adults with intellectual disability, health professionals and hospital executive ensure

- (a) the establishment of reasonable adjustments to care to improve access for adult patients with intellectual disability including hospital doctors and other health professionals:
  - i. finding out about the adaptive skills associated with the disability and adjusting communication style appropriately
  - ii. working with the patient’s functional supports in daily care
  - iii. taking time to find out about the patient as a person in their usual well self
  - iv. taking extra time required to undertake a thorough assessment
  - v. follow up more regularly if unsure
  - vi. not necessarily attributing symptoms to disability (diagnostic overshadowing)
  - vii. ensuring correct knowledge on consent procedures
  - viii. ensuring robust discharge planning to include communicating clearly to immediate family members/carers, or disability support staff present and as well to the patient’s regular daily network of specialist disability support providers
  - ix. ensuring documentation of admission and discharge about continuing management, treatment plan (or activity adjustments/diets/equipment use) is communicated to

appropriate people, and plan for the prevention of the need for readmission
    x. provision of clearer easy read information in a more accessible format

(b) integrating positive attitudes to disability, disability equality and normalisation in medical education and training, and incorporate into usual hospital quality assurance programs

(c) clarification of the nature of occupational, health and safety aspects of disability support workers in the hospital setting assisting their clients

(d) establishment of memorandums of understanding and invoicing processes for appropriate payment of disability service providers for their functional disability supports in hospital

20 In consideration of the unique role the disability support providers for functional supports required by adult clients with intellectual disability in hospital,

(a) disability service providers have a responsibility to ensure that
    i. all their clients have individualised functional supports plans for hospital that is pre-planned and documented
    ii. staff are educated on their functional support roles in hospital

(b) processes and protocols for emergency hospital admissions with regard to staffing rosters and responsibilities are in place

(c) individual's functional supports plans for hospitalisation are incorporated into their NDIS planning sessions.

21 In consideration of the unique role of NDIA in the functional supports for participants with intellectual disability requiring hospitalisation, senior NDIA management is required to

(a) acknowledge the importance of functional supports planning for adult participants with intellectual disability in the hospital setting, and that in the hospital setting usual numbers of hours of functional supports may need to be increased

(b) educate NDIS planners on their specific role in facilitating functional supports planning for adult participants with intellectual disability in the hospital setting, and the types of relevant functional supports so that each adult participant with intellectual disability has a plan for functional support when hospitalisation is required

(c) engage with health on clarifying the demarcation of funding of functional supports in hospital between health and disability**.**

Procedural recommendations

In fulfilling these policy guidelines, the following procedural processes are necessary

22 Tasmanian NDIA undertake to develop

(a) an engagement strategy to include a dedicated and ongoing NDIA outreach to senior executive and clinical staff of the 3 main public and state wide private hospitals across Tasmania to assist in health sector education about what NDIS is, its values, and about eligibility and planning processes, and the roles of physicians, and operational aspects of NDIS-disability-health interface

(b) guidelines for participants and their families/carers as to how to optimise health and well being, including for hospitalisation experiences, through NDIS planning. This would involve NDIA upskilling its Local Area Coordinator partners on how to optimise participants' NDIS planning for reasonable and necessary disability supports for health and well being, especially hospitalisation

(c) a commitment to discuss the present Position Paper with colleagues in national NDIA for feedback and review.

23 **That National Disability Services** (NDS) as a peak body representative of disability service providers, expand its leadership role in facilitating

(a) increased awareness of the importance of functional supports as provided by disability service providers, in accessing optimal healthcare of its clients with intellectual disabilty especially when they are ill enough to require hospitalisation

(b) logistics supports such as in staffing implications for emergency hospitalisations of clients with intellectual disability

(c) engagement with the health sector on memorandum of understanding for streamlining invoicing processes for functional supports provided in hospital by disability service providers

(d) increased engagement opportunities with health sector to improve cross fertilization of values, protocol and processes within the systems

24 Each Tasmanian public and private hospital

(a) appoint an "NDIS-disability-health liaison staff member" to act as a NDIS and disability expert in that location with access to local NDIA staff and NDS peak body to implement policy and practical aspects of the NDIS-disability-health interconnection including the funding aspects

(b) develop an improved inclusive "best practice" model, transparent, accountable extending and improving accreditation/compliance standards as far as disability is concerned

(c) clarify internally and liaise with the National Health Reform Body

25 **Funding responsibility** of the required functional disability supports plan for NDIS adult participants with intellectual disability in hospital setting is shared between health and the NDIS. As a default position, but to be individually considered, the adult participant with intellectual disability will have 6 hours per day of the required functional supports for hospitalisation funded in their NDIS plan, and other required daily hours of functional supports are funded by health sector (public and private). Furthermore, the National Health Reform Agreement for public hospitals to be reconsidered in this light. Private hospitals to evaluate the implications of such funding responsibilities.

26 **Ongoing review** of the policy and procedures as presented continue as part of the formal NDIA-disability-health (public and private) engagement group. Furthermore, efforts to broaden information sharing of policies and procedures with other stakeholders such as consumers' groups, advocacy organisations and disability service providers outside of the NDS others will comprise part of the core outcomes of the engagement process

1. *The Tasmanian NDIA-disability -health advisory group*

About the group

The Tasmanian National Disability Insurance Agency (NDIA, the Agency)-disability -health advisory group, established in 2016, is an independent body comprising senior representatives from stakeholders such as NDIA, National Disability Services (NDS), other Specialist Disability Service providers, Department of Health and Human Services (DHHS), Consumers, Advocacy and health professionals. The group meets every 6 to 8 weeks with the primary goals of refining practical aspects of the interface of National Disability Insurance Scheme (NDIS, the Scheme) with health for NDIS participants and their families, NDIA, health and disability service sectors. It must be said that the recommendations of the Advisory group, although emanating from the joint group members' discussions, may not necessarily be the formal view of the party represented in the group, but are forwarded to the stakeholder bodies represented for further consideration.

Tasmanian NDIS participants

In Tasmania by the end of roll out, it is anticipated there will be more than 10,000 NDIS participants, most of whom, if not all, will be accessing our hospitals either as inpatients or out=patients multiple times during their lives. Adults with intellectual disability form one of the largest NDIS participant groups in Tasmania.

Support for the NDIS and its values

The NDIA-Disability-Health Advisory group wholly supports the NDIS and its underpinning values (Table 1) for people living with disability, such as person centredness, autonomy, the value of reasonable and necessary supports to facilitate full and effective participation and inclusion in society, the requirement for mainstream services to develop reasonable adjustments to facilitate access to their service, and those human rights expressed by the Convention on the Rights of People with Disability. Specifically regarding health, article 25 of the Convention article is the requirement that medical treatment should not be withheld based on disability.

Effective implementation of the NDIS requires the development of interconnections between NDIS and mainstream services including health. In 2017, the nature of such NDIS-disability-health interface is underdeveloped and grey areas of interpretation exist.

The first problem: NDIS-disability-health interface in the adult inpatient hospital situation

The first central practical problem of NDIS-disability-health interconnection reviewed by this group: ensuring best possible health outcomes for adults with intellectual disability (who are NDIS participants) when they are inpatients in hospital- implications for consumers and their families, health professionals and sector, NDIS registered disability supports and service providers, NDIS funding and planning.

In 2017, how NDIS, disability and health work together and decisions on respective fiscal, logistical and service responsibilities is as unclear as it was in pre-NDIS era. In pre -NDIS funding arrangements for disability service provider supports of their clients for the inpatient setting were haphazard with cases of adult inpatients with intellectual disability with their disability supports provision always present, sometimes present, and never present, and funded sometimes by the public hospital, sometimes by the disability service provider, sometimes by the participant, or provision of disability support wholly informal supports such as family. The roles of the disability supports in adult hospitals have never been clarified and there has been no established forum in which to talk about how disability and health interface for adults with intellectual disability accessing health services.

The Council of Australian Governments (COAG) has agreed to principles that determine the nature of the NDIS interaction with mainstream health, but the practical protocols, fiscal and operational aspects of interface and the subsequent responsibilities of NDIS, disability and health sectors in functional supports are not completely defined yet. Nevertheless, it has released an indicative role of the NDIS in terms demarcating reasonable and necessary NDIS funded supports versus the health service responsibilities for eligible people (Appendix 1). This includes a statement that NDIS funding in a person's package would continue for supports for people with complex communication needs or challenging behaviours while accessing health services, including hospitals and in-patient facilities. This point is particularly relevant for adult patients with intellectual disability who are NDIS participants, a group in whom communication limitations and behavioural issues are extremely common in the hospital setting. In the front line, however, the specifics of NDIS planning for functional supports for individuals with intellectual disability and their families/carers, Agency planners, and the organisational implications for disability service providers when acute and unexpected hospitalisation is required is rarely formally organised. Moreover, adults with intellectual disability may have increased functional or behavioural support needs when they are seriously acutely unwell, and which body would fund the required extra supports is unclear.

This lack of specifics potentially leaves participants without crucial disability supports when they are most vulnerable, leaves disability service providers out of pocket and in an unsustainable position should they provide functional supports which are not formally planned for in NDIS or funded during hospitalisation, places the financial and emotional burdon of functional care on participants themselves or families, or simply creates an unwanted atmosphere of added confusion and stress.

2. *Associations between living with intellectual disability and health*

Concept of intellectual disability

Intellectual disability refers to substantial limitation in present functioning. It is characterised by significantly sub average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skills areas: communication, self-care, home-living, social skills, community use, self-direction, health and safety, functional academics, leisure, work. It manifests before the age of 18 years. Understanding intellectual disability in this way provides a practical framework for addressing a wide range of problems facing people with intellectual disability, including health, rather than simply highlighting a cognitive deficit.

Guided by this definition, and in line with NDIS values (Appendix 2), as part of the health history, physicians should seek to find out the usual level of cognitive, adaptive and physical skills, usual behaviours and demeanours of their adult patients with intellectual disability to assist in adaptations in communication and service delivery, to assist in determining what level of disability supports their patients require in hospital to access the best healthcare (including if their level of skills has reduced in the acute illness), and to assist in optimising the individual patient's capacity to participate in their own healthcare. Such information is also of relevance in preparing the functional supports required for hospitalisation in their NDIS planning.

The impact of intellectual disability on health evaluation

The impact of cognitive impairment and limitations in adaptive functioning associated with intellectual disability must be considered when organising effective participation in mainstream healthcare, and preparing both the healthcare plan from healthcare professionals, and the appropriate adult disability supports required to access this healthcare. Moreover, the usual level of intellectual disability may be further functionally affected by having acute illness of a severity requiring hospitalisation.

Effective participation in health evaluation process requires multiple standard processes to be undertaken such as making appointments and getting there and back home, going through the emergency department, admission to the ward, daily ward rounds, discharge planning, describing a history of symptoms and progress, what has happened leading to the presentation, side effects of medication or treatment, managing staying in hospital wards such as going to the bathroom, pressing the call button, ordering meals on the menu, giving past medical history, medications, doses, allergies, family history, having tests and examinations, understanding diagnoses and management, providing consent, managing emotions and behaviours, and discharge planning that encompasses preventative re-admission.

When intellectual disability is present additional information on the nature and etiology of the disability, how this information impacts on daily living (including the possibility of behavioural issues) and what disability supports are usually needed for daily living is required. Many people with intellectual disability can participate to some extent in the performance of these tasks, but to achieve a level of information required to ensure safe medical evaluation, the active presence of family or disability supports whom the patient knows well is required. This practice of inclusion of family/carers in health evaluation is part and parcel in paediatric care of children with developmental disabilities but is a foreign concept in adult health settings, even though the disability remains relevant to receiving comprehensive health care.

Due to an increased complexity of care following discharge from hospital, a personalised discharge plan containing a health plan from the doctors and a functional supports plan to undertake the healthcare is often necessary. Discharge planning between the health professionals and the disability supports of the adult patient with intellectual disability is important to coordinate and organise the various tasks. Examples of other tasks requiring functional support in hospital include monitoring and taking new medications, reactions, meal management techniques, selecting meals, assisting the patient participate in admission, daily wards rounds to check on response to treatment, understanding diagnoses, efficient and accurate exchange of information, organising y of caregiver supports, identifying roles and responsibilities of the disability supports for maintaining health management more effectively. In summary, most adults with intellectual disability, by nature of the limitations in cognitive and adaptive functioning and supports arrangements, require additional and necessary disability supports to access healthcare.

Adult health professionals often do not necessarily appreciate the impact of intellectual disability on their patient's health presentations, and do not adequately consider the impact of living with intellectual disability in their biopsychosocial reviews while making diagnoses and management. They often get things wrong and attribute symptoms of physical illness to the disability, when in fact they are a manifestation of an acute illness requiring treatment. This is called diagnostic overshadowing.

Disability support professionals may have to provide disability supports by assisting in provision of the medical history by proxy speaking on behalf of their client who may not be able to adequately verbally communicate. But poor health literacy among disability support workers, poor recognition of health problems of their clients, and poor appreciation of the scope of their responsibilities in the inpatient setting also impact negatively on the ability of adult inpatients with intellectual disability to undergo optimal health evaluation.

Disability and health systems also cater badly for their adult clients/patients with intellectual disability needs when they are in hospital. Multiple attitudinal, policy and procedural barriers to receiving quality mainstream healthcare in hospital faced by adult patients with intellectual disability are well documented. Disability support services have minimalistic or non reliable disability support plans in the event of 1:1 care required for hospitalisation, and may simply send in their clients with several folders of information instead of a disability support staff member who is known well to the patient, or may rely on family members, who themselves may be elderly and fatigued. The range of reasonable adjustments required to improve accessibility of mainstream hospitals for adults with intellectual disability are well described though rarely in place in adult health settings. The optimal roles of disability supports in hospital settings are well described in a number of Australian state publications. Yet room and funding for such disability supports are rarely acknowledged and formalised in the mission and budgeting of disability support services.

More illnesses per person

Data confirm that when compared to their peers without disability, adults with intellectual disability have more medical problems each (about 5 or 6), many of which require specialist care, they are high users of the hospital, and have lower rates of participation in health promotion activities compared to their peers without disability (Appendices 3, 6). The range of medical conditions experienced by this population are well described and may be due to the same cause of the disability, or unrelated to this, unhealthy living, poor access to healthcare, or other environmental and social causes. Other life circumstances associated with living with intellectual disability such as lower income, lower education, inappropriate housing, fewer employment opportunities, fewer social networks, supported transport dependence, social exclusion, lower rates of autonomy, and the general functional limitations due to the disability also contribute to increased vulnerability with respect to health and well being.

These data highlight the existence of an inherent overlap between having disability, especially intellectual disability, and having health issues. Health and disability professionals and their respective systems should be aware that any adult with intellectual disability in their care should be assumed to have multiple medical co-morbidities. In turn, this implies that health professionals and systems should be very disability aware and disability support professionals and systems should be health aware in systemic policy and procedural frameworks, and key performance indicators. This awareness should be embedded in the fundamentals of all disability and health service delivery.

Poorer health outcomes

All people should enjoy the benefits of a robust health system, yet people with intellectual disability as vulnerable community members and with well documented high numbers of medical problems continue to experience appalling health outcomes especially in hospital (Appendices 3, 8). It also follows that these poor health outcomes and undetected health issues such a vision or hearing deficits or pain, can effectively and unnecessarily increase disability and so limit best possible participation in society and quality of life, and quantity of life. This population experiences a higher rate of preventable adverse medical events and deaths in hospital, and a lower life expectancy by up to 30 years compared to their peers without disability. They also have lower rates of healthy living practices and prevention of progress of chronic diseases.

These devastating health outcomes among adult populations with intellectual disability are not inevitable, and are not usually due to the disability per se. Although the presence of intellectual disability may imply limitations in ability to participate independently in the health evaluation process, with adequate disability supports and an accessible mainstream health system these limitations can be managed. Analysis of the preventable adverse events and deaths do suggest dual liability of these current unacceptable inadequacies to failures in both health and disability support systems.

Dual responsibilities of health, disability to address the health disparity

To improve the health and life expectancy of people with intellectual disability requires both health and disability working together.

On a systemic level, to address the multitude of physical, policy and attitudinal barriers which impede the delivery of optimal hospital level healthcare to adults with intellectual disability, to address the ambivalent attitudes of disability service providers about their perceived responsibilities with regard to provision of disability supports for healthcare of their clients, to address the preventable deaths and adverse health outcomes experienced by adults with intellectual disability during inpatients, formal collaboration and engagement between consumers, advocates and disability and health professionals and sectors, and other key stakeholders, and now including NDIA, must be established to solve the identified problems and make action plans.

