

NDIS : Have your say

Consultation paper: access and eligibility policy with independent assessments

Submission by Healthy Dying for People with Disability Project
Li-Ve Tasmania

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NDIS Consultation paper: Access and Eligibility Policy with independent assessments

Introduction

This response to the National Disability Insurance Agency's Consultation Paper: Access and Eligibility Policy with independent assessments 2020 is provided by the Healthy Dying for People with Disability Project which operates within the disability service provider Li-Ve Tasmania.

Li-Ve Tasmania has been supporting Tasmanians living with a disability for over sixty-five years. In 2021 it supports over 300 individuals and employs over 400 staff. The organisation's portfolio includes 18 group homes and a diverse range of State-wide community access programs. Li-Ve Tasmania provides genuine person-centred support to people with disability in Tasmania throughout the life course. This includes people with intellectual and cognitive disability who require support with a life limiting diagnosis and end of life care. Over recent years, our service has supported a number of people with life-limiting illness to remain in their own homes until death.

Li-Ve Tasmania demonstrates its goal of equitable access to quality end of life care by –

- investing in research to build the evidence base
- establishing and sustaining relevant relationships and networks
- leading specific end of life initiatives
- offering training to disability support and healthcare workers on disability and palliative/end of life care

Initial research by Li-Ve Tasmania found that Tasmanians with disability feel confused, uninformed, isolated, and excluded from treatment planning and prognostic conversations. They also reported not being connected with palliative care services in a timely manner. Families and service providers reported a lack of confidence and capability to engage in the topic of death and dying. This research highlighted the need for a practical, cultural and systems-based approach to improving access and delivery of palliative and end of life care for people with disability (<https://livetasmania.org/end-of-life>).

In recognition of this foundational work, Li-Ve Tasmania was awarded an ILC grant to deliver the 'Healthy Dying for People with Disability' ('Healthy Dying' project). The project (launched in August 2020) seeks to collaboratively build organisational capacity and capability within Tasmanian health services to deliver tailored end of life care for people with intellectual or cognitive disability. Project activity focuses on clinical pathways, education/training and building sustainable cross sector/service relationships.

The Healthy Dying Project and Li-Ve Tasmania appreciate this opportunity for input and welcome any chance for ongoing engagement with the National Disability Insurance Agency on the functioning of the NDIS and associated workforce education/training needs.

Given the nature of this NDIS consultation, the focus of this response is those currently supported by the NDIS. We also wish to acknowledge however, the need to address the access, equity and continuity of support issues experienced by people who do not receive NDIS packages.

The responses to the consultation questions below are focused on the needs of people with (intellectual or cognitive) disability in the context of a deteriorating acute/chronic illness or diagnosis of a palliative condition.

Context

The current experience of people with disability and access to palliative care services and support

“Mike had the same intellectual (and developmental) disability for decades. Literally decades. And here we are facing the end of his life.... I knew that Mike would not understand. I knew that we, the family, had to help him through this last experience he would have on this earth...”

(Quote from “Mikes Journey” - <https://www.mikesiddjourney.com/journey/>)

“I was confused – I didn’t know what would happen next” *

“Everybody else talked around me but no-one talked to me”*

*Quotes from people with Intellectual and/or cognitive disability about their experience of access to palliative care services; Holliday, A. (2016) Li-Ve Tasmania: Quality end of life care for people with disability, a Tasmanian perspective, Tasmania, Australia

In 2018 Australian Healthcare Associates (AHA) was engaged by the Australian Government Department of Health to conduct an exploratory analysis of barriers to accessing quality palliative care for people from under-served populations or people with complex needs. Li-Ve Tasmania was a key informant in the consultation process.

In 2019 AHA produced an Issues Report on People with Disabilities, highlighting late or non-referral to services due to inadequate and delayed recognition of the palliative care needs of people with disability. The report also referred to the relevance and prevalence of diagnostic ‘overshadowing’ (defined as “attributing the symptoms of a disease to the disability and thereby failing to diagnose or treat it”) noting: “overshadowing can be a significant impediment to the timely introduction of palliative care... (and is) also a contributing factor in premature mortality among people with intellectual disability”.

