

NDIS : Have your say

Consultation paper: planning policy for personalised budgets and plan flexibility

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

Contact details:

Darren Mathewson
Chief Executive Officer
Phone: (03) 62275400
Email: dmathewson@livetasmania.org

NDIS Consultation paper: Planning policy for personalised budgets and plan flexibility

Introduction

This response to the National Disability Insurance Agency's Consultation Paper: Planning Policy for Personalised Budgets and Plan Flexibility 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.

Note

- 1) A response has also been submitted to the Consultation Paper: “Access and Eligibility Policy with independent assessments 2020”. The same relevant contextual detail has been provided in each document in case the two responses are reviewed by different readers
- 2) Responses to both papers should be read in light of the context provided by the illustrative case study

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...”.

<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). 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 best to handle the timing of release of funds into plans and rollover of unused funds?
(plus additional comments about:

- **fixed budget,**
- **check-ins**
- **flexibility of disability support delivery**
- **workforce development**

The NDIS consultation paper proposes that funds be allocated into the individual's plan to purchase supports on a schedule basis, with the option of monthly or quarterly release of funds (depending on assessment of risks and circumstances). Whilst this approach offers choice and some flexibility, a gradual release of funds has the potential to negatively impact participants who need sustained/continuous care or care that can be adjusted around deterioration, increased support/care needs or a new palliative diagnosis.

The suggested revised approach aims to avoid early over utilisation of funds but also needs to support flexible and timely – sometimes urgent – access to funds to purchase supports for participants with an acute change in their presenting need such as those with terminal diagnosis who may:

- 1) have a short trajectory between diagnosis and death:
- 2) have escalating (or fluctuating) needs and
- 3) may experience significant unnecessary emotional and/or physical distress without additional care/support/aids in their final phase of life.

For a participant with a known diagnosis of life limiting illness at the time of planning (and budget), inclusions in the 'fixed' (or not fixed) budget require careful consideration. Timely access to flexible funding is critical to enable participants who are deteriorating or approaching end-of-life to access specialist clinical supports that may be needed (and those which people without disability can navigate independently).

Whilst s48 of the NDIS Act 2013 allows participants to identify a change of circumstance and request a plan review, the timeliness of s48 request approval (and associated review) needs particular consideration in the context of a palliative diagnosis. Li-Ve Tasmania has gathered anecdotal evidence from its peer service providers that they have had people with disability die whilst waiting for their plan to be formally reviewed.

We note the newly proposed Planning Process (Figure 1) has more steps than the previous process, with a draft and consultation with the participant now becoming standard practice. This poses a potential greater risk in relation to plan approval times.

Whilst we appreciate it is not the responsibility of the NDIS to approve/fund supports that are most appropriately funded by other mainstream services/systems, the impacts that

deteriorating health or a palliative diagnosis can have a person's functional capacity and associated support needs requires distinct consideration.

It seems there are two options to best respond to the dynamic and sometimes fast changing needs of people with disability who are dying (particularly in shared care settings). The first, and preferred option is to recognise that within the persons end of life experience there will be significant and sustained (albeit short term) increases in their need for care and support.

This may include access to High Intensity skills training for their staff team, so they can perform procedures to manage care and implement quality person centred palliative care approach. Additionally it may be to support co-ordination of care required as the intensity of a person's needs changes often and needs close monitoring and co-ordination with mainstream palliative care service providers to ensure the person is receiving equitable services and support to those living without disability. Regardless of the individual need, their package of supports will need to be flexible in order to allow for maximum choice and control within their end of life experience.

The proposed procedure for gradual release of funds may prove insufficiently agile or flexible to provide timely, appropriately tailored care/support. The 2019 Review of the National Disability Insurance Scheme Act 2013 noted that participants reported feeling that "NDIA staff did not understand the nature of their disability or appreciate the challenges they encountered in everyday life". Add to that the need to recognise/respond to the challenges of a life limiting illness and the risk of a rigid approach to funds release is high.

Providing delegates with the authority to make a wider range of decisions around the release of budget funds would allow room for more contextualized, person-centred decisions that support choice and control. Further to this, where an s48 request is made by a person living with a life limiting illness, an expedited pathway is needed to facilitate an urgent response. Degenerative conditions and terminal illnesses can lead to a rapid decline in health. In some cases, the time between diagnosis and death is short. Timeliness is critical.

Similarly, the timing of check-ins by staff needs to be approached differently for participants who have been diagnosed with a life limiting illness. The provision for priority/urgent check-ins following a palliative diagnosis should be considered. The schedule for check-ins should align with the likely trajectory associated with the diagnosis and the circumstances of the participant (including their disability). The diagnosing doctor or palliative care professionals (specialist or community) should be included in the communication to confirm level and complexity of medical needs.

While addressing the need for flexibility within a participant's plan, in light of a life-limiting diagnosis, consideration should also be given to enabling disability support activity to be easily substituted depending on the participant's ability eg: day support being superseded by residential support. The reality of a life-limiting diagnosis means that additional and different disability supports will be required as the participant's ability declines with their illness trajectory. Indeed, as the participant's abilities decrease, they will require greater disability

support. As such, the participant's disability support workers may require further appropriate training to provide adequate support. This growing complexity for the disability support worker should be accommodated for by providing timely access to funding within the participants plan for training and education of disability support workers.

How can the NDIS ensure positive relationships between participants and planners?