On an individual level, adults with intellectual disability and their families should seek to specify supports and roles and responsibilities from Specialist Disability Service Providers and have in mind expectations of quality healthcare provision before being faced with acute or elective hospitalisation.

Table 1 Associations between living with intellectual disability and health

The Advisory group acknowledges that regarding disability-health associations in the hospital setting

that living with intellectual disability has associated cognitive, health, psychological, social and environmental implications, that is biopsychosocial, all of which increase the vulnerability of that person when unwell in hospital,

the unacceptably high rates of preventable mortality and morbidity of adults with intellectual disability especially in the hospital setting compared to peers without disability are not inevitable

potential for breach of duty of care- a dual liability of health and disability in the cause of these health disparities, and a need for a cooperative approach to resolve these deficiencies

that disability supports are usually required for adults with intellectual disability to access and participate in the healthcare system especially in hospital

the biopsychosocial implications of living with intellectual disability must be acknowledged and taken into account by both health and disability workers and systems in the provision of their services when the individual with intellectual disability is in hospital

The Advisory group recommends

that adults with intellectual disability have healthcare plans made by hospital specialists and funded by health for hospitalisation and outpatients. These plans could also predict expectations of functional supports to enable access to hospital level healthcare

that adults with intellectual disability have prepared functional/disability support plans to meet their needs if they require presentation to the emergency department, inpatient or outpatients. These plans should also predict deliverable expectations from the health services. These plans would be activated in the event of unexpected or planned hospital admission.

3. *NDIS, disability and health interconnections*

The NDIS affords an opportunity to:

- recognise the individual needs of people with intellectual disability
- provide reasonable and necessary supports to people with disability to enable mainstream service access, societal participation and contribution
- raise community awareness about social and economic participation of people living with disability
- develop an optimal interface between NDIS and mainstream services

Together these strands have the potential to transform health outcomes for adults with intellectual disability. Planning disability supports in the event of hospitalisation necessarily is involved within the scope of NDIS planning. NDIS is not the panacea to solve all problems, but the Scheme fundamentally draws mainstream health services and disability domains together Facilitating the preconditions to become and essential link to a more certain future.

In the NDIS era, the keys to better health outcomes in the hospital setting are:

(a) Partnership development between consumers, NDIA, health and disability sectors (Table 2)

This is of fundamental importance to facilitate understanding of the NDIS and its values among hospital health workers and systems, engagement and cross fertilisation of values, sharing of information on the association between living with intellectual disability and health, and about NDIS, policies, processes within NDIS, to act as a forum on feedback on reasonable adjustments proposals made to mainstream health, to develop methods to determine the best disability supports required for an adult patient with intellectual disability in hospital, to problem solve pragmatic aspects of logistics and funding of required disability supports for adults patients with intellectual disability in hospital settings, to ensure quality and safety standards of disability supports provision by disability service providers for health situations, in NDIS-health interface to demarcate the funding sources of disability supports in various health settings, and to review the success or failure of interconnections developed.

(b) Receiving quality services from the health system as a mainstream provider (Table 3)

Individual clinicians and health systems must acknowledge that living with disability can have a significant impact on an individual's health and well being. Appropriate resources must be provided to not only promote enlightened disability culture in health settings, but to ensure, check and report on the achievement of the same quality of healthcare outcomes as for people without disability.

They should view the opportunity to work with the disability sector and learning about the NDIS as a means to develop reasonable adjustments to mainstream services to address the current differential barriers to care for patients with intellectual disability. "Reasonable adjustments" are defined as changes to their usual services to make them as accessible and effective as they would be for people without disabilities. Such changes are based on the same values as those that underpin the NDIS, such as person centredness, autonomy, use of mainstream and least restriction. Examples of reasonable adjustment for mainstream hospitals are shown in Appendix 4.

Health professionals and health systems must willingly engage with NDIS to find out their roles and responsibility at individual clinician and sector levels.

Table 2 Partnership development between consumers, NDIA, health and disability sectors

The Advisory group recommended actions on NDIS-disability-health partnerships:

- *that Tasmanian NDIA engagement strategy include a dedicated and ongoing NDIA outreach to senior executive and clinical staff of the 3 main public and state wide private hospitals across Tasmania to assist in health sector education about what NDIS is, its values, and about eligibility and planning processes, and the roles of , and operational aspects of NDIS-disability-health interface*
- *that each hospital consider appointment of an "NDIS-disability-health" liaison staff member (with no extra funding) to be the reference NDIS and disability expert in that location and who would have easy access to local NDIA staff and NDS peak body to clarify aspects. To note likely absence for further funding of such positions, and so to be innovative in creating robust health-disability-NDIS engagement and experts with existing resources in hospitals.*
- *NDS as a peak body representative of disability service providers, similarly, consider appointment of an NDIS-disability-health liaison staff member to be the NDIS and health interface expert and who would have easy access to local NDIA and health sector staff. To note likely absence for further funding of such positions, and so to be innovative at how to create robust health-disability-NDIS engagement and experts with existing resources in NDS.*
- *that NDIA specifically provide guidelines to participants and their families on how to optimise health and well being, including for hospitalisation experiences, through NDIS planning. This would also involve NDIA upskilling its Local Area Coordinator partners on how to optimise participants' NDIS planning for reasonable and necessary disability supports for health and well being, including hospitalisation.*
- *that these recommendations would be written in a letter to Mr Pervan, secretary of THS, Mr David Clements, State Manager NDS, and CEOs of private hospitals, NDIA State Manager, State Engagement Manager, and National CEO, Local Area Coordinator partners, Intellectual Disability Reference Group for further advancement of the deliberations beyond the state level.*
- *that disability consumer bodies and advocacy groups, syndrome support groups and other disability organisations seek to increase their knowledge of areas of disability and health interface, and are supported to access and engage with NDIS health and disability experts in both hospital settings and within generic disability and health service providers.*
- *the Advisory group itself remain available for contact by colleagues and administrators in NDIA, health and disability about any problem issues of NDIS-disability-health interconnection*
- *existence of the Advisory group and contact point be promoted in NDIA regular communiqués, in health newsletters, and in disability newsletters as a forum for presentation of common concerns to NDIS, disability and health*

Table 3 Receiving quality services from the health system as a mainstream provider

The Advisory group recommended actions on promoting quality services from the health system as a mainstream provider:

- *write a letter to State Ministers for Health and Community Services, and Chief Executive Officers of private hospitals suggesting the development of reasonable adjustments to the way mainstream Tasmanian Health Services and private hospitals provide care for adults with intellectual disability*
- *request the development of plans for improving disability awareness in hospital settings*
- *request the development of plans for auditing the health outcomes of patients with intellectual disability in comparison to their patients without disability*

(c) Continuity of disability support and expertise during hospital admission (Table 4)

As described, the limitations in cognition and adaptive functioning associated with having intellectual disability mean that well organised disability supports are usually required to assist the individual with disability to access any healthcare systems. Even in the presence of reasonable adjustments to health services, certain information is required from any patient for optimal healthcare provision, information that the person with intellectual disability may not be able to provide on their own. People with intellectual disability frequently have behavioural and emotional problems in new situations, or exhibit more disability as a manifestation of their serious illness and more than usual disability supports may be required. The hospital setting is particularly complex and the level of illness present in accessing hospital care of more severe, leaving adults with intellectual disability even more vulnerable. This is why the NDIS plan for adult participants with intellectual disability should contain a specific plan of functional supports when acute hospitalisation is required, often acutely and unpredictably. Guides for participants and their families on NDIS planning for functional supports in the hospital setting are provided in Appendix 5.

Notwithstanding the need for individualised disability supports planning, as a rule, the usual number of disability supports required in day to day living when well, would presumably be required in the inpatient situation, and frequently more disability supports might be required when the person is in hospital. Examples of considerations in NDIS planning for

Disability and health systems and the Agency should talk and clarify the implications of having these plans and operationalising them in terms of NDIS planners, disability support service providers staffing and on call arrangement, invoicing arrangements, and of course consider them in terms of quality and safety for participants. Good models of how disability and health professionals and sectors work together in hospital are described in Appendix 7.

Table 4 Continuity of disability support and expertise during hospital admission

The Advisory group recommended actions on disability supports preparation for NDIS adult participants with intellectual disability:

- *adults with any level intellectual disability have their own individualised and documented plan for necessary and reasonable disability supports to be activated for hospitalisation including daily hours of required disability supports*

- *such plans should be developed with the participant, their families and disability supports with health professionals, formally documented, reviewed yearly, and funded by health and these available for NDIS planning sessions*

- *generally, the usual total number of hours for disability supports the individual has during a usual day would have to be considered as being required during hospitalisation at a minimum, but often more hours may be required*

- *that approved and registered disability service providers have transparent policies and protocols on ability to guarantee provision of the participant's usual disability supports, on quality and safety, and on call emergency response times available for participants and their families on hospital presentation.*

- *public and private hospitals provide supports and tips sheets to assist adult health professionals develop individualised appropriate disability supports plans*

- *public and private hospitals adopt, adapt and make transparent an existing hospital-disability supports framework for use in Tasmania (and this be a factor in accreditation standards of the hospital)*

- *that those approved suitable entities given their qualifications, capacity and experience which are approved and registered as NDIS Specialist Disability Service providers to provide the kinds of supports necessary, or to manage funding of disability-health supports, develop transparent policies and protocols on what they will and will not provide in terms of functional supports for hospitalisation of its clients*

- *advocacy organisations have available to them the accreditations status of hospitals and disability service providers in terms of healthcare and disability supports for adults with intellectual disability*

Proposal for funding of disability supports of participants in hospitals (Table 5)

Among other things, success of any program of disability supports mechanisms for inpatient care requires a reliable and predictable means of funding, even though there is some unpredictability in when these services would be required. The scope of funding such disability supports should cover

- direct provision of disability supports for the individual adult patient with intellectual disability,
- broader systemic issues such as policy development on quality and safety, occupational, health and safety of disability service employees effectively working in hospitals,
- emergency on call rosters for suitably approved and registered Specialist Disability Service providers
- managing funding shortfalls for group homes where a single client now requires 1:1 care,
- accommodation costs of the disability support worker in the hospital wards
- the actual preparation of recommendations for the degree of disability supports required for that individual,
- upskilling of local area coordinator to ensure that NDIS planning processes covers the adequacy of disability supports for unexpected inpatient hospital, and the allocation of the funding source
- invoicing procedures
- covering situations where patients are not NDIS participants

The Advisory group believes would seem practically reasonable that to some extent there is a shared health and NDIS arrangement of funding, with the underlying principle that the hospital plan of disability supports is adhered to.

Table 5 Proposal for funding of disability supports of participants in hospitals

The Advisory group recommended actions on NDIS and health funding for disability supports for inpatients:

- ***as a default position, NDIS participant should be funded by their NDIS funds for up to 6 hours per day in inpatient settings.*** *This derives from an estimation that up to 6 hours per day is required for necessary and reasonable usual disability core supports to access mainstream community. Some participants will require less than this.*

- *for participants who require more than 6 hours per day of disability supports to effectively access healthcare during inpatient care, these additional disability supports should be funded by health. It should be acknowledged that the usual degree is disability supports may differ for the inpatient situation , for example 1:1 care, would not be required had the individual not been an inpatient.*

- *Adults with intellectual disability who are not NDIS participants also require hospital disability supports plans, the funding of these supports to be the responsibility of health (these are current guidelines on DHHS website)*

- *NDIS planning staff and processes consider the high likelihood unpredictable emergency hospital care as experienced by this population, and build into NDIS funded supports planning a degree of flexibility for the provision of up to 6 hours of daily funded 1:1 disability supports as required by the participant and recommended by health professionals.*

- *NDIA, disability and hospital services resolve to have the same funding rates for disability supports as required by the award for 1:1 disability supports,*

- *NDIA resolve with disability service providers how to make up any shortfall in funding for the extra staff member seconded from group homes and the subsequent shortfall in funding from remaining group home residents at home for remaining shared staff, and the requirement for on call rosters funding*

- *that disability service providers develop memorandums of understanding with hospitals regarding arrangement for timely invoicing and payments for disability supports*

4. Implications of proposal for funding of disability supports in hospital for stakeholders

The detail and implications of our recommendations need to be considered by the various stakeholders.

Examples for NDIS participants' and families' consideration:

- Preparation of anticipated disability supports required during a hospitalisation either planned or unplanned would be helpful to take to NDIS planning session. A tips Sheet resource to assist in this is shown in Appendix 5. This documentation ideally focuses on disability supports required for daily living skills also relevant in the hospital setting, and the specific disability supports roles in such a setting for example helping give a history. It may be that the number of hours of disability support anticipated for hospitalisation may be more than usual. In filling out the Tips sheet it is recommended that the participant and their family discuss recommendations by their allied health professionals, and health practitioners. Consideration should be given as to the amount of disability supports that would be informally provided.
- Ideally to have a hospital package which contains information about the participant's regular health, about the nature of the disability, communication issues, potential internal or external challenging behaviour triggers, and about the person such as their family, home, interests, hobbies which is available to give to hospital based professionals who may not know the participant.
- How the disability supports plan for hospital works in with the NDIS plan- roles and responsibilities in regard to care/support expected and approved needs to the in the Participant's Agreement with the Residential Provider and delivery of those supports in the event of hospitalisation

Examples for NDIA consideration:

- Acknowledgement that a default baseline level of disability supports is required for access to mainstream health, and that 6 hours per day as baseline core reasonable and necessary disability supports as a default position.
- Ability to add flexibility to participants plan for the 6 hours of 1:1 disability supports in hospital at short notice. Have this plan pre-determined. The participant needs a signed Service Agreement with a registered provider.
- For the NDIA quality and safety group to set out expectations of NDIS registered disability supports in these settings.
- For participants in group homes, NDIA to clarify the implications for payment to NDIS registered residential service providers for disability supports required for flatmates

remaining at home while one household member is away from the house receiving 1:1 supports in hospital.

- To liaise with National Health Reform Body regarding the management of invoicing mechanics for the 6 hours of NDIS funding and the health funded other hours of disability supports.

Examples for NDIS registered Specialist Disability Service provider consideration

- To maintain an understanding and acknowledgement of their roles and responsibilities to meet obligations when faced with their NDIS clients needs for disability supports in the event of hospitalisation .
- Residential services to further develop their knowledge about practices, processes and key principles around duty of care when faced with their NDIS clients' needs for disability supports in the event of hospitalisation
- Residential services to undertake risk management analysis and planning to develop strategies associated with legal obligations to NDIS participants who may need hospitalisation
- To have appropriate rostering and on call staff to meet the agreed functional needs of their clients urgently needing hospitalisations
- Disability residential service providers to make readily available to the hospital any inpatient plans of disability supports for their adult resident with intellectual disability and to include how the invoicing of clients' NDIS and hospitals is to occur and the amount.
- To have ready available all health and medical information on the resident as well as a personal profile of the individual
- To have acute and elective hospital management plans for activating 1:1 disability supports for every client in residential services, these plans meeting accreditable standards of quality and safety.
- For NDIS registered nurses and allied health professionals, to have handover notes relating to their patients participating in NDIS relevant for their colleagues in hospital setting
- To have clear knowledge of how the invoicing of clients' NDIS and hospitals is to occur and the amount.
- For the hospital inpatient plans of disability supports be readily available for information of disability residential service providers.
- For Disability residential service providers find a point of contact and engagement with hospital staff to address mutual queries and problem solve.

Examples for Advocacy organisations consideration

- To assist participants and their families become aware of the presence of an NDIS-health interface and tips for planning for hospital admission and all aspects of health and disability interconnections. To advocate for participants when their hospital health needs are clearly not adequately covered in their NDIS planning, or by their disability supports or by their health professionals.

Examples for Local area coordinators/supports coordinators consideration

- To be knowledgeable about the interface between health and disability, to be familiar with hospital processes, and ensure that the planning includes outline of the functional supports required specifically for hospital admissions.