Also noted in the report are capacity/capability challenges including –

- insufficient knowledge and understanding of palliative care among many health professionals outside of specialist palliative care services
- lack of confidence by some palliative care providers to deliver palliative care in community living services (e.g. group homes or supported accommodation) because they are unfamiliar with the setting and processes

The NDIS recognises that people with disability have the same right of access to services as all Australians, consistent with the goals of the National Disability Strategy (2010-2020) [we note the new strategy is due for release mid-2021].

The 2020 review of the Strategy noted the interface with the NDIS as a high priority and highlighted the particular needs of “people who receive NDIS packages and still require access to mainstream services.” In relation to the deterioration of an existing chronic condition, the onset of a life-threatening acute condition or the new diagnosis of a life limiting condition, the provision of equitable, best practice care remains a considerable challenge in the context of disability.

Palliative care is explicitly listed in the services that the NDIS is not responsible for funding. There is an expectation that “the NDIS and the health system will work together at the local level to plan and coordinate streamlined care”. The goal is “interactions of people with disability with the NDIS and other service systems (that are) as seamless as possible, where integrated planning and coordinated supports, referrals and transitions are promoted”.

As a provider in the sector, Li-Ve Tasmania recognises that the delivery of medical care is not the domain of disability services. It also strongly supports the aspiration of integrated and coordinated support with seamless interactions. Li-Ve Tasmania and the Healthy Dying Project are specifically working to support the realisation of this aspiration via capability building in the disability and health service sectors. However this is a ‘work in progress’, and meanwhile participants supported by Li-Ve Tasmania staff are not receiving the timely, quality palliative care they need (refer to illustrative case study in appendix below). This kind of concerning experience has also been reported to Li-Ve Tasmania by other Tasmanian disability providers. Common features of the cases include:

- person with a disability dependent on care/support from a paid disability worker in a supported independent living or specialised accommodation setting
- delayed recognition of signs of deterioration by disability support worker(s) and lack of timely referral
- lack of disability support worker training in relevant ‘high intensity activity’ related to the particular individual concerned (e.g. bowel care, feeding, catheters, subcutaneous injections)
- inadequate access to flexible and quick release funding to support an increased need for disability support related to decline in functional capacity (e.g. transition from day program to home visits)
- prohibitions on disability support worker scope of practice e.g. not permitted to administer or assist with the self-administration of S8 medications other than those specified as a ‘specified narcotic substance’ in the Poisons Regulations (2008) i.e. a) dexamphetamine and b) methylphenidate
- lack of timely access to appropriately qualified/experienced clinical support (symptom management needs can and do fluctuate and escalate outside standard service hours e.g. breakthrough pain overnight or on the weekend)

How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?

The distinction between disability and chronic or acute conditions that are or become palliative

The context outlined above makes clear the importance of –

- clearly communicated, workable definitions of disability vs acute, chronic or palliative conditions
- taking heed of the impact of distinguishing disability and acute, chronic or palliative conditions, ALL of which may necessitate high level care ('high intensity activity') at different times for different (potentially interrelated) reasons
- the work of the NDIS Research and Evaluation Branch in facilitating the use of evidence in decision-making, including data/insights from disability support and palliative care practice/ research

Definitions need to be 'reality tested' at ongoing, reasonable intervals to ensure that 1) the definitions reflect and support the overall goals of health and wellbeing and choice and control for people with disability, and 2) those in practice at the interface of disability support and health care delivery are working with role clarity that supports multidisciplinary, coordinated, quality care.

Policy makers need to be alert to the possibility of unintended consequences of assessment and review delays involving disability and acute/chronic/palliative condition definitions. For example, is it possible that current definitions support a situation where a person with a disability receives funded support for high level care that can be provided by a family carer, whilst a person with a disability in specialised or supported accommodation is dependent on timely access to a doctor, registered nurse or hospital-based specialist?

If it is assumed that palliative care will be funded by the primary, acute or specialist care systems, the realities of life and care for those living in specialised or supported accommodation need heeding. Where and in what circumstances the person with disability lives may necessitate transfer to hospital (possibly via emergency and often by ambulance) which has implications for –

- overall health system costs
- the person's mental/emotional comfort
- the person's social connectedness
- the person's access to disability support workers who are trained and experienced in supporting communication and participation and
- the persons choices around medical interventions and place of dying/death

Australia's National Palliative Care Guidelines (PCA 2018) note that "the staff engaged to support people living with a disability in residential services generally will not have additional health care training" but suggest they "may be able to support palliative care through the provision of information about the person" and assistance with "alternative communications strategies" where needed.