Transparent and confident decision making, alongside participants understanding their rights and pathways will support positive relationships and facilitate more effective functioning of the NDIS.

The requirement for transparent decision making by a NDIS delegate (s34) is crucially important to the rollout of any changes to the planning/budget process. Participants also need clearer pathways to challenge decisions they do not agree with (s100).

The proposed new planning process for new and existing participants aged 7 to 65 includes step 3 where the participant receives a draft of the plan, including a draft plan budget. It is to be expected that in some situations, participants may request supports that have not been included in the draft submitted to them.

The 2019 Review of the National Disability Insurance Scheme Act 2013 notes that participants have found the NDIS confusing, frustrating and lacking transparency. If it is determined at step 5 that supports requested by the participants have been declined, the approving delegate needs to provide transparent, detailed reasons, identifying what specific subsection of s34 was not met.

The 2019 report from People Living with Disabilities Australia noted that "many of the issues that people with disability experience with the scheme stem from the contested concept of 'reasonable and necessary' supports. Reasonable and necessary supports should be more clearly defined". Pathways and options to challenge s34 decisions should be made clear to participants, including AAT involvement in instances where agreement between the participant and NDIS delegate cannot be established.

For participants of the NDIS whom also live with a chronic health condition or a life limiting illness, it is essential that NDIS Planners and Delegates are able to explain what parts of s34 have not been met as often, s34 part (f) can be specifically cited where supports are more appropriately funded through other mainstream, community or informal supports. When provided with clear reasons, participants have the opportunity to engage further with their representatives. Participants should be aware of the pathway to challenge s34 decisions and/or linked to appropriate mainstream, community or informal resources by their NDIS Planner or Local Area Coordinator.

As per our response to the Consultation Paper on "Access and Eligibility Policy with independent assessments 2020", the context of life limiting illness and palliative care requires special consideration. Challenges to the delivery of coordinated, integrated care remain considerable. This type of care is an appropriate and worthy aspiration, but the evidence tells us it remains a work in progress. The interface between the NDIS/disability

services and mainstream health remains a challenging space. It requires a multi-pronged approach to implementing improvements and achieving better outcomes.

The right to care/support to enhance mental and emotional wellbeing, physical comfort and social connectedness is as important in dying as it is in living:

“A clear line of distinctness must be drawn between the environment of the body and the environment of the mind or both the body and the mind be regarded as intertwined and be deprived of strength... When the body is in crises, the mind must not be...such is tenacity and nimbleness... life never ends until we come to the end of our lives.”

(— Ernest Agyemang Yeboah)

The Healthy Dying Project and Li-Ve 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.

“I've never thought I was going to die young. But I'm aware, sometimes painfully so, that there are people who do.... The National Disability Insurance Scheme is an investment in all Australians. It's not about people like me who currently live with disabilities, it's about all of those who might in the future.”

(- Stella Young <https://www.abc.net.au/news/2014-12-08/17-things-stella-young-wanted-you-to-know/5950814?nw=0>)

The Healthy Dying Project and Li-Ve 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.

Contact details:

Darren Mathewson - Chief Executive Officer

(03) 62275400

dmathewson@livetasmania.org

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.

Reference List

1. Australia's Welfare 2017, 8.1 People with Disability, Australian Institute of Health and Welfare, (2017)
2. 2010-2020 National Disability Strategy : an initiative of the Council of Australian Governments Commonwealth of Australia [Canberra, Australian Capital Territory] 2011
3. Australian Government (Disability Ministers), Statement of Continued Commitment: National Disability Strategy 2010-2020 (Dec 2020)
<https://www.dss.gov.au/disability-and-carers-supporting-people-with-disability-resources-supporting-people-with-disability/statement-of-continued-commitment-national-disability-strategy-2010-2020>
4. Holliday, A. (2016) Li-Ve Tasmania: Quality end of life care for people with disability, a Tasmanian perspective, Tasmania, Australia
5. Davy, L., Fisher, K.R., Wehbe, A., Purcal, C., Robinson, S., Kayess, R., Santos, D. (2019). Review of implementation of the National Disability Strategy 2010-2020: Final report. (SPRC Report [4/19]. Sydney: Social Policy Research Centre, UNSW Sydney.
6. Palliative Care Australia 2018, National Palliative Care Standards 5th edn, PCA, Canberra
7. Review of the National Disability Insurance Scheme Act 2013, Mr David Tune AO PSM, (2019)
8. The Illusion of "Choice & Control": The difficulties for people with complex and challenging support needs to obtain adequate support under the NDIS, The Office of the Public Advocate, (2018)
9. Tune Review of the NDIS Act, People Living With Disability Australia, (2019)
10. National People with Disabilities and Carers Council. and Australia. Department of Families, Housing, Community Services and Indigenous Affairs. Shut out : the experience of people with disabilities and their families in Australia : National Disability Strategy consultation report / prepared by the National People with Disabilities and Carers Council Dept. of Families, Housing, Community Services and Indigenous Affairs, Greenway, A.C.T 2009
11. Ernest Agyemang Yeboah, The Untapped Wonderer In You: dare to do the undone, published August 25th 2014 by Createspace Independent Publishing Platform
12. Department of Communities Tasmania: Disability Services Medication Management Framework For Individuals' and Disability Service Providers (2017)
https://www.communities.tas.gov.au/disability/publications/policies,_procedures_and_guidelines/medication_management_framework