Examples for Public and private hospitals' consideration

- To establish NDIS-disability-health experts in the hospitals
- To have on admission an alert on NDIS participation and subsequent disability follow up, and possible requirements to fund some disability supports
- To promote disability awareness in the hospital and monitor and audit standards
- To develop reasonable adjustments to mainstream adult healthcare
- To provide the infrastructure for dedicated service delivery in mainstream
- To understand and accept the fiscal responsibility in funding disability support workers and have clear mechanisms for invoicing

Examples for Health professional (nurses, allied health professionals and doctors) consideration

- To understand the biopsychosocial implications of living with intellectual disability and incorporate in adjustments to clinical care
- To assist in NDIS processes such as eligibility and planning for disability supports required in the hospital setting
- To provide handover notes from NDIS community allied health and nursing notes to hospital peers

Summary

Adults with intellectual disability and their parents entrust the care of their adult children with intellectual disability to Specialist Disability Service providers and doctors in the health system, yet when adults with intellectual disability are ill enough to require hospitalisation, there is no guaranteed system of disability supports present to assist them to participate in health processes, no assurance that the health professionals or health systems have any understanding of the impact of intellectual disability in terms of healthcare delivery, and no established means for health and disability to work together to solve these problems and improve outcomes. These states exist despite sound data showing adults with intellectual disability have high rates of hospital use, high rates of preventable deaths and adverse events in hospital due to deficits in both health and disability supports, and the presence of sound models of health-disability interconnections to address these problems. That optimal healthcare afforded to Tasmanians without disability is not being made available for adults with intellectual disability is not good enough. This must change. Implementation of the NDIS, by way of its values, by way of its requirement for interconnections between NDIS-disability- mainstream health to be developed provides a welcomed opportunity to do this.

The Tasmanian NDIS-Disability-Health Advisory Group in addition to highlighting the avoidable health disparity faced by adults with intellectual disability when requiring hospitalisation, has identified and outlined a powerful opportunity to build on NDIS-disability-health interconnections to potentially reverse this disparity. It has made a series of policy and procedural recommendations for stakeholders as foundation for a considered solution to mechanisms and funding of this aspect of NDIS-disability-health interface

The Advisory Group position paper is based around a central policy that states through NDIS processes and interactions between participants, hospitals and disability support sectors, that adult participants with intellectual disability have specific pre-planned NDIS-planned functional supports when they require hospitalisation, quality healthcare plans provided by doctors in hospital when such participants are ill enough to require hospitalisation, pre-determined fiscal boundaries between health and disability sorted and fully operationalised (the Advisory Group has further suggested a 6 hour default position, that is, that 6 of the required inpatient daily hours of functional support hours be funded in the participant's NDIS plan, and the rest by health), and that there must be establishment of local, state and national routine, formal communication opportunities between adults with intellectual disability and their representatives, health and disability professionals and their sector representatives, other relevant stakeholder representation, and the National Disability Insurance Agency to ensure the establishment of such quality health and functional supports, and their funding.

This position paper requires further consideration by all the stakeholders: the National Disability

Insurance Agency (national, state and territory leaders), National Disability Services as Australia’s peak body for non-government disability services, NDIS participants and their families/carers, NDIS registered disability service providers, advocacy groups, consumer groups, health and disability national and state ministers, Anti-Discrimination Commissioner, consumer groups, public and private hospitals executives and health professional bodies, public and private health systems and health professionals, disability service providers and the NDS, NDIA and planners, consumers, advocacy, other NDIS registered providers and interested members of our community and will be forwarded to them for response.

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Appendix 1 Appendix 1 Council of Australian Governments indicative role of the NDIS and health: principles and table of support https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf *November 2015*

TABLE OF INDICATIVE ROLE OF NDIS AND HEALTH	
REASONABLE AND NECESSARY NDIS SUPPORTS FOR ELIGIBLE PEOPLE	OTHER PARTIES
– Elements of community re-integration which enable the person to live in the community such as assistance with activities of daily living and home modifications. – Active involvement in planning and transition support, on the basis of the person having reached a point of stability in regard to functional capacity, prior to hospital discharge (or equivalent for other healthcare settings) wherever there is a need for ongoing maintenance support. – Prosthetics, orthoses and specialist hearing and vision supports (excluding surgical services) where these supports directly relate to a person's permanent impairment. – Allied health and other therapy directly related to maintaining or managing a person's functional capacity including occupational therapy, speech pathology, physiotherapy, podiatry, and specialist behaviour interventions. This includes long term therapy/support directly related to the impact of a person's impairment/s on their functional capacity required to achieve incremental gains or to prevent functional decline. Also includes allied health therapies through early intervention for children aimed at enhancing functioning. – The delivery of nursing or delegated care by clinically trained staff (directly or through supervision), where the care is required due to the impact of a person's impairment/s on their functional capacity and integral to a person's ongoing care and support to live in the community and participate in education and employment (including, but not limited to, PEG feeding, catheter care, skin integrity checks or tracheostomy care (including suctioning). – The delivery of routine personal care required due to the impact of a person's impairment/s on their functional capacity to enable activities of daily living (e.g. routine bowel care and oral suctioning) including development of skills to support self-care, where possible. – Any funding in a person's package would continue for supports for people with complex communication needs or challenging behaviours while accessing health services, including hospitals and in-patient facilities.	– [Jointly with NDIS] Provision of specialist allied health, rehabilitation and other therapy, to facilitate enhanced functioning and community re-integration of people with recently acquired severe conditions such as newly acquired spinal cord and severe acquired brain injury. – Acute and emergency services delivered through Local Hospital Networks including, but not limited to, medical and pharmaceutical products (available through PBS), medical transport, allied health and nursing services (where related to treatment of a health event), dental services and medical services covered under the Medicare Benefits Schedule, or otherwise government funded (including surgical procedures related to aids and equipment). – Sub-acute services (palliative care, geriatric evaluation and management and psychogeriatric care) including in-patient and out-patient services delivered in the person's home or clinical settings. – Rehabilitative health services where thethepurpose is to restore or increase functioning through time limited, recovery oriented episodes of care, evidence based supports and interim prosthetics, following either medical treatment or the acquisition of a disability (excluding early interventions). When a participant is receiving time limited rehabilitation services through the health system, the NDIS will continue to fund any ongoing 'maintenance' allied health or other therapies the person requires and that are unrelated to the health system's program of rehabilitation. – Preliminary assessment and disability diagnosis as required for the determination of an individual's eligibility for the NDIS (e.g. developmental delay). – General hearing and vision services unrelated to the impact of a person's impairment on their functional capacity as determined in the NDIS eligibility criteria (e.g. prescription glasses).

– Training of NDIS funded workers by nurses, allied health or other relevant health professionals to address the impact of a person's impairment/s on their functional capacity and retraining as the participant's needs change. – Aids and equipment to enhance increased or independent functioning in the home and community. – In relation to palliative care, functional supports as part of an NDIS participant's plan may continue to be provided at the same time as palliative care services, recognising that supports may need to be adjusted in scope or frequency as a result of the need to align with the core palliative care being delivered through sub-acute health services. – Funding further assessment by health professionals for support planning and review as required. – The coordination of NDIS supports with supports offered by the health system and other relevant service systems.	– Inclusion of people with disability in preventative health and primary health care delivered through General Practice and community health services, including dental and medical services covered under the Medicare Benefits Schedule. – Intensive case coordination operated by the health system where a significant component of case coordination is related to the health support.

PRINCIPLES TO DETERMINE THE RESPONSIBILITIES OF THE NDIS AND OTHER SERVICE SYSTEMS All governments have agreed that our vision is for an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens. To achieve this vision, all Australian governments, non-government organisations, business and the wider community have a role to play. The interactions of the NDIS with other service systems will reinforce the obligations of other service delivery systems to improve the lives of people with disability, in line with the National Disability Strategy. Governments agree that the principles outlined in this document will be used to determine the funding and delivery responsibilities of the NDIS in achieving this vision. The NDIS launch sites provide governments with an opportunity to review interactions between the NDIS and other service systems and consider any lessons arising out of launch. These applied principles, and arrangements needed to operationalise them, have been reviewed through the process set out in Part 8 of the Intergovernmental Agreement for the NDIS Launch. Based on this review and on the lessons from trial, the Disability Reform Council may provide advice to COAG on amendments to the Applied Principles and 'tables of supports'. The Agency Board may also report to the Disability Reform Council and COAG on the operation and effectiveness of the interface with other service systems.

1. People with disability have the same right of access to services as all Australians, consistent with the goals of the National Disability Strategy which aims to maximise the potential and participation of people with disability.

2. The NDIS will fund personalised supports related to people's disability support needs, unless those supports are part of another service system's universal service obligation (for example, meeting the health, education, housing, or safety needs of all Australians) or covered by reasonable adjustment (as required under the Commonwealth Disability Discrimination Act or similar legislation in jurisdictions).

3. Clear funding and delivery responsibilities should provide for the transparency and integrity of government appropriations consistent with their agreed policy goals.

4. There should be a nationally consistent approach to the supports funded by the NDIS and the basis on which the NDIS engages with other systems, noting that because there will be variation in non-NDIS supports funded within jurisdictions there will need to be flexibility and innovation in the way the NDIS funds and/or delivers these activities.

5. In determining the approach to the supports funded by the NDIS and other service systems governments will have regard to efficiency, the existing statutory responsibilities and policy objectives of other service systems and operational implications.

6. The interactions of people with disability with the NDIS and other service systems should be as seamless as possible, where integrated planning and coordinated supports, referrals and transitions are promoted, supported by a no wrong door approach.

APPLIED PRINCIPLES — HEALTH

1. Commonwealth and State and Territory health systems have a commitment to improve health outcomes for all Australians by providing access to quality health services based on their needs consistent with the requirements of the National Healthcare Agreement and other national agreements and in line with reasonable adjustment requirements (as required under the Commonwealth Disability Discrimination Act or similar legislation in jurisdictions).

2. The above health system will remain responsible for the diagnosis, early intervention and treatment of health conditions, including ongoing or chronic health conditions. This may involve general practitioner services, medical specialist services, dental care, nursing, allied health services, preventive health care, care in public and private hospitals, and pharmaceuticals (available through the PBS).

3. Health systems are responsible for funding time limited, recovery-oriented services and therapies (rehabilitation) aimed primarily at restoring the person’s health and improving the person’s functioning after a recent medical or surgical treatment intervention. This includes where treatment and rehabilitation is required episodically.

4. The NDIS will be responsible for supports required due to the impact of a person’s impairment/s on their functional capacity and their ability to undertake activities of daily living. This includes “maintenance” supports delivered or supervised by clinically trained or qualified health professionals (where the person has reached a point of stability in regard to functional capacity, prior to hospital discharge (or equivalent for other healthcare settings) and integrally linked to the care and support a person requires to live in the community and participate in education and employment.

5. The NDIS and the health system will work together at the local level to plan and coordinate streamlined care for individuals requiring both health and disability services recognising that both inputs may be required at the same time or that there is a need to ensure a smooth transition from one to the other

Note: In applying these principles, consideration will be given to alignment with services funded under the National Health Reform Agreement, with a view to avoiding overlap or gaps

Appendix 2 Examples of NDIS and health values

United Nations Convention on the Rights on People with Disability:
Basic tenets of the Convention: Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of person, Non-discrimination, Full and effective participation and inclusion in society, Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity, Equality of opportunity
Accessibility, Equality between men and women

Article 25 reinforces the rights of people with disability to enjoy the highest attainable standards of health without discrimination on the basis of disability; people with disability should have the same range, quality and standard of affordable healthcare and programs, should have access to service needed because of their disabilities including early identification and intervention as appropriate and services designed to minimise and prevent disabilities including among children and older people, that these health services should be as close as possible to people's own communities, including rural areas, that health professionals should provide the same quality of care to people with disability as others and raise awareness of human rights, dignity, autonomy and needs of people with disability through training and promulgation of ethical standards for public and private healthcare, that discriminatory denial of healthcare or health services or food or fluids on the basis of disability should be prevented.

biopsychosocial: *the biopsychosocial approach to healthcare is one advocated by the World health Organisation in their definition of health.In this approach, consideration of an individual's personality, behaviour, occupation, standing in society, environmental factors and culture form an essential contribution to the assessment of health and impact of disease for that individual..*

diagnostic overshadowing*: a process where health or disability professionals wrongly presume that present physical symptoms are a consequence of their patient's/client's disability, when actually they represent a physical illness.*

health: *is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*

least restrictive principle: *refers to the limitation of special intervention in an individual's life to the minimal extent required by the disability.*

autonomy/person centred approach: The person centred approach to healthcare has been defined as "*an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. Patient- and family-centred care applies to patients of all ages, and it may be practiced in any health care setting.'*

The dimensions of a patient centred approach include: respect for patients' preferences and values [not providers], emotional support, physical comfort, information, communication and education, continuity and transition, coordination of care, the involvement of family and friends, access to care.

normalisation: *making available to people with intellectual disability patterns and conditions of everyday life, which are as close as possible to the norms and patterns of mainstream society. It is import to use means which are as culturally normative as possible, in order to establish or maintain behaviours and characteristics which are culturally normative as possible.*

reasonable adjustments: *the way mainstream services make their services available to people with disabilities, to make them as accessible and effective as they would be for people without disabilities*

Appendix 3 Data on health outcomes for adults with intellectual disability in hospital settings (see references)

Baseline of negative social determinants of health experienced by adults with intellectual disability: limited employment opportunities post schooling, premature transition out of the workforce, reduced social networks, increased risk of social, physical and financial abuse, sustained economic hardship, family breakdown

Experience about 5 to 6 medical problems each some of which syndrome related, some related to negative social determinants of health, some related to their level of disability

Reduced life expectancy by up to 30 years

Mortality elevated compared to general population, with more than a third of deaths potentially avoidable through appropriate intervention (vs just over 10% for general population)

Deaths not due to disability cause usually

High users of the hospital system compared to general population

Causes of preventable deaths and adverse medical events:

attitudinal, policy and procedural barriers in hospitals,

allocated palliative status for usually treatable conditions,

attributing behaviours to the disability instead of correctly as a manifestation of physical health symptom,

hospital staff pushing for early discharge,

lack of appropriate disability supports in the hospital,

support workers doing their own thing on health, not recognising ill health, not having any processes in place to manage medical emergencies,

poor health literacy among support workers,

Causes of health problems differ compared to general population: more epilepsy, infectious diseases, falls and trauma, gastrointestinal problems, less smoking and excessive alcohol, more sensory impairments

Appendix 4 Examples of reasonable adjustment for mainstream hospitals

- *integrate dedicated specialised adult disability consultation services in adult medicine as continuation from established paediatric services using recommended models (regs),*
- *finding out about and formally documenting the functional impact of disability in their patient's daily living and how that impacts on inpatient care with respect to resources, communication, roles of disability supports, during admission, daily reviews, discharge planning*
- *consideration of development of template documentation/alerts on intellectual disability*
- *undertaking review of established methods of disability and health interactions in hospitals*
- *additionally dedicated focus on what the patient with disability is like as a person as part of the using an amended biopsychosocial approach*
- *defining the impacts of disability on health service delivery and health education for that individual patient*
- *specific consideration of the roles of disability supports system and family unit in hospital settings*
- *improving disability awareness and conducting disability competence standards,*
- *conducting audits of care and outcomes,*
- *clarifying with the disability/family supports their roles in hospital,*
- *longer and if required more frequent appointments,*
- *adapting communication styles to suit the patient, eye contact with the patient and not just the carer*
- *having adequate examination equipment such as hoists,*
- *having ability to arrange multiple tests opportunistically such a ophthalmological examinations while the patient is having a dental review under general anaesthetic,*
- *plenty of room for equipment wheelchairs and carers in the consultation rooms,*
- *better communication with patients, carers, GP*
- *keeping timely appointments*
- *being receptive to learning about disability values such as those that underpin the NDIS as person centred care*
- *being receptive in learning about NDIS and its interface with health and the roles and responsibilities of physicians and hospitals in these processes*
- *including additional sessions to accommodate for NDIS eligibility requirements from health professionals*
- *developing systems of examination and investigations with minimal distress for the patient*
- *including additional session to accommodate for NDIS planning with regard to health and well being, early intervention to minimise the impact of disability, equipment and consumables, disability supports for healthcare access, and improving capacity for healthy living, taking into account the family unit.*

Appendix 5 Tip Sheet for Adult NDIS Participants and their Families for NDIS Planning for *Disability Supports for Health and Well Being*

DRAFT ONLY: Tip Sheet for Adult NDIS Participants and their Families for NDIS Planning for *Disability Supports for Health and Well Being*

How to use this document

This tip sheet is a guide for adults and their families to use in preparation for their NDIS planning meeting with regard to the *Health and Well Being* section. It is a guide only, on how to organise the types of disability supports to achieve best health and well being– not all areas need to be considered for each adult NDIS participant, and not all disability supports may be covered by NDIS funding, but still need to be planned.