Whilst this is appropriate recognition of disability support staff skill in knowing the people they care for, it is notable that in the context of residential aged care the expectation is different – “for many people a residential aged care facility is their home, and it is important they have access to the same range of community and inpatient based services available to people residing in their own homes. This includes access to... consultative support and/or direct care from specialist palliative care services on a needs basis”. This begs the question, are different standards being set for aged care and disability residential settings and are their associated funding mechanisms operating differently to effectively facilitate (or not) timely access to specialist palliative care?

“Until the concept of disability disappears and is replaced by a society that is structured to support everyone's life relatedness and contribution—until that day my life and opportunities and the lives of every other person who carries the label ‘disabled’ depends on the goodwill of people in the human service system”

(Quote from ‘Shut out’ - NDS consultation report 2009)

Disability and palliative care services are both part of the human service system. People with disability depend on the services’ respective capabilities and their capacity to coordinate to deliver integrated care. The concept of “palliative condition” needs to be considered holistically to determine 1) what responsibilities best sit with disability or mainstream services and 2) what capacity and capability still need to be built in the respective service systems; supported via education/training and clear, evidence-based care pathways. The risk of suboptimal care involving unnecessary or avoidable suffering remains too high.

What are the traits and skills that you most want in an assessor?

Critical to the capability of an assessor is her/his ability to consider all decisions regarding the health/well-being of a participant through the lens of vulnerability. Structural vulnerability permeates the life of a person with disability. Add to pre-existing vulnerability, a deteriorating acute/chronic illness or a new palliative condition, and the risk of suboptimal care/support is unacceptably high.

Health status impacts upon an individual’s functional capacity, sometimes in similar ways to a recognised/diagnosed disability. This creates the risk for increased disability needs to be unsupported in the context of serious illness or for oversimplified and unhelpful ‘reasonable and necessary’ decisions. In turn this can lead to a lack of consistency in funding for participants with similar support needs. Awareness of how new or additional diagnoses may impact upon a participant’s functional capacity provides the best opportunity for the most appropriate, evidence informed plan/decisions. Achieving this awareness may necessitate –

- education for independent assessors in the structural (and thus system) vulnerability of people with disability, in particular those living in specialised or supported accommodation
- education for independent assessors around the interplay between disability and health status and the ‘work in progress’ aspiration of coordinated and integrated care

- training for independent assessors in –
 - understanding different service/system roles and responsibilities
 - referral and navigation within and between systems and
 - the timely use of expert informants with appropriate disability experience or medical/healthcare training

Simultaneously, the work to increase disability capability in the mainstream health workforce and health capability in the disability workforce needs to accelerate and expand, particularly for the most vulnerable participants like those deteriorating due to serious acute/chronic illness or a palliative diagnosis.

What are the limited circumstances which may lead to a person not needing to complete an independent assessment?

Exceptions for independent assessment should be considered for those participants diagnosed with a new or deteriorating condition that has been assessed by an appropriate medical or health professional as life limiting - particularly in cases where the anticipated trajectory is rapidly increased support/care needs and/or a short timeline between diagnosis and death.

The NDIS should consider working with disability and relevant mainstream health services to support the development and promotion of a pathway for participants diagnosed as seriously deteriorating or needing care/support for a life limiting illness. This pathway would involve assessment and decision-making processes that could be –

- escalated in priority
- expedited to ensure timeliness
- flexible/agile in relation to the availability/release of funds to support disability services to participate in collaborative end of life care with mainstream health services (including specialist palliative care)

The Healthy Dying Project and Li-Ve Tasmania strongly support the aspiration of choice and control, but must signal that without systemic support for capability/capacity building, the aspiration is at high risk of being rhetoric only. Without increased literacy within the NDIS, disability and mainstream health services regarding the disability and health needs of participants, choice and control remain concepts rather than a lived reality. The right to care/support to enhance wellbeing and enable participation is as important in dying as it is in living:

“(Even if) they can’t say I am dying...what is going to happen...will it hurt.. (because) they don’t have those thought processes, they are due exactly as much as the adult who does know the journey they are about to take...”