By *Health and Well Being* is meant having the right amount of

- how to live a healthy life such a having a healthy weight, eating well, exercising, going to the dentist, immunisations, mammograms, not smoking
- visiting your GP, dentist, specialists, allied health professionals
- managing your medications
- understanding and having proper care at home for medical conditions that you have
- knowing what disability supports are required and available for you to seek attention for your health, and to keep healthy
- having a hospital plan- having the right disability supports for you on admission, during the stay and on discharge
- getting/updating equipment and medical aids for your disability
- input from allied health care such as nursing, physiotherapy, speech therapy, occupational therapy for disability,
- early intervention to reduce future disability
- sexual and relationship health

Important information about NDIS and *Health and Well Being*

Your NDIS plan on Health and Well Being is about getting the right supports you need due to your disability to access the health care. Your NDIS funding does not ever pay doctors, no matter what the circumstances. Your NDIS funding, if in your plan, may be used for physiotherapists, speech therapists, nurses and some other allied health professionals if the need is for your ongoing usual disability or to prevent future disability. Your NDIS funding does not pay for allied health care for temporary conditions, only those which are related to your usual disability and functional needs. Your NDIS funding does not pay for medications, health insurance, dental care. This Tip Sheet will help you to consider your needs regarding everyday activities and safety in the areas of: *Health and Wellbeing*

Participant's Name: **Date of birth:**

Parent/Person Responsible:

Residential service provider and name of coordinator:

Usual number of daily NDIS funded hours:

General Practitioner:

Specialists seen in the last year:

Dentist:

Allied Health Professionals:

Private Health Insurance:

Usual public hospital:

Known medical problems:

Using this Tip Sheet in preparation for your NDIS planning and selection of service providers you will able to have the following checklist completed

Type of healthcare	Disability supports planned	Funding by NDIS or Other
Healthy living (weight, exercise, immunisations, good diet, self and staff education)		
Managing chronic conditions at home (eg diabetes, epilepsy, spasticity, PEG, staff training)		
Visiting GP, dentist, specialists (making appointments, transport, helping with communication, being prepared for the appointment, assisting at the appointment, following up recommendations at home, knowing what is and is not NDIS funded)		
Being an inpatient in hospital (getting there, having correct documentation, having adequate disability supports present in emergency department, during inpatient stay, on discharge, follow up at home, knowing what is and what is not NDIS funded)		
Allied health supports and nursing (physiotherapy, speech therapy, nursing, occupational therapy)		
Equipment (eg PEG, catheters, chairs, belts, wheelchairs, shoes etc and staff training, and where to get these)		
Employment supports (occupational health physician if required, allied health input)		
Choosing health provider		
Choosing residential disability support service		
Substitute decision maker/Person Responsible		**Not applicable**

What are the current *Health and Well Being* needs and goals for you?

Emergency health problems and going in hospital	***Consider what I will plan for*** • *What to do with an emergency health problem* • *How will my support workers help me? Will my parents have to stay with me all the time?* • *Who will help me in the emergency department, while I am staying in hospital* • *Who will help me in the hospital ward, on daily ward rounds and on discharge* • *Who will help me with communication, telling the doctors why I am there, understanding diagnoses and treatments* • *Who will help me get home* • *Who will help me with any new equipment I need as a result of this emergency* • *Who will help me know if it is safe for me to go home* • *Who will help me make medical decision about my health* • *Who will help me select the menus, go to the toilet, help me get to sleep at night, press the call button, find my way around* • *Who will make sure that I am not in pain* • *Who will support me emotionally while I am in hospital* • *Will NDIS pay for my disability supports I need in hospital*
My doctor's opinion on my need for disability supports in the emergency department and inpatient situation	☐ *No, does not need assistance.* ☐ *Yes, needs assistance in the emergency department and on discharge* ☐ *Yes, needs assistance in the emergency department, for daily updates from medical staff, and for discharge planning* ☐ *Yes, needs assistance for emergency department, all inpatient stay and on discharge planning*
My allied health and nurses opinion	*Do they have handover notes for when I go to hospital?* *Will the hospital nurses and allied health give a handover?*

My disability supports plan for emergency hospital presentation, inpatient stay, discharge, and follow up at home:

Early intervention for disability, assistive equipment , medical equipment	***Consider for my care about*** • *Motor skills and mobility: moving around the home, getting in or out of bed or a chair; leaving the home and moving about in the community* • *Need for mobility equipment, technology, access to transport – e.g. wheelchair, hoist, walker, standing frame, tilt table, swivel seat (consider prescription, repair and maintenance)* • *Need for equipment to support daily living skills(consider prescription, repair, maintenance)* • *Orthoses, artificial limbs (consider prescription, repair and maintenance)* • *Communication needs – communication support and/or speech devices (consider prescription, repair and maintenance) and staff training* • *Nutrition, nasogastric, PEG, other feeds e.g. special formula, pump feed, consumables* • *Motor skills – fine and gross, mobility* • *Daily living skills consider if assistance is required with transfers; equipment or aids are required for PEGs, tracheostomies care and availability and do my carers know how to use these* • *Eating and identifying and managing choking risk, bathing/showering, toileting equipment,* • *Overnight care e.g. assistance to turn in bed* • *Need for support with behaviour, mood/adjustment and social skills, to problem solve issues that arise with equipment and use of it* • *Who will train my staff about my how to use my devices and equipment* • *Therapy for prevention of progression of motor disability* • *How much will NDIS fund?*
My allied health professionals comments on this	
My doctor's comments on this	

My needs for disability supports in early intervention, medical and assistive equipment:

Visiting health professionals including GPs, dentists, allied health professionals, specialists	***Consider*** • *If my parents are no longer looking after me, who is going to help me take care of my health including going to the GP, the outpatient and hospital* • *Whom would I like as your GP, how often do I need to see them, how do I get there and who helps me during the visit if required* • *How do I make sure I see the dentist every year and how do I get there* • *Do I need to visit allied health professionals such as nurses physiotherapists, speech therapists for my disability or other health matters not related to my disability* • *How do I get to specialists appointments and who helps me talk to them and tell them an update or the new health problem, and its management* • *Do my support workers have a system in place so that they communicate with the rest of the team about my health and doctors visits* • *Do my support workers have first aid certificates* • *Should I have private health insurance* • *I wish to understand more about what is paid for by medicare and what is paid for by my NDIS plan*
My doctor's opinion on my need for disability supports in the visiting doctors	☐ *No, does not need assistance* ☐ *Yes, needs assistance to get there and home only* ☐ *Yes, needs some assistance in the rooms to discuss the medical issues, diagnosis, medication, treatment* ☐ *Yes, needs full assistance in the rooms to discuss the medical issues, diagnoses, medication, treatment*

My needs for disability supports for health professional visits:

Healthy living	***Consider how I can best achieve a healthy lifestyle*** • *I understand how healthy living is important for going to work, day activity, enjoying myself and coping with ups and downs* • *Medications (including taking medications)* • *How will I achieve healthy weight for my height, healthy shopping and cooking, and healthy exercise* • *Can I achieve half an hour of exercise most days* • *What about immunisations* • *Getting to/from appointments with health professionals and getting to know a GP* • *Will my service providers have first aid certificates and will they come with me when I am urgently unwell?* • *Mental health or emotional health issues* • *Getting support to look after your physical health* • *How you and your family are coping* • *learning and taking responsibility for my own health, medications* • *Who is going to teach my support staff and family about my complex health issues and healthy living*
My doctor's comments on disability supports for healthy living	
My own needs for disability supports to keep up my health and wellbeing.	

Chronic health problems	***Consider the medical problems that you have*** • *Has my paediatrician given me a very up to date medical summary now that I am an adult?* • *Have they organised for me to see an adult physician now?* • *Does the cause of my disability have any special health problems with it?* • *Do the planners know what these are and do I have a list of these* • *Do I, my family and carers understand my health problems and the medications? If not is NDIS going to help this* • *How often have I been to hospital in the last year?* • *Does the support provider commit to help me with my medical problems and have the expertise to do this?* • *How does my disability service provider manage my medical notes?* • *Do they understand that my health problems can interfere with my ability to work and enjoy myself and look after myself?* • *Do my support workers need some education about my health problems?* • *Will someone know if I am in pain?*
My doctor's comments on disability supports for my chronic health problems	
My needs for disability support with my chronic health problems:	

Choosing my disability service providers	***When choosing a disability service provider think about*** - *How well can they can help me look after my health* - *How they would assist me if I were in hospital* - *Do they accompany me when I visit the doctor if I wish* - *How well can they help me achieve my healthy living plan* - *How do the support workers share my health information between them* - *What education have they had about my disability and my health*
Choosing my health providers	***When choosing a doctor or other health professional think about*** - *How easy is it to talk with my doctor about myself and my health* - *How well do they know me as a person* - *Do they understand what it is like living with disability* - *Do they have sufficient knowledge about my disability* - *How can I help them understand more about me* - *Do they make time to listen to my disability support workers and family*
Qualities that are important in my selection of my disability service providers and health providers regarding my health and well being	

Other things in my health and well being plan that may not be covered by your NDIS funding	***When thinking about my health and well being needs be aware that the following items are not covered by my NDIS funding, and for which I may have to budget*** • *Doctors bills (some costs paid by medicare)* • *Dentists bills* • *Gym memberships, sporting events entry* • *Special diets such as weight watchers* • *Medications* • *Private health insurance* • *Allied healthcare for injuries not associated with your disability (some may be covered by medicare)* • *Hearing tests, optometry (some may be paid by medicare)*

My health and well being needs that are not covered by NDIS

INDICATIVE ROLE OF THE NDIS AND— HEALTH (FROM COAG WEBSITE NOVEMBER 2015)

REASONABLE AND NECESSARY NDIS SUPPORTS FOR ELIGIBLE PEOPLE	*OTHER PARTIES*
– Elements of community re-integration which enable the person to live in the community such as assistance with activities of daily living and home modifications. – Active involvement in planning and transition support, on the basis of the person having reached a point of stability in regard to functional capacity, prior to hospital discharge (or equivalent for other healthcare settings) wherever there is a need for ongoing maintenance support. – Prosthetics, orthoses and specialist hearing and vision supports (excluding surgical services) where these supports directly relate to a person's permanent impairment. – Allied health and other therapy directly related to maintaining or managing a person's functional capacity including occupational therapy, speech pathology, physiotherapy, podiatry, and specialist behaviour interventions. This includes long term therapy/support directly related to the impact of a person's impairment/s on their functional capacity required to achieve incremental gains or to prevent functional decline. Also includes allied health therapies through early intervention for children aimed at enhancing functioning. – The delivery of nursing or delegated care by clinically trained staff (directly or through supervision), where the care is required due to the impact of a person's impairment/s on their functional capacity and integral to a person's ongoing care and support to live in the community and participate in education and employment (including, but not limited to, PEG feeding, catheter care, skin integrity checks or tracheostomy care (including suctioning). – The delivery of routine personal care required due to the impact of a person's impairment/s on their functional capacity to enable activities of daily living (e.g. routine bowel care and oral suctioning) including development of skills to support self-care, where possible. – Any funding in a person's package would continue for supports for people with complex communication needs or challenging behaviours while accessing health services, including hospitals and in-patient facilities. – Training of NDIS funded workers by nurses, allied health or other relevant health professionals to address the impact of a person's impairment/s on their functional	– [Jointly with NDIS] Provision of specialist allied health, rehabilitation and other therapy, to facilitate enhanced functioning and community re-integration of people with recently acquired severe conditions such as newly acquired spinal cord and severe acquired brain injury. – Acute and emergency services delivered through Local Hospital Networks including, but not limited to, medical and pharmaceutical products (available through PBS), medical transport, allied health and nursing services (where related to treatment of a health event), dental services and medical services covered under the Medicare Benefits Schedule, or otherwise government funded (including surgical procedures related to aids and equipment). – Sub-acute services (palliative care, geriatric evaluation and management and psychogeriatric care) including in-patient and out-patient services delivered in the person's home or clinical settings. – Rehabilitative health services where the purpose is to restore or increase functioning through time limited, recovery oriented episodes of care, evidence based supports and interim prosthetics, following either medical treatment or the acquisition of a disability (excluding early interventions). When a participant is receiving time limited rehabilitation services through the health system, the NDIS will continue to fund any ongoing 'maintenance' allied health or other therapies the person requires and that are unrelated to the health system's program of rehabilitation. – Preliminary assessment and disability diagnosis as required for the determination of an individual's eligibility for the NDIS (e.g. developmental delay). – General hearing and vision services unrelated to the impact of a person's impairment on their functional capacity as determined in the NDIS eligibility criteria (e.g. prescription glasses).

capacity and retraining as the participant’s needs change. – Aids and equipment to enhance increased or independent functioning in the home and community. – In relation to palliative care, functional supports as part of an NDIS participant’s plan may continue to be provided at the same time as palliative care services, recognising that supports may need to be adjusted in scope or frequency as a result of the need to align with the core palliative care being delivered through sub-acute health services. – Funding further assessment by health professionals for support planning and review as required. – The coordination of NDIS supports with supports offered by the health system and other relevant service systems.	– Inclusion of people with disability in preventative health and primary health care delivered through General Practice and community health services, including dental and medical services covered under the Medicare Benefits Schedule. – Intensive case coordination operated by the health system where a significant component of case coordination is related to the health support.

Appendix 6. *NDIS Health Interface and People Living with Disability* –Notes for health professionals (modified version of this article submitted for publication to Internal Medicine Journal and accepted for publication)

With a good understanding of the nature of their disability and the right supports in place, adults with intellectual disability, comprising the largest cohorts of NDIS participants, can be assisted to lead rich, rewarding and long lives, and participate in and contribute to mainstream society and community. Robust health and well being is generally regarded as a vital component for any person launching into life's other interests though frequently, achieving this is a problem for adults with intellectual disability. Adults with intellectual disability have a wide range of medical illnesses, so just about every physician at some time will have adult patients with intellectual disability, many of whom will be NDIS participants. To play their role, physicians have a responsibility to improve their understanding of the biopsychosocial aspects of the lives of adult NDIS participants and would benefit from an appreciation of the interplay between health, disability and NDIS. .

How does having intellectual disability impact upon an adult's health and well being and their opportunities for participation in society?

(a) Health outcomes and experiences in health systems

Compared to their peers without disability, adults with intellectual disability have more medical (physical and mental health) problems each (on average 5 to 6 each), some of which may be syndrome related, and at least a third of which would normally require specialist input (Beange *et al*, 1995; Wallace, 2001; Baxter *et al,* 2006; Traci et al 2002, Smiley 2005; Emerson *et al*, 2016; Hattton *et al* 2017). They have reduced life expectancy by up to 20 years but death is usually not due to any biological connection to the disability (Bittles *et al,* 2002, Durvasula *et al*, 2002). The average life expectancy of adults with Down syndrome has increased from 18 years in 1963 to 60 years in 2002 and has been attributed partly to a shift in public attitudes which facilitated improved access to care (Bittles and Glasson 2004)

They are higher users of the hospital system (Balogh *et al*, 2005, Hsieh, 2005, Janicki *et al* 2002), endure higher rates of preventable in-hospital mortality and morbidity (Heslop *et al*, 2014), In hospitals, they are more often allocated palliative care status for conditions that would be treated in peers without disability, or are faced with a nihilistic approach by health professionals (Mencap 2002, Mullane, 2002, Tuffrey-Wijne *et al* 2014), and face other numerous physical, policy, procedural and attitudinal barriers to access healthcare (Lagu *et al* 2014). Families and group home staff report negative experiences in the hospital setting such as pushing for early discharge, not communicating, lack of knowledge about intellectual disability compounded by ageing family members and staffing issues in group homes when providing care to adults with intellectual disability (Webber et al 2010).

In terms of disease prevention, they participate less in healthy living activities (Wallace & Schluter, 2008, Robertson *et al* 2000), have poor personal hygiene and environmental hygiene practices, are vulnerable to dependence on smoking and excessive use of illicit drugsat a rate inversely proportional to the level of intellectual disability (Robertson *et al* 2000). They are more often overweight compared to peers without disability.

(b) Daily living and social determinants of health

Disability can be a cause and consequence of disadvantage. Adults with intellectual disability generally endure more negative social determinants of health including reduced social networks, lower income with the disability support pension their single source of income, less likely to be married or have children, lower education levels all leading to loss of any sense of autonomy, chronic sense of frustration, and leading to them being attributed, incorrectly, lower social worth (Edwards 1997; Scheepers *et al* 2005; AIHW 2008). Those with more mild disability are the most likely group to have inappropriate housing (Bentley 2011), and endure health consequences because of this (NSW Ombudsman report 2015).