(adapted from McLaughlin, D., Barr, O. et al (2015))

The Healthy Dying Project and Live Tasmania look forward to progressing their work to ensure equitable, quality palliative/end of life care for people with (intellectual or cognitive) disability. We extend an open invitation to the NDIA to work together to make this aspiration a reality.

Li-Ve Tasmania appreciates the opportunity to contribute to the NDIS Have your say: Consultation paper: Access and eligibility policy with independent assessments. It welcomes the opportunity to speak to the experiences of participants it supports and assist to achieve healthy dying for people with disability.

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Appendix: Case Study: Healthy Dying for People with Disability Project and Li-Ve Tasmania Submission

John is a 63yr year old gentleman living with an intellectual disability. He is non-verbal, and lives in a Supported Independent Living 4 bedroom group home with 3 other housemates. He does not have a current complex health care plan. He has 1:1 funding for Community Access during weekdays and a lower ratio for care (1:3) for the evening and overnight; and a plan review has been requested to include Behaviour Support Intervention funding, as John has developed an aversion to any medical care/intervention and can display significantly resistive behaviour.

John's sister is his Person Responsible, with the public trustee appointed as his financial administrator. John's sister lives interstate and he has no other relatives.

John's Disability Support staff noted that he has become increasingly lethargic over the past week, looks pale, has decreased urinary output, has had a persistent cough and is displaying behavioural signs of right sided chest pain. John was admitted to the Emergency Department of the local hospital at 7.30pm Friday evening as a result of these growing concerns for John's health.

Clinical investigations revealed pneumonia and a questioned possible malignant growth in his right lung. After discussions with clinical staff over the next 24hrs, exploring all possible investigation and treatment options, John's sister decided to choose conservative treatment, which involved antibiotics for John's pneumonia and no further investigation or treatment for the suspected malignancy. John was referred to the Specialist Palliative Care Service.

Over the next 2 days, John's sister and support workers explained to him the situation and John indicated he wanted to stay in his own bedroom and became agitated and aggressive with any suggestion of going to hospital. John's sister requested he remain in his home.

Over the course of the next 3 weeks, John's health continued to deteriorate and he was supported by his GP, the Community Health Nurses, the Specialist Palliative Care Service and his disability support service to stay at home in a familiar environment. John's support needs significantly increased over this time as his health declined. These support requirements included mobility aids, a hoist for transfers from bed to wheelchair, an adjustable mobile hospital bed, 1:1 24 hr support and regular pain relief interventions administered through the Community Health Nurse team.

There were regular instances over the last week of his life, where John was requiring breakthrough pain relief after hours. Due to his support workers being unable to deliver this pain relief under the scope of their practice; John's sister being unable to provide the required medication and the Community Health Nurses not operating between the hours of 9pm to 7am; the disability support service made the decision to engage a casual Registered Nurse, to ensure the timely access to afterhours pain relief for John. This enabled John to stay in his home, a familiar environment, surrounded by people who knew him, which reduced his distress and terminal restlessness.

John died in his home in the early hours of Monday morning, 3 weeks after his initial diagnosis, supported by support staff and the casual Registered Nurse.

Issues:

- No funding within his current plan to cover the immediate and necessary additional supports of mobility equipment, hospital bed and extra support staff around the clock
- The disability support service absorbed the cost of the equipment, extra staff and the engagement of the Registered Nurse to deliver break through pain relief.
- Swift decline of John's daily functioning, impacting his support needs with no timely access for a plan review
- The swift deterioration in John's condition resulted in escalating complexity of his care needs. This resulted in support staff not having adequate time to be trained to address the high intensity support needs prior to his death, thus the need for immediate support from a Registered Nurse for afterhours support.
- Johns staff team and supporting organisation donated hours of unpaid support time to co-ordinate and respond to his constantly changing care needs, liaise with services and nurture his relationship with his housemates and sister. This included informal team meetings, liaison with palliative care practitioners, grief and adjustment supports to best include John, his sister and his housemates in his end of life care and ultimately to ensure that staff were able to contribute their extensive person centred knowledge of John to those who were sharing his care. Additionally after his death, there is an extended service provision to care for his body and possessions with the same respect and attention John was given when he was alive.

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