Although younger people with intellectual disability have good school rates of participation they are far less likely to move into post-secondary education and into training and employment compared to their peers without disability (AIHW 2008). As well transitions out of the workforce are common after the ages of 30 to 34 onwards (AIHW 2008). People with disability often experience marginalisation in the community, and higher rates of unmet needs in housing, work and training opportunities and social networks. They experience higher rates of physical, sexual, financial and social abuse (Baladerian 2012), making efforts to improve life circumstances harder.

The associations between lower and poorer living conditions are well recognised, perhaps accounting for up to 20 to 50% of the poorer health outcomes experienced by adults with intellectual disability (Emerson et al 2012, Emerson and Madden 2011, Emerson and Vick).

(c) Participation in the health system

Individual participation in the health assessment process for someone with intellectual disability may be hard. They may not independently visit the doctor, have limitations to verbally provide a history, may suffer panic and anxiety, marked distress or exhibit phobias more so than the general population when faced with procedures or unknown environment, may not understand the need to undergo examination and tests, and understand the diagnosis and its management. They may have varying difficulty learning and applying health knowledge and in health decision making, and especially with communication, managing emotions and relating to other people (AIHW 2008).

Adults with intellectual disability naturally progress to independence from their family home setting, as their parents themselves develop illness and disability or if there are family crises affecting care-giver ability, as their siblings become involved with their own families and careers, so tend to have supports shifted more to the adult disability service provider sector. The degree of health literacy among support workers (Australian Commission on Safety and Quality in Healthcare, 2012) and older but loving and fatigued parents may be low, so the reliability, credibility, and quality of support is not always available, or considered essential, by carers, or fatigued but loving families, meaning that they may not be adequately supported to undergo health assessments and treatments (Kastner *et al* 1993, Tuffrey Wijne *et al* 2014).

As well, people with disability face other numerous physical, policy, procedural and attitudinal barriers to access healthcare (Lagu *et al* 2014). Doctors may interpret behavioural changes as part of the disability, when in fact they represent a physical or mental health symptom requiring immediate treatment, a concept known as diagnostic overshadowing. Medical mishaps endured by adults with intellectual disability are viewed as being part and parcel of disability instead of being recognised as resulting from inadequate medical and disability care. The sorts of reasonable adjustments to facilitate access in health mainstream systems, and ideal models of service delivery (Manifesto and Wallace) have been proposed though infrequently implemented in adult services (Kastner *et al* 1993, Tuffrey Wijne *et al* 2014).

Deficiencies within the health education domain also contribute to the overall problem of access, care and the observed health disparity. Contemporary health professionals receive little training as medical students, mainstream clinicians or as training specialists in disability (Troller *et al* 2016; Duff et *al 2000*).

Analysis of these well documented data of health outcomes and experiences for adults with intellectual disability paint a bad picture, but also show that these outcomes are not inevitable. The data identify and well describe factors for solution however rely on both health and disability sectors stepping up and working together and involving consumers with intellectual disability, defining the nature of their interface with each other and the practicalities of their engagement. The NDIS provides an opportunity for such collaboration, in fact requires it for successful implementation (ref in NDIA document).

What can an adult participant with intellectual disability expect to achieve from NDIS participation especially with respect to health and well being?

(a) Living with improved social determinants of health

Effective health and well being planning within NDIS can act to reverse the impact of the negative social determinants of health by assisting and enabling adults living with disability to develop skills and undertake training to prepare for work, allowing people with disability to reap the health, social and economic benefits of training and employment. Evidence shows that work in general, maximises health outcomes, financial security, self-esteem and independence. It is anticipated that the NDIS will support 25,000 to 40,000 people living with disability to find work and enable 34,000 carers back into the workforce, thus contributing to a significant increase and participation in Australia's economy. Employment can provide people living with disability with increased income, and with this, higher living standards and financial independence. Employment can contribute to a sense of identity and self-worth and have positive health impacts for people with disability. The NDIS can also provide funded supports for adult participants to engage in the daytime activities they choose, and levels of daily support required for participants to get ready for work.

(b) Having health aids, equipment and therapies required by their disability and early intervention

The NDIS does not pay for participants' health services provided by doctors, even when required, but does fund other health goods and services deemed necessary and reasonable and integral for them to live in the community and participate in education and employment, and as long as they are for conditions related to the participants' permanent impairment. These include prosthetics, orthoses, and specialist vision and hearing supports (excluding doctors), allied health supports for managing a participant's functional capacity, behavioural needs, to achieve incremental gains or prevent decline are also fundable, and education from nurses to participants for self care or carers in management of bowels, skin, tracheostomy, PEG for example. Funding is not provided for any of these goods and services for acute, sub acute conditions or rehabilitation. (see Guides)

(c) Having supports for healthy living, acute and chronic health problems

This is a significant grey area of interpretation and one requiring further clarification, and testing of the boundaries as far as the limits of NDIS funding for disability supports in hospitals is concerned, but does not mean that the participants cannot have a plan for health issues supports.

Being in the Scheme does mean that non NDIS supports can be considered and planned for thereby investing in necessary and reasonable supports for healthy lifestyle such as having

- an adequate standard of domestic and personal hygiene. There are many sicknesses which can be caused by inadequate domestic or personal hygiene, let alone the social stigma. Education and ongoing supported training in these skills for many adults with intellectual disability is fundamental to not only health and well being, but social participation
- a healthy weight, eating and exercising well within their usual community, work and home settings, and
- the funding of these supports clarified.

There should be provision in participants' usual plans for contingency NDIS supports plans if they are acutely unwell and have to stay at home for care and unable to attend usual day activities, for example. The line between NDIS and NDIS funded supports is grey but each participant should be able to make a plan for these sorts of daily and unexpected health access supports if required. (see Guides)

(d) Having supports for visiting doctors, and inpatient hospital care

Adults with intellectual disability should be confident that in NDIS participation they achieve a plan whereby they have necessary and reasonable supports they require for visiting doctors for routine, crises or for receiving the daily functional support they need for inpatient healthcare. In NDIA documents, particularly in the inpatient circumstance where the individual is potentially most vulnerable, the rules for funding of usual supports are ill-defined, though it is clear that doctors are never funded by NDIS. Until the grey area is clarified, adult participants and their families and advocates should discuss with potential service providers what their own approach is in this situation, plan in advance for supports plans, and the funding implications. Organising such supports also has implications for service providers in terms of their roles and responsibilities of support in the health facility setting, and how health and disability professionals work together. Clarification of this issue is an urgent one and requires consumers, health and disability professionals and NDIA to resolve.

How can adult physicians best support their adult patients in NDIS?

(a) Learn about NDIS

The introduction of the NDIS, the increased media publicity on disability should trigger adult physicians to reflect on their own attitudes towards people with intellectual disability. They must actively become familiar with the NDIS operational aspects and underpinning principles, including the grey areas, and know their role in enabling NDIS participation. (guides). They must understand more about people with intellectual disability and appreciate the types of adjustments that must be made to optimise their health encounters with physicians and in hospitals, including taking into account their disability supports.

(b) In assisting with eligibility

Adult physicians need to know about NDIS eligibility requirements from health professionals for adult patients with intellectual disability, especially for those who are not currently in disability services, and provide necessary documentation to the potential participant about their disability etiology and its functional impact if requested (see Guides). Physicians are not funded by NDIS to provide this information.

(c) In assisting with planning

Adult physicians need to have an overall understanding of the processes involved in adult participant NDIS planning for necessary and reasonable supports, and some may be directly helping in health and well being pre- planning for their patients who are participants. It is useful being familiar with the scope of NDIS funded and unfunded supports for health and well being (link), and of course, know about the participants, their families and service providers. Adult physicians have a potential role in guidance on the type of supports required for that participant to enjoy healthy living at home, supports for safe management of the acute and chronic health conditions that physicians oversee, and plans for optimal supports for inpatient healthcare (see tips proforma). These plans may require physician lead advocacy and brokering negotiations between the hospital funding body and the disability service provider if deemed supports are not NDIS funded in the hospital setting.

(d) By use of a biosychosocial approach

Concerning their own service delivery for their adult patients with intellectual disability, the adult physician is encouraged to stick to biopsychosocial approach (Engel 1978) as this provides the best opportunity to use a person centred approach and the development of individualised reasonable adjustments to standard disease management plans. This involves consideration of the individual's personality, behaviour, occupation, interests and activities, standing in society, social and family networks, current supports, environment, home, and culture, a thorough understanding of the nature and day to day implications of their intellectual disability along with a developmental history and review of etiology and an assessment of their mental and physical symptoms and conditions. The subsequent management plan is tailored to meet the needs of the individual with disability and includes clarifying the role their disability supports, without compromise of standards of care. *)*

(e) By working with disability supports

In clinical encounters with their individual adult NDIS patients with intellectual disability and behind the scenes, adult physicians have an essential roleto appropriately include NDIS patients' disability support workers and families in healthcare management, by listening to and sharing with them and the patient, understandable information about the diagnosis and treatments, and the sorting out of the best roles of supports in the context of their NDIS funding. In turn, disability service supports and families can gain awareness of the extent of the information required to take a history, and what their role might be in inpatient and outpatient settings, and how to navigate around hospital policies and protocols. Any limitations of NDIS funding that impact upon individual participants to access best care should be explored and gaps in care covered by resourceful means.

(f) By making reasonable adjustments to health provision

By reasonable adjustment is a term used to describe the way services or individuals make their services available to people with disabilities, to make them as accessible and effective as they would be for people without disabilities (Oulton *et al* 2016). Such reasonable adjustments for individual physicians and their adult patients with intellectual disability include, making longer appointments, booking to ensure minimal waiting time, having easy read resources,adjust conversation by using simple language and explain things that may be unfamiliar. Excellent examples of reasonable adjustments in undertaking usual individual clinical encounters and those required on a more systemic health-disability level in hospital settings are well described (Western Australian Department of Health, 2016; National Disability Services 2014; NSW Ombudsman 2015; Webber *et al* 2010; Tuffrey-Wijne *et al* 2014; Tuffrey-Winje *et al* 2013; Outlton *et al* 2016) .

What is the role of adult physicians in the interplay between health, disability and the NDIS?

(a) Recognising stakeholders and reaching out

Successful implementation of the NDIS relies on successful interface development with mainstream services, including health (Principles of NDIA). Achieving this mandates collaboration between NDIA, health and disability government department and services, to develop mechanisms interface to reduce gaps in service, to optimise efficiency, and to ensure that other service systems, including health, meet their usual universal service obligations. In turn, for this collaboration to have any meaningful positive impact for NDIS participants, involvement from front line clinicians and disability professionals is required in this interface. In adult health, this particularly presents challenges as surprisingly there is usually no recognised specialised disability service within adult medicine. Nevertheless, individual adult physicians do have a role, and given the health outcomes of their adult patients with intellectual disability, are challenged with a new responsibility to seek opportunities for engagement with NDIA, disability service providers, disability advocates as representatives of their peers. It may take an episode of individual clinical leadership and advocacy to reach out.

(b) Participation in a stakeholder forum

It is proposed that formation of such health, disability and NDIA collaboration should include stakeholder representation from consumers, and advocacy representation along with senior representations of clinicians, NDIS registered allied health providers, hospital administrators, disability and health government agencies, primary healthcare networks, private hospitals , disability service providers, educators and NDIA. Moreover, it is suggested that the collaboration take the format of an advisory group, where, for example, any representatives could raise problems or present potential solutions for problematic operational or conceptual aspects of health –disability- NDIS interface, to this already established forum. The group should have a formality about it with terms of reference, minutes and agenda preparation, delineation of membership, a chair, and self assessment periodically. Pre-empting means of resolving conflict which will inevitably arise could be considered.

Such NDIS-disability-health advisory groups could be established within individual adult medicine departments, hospitals, regional, state and territory and national levels, depending on the topic and scope of the problems to be addressed, and likely all levels are beneficial, especially in the earlier stages of NDIS implementation.

(c) *Outcomes for collaborative work and sphere of influence*

In general terms such a forum, if well organised, will have benefits of cross fertilisation of health, disability and NDIA concepts to all members of the group, and in its own right improve health and disability engagement (Smith-Merry 2016).

A current priority issue for such collaborative work very much concerns adult NDIS participants accessing hospital services, this being, clarifying the grey area of NDIS funding of disability supports for adult NDIS participants who require outpatient and inpatient hospital care. There will be logistical implications of this for many of the stakeholders in the group. Logistical implications of such a resolution need to be considered in the light of stakeholder input. In this sense, the forum facilitates testing of the boundaries of NDIS in its interface with other mainstream services.

Other projects for collaborative work by this group could be development of strategies on how best to promote the integration of disability values in hospital services, and improve the general knowledge and operational aspects of NDIS among physicians and other adult medicine health workers, stakeholders view and NDIS implications on proposed ideal but untested models of healthcare for adults with intellectual disability (eg Meijer et al 2004, Wallace and Beange 2008)
.

The scope of outcomes could be relevant for members of national, state and territory NDIA, workforce who are involved in the provision of healthcare including clinical colleagues in adult, paediatric and mental health, public and private health service executive and managers, providers of clinical education, advocacy services, planners and policy makers responsible for the delivery of health and disability services.

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Hospital Stay Guideline for Hospitals and Disability Service Organisations

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Important disclaimer

Contact information

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Purpose of the Guideline

The *Hospital Stay Guideline for Hospitals and Disability Service Organisations* (the *Guideline*) was developed by the Disability Health Network and outlines a best practice approach for disability service organisations and hospitals when managing the hospital experience of individuals with disability.

The *Guideline* outlines opportunities for all areas of the health system (including non-hospital based services) and the disability sector to enable better engagement and planning when an individual with disability is:

- attending the emergency department
- being admitted to hospital
- being discharged from hospital back into the community.

For individuals with disability to maintain and achieve good health outcomes, the hospital system and disability service organisations must maintain effective partnerships. Through developing these partnerships, Health Service Providers and Disability Service Organisations (DSOs) can more appropriately and effectively support individuals with disability when there is a need for emergency or planned health intervention. A partnership also enables the hospital to gain a better understanding of the needs of individuals with disability and the disability sector.

The *Guideline* was developed through collaboration between health service providers and Disability Service organisations and is shaped by the following principles from the *WA Disability Health Framework: Improving the health care of people with disability 2015–25:*

- responsible and flexible
- respect and dignity
- person-centred
- collaboration
- continuous improvement.

This *Guideline* is intended to share expertise to ensure that individuals with disability achieve the best health care outcomes. Establishing collaborative and respectful partnerships between hospital staff and DSO staff in the context of a multidisciplinary approach is critical to improving the patient journey.

Critical factors for consideration

As an individual moves from their home environment into a hospital the responsibility support may change as well. In some cases additional support may be required in hospital to enable the individual to access the care they need. The extent and arrangements for that support should be planned and agreed to by both those who provide the support in the home environment and the hospital. At the time of a health emergency this is difficult, so anticipatory planning is critical.

It should be noted that the family, friends and carers of an individual may still be providing a caring role when the individual they care for is in supported accommodation. There may be some cases where the family, friend or carer (where present) have the longest relationship with the individual and are ideally placed to provide valuable information about the individual, particularly where the individual has limited communication or decision making ability. The family or a carer may be the decision-maker for an individual or there may be a Guardian in place. These are both important considerations.

It is the responsibility of both DSO staff and hospital staffs to have a clear understanding of the role of the family, friend or carer (where present) in the individual's care and to keep them informed and involved as appropriate. This responsibility is implied throughout the following sections wherever there is reference to communication between the DSO staff and hospital staffs.

Please note for simplicity, the term 'individual' has been used throughout the Guideline to refer to the 'individual with disability'. This also includes their family and/or carer, as appropriate.

Refer to the Glossary for further clarification of the terms used in this *Guideline.*

How to use the *Guideline*

This *Guideline* is presented in two parts:

- **Part 1** consists of four sections, providing practical advice for hospital and disability service organisation staff in managing the individual's hospital stay from admission to discharge
- **Part 2** covers the background information of the guideline, associated policies and frameworks, and information on the Disability Health Network working group who developed the document.

Section 1: Emergency Department Admission (with flowchart)

Attendance at a hospital Emergency Department, either via the DSOs transport or by ambulance. The individual may be treated in the Emergency Department (ED) and discharged, or a decision to admit may be made. Consideration should be given as to whether attendance at the ED is the best possible treatment option, or whether it is more appropriate to attend a General Practitioner (GP) or other primary health care provider.

Section 2: Planned admission to ward (with flowchart)

A planned admission occurs following the identification of a health care need that requires non- urgent hospitalisation. This process will occur through the GP or specialist initiating the admission process. It is imperative that from this early stage the identification of hospital type and location is considered. This may be influenced by previous hospital stays, whether or not the individual has private health insurance and the referring doctor.

Section 3: The hospital stay

During the hospital stay, the support needs of the individual will require negotiation between DSO and hospital staff. At this time, planning for discharge needs to begin, especially if there will be changes to care and support requirements once the individual leaves the hospital.

Section 4: Discharge from hospital

The aim of discharge is to return the individual to the environment they left, and to ensure the appropriate supports are in place to protect both the individual and the facility. If an individual's support needs have changed significantly as a result of the hospital admission, the discharge plan will require revision.

Who should use the *Guideline*

This guideline has been developed with the needs of front-line staff in mind, to enable the best possible experience for the person with disability. It is our hope that clinical staff, carers, and all others involved in supporting a person with disability through their hospital stay will utilise sections of this guideline as applicable to their situation.

Whilst the *Guideline* focuses on action to be taken by DSOs that provide supported accommodation and hospitals, it may also be used by DSOs that provide different services, as well as by individuals, families and carers. The principles and strategies can be applied to individuals at any age, not just adults living in supported accommodation settings. Non- accommodation provider DSOs, individuals, families and carers who look to use the Guideline should be aware that it is written to provide guidance for the role of the DSOs described here. This may mean that not all aspects of this guideline are applicable to their specific situation.

The *Guideline* may also be used for people living in rural or remote areas who require a hospital stay, however additional anticipatory planning by DSOs and hospitals should be undertaken, especially in situations requiring transfer to a metropolitan health service.

Guiding Principles

The *Guideline* has been written in conjunction with the Guiding Principles of the WA Disability Health Framework:

- Person Centred – Individuals with disability, their families and carers are supported to make informed decisions about and to successfully manage their own health and care.
- Responsive and Flexible – Services and strategies will be responsive to the needs of individuals with disability.
- Respect and Dignity – Individuals with disability have the right to be respected, to make their own decisions, to feel save, and to have opportunities to live a meaningful life.
- Collaboration – Collaboration between people with disability, their families and carers and service providers will benefit positive health outcomes.
- Continuous Improvement – programs and services will undertake continuous improvement processes to achieve best practice results.

Please refer to page 30 for further information on the Guiding Principles.

Documentation to be included

Clear, accurate and up-to-date documentation facilitates communication between the hospital and DSO and is vital for effective clinical handover during both emergency and planned hospital admissions. This should include information regarding the individual's:

- demographics
- health profile
- decision-making capacity
- individuals representative (where applicable)
- family or carer contacts.

Appendix 1 provides a list of recommended information to be exchanged between DSOs and hospital system.

To ensure this information is available at the time of emergency presentation or admissions, DSO staff should keep the following documentation up-to-date and readily accessible at all times:

- Personally Controlled eHealth Record (PCEHR) - if used by the individual
- Hospital support plan – the range of management and support plans to be included in the hospital support plan will depend on specific needs and requirements of each individual.
- Dose administration aids (e.g. blister packs, asthma spacers, insulin pen) and other required medications
- Medication chart
- Copy of Guardianship Order
- Advance Health Directive, if one exists
- Health Care Card
- Medicare Card
- Department of Veterans Affairs (DVA) health card
- Private health insurance details.

It is also important that the information provided to the hospital is in a suitable format that is easy to use and is consistent with other record keeping procedures. A client transfer form used by an aged care provider is provided in Appendix 2 as an example of how this information may be recorded and presented.

All relevant documentation should accompany the individual throughout their hospital stay; this includes at the emergency presentation, pre-admission clinic, during the hospital stay and after discharge.

A copy of this *Guideline* should be available for DSO staff to take with them to hospital if accompanying an individual

Characteristics of Service Providers

The disability sector	The hospital system
Characteristics • Provides services to assist individuals with disability to engage in everyday life. • Some DSOs may have health care staff. Those that do may or may not provide 24 hour health support service. • Individuals who are in supported accommodation may only be supported by support workers with no medical training. • The role of the DSO staff is vital in ensuring the individual has a safe and comfortable journey through ED and during admission. • The capacity for DSOs to support individuals with disability whilst they are in hospital varies considerably.	**Characteristics** • Provides types of health services that generally can't be provided in the community (e.g. by GPs). • Emergency departments are very busy places with lots of noise, activity and a variety of people with differing roles. • An individual may be moved multiple times within the ED area and may have contact with many different hospital staff. • Staff in hospitals care for a number of individuals with differing health care needs that can change dramatically in a short space of time. • Individuals will be discharged when their health care needs no longer require hospitalisation.
Considerations for DSOs: • the appropriate healthcare setting for the individual: primary care or hospital • strategies and actions that the DSO can take to prevent a hospital stay • the impact that the hospital stay has on the individual, during and after discharge • the history of hospital stays for the individual and how they were managed • what responsibility the DSO has to ensure the hospital stay goes well • whether the individual's health needs will be able to be met at their existing accommodation option post-discharge • acknowledge that the priority of hospital staff is the medical issue the individual presents with upon admission, not the disability-related needs of the individual • occasionally hospitals will not have capacity to admit an individual or may seek to discharge an individual earlier than anticipated - this may result in the individual being returned to their accommodation or transported to an alternative hospital.	**Considerations for hospitals:** • the appropriate healthcare setting for the individual: primary care or hospital • alternative services to hospital admissions such as Hospital in the Home, Rehabilitation in the Home, Silver Chain • review the hospital 'environment' to ensure it is disability friendly and welcoming • consider the support needs of the individual in planning and delivering hospital care • strategies and actions that the hospital can take to ensure the individual's hospital stay goes well and provides the best health outcome • the impact that the hospital stay has on the individual, during and after discharge • the history of hospital stays for the individual and how they were managed • type of healthcare, if any, which can be provided in the individual's supported accommodation or home setting • what other DSOs exist and what healthcare services they provide

The disability sector	The hospital system
	• individuals with disability may have a large team of people who support them in the community, but those people may be unavailable in the hospital setting • communication with the individual and their representative is critical to ensure that consent for healthcare is informed and legal and planning and delivery of hospital care is person-centred • DSO staff can provide crucial information about the individual's support needs to assist the delivery of healthcare.

Part 1

Flowchart – Going to the emergency department

- Call ambulance
- Keep individual safe and comfortable

- Gather information relevant to the individual

- Pass documentation to ambulance staff
- Alert ambulance staff to key items

- Contact person and confirm their attendance. Ensure individuals representative is also contacted, if required.

- Alert triage staff of individual attending by ambulance and documentation with ambulance staff

- Wait times will vary on the state of the individual's health and those who are also presenting to the emergency department at the same time

- Hospital staff will assess health needs of individual
- Keep individual safe and comfortable

- Support individual to participate in investigation or

- Medical staff assess health care

- Support individual to return to accommodation
- **Transport**

  Ensure individual has suitable transport

  Arrange support for

- Alert medical staff to individual's support needs
- **Admission to hospital ward**
  - Wait times will vary according to bed availability and stability of individual's health (see planned hospital stay flowchart

- Communicate outcome of emergency department assessment to relevant staff and family
- Document outcome in individual’s records

Section 1: Emergency Admission – Going to the emergency department

Going to emergency department	**Disability service organisation roles and responsibilities**	**Hospital staff roles and responsibilities**
Transport to emergency department	Ensure relevant documentation and required aids/ equipment (see Appendix 3 for list) are collected and taken with the individual to hospital. If the individual is transported by ambulance ensure: • the individual's documentation and required aids/ equipment go in the ambulance • the attending paramedics are briefed on: ▪ the presenting circumstances that required the ambulance call-out ▪ any characteristics that may impact on the individual's ambulance journey and presentation to ED. If the individual is transported by ambulance but the DSO staff does not accompany the individual ensure: • the paramedics have the DSO provider's contact details • the DSO staff is advised which hospital the individual is being transported to. It is essential that the DSO provider ensures an appropriate person attends ED to support the individual. This may be a staff and/or a family member or carer. Consider taking a copy of this *Hospital Stay Guideline*	Ensure relevant documentation and aids/ equipment (see Appendix 3 for list) are collected when the individual presents at hospital. If the individual is transported by ambulance ensure: • the individual's documentation and required aids/ equipment are in the ambulance and stay with the individual upon arrival at the hospital. If the individual is transported by ambulance but the DSO staff does not accompany the individual ensure: • the DSO staff is contacted upon the individual's arrival at the hospital.

Going to emergency department	Disability service organisation roles and responsibilities	Hospital staff roles and responsibilities
At the emergency department	In the ED: • support the individual with information and assistance to reduce fear and anxiety and to make them as comfortable as possible • assist the hospital staff with any required information • ensure the individual's relevant documentation is passed on to hospital staff • report to hospital staff any observations of behaviour that may be difficult to interpret or any other responses by the individual • familiarise hospital staff with, and demonstrate if necessary, the individual's method of communication • remain with the individual during admission until decisions are made about the individual's care coordination and treatment plans • participate in any other care coordination discussions as required • communicate care coordination and transfer of care discussions to the individual and/ or their representative.	In the ED: • discuss the requirements of the individual with the individual and the DSO staff • alert the DSO staff if the individual exhibits behaviour that is difficult to interpret • engage in care coordination discussions with the DSO staff as required • communicate care coordination and transfer of care discussions to the individual and/ or their representative (or DSO worker if others are unavailable).

Going to emergency department	Disability service organisation roles and responsibilities	Hospital staff roles and responsibilities
Triage Triage is a system of assessment which identifies those of greater need to be treated first. This occurs before any admission to ED. Individuals are rated in priority (1-5) by case severity of health needs. Rankings can fluctuate according to other ED presentations.	At triage: • be prepared for a possible lengthy wait • keep the individual comfortable and ensure they do not become distressed • support the individual to participate in the triage process • be available to answer any questions from hospital staff • support the individual to participate in the triage process • be prepared to advocate for the individual if required.	At triage: • assess the individual's health condition within a short period of time and assign a ranking (1-5) according to i) case severity, and ii) other ED presentations • keep the individual and DSO staff informed of changes in the individual's triage rating and estimated time • consider the emotional needs of the individual regarding waiting times, environmental conditions, noise levels and other issues that may impact on the wellbeing of the patient.
Post-triage Triage will result in the individual being: i) admitted to the Emergency Department immediately or, ii) asked to wait due to the ranking assigned in Triage.	The activities undertaken by the DSO staff will vary according to the nature of the individual's case. The DSO staff accompanying the individual to ED needs to be prepared for either an admission to hospital or their being discharged home – a discharge decision may be made within as little as two hours from presentation. If the individual is to be admitted to hospital then DSO staff and relevant hospital staff to ensure that risks to the safety and wellbeing of the individual while in hospital are identified and communicated to hospital staff.	When the individual is admitted to ED, the hospital staff should communicate to the DSO staff if any further assessments and investigation – such as blood test, x-ray, ultra-sound – are to be undertaken. Some procedures may result in additional waiting time as medical staff await results or consider treatment options. If the individual is to be admitted to hospital then the hospital staff need to ensure that risks to the safety and wellbeing of the individual while in hospital are identified and documented (in clinical and nursing handover documents).
Case conference	The DSO staff should be aware that they may be included in a case conference around the health care management plan for the individual.	The hospital staff should contact the DSO staff to arrange the case conference, enabling the DSO staff to identify who should attend.

Going to emergency department	Disability service organisation roles and responsibilities	Hospital staff roles and responsibilities
Transport back from the emergency department Attendance at ED does not automatically lead to admission or an overnight stay in ED – only 40% of people are admitted from ED to ward.	When the individual is discharged from hospital: • have transport prepared in advance – discharge will occur regardless of whether or not transport is available • ensure transport strategies are available at any time as discharge can occur at any time (e.g. 2am) • ensure the individual's medication and any aids/ equipment are with them • monitor the individual for a period of time after discharge in case the individual's condition deteriorates necessitating readmission to ED.	When the individual is discharged from the hospital: • offer to assist in organising transport options • ensure that a discharge letter accompanies the individual upon discharge • ensure all equipment belonging to the individual is transported with them.

Planned admission process

- Pre admission clinic or other referral pathway
- Ensure all relevant documentation is up to date and bought to the appointment
- Ensure appropriate communication between referring GP or specialist and DSO staff and/or individual's representative. Continue communication throughout process.

- Arrange transport for individual to

- Contact person and confirm their

- Keep individual safe and

- Ensure all relevant documentation is up to date and bring to admission
- Alert admission clerk or ward staff to key items.

- Support individual to participate in investigation or treatment.

- Medical staff provide health care needs
- Provide appropriate support during hospital stay to individual
- Ensure all appropriate aids/ equipment are available to the individual.

- Support individual to return to

- Arrange transport for individual
- Arrange appropriate support for individual in

- Communicate outcome of hospital admission to relevant staff and family
- Document outcome in the individual's records.

Section 2: Planned admission to ward

A planned admission occurs following the identification of a health care need that requires non-urgent hospitalisation. This process will occur through the general practitioner (GP) or specialist initiating the admission process. It is imperative that from this early stage the identification of hospital type and location is considered. This may be influenced by previous hospital stays, whether or not the individual has private health insurance and the referring doctor.

Planned admission to ward	Disability service organisation roles and responsibilities	Hospital staff roles and responsibilities
Admission via regular GP A potential health issue is identified by the DSO staff requiring GP referral.	Refer the individual to his/her GP as the first point of contact – the GP will then determine the required need and admission. Ensure that communication between the GP and the DSO staff and/or the individual's representative occurs. Where required the GP will then commence the process either through planning this admission directly (if admitting rights are present) or referring to the appropriate specialist.	• Liaise with the individual's GP and the DSO staff (or individual's representative) to facilitate admission of the individual to hospital.
Admission via specialist (if applicable) Following identification of a potential health issue by the DSO staff, the individual is referred to a Specialist (also via GP referral).	• Accompany the individual to their appointment (if appropriate) or organise their representative to accompany them. • Support the individual to participate in the consultation. • Ensure that communication between the specialist and the individual's representative occurs if the Representative is unable to accompany the individual to their appointment. • Either attend or ensure the individual's representative attends this consultation to ensure the needs of the individual are identified and planning commences. • Ensure that discharge planning will be suitable and appropriate to the facility or identify the need for alterative accommodation.	• Liaise with the specialist and the DSO staff (or individual's representative) to facilitate admission of the individual to hospital.

Planned admission to ward	Disability service organisation roles and responsibilities	Hospital staff roles and responsibilities
Pre admission clinic Pre admission clinic appointments are critical to ensure optimal patient care occurs at admission and at discharge. The individual who has legal responsibility for consent should accompany the individual to this appointment – if this is not possible the DSO staff should attend. If the clinic does not occur then pre-admission planning with the specialist will still require appropriate communication.	At the pre-admission clinic: • ensure all documentation is collected and taken to the hospital at the point of admission • ensure that discharge planning occurs and that the individual, their representative and the DSO are all aware of the process • ensure that adequate time is allowed for the required needs to be actioned for the hospital stay – i.e. appropriate bed, equipment, consent • communicate admission plan details to the individual's representative • ensure discharge planning is appropriate to the individual's DSO – this may require someone with decision-making authority from the DSO to be available/present.	At the pre-admission clinic: • meet with the DSO staff to help plan discharge • ensure that the individual's hospital notes and admission details are 'flagged' as requiring additional or specific needs • advise the individual and their representative or DSO staff of the outcome of the pre admission clinic which may be: ▪ cancellation ▪ postponement ▪ re-schedule ▪ admission as planned.

Section 3: Admission into hospital

Admission into hospital	Disability service organisation roles and responsibilities	Hospital staff roles and responsibilities
Planning and preparation for admission to hospital	• provide contact details of the individuals' representative to hospital admissions staff once the decision is made to admit the individual to hospital (if the individual is unable to provide consent) • inform and involve the individual's representative in planning for the admission, where appropriate • attend a pre admission process meeting (arranged by the hospital) to include relevant hospital staff, DSO staff, the individual and their representative, if possible • arrange a hospital stay planning meeting with the DSO staff, individual and individual's representative – this is scheduled by the DSO • ensure that information about the hospital admission, hospital routines and procedures are communicated to the individual in the individual's own communication style • prepare the individual's documentation, as per the Appendix 3, to be up to date and ready to go with the individual on the day of admission • identify the support needs of the individual whilst in hospital and clarify the availability of DSO staff to meet needs during the admission • ensure that equipment needs are identified, these may include mobility aids, communication aids and medical and therapeutic devices • take a copy of the Hospital Stay Guideline with them if accompanying an individual to hospital.	• ensure that effective communication between key stakeholders involved in the admission is maintained including clear communication of medical consent and decision-making protocol – this includes the individual, their representative, GP, DSO, specialist, pre admission clinic • clarify support roles with the DSO staff, e.g. the need for special nurses • arrange a pre admission process meeting to include relevant hospital staff, DSO staff, the individual and their representative, if possible
Providing equipment	• Continuously update the individual's property	• Ensure all property that enters the hospital with

Admission into hospital	Disability service organisation roles and responsibilities	Hospital staff roles and responsibilities
Ensure all equipment that is provided by the DSO is labelled (property bag and list)	as required to ensure no equipment goes missing.	individual is labelled and returned to the individual upon discharge.
Period of admission The period of admission can range from a few hours (for day surgery) to several weeks. Planning should start as soon as the admission is scheduled in order to prepare the individual for the admission and ensure their safety and wellbeing during the hospital stay.	Consider the support the individual will require during his/her hospital stay, including: • re-clarifying medical consent and decision making protocol • liaising with the hospital staff around possible behaviour support issues and assistance required with individual care e.g. meals, bathing, equipment • considering support to be provided by the DSO • clarifying support roles between the hospital staff and the DSO staff, e.g. the need for special nurses • considering information required from the hospital to the DSO provider at the time of discharge • adequate planning around discharge timing to ensure the necessary supports are in place at the disability facility • jointly agreeing and document supports to meet the individual's needs - this should be done as soon as practicable either prior to transfer to the word, or once the individual is settled in the word	Consider the support that can be provided in order to deliver optimal patient care, including: • liaising with DSO staff around possible behaviour support issues and assistance required with individual care e.g. meals, bathing, equipment • negotiating the supports required by individual with the DSO staff and maintain accurate documentation of these needs • clarifying communication points with the DSO • ensuring that the medication profile is reviewed by the regular pharmacist and that the medication administration system is up to date (this may include medication blister packs and medication charts and signing sheet) • ensuring the hospital pharmacist consults with DSO staff regarding medication history • reviewing discharge plans (timelines, bed movement).

Section 4: Discharge from hospital

Optimising care	
	An effective discharge from hospital is reliant on good discharge planning; this requires partnership between the individual, the DSO and hospital system. • discharge coordination for individuals with complex needs requires a holistic focus on the needs of the individual and the capacity of the DSO to meet those needs. "Key information that hospital staff need to know about the individual and their support needs should be provided in a universally consistent format and travel with the individual around the hospital so that any health care professional can access it."23 Key considerations regarding the discharge process include: ☐ individuals with disability and/or their representative are the natural authorities of their own lives and have the right to be involved in decisions about their services and supports. ☐ planning for discharge should commence at the time of admission and should include all stakeholders. ☐ Individuals presenting with acute health issues may incur changes to their disability support needs due to that health incident. These changes should be considered in accordance with their original accommodation circumstances and its ongoing ability to support those changes. • the hospital system and the DSO have a shared accountability for the individual's ultimate discharge outcome. ☐ discharge planning needs to consider the long term sustainability and suitability of the discharge option with a view to preventing readmission and/or discharge to inappropriate accommodation options. ☐ the hospital staff sharing the appropriate information with the DSO will help enable a safe and timely discharge.

Discharge from hospital	Disability service organisations roles and responsibilities	Hospital staff roles and responsibilities
Planning discharge	• ensure the hospital has all documentation regarding confidentiality and release of information back to the DSO so that all relevant discharge information can be provided • obtain regular updates, preferably daily, on the individual’s progress and treatment to understand their current and future support needs • communicate information regarding changes to health and care needs and the impact on long term support requirements to the individual and their representative • communicate information to the relevant funding agency regarding possible changes to long term care and support • support the individual during any transfer across health services to ensure continuity of support and carry-over of essential discharge information • participate in planning for the individual’s care coordination in hospital and transfer of care out of hospital • determine if the individual’s mobility has changed as an inpatient and if they require any mobility aids and/or additional rehabilitation, or referral to a community physiotherapist • facilitate participation in discharge planning of the individual and significant others • reassess the individual prior to the proposed discharge date to ensure that the individual is now able to be supported within their current accommodation option • ensure that the individual has appropriate transport on the day of discharge	☐ advise the DSO of planned time of discharge and arrangements available if immediate transport is unavailable • obtain and consider all relevant information regarding the individual’s disability and the impact of that disability and their current health issues on long term care and support ☐ provide appropriate documentation (discharge summary, typically sent to GP and next of kin) to the DSO on discharge to ensure continuity of care and ongoing management of new or existing health issues ☐ advise of any changes in mobility aids and/or equipment required by the individual ☐ identify if the staff at the DSO require education and training regarding ongoing care of new health issues and liaise with the contact individual at the DSO to arrange for that to be provided ☐ refer to relevant primary/community based health providers • liaise with the individual’s GP to ensure continuity of care from hospital to home ☐ provide relevant information regarding that referral and the associated program to the DSO and the individual and significant others ☐ ascertain if education is required from the hospital pharmacist/asthma educator/diabetic educator e.g. warfarin education, insulin education, inhaler administration technique, and who that education should be provided to • liaise with the individual’s pharmacist to ensure that medication will be dispensed and packaged on

Discharge from hospital	Disability service organisations roles and responsibilities	Hospital staff roles and responsibilities
	• where possible, ensure time of discharge allows for someone at the accommodation to receive the individual and has a full understanding of any changes to care requirements.	discharge - arrange for the hospital pharmacy to provide five days of medication for medication that is not readily available or where the individual will be discharged after hours or on a weekend.
Considerations for successful discharge	• the individual's usual ability • the individual's current level of functioning and whether it is the same as their usual ability pre-admission or if their care needs have changed since their hospital admission • if the discharge care plan provides a guide/criteria of what support can be accessed in the community to support changes in care needs • who makes the decision that the individual can return to their original accommodation option and/or who is responsible for planning and decision making if the individual will require alternative accommodation • who the hospital liaises with to explore alternative accommodation options • what services the individual is eligible for, whether they are able to access services in their area to support changed care needs and if they connected into those services. Examples of services: ▪ Silver Chain Priority Response Assessment Team (PRA), nurse or medical referred or St John Ambulance ▪ Hospital in the Home (HITH) ▪ Rehabilitation in the Home (RITH) ▪ Complex Needs Coordination Team (CoNeCT) ▪ Community Mental Health Services • if the individual requires new services or if pre-existing services on hold and need to be reinstated	The hospital should provide the following information as part of the individuals discharge information pack (where applicable): • discharge summary for the GP with a copy for the DSO • nursing transfer letter • wound care plan • contacts for referrals to community services • contact GP follow up visit booking • outpatient appointments for individual specialties with date/time/location • phone contacts for arranged service providers e.g. HITH, RITH, Silver Chain, CoNeCT, palliative care • access to Community Mental Health • nurse or GP referral to Silver Chain Service Priority Response Assessment Team (PRA) • The hospital worker should consider if a meeting needs to be arranged with the individual and DSO staff to formalise ongoing care requirements, i.e. establishing who takes responsibility for each task • identify the individual's representative to invite and assist in coordinating the meeting.

Discharge from hospital	Disability service organisations roles and responsibilities	Hospital staff roles and responsibilities
	Chain) • if the individual requires completion of funding applications for access to new services • if there are any services that are already being provided to a housemate of the individual and can they be coordinated to be delivered at the same time to create efficiencies (e.g. Silver Chain) • if the individual's living environment has been assessed to support changes to physical and cognitive function • if a home visit is required and if home modification needs to be arranged • if the individual's dietary requirements have changed including swallowing ability and can that change be supported in their current living environment • if the DSO staff requires education/training before the individual's discharge • the individual's new medication profile and who supervises/administers their medication - is all medication able to be packaged to allow for administration by the DSO staff and if not what other arrangements are required • if the individual requires palliative care and if this be provided in their current accommodation option.	
Proposed long term accommodation options	Consider: • who the key contact people are at the DSO, what their contact details are and when they are available • how information should be received by the DSO and whether information can be entered by the hospital health care workers into the service organisation's records on the individual	Consider: • arranging a meeting with the DSO, the individual and their representative to formalise ongoing care requirements including: ▪ who the key contact people are ▪ how information should be received by the DSO ▪ what capacity the accommodation care provider

Discharge from hospital	Disability service organisations roles and responsibilities	Hospital staff roles and responsibilities
	• where the individual's care plan is held in the facility and what format is it held in e.g. electronic or hand written • what the qualifications and capabilities of staff at the individuals home are • if nursing staff are available at the facility and if they can continue to provide current treatment required. • if the facility is legally able to manage the individuals health requirements • what the physical environment within the home is and if it is suitable to accommodate any changes in the individual's equipment requirements • if the individual's nursing staff are at the home and/or whether staff are able to provide health management including: ▪ wound management and dressings ▪ catheters ▪ Percutaneous Endoscopic Gastrostomy (PEG) meals ▪ tracheostomy care ▪ respiratory devices – Continuous positive airway pressure (CPAP), ventilator, nebuliser, suctioning, oxygen ▪ Peripherally Inserted Central Catheters (PICC lines) lines – intravenous antibiotics ▪ injections ▪ medications – Schedule 8, Warfarin ▪ blood sugar levels and insulin administration ▪ pain management ▪ ostomy management • if the home is no longer suitable for providing long term care and support what other options the DSO may be able to provide in the short and long term	▪ booking the individual in for future appointments • maintaining constant and transparent communication with the individuals and all relevant members involved in their care about the potential long term placement and providing support in finding the right place • liaising with the receiving facility and providing all necessary documentation and information required prior to day of discharge including providing clinical handover, faxing medication scripts, setting up services like Residential Care Line (RCL) for wound care advice or trial of void.

Discharge from hospital	Disability service organisations roles and responsibilities	Hospital staff roles and responsibilities
	• If the individual is from rural/remote area whether they can they be transferred (step-down) to a country hospital and would that be for ongoing medical treatment or rehabilitation • how long the individual would need to stay in the country hospital and what the long term plan will be • whether the individual be able to return to their previous support accommodation or whether there is another option that they can relocate to in the same regional area.	

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Part 2 – Background information

Partnerships between disability services organisations and the hospital system

For individuals with disability to maintain and achieve good health outcomes, the hospital system and disability service organisations must maintain effective partnerships. Through partnering with Health Service Providers, DSOs can more appropriately and effectively support individuals with disability when there is a need for emergency or planned health intervention. A partnership also enables the hospital staff and services to gain a better understanding of the needs of individuals with disability and the disability sector.

This *Guideline* has been developed to assist DSOs and the hospital system to understand and interact more effectively. It provides information to enhance interaction with and support of, an individual with disability.

This *Guideline* is intended to share expertise to ensure that individuals with disability achieve the best health care outcomes. Establishing collaborative and respectful partnerships between hospital staff and DSO staff in the context of a multidisciplinary approach is critical to improving the patient journey

The *Guideline* will facilitate opportunities to:

- identify areas for action to be undertaken by WA Health and DSOs
- inform service development and improvement initiatives for WA Health and DSOs to improve health outcomes for individuals with disability by enhancing their hospital experience
- create meaningful partnerships and collaboration between WA Health and DSOs
- provide opportunities for other parts of the health system to partner with the disability sector
- undertake research and evaluation with respect to the health and disability system interface.

Why is the Hospital Stay Guideline important to individuals with disability and disability service organisations?

There is clear evidence that adults with disability have relatively poor access to health interventions and health promotion programs. In addition, compared to the non-disabled population in WA, adults with disability have a significantly higher incidence of long-term health conditions and higher use of health services, including hospitalisation.[1] These inequities reinforce the importance of the *United Nations Convention on the Rights of Persons with Disabilities*.[2]

In addition to this, it has been found that people with disability regularly present to hospital for primary care issues that are more appropriate for a GP consultation. There were 2.2 million GP-type presentations to WA public hospital Emergency Departments in 2013-14 [3] On average, only 22% of ED presentations are admitted. Whilst data is not collected on how many of these presentations were by a person with disability, it is likely that some were. By increasing community understanding and support of the health care coordination of individuals with disability, it is anticipated that hospital presentations not resulting in admission will be limited.

The importance of ongoing, coordinated health care between services was highlighted by the Australian Institute of Health and Welfare *Access to health services by Australians with disability 2012 report*[4]. The report found that approximately 13% of individuals with disability who reported a need for ongoing help or supervision with health-care activities (such as taking medication, manipulating or exercising muscles or limbs) had no source of assistance.

At the local level, the key findings of the *WA Study of Health and Intellectual Disability 2013*[5] strongly support the need for the development of strategies to improve health and wellbeing for individuals with intellectual disability. The findings include:

- participants reported high rates of chronic and long-term health conditions
- medication use was high, as was the use of multiple medications
- health services usage, including mental health and hospital based services, was high
- many participants lived a sedentary lifestyle
- substance use was low in the study group when compared to the general population
- generally insufficient health screening/prevention for participants.

Furthermore, feedback from a range of stakeholder consultations including Clinical Senate debate on disability and health[6]; the Disability Health Consultative Group; Disability Health Network Executive Advisory Group and the Ministerial Advisory Council on Disability[7], indicates that potential health outcomes and effective engagement with the hospital system can sometimes be diminished by:

- poor communication between hospital staff, DSO staff, the individual and their family or carer
- information provided that is not fit for purpose
- the lack of an appropriate representative for the individual, or the inability to identify the individual's representative, to assist the hospital to understand the needs of the individual.

The Disability Health Network has identified that the interaction and engagement of both individuals with disability and DSOs with the hospital system is varied and there is an opportunity to improve the overall experience for all parties. The *WA Disability Health Framework: Improving the health care of people with disability 2015–2025*[8] lists four priority areas as identified through stakeholder consultations. The four priority areas align with international and national areas for action and include:

1. Understanding and recognition
2. Health and wellbeing
3. Workforce capability
4. Inclusive healthcare.

This *Guideline* is one strategy to address the health disparities for individuals with disability in the priority areas mentioned above.

Taking a quality approach

The disability sector is made up of individuals with disability, their families and carers, who may be supported by a diverse range of DSOs. Support to individuals is provided through a range of community based options including independent living, in-home support and group home accommodation.

Currently, the disability sector does not have a mandated clinical governance framework. Consequently, responses to and support of the health needs of individual varies, based on:

- their individual health needs
- their capacity to make informed decisions about the management of their own health requirements
- their personal living arrangement
- the identification, recognition and involvement of the family and/ or carer
- the capacity of the DSO
- the skills of the DSO staff.

The *Guideline* is an opportunity for DSOs and the hospital system to collaborate in the development of a clinical governance framework that supports the health needs of individuals.

It is the responsibility of DSOs to translate the information contained within the *guideline* to enhance their current health related policies and practices. Likewise it is the responsibility of the hospital system to translate the information contained in this *Guideline* to improve their services to individuals. This may also require both sectors to provide training for staff to implement the strategies outlined.

What the Guideline should do

The *Guideline* provides a shared understanding of the roles and responsibilities of the DSOs and hospital system in enabling safety and quality health care to be provided in a hospital setting.

The *Guideline* clearly defines the responsibilities of the DSO staff and the hospital staff in the individual's hospital stay and covers the individual's journey from pre-admission to discharge.

Policy linkages

The *Disability Hospital Stay Guideline* aligns with the *WA Health Strategic Intent 2015-2020* [9] vision to "deliver a safe, high quality, sustainable health system for all Western Australians". Other government frameworks and policies that complement and support the *Guideline* are:

- the *WA Disability Health Framework: Improving the health care of people with disability 2015-2025*[8] which articulates system-wide priorities for health and disability service providers to address. The aim is for individuals with disability in WAto be able to achieve the best possible health and wellbeing outcomes throughout their lives
- the *National Disability Strategy*[10] - a ten-year national policy framework for improving life for Australians with disability, their families and carers. It aims to create change in all mainstream services and programs as well as community infrastructure by ensuring the principles underpinning the United Nations Convention on the Rights of Persons with Disabilities are incorporated into public policy across governments
- *Count Me In: Disability Future Directions* [11], developed by the Disability Services Commission, sets out a long term strategy designed to guide all Western Australians when responding to individuals with disability
- the *Carers Recognition Act 2004*[12] and the *Carers Charter* [13] provide clear direction on how carers are to be treated and how carers should be involved in the decision making and delivery of services
- the *Policy Framework on Substantive Equality*[14] which recognises that specific needs of certain groups in the community can only be met by adjusting government policies, procedures and practices.

- the *WA Health Disability Access and Inclusion Policy* [15]*which* outlines WA Health's commitment to ensuring that individuals with disability, their families and carers are able to fully access the range of health services, facilities and information available in the public health system
- the *WA Health Promotion Strategic Framework 2012-2016*[16] provides direction for primary prevention of health conditions in WA. It recognises individuals with disability as a vulnerable population and acknowledges they are a difficult population to access for the provision of health promotion activities
- other WA Health specific policies include:
    - *WA Health Consent to Treatment Policy*[17]
    - *WA Health Clinical Handover Policy, January 2014*[18]
    - *WA Health Language Services Policy, September 2011*[19]
    - *Operational Directive: Boarders, 1 November 2007*[20].

Standards

There are Standards that apply to the aspect of service delivery outlined by this *Guideline*.

The *National Safety and Quality Health Service Standards*[21] aim to protect the public from harm and to improve the quality of health service provision.

Implementation of the *Guideline* supports the actions required to achieve Standard 2: Partnering with Consumers and Standard 6: Clinical Handover.

There are six *National Standards for Disability Services*[22] that apply to DSOs. Standards 1, 2, 3 and 4 are relevant to the *Guideline*.

1. Rights: The service promotes individual rights to freedom of expression, self-determination and decision making and actively prevents abuse, harm, neglect and violence.

2. Participation and inclusion: The service works with individuals and families, friends and carers to promote opportunities for meaningful participation and active inclusion in society.

3. Individual outcomes: Services and supports are assessed, planned, delivered and reviewed to build on individual strengths and enable individuals to reach their goals.

4. Feedback and complaints: Regular feedback is sought and used to inform individual and organisation-wide service reviews and improvement.

Guiding principles

The *WA Disability Health Framework: Improving the health care of people with disability 2015- 25* [8] contains guiding principles that equally apply to this *Guideline*. This *Guideline* identifies how DSOs and the hospital system can use the *Framework*'s guiding principles with respect to hospital stays for individuals in supported accommodation. Examples of the application of the *Framework* principles for hospital stays are provided as dot points under each principle.

Person centred

Individuals with disability, their families and carers are supported to make informed decisions about, and to successfully manage, their own health and care. They are able to make informed decisions and choose when to invite others to act on their behalf. This may require partnerships to deliver care responsive to people's individual abilities, preferences, lifestyles and goals.

- Promoting an understanding amongst the services that not all individuals are able to make autonomous decisions, and ensuring that the appropriate mechanisms are in place to support them.
- The health service and disability service organisation have a shared accountability for the individual's healthcare.

Responsive and flexible

Services and strategies will be responsive to the needs of individuals with disability including those from all cultural and linguistic backgrounds residing in communities across WA, including rural and remote locations.

- Individualised support strategies should be flexible, forward thinking and evidence based to meet the changing needs of the individual.
- Recognising that systems exist in both the health and the disability sector and that they both must be responsive and flexible to improve the health outcomes of individuals.
- Planning for hospital stays for individuals should take place before a health emergency.
- Hospital stay planning should include all stakeholders including the hospital, disability service organisation, the individual and their representative.
- Discharge planning needs to consider the long term sustainability and suitability of the discharge option with view to preventing readmission and/or discharge to inappropriate accommodation options.
- Culturally specific needs (e.g. interpreters, female staff for female patients of Muslim faith) should be identified when planning for hospital stays.

Respect and dignity

Individuals with disability have the same rights as everyone else – to be respected, to make their own decisions, to feel safe and have opportunities to live a meaningful life.

- Individuals with disability have the right to an inclusive disability and health support system that enables them to enjoy the highest attainable standard of health and wellbeing.
- Individual's information when shared will be done in a manner that respects privacy and dignity.
- Individual's right to exercise self-determination in decision-making will be promoted where possible.

Collaboration

Through collaborating, sharing an understanding of roles and responsibilities, and building partnerships, positive health outcomes for individuals with disability can be obtained more efficiently and sustainably.

- The unique expertise of the individual, their families and carer will be recognised and valued by the health and disability system.
- The unique expertise of both the health system and disability service organisations is recognised and valued.
- The individual and their representative, the health service and disability service organisation have a responsibility for collaborating in the interests of the individual with disability.
- Effective collaboration will be achieved in an environment of mutual respect and clear communication as well as an understanding of the responsibilities, capacities and constraints of the health and disability system.
- Disability service providers have a responsibility to provide appropriate information and support to enable an individual to effectively interface with the health system and ensure that their representatives, families and carers are appropriately informed.

Continuous improvement

Programs and services are involved in continuous improvement processes to achieve best-practice. Services delivered meet best standards of practice based on best available evidence.

- Learnings should be applied to improve the relationship and collaboration interface practices.
- Recognise that the sectors, their relationships and interface are evolving
- The *Guideline* provides a foundation for continuous improvement.
- Having clear feedback processes will enable both the health system and disability service organisations to receive important information that can help them continuously improve their service.

Reviewing the *Guideline*

The *Guideline* will be reviewed at intervals no longer than five years, or sooner if required.

Date of last review: N.A

Supersedes: N.A

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Glossary

Carers

People who provide ongoing (unpaid) care and support to family members and friends who have disability, a mental illness, chronic condition, terminal illness or are frail aged (Carers Recognition Act[24]).

Consent

See Informed Consent.

Disability service organisation staff

Any staff member employed by the disability service organisation to contribute to the care and wellbeing of the individual with disability.

Individual with disability

Referred to as the individual within this document. Use of the term individual includes the individual's family and/or carer, if appropriate.

Individual's representative

Any person who has recognised decision making capacity/authority on behalf of the individual as identified in the Guardianship and Administration Act 1990 hierarchy of treatment decision-makers[25] – this may include a family member or carer or a person appointed in accordance with the Act.

Informed consent

A process of communication between the individual with disability and their health care worker that results in the individual's authorisation or agreement to receive health care. This communication should ensure the individual has an understanding of all the available options and the expected outcomes.

Hospital staff

All persons employed to provide services for the purpose of improving an individual's health and well-being in a hospital. This includes but is not limited to doctors, nurses and allied health care workers.

Policy

A set of principles that reflect the organisation's mission and direction. All procedures and protocols are linked to a policy statement.

Service provider

A person or organisation who receives remuneration for providing support services to individuals with disability.

Services

Products of the organisation delivered to people or units of the organisation that deliver products to people.

Acronyms

CPAP	Continuous positive airway pressure
CoNeCT	Complex Needs Coordination Team
DSO	Disability service organisation
DVA	Department of Veterans' Affairs
ED	Emergency department
GP	General Practitioner
HACC	Home and Community Care
HITH	Hospital in the Home
PEG	Percutaneous Endoscopic Gastrostomy
PRA	Silver Chain Priority Response Assessment Team
RITH	Rehabilitation in the Home
WA	Western Australia

Appendices

Appendix 1: Recommended information to be provided between the disability service organisation and hospital settings

Information provided by the disability service organisation to the hospital Demographics

- ☐ Photo
- ☐ Name/known by
- ☐ Date of birth
- ☐ DSO accommodation provider name, address and phone numbers (including after hours)
- ☐ DSO accommodation provider key personnel names and phone numbers (including after hours)
- ☐ DSO accommodation provider description (including what health care facilities and nursing care is available)
- ☐ Next of kin (relationship, contact details, level of involvement - contact in emergency only or involve in all decision making)
- ☐ Family/ carer (relationship, contact details, desired level of involvement -)
- ☐ Communication needs
- ☐ Personal profile (likes dislikes, concerns etc)

Health profile

- ☐ Atypical signs and symptoms
- ☐ Health implications of disability type
- ☐ Pain profile
- ☐ Relevant medical/ surgical history
- ☐ Alerts and allergies
- ☐ Medication chart (including contact number of pharmacy)
- ☐ Support needs
- ☐ Transportation requirements
- ☐ Mobility needs
- ☐ Allied health needs
- ☐ Aids accompanying individual (e.g. glasses, hearing aids, alternative augmentative communication (AAC) device, other)
- ☐ Dietary needs
- ☐ Advance Health Directive
- ☐ Hospital Support Plan

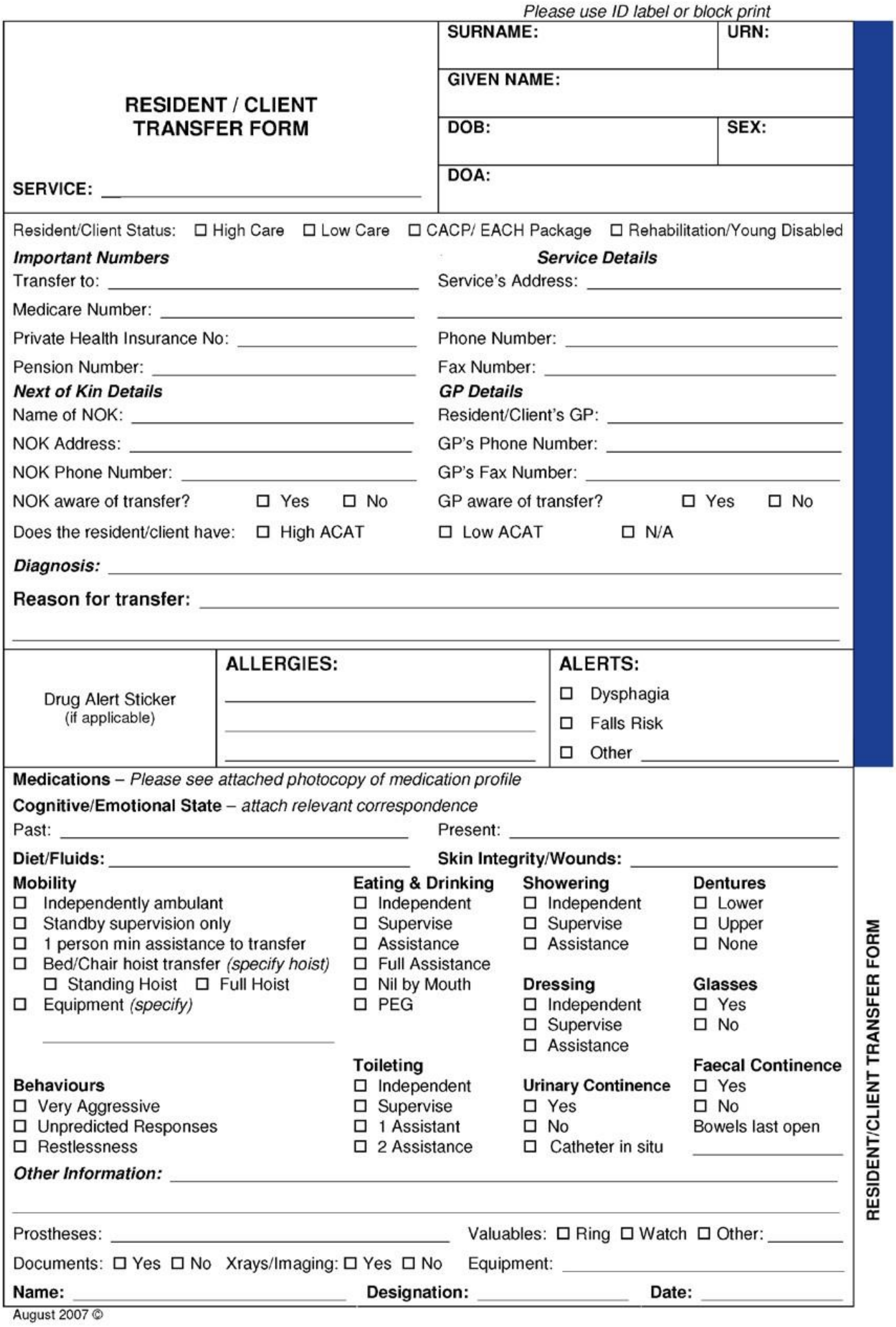
Consents and notification

- ☐ Person with legal decision-making authority (including out-of-hours phone number)
- ☐ Person to contact for information regarding medical history (including out-of-hours phone number)
- ☐ Copy of Enduring Power of Attorney / Guardianship Order and/or next of kin/family members/carers including any legal restrictions

Information provided by hospital to disability service organisation

- Discharge summary
- Nursing summary
- Medication scripts
- Allied health documents

Appendix 2: Example of individual health profile



Please use ID label or block print

RESIDENT / CLIENT TRANSFER FORM

SERVICE: ______________________

SURNAME:
URN:
GIVEN NAME:
DOB:
SEX:
DOA:

Resident/Client Status: ☐ High Care ☐ Low Care ☐ CACP/ EACH Package ☐ Rehabilitation/Young Disabled

Important Numbers

Transfer to: ______________________

Medicare Number: ______________________

Private Health Insurance No: ______________________

Pension Number: ______________________

Next of Kin Details

Name of NOK: ______________________

NOK Address: ______________________

NOK Phone Number: ______________________

NOK aware of transfer? ☐ Yes ☐ No

Service Details

Service's Address: ______________________

Phone Number: ______________________

Fax Number: ______________________

GP Details

Resident/Client's GP: ______________________

GP's Phone Number: ______________________

GP's Fax Number: ______________________

GP aware of transfer? ☐ Yes ☐ No

Does the resident/client have: ☐ High ACAT ☐ Low ACAT ☐ N/A

Diagnosis: ______________________

Reason for transfer: ______________________

Drug Alert Sticker
(if applicable)

ALLERGIES:

ALERTS:
☐ Dysphagia
☐ Falls Risk
☐ Other ______________________

Medications – *Please see attached photocopy of medication profile*

Cognitive/Emotional State – *attach relevant correspondence*

Past: ______________________ Present: ______________________

Diet/Fluids: ______________________ **Skin Integrity/Wounds:** ______________________

Mobility
- ☐ Independently ambulant
- ☐ Standby supervision only
- ☐ 1 person min assistance to transfer
- ☐ Bed/Chair hoist transfer *(specify hoist)*
  - ☐ Standing Hoist ☐ Full Hoist
- ☐ Equipment *(specify)* ______________________

Behaviours
- ☐ Very Aggressive
- ☐ Unpredicted Responses
- ☐ Restlessness

Eating & Drinking
- ☐ Independent
- ☐ Supervise
- ☐ Assistance
- ☐ Full Assistance
- ☐ Nil by Mouth
- ☐ PEG

Toileting
- ☐ Independent
- ☐ Supervise
- ☐ 1 Assistant
- ☐ 2 Assistance

Showering
- ☐ Independent
- ☐ Supervise
- ☐ Assistance

Dressing
- ☐ Independent
- ☐ Supervise
- ☐ Assistance

Urinary Continence
- ☐ Yes
- ☐ No
- ☐ Catheter in situ

Dentures
- ☐ Lower
- ☐ Upper
- ☐ None

Glasses
- ☐ Yes
- ☐ No

Faecal Continence
- ☐ Yes
- ☐ No

Bowels last open ______________________

Other Information: ______________________

Prostheses: ______________________ Valuables: ☐ Ring ☐ Watch ☐ Other: ________

Documents: ☐ Yes ☐ No Xrays/Imaging: ☐ Yes ☐ No Equipment: ______________________

Name: ______________________ **Designation:** ______________________ **Date:** ______________________

August 2007 ©

RESIDENT/CLIENT TRANSFER FORM

Appendix 3: Hospital Stay *Guideline* Project Group membership

The Disability Health Network acknowledges the individuals, groups and organisations who contributed their time and experience into shaping the *Hospital Stay Guideline*, in particular the Hospital Stay *Guideline* Project Group.

Hospital Stay *Guideline* Project Group membership

First name	Position and organisation
AJ Rajagopal	Discharge Coordinator, Patient Flow Unit, Royal Perth Hospital
Amanda Crook	Health Services Manager, 360 Health + Community
Nicole Deprazer / Jenny Howson	Senior Development Officers, Health Networks, WA Department of Health
Tricia Dewar	Principal Disability Health Coordinator , Disability Services Commission
Carol Franklin	Carer representative
Robyn Lieblich	Sir Charles Gairdner, Long Stay Young Disabled/SW Manager, Sir Charles Gairdner Hospital
Merinda March	Health Services Manager, 360 Health + Community
Sue Morrison	Nursing Services Manager, Disability Services Commission
Helen Nys	Director, Local Area Coordinator, Disability Services Commission
Gail Palmer	Manager of Community Programs, MS Society WA
Sue Shapland	General Manager, Member Services, MS Society WA
Gordon Trewern (Chair)	Chief Executive Officer, Nulsen
Janet Wagland	Manager, Services for Younger People, Brightwater Group
Emma Williams	Development Officer, Health Networks, WA Department of Health

This document can be made available in alternative formats on request for a person with disability.