

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Submission by Li-Ve Tasmania

Health care for people with cognitive disability *Issues paper*

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Li-Ve Tasmania has been supporting Tasmanians living with a disability for over sixty-five years. In 2020 it supports over 300 individuals and employs 400 staff. Li-Ve Tasmania provide genuine person-centred support to people living with disability in Tasmania. The organisation's portfolio includes 21 group homes and a diverse range of community access programs, state-wide. It supports participants of all ages with diverse support needs arising from a broad range of disability. Li-Ve Tasmania demonstrates particular expertise in services supporting people living with acquired brain injury and/or dementia, and at end-of-life.

At Li-Ve Tasmania, service delivery is focused on enriching the lives of people living with disability. We recognise that everyone's needs are different and that supports should be specifically tailored to suit what each person wants and needs. Li-Ve Tasmania supports the National Disability Insurance Scheme (NDIS)'s vision of an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens.

During the decades of block funding administered through the Tasmanian Government, the interface between people living with an intellectual disability and the acute health system has been problematic. In the absence of consistent policy or the development of practical process and procedures between Disability Services (as the lead agency) and the Tasmanian Health system, the general approach involved having to advocate on a case by case basis. Similarly, this occurred in the private health system for those who were able to access health insurance or were compensable.

The introduction and move towards full roll-out of the NDIS has seen an escalation in the disability/health interface issues as there is now multiple 'third parties'. The traditional issues are now compounded by NDIS funding and administration requirements, planners, local area coordinators (LAC's) as well as the existing state health and private hospital bureaucracies.

Question 1: What do you think about the quality of health care for people with cognitive disability?

Li-Ve Tasmania defines quality health care as one that offers responsive, consultative, inclusive and outcomes-based healthcare via transparent and consistent structures, processes and culture. For sixty-five years, Li-Ve Tasmania has supported people with diverse cognitive disability to access health care services across numerous service types and outlets (public health services including hospitals, medical clinics, dental services and allied health settings).

With this extensive experience in mind, Li-Ve Tasmania reflects that overall, the quality of the Tasmanian health care services does not match its definition of 'quality'. There are many examples where people living with cognitive disability (across a broad spectrum of ages) have not received personalised, responsive or outcomes-based health care -

- clinicians and treating personnel recommending a course of treatment that was not preventative based and/or high prevalence of diagnostic overshadowing

- poor communication, typically in the form of not listening to the person and/or their carers, or the absence of plain English formatted information to explain procedures (i.e. what does a tooth extraction or cancer treatment involve), treatment options (i.e. how to consider medicine A versus medicine B) and service models (i.e. what is community nursing, who is the service for, and how do you access it) and/or staff choosing not to interact directly with the person (perhaps due to a lack of confidence and/or capacity to communicate with people with diverse needs)
- consultations not being allocated sufficient time for adequate assessment and treatment determination, often resulting in delayed diagnosis
- poor attitudes among health professionals towards the needs and experiences and ability for people with cognitive disability to contribute to, and potentially lead on their health care decisions.

Question 2: Can you tell us about any barriers that people with cognitive disability have experienced in accessing health care?

Further to the response to Question One, the primary set of barriers faced by people living with disability and supported by Li-Ve Tasmania could be described as

- structural - lack of consistent, transparent and contemporary policy and operational procedures to accommodate the needs of people living with disability, particularly those with complex needs
- cultural - lack of insight into the experiences and perspectives of people living with disability and the impact the disability has on a personal capacity to participate, negotiate services, access support and health care. Similarly, it seems that often the value of treatment (person) is potentially determined by the persons cognitive capacity i.e. is it worth putting them through the treatment because (it is presumed) they won't understand or cope; and
- practice based - limited tools and resources available within the mainstream health setting to appropriately guide staff and patients to make informed/supported choice or express their preferences and wishes for consultation, assessment and/or treatment.

Question 3: Can you tell us about any problems that people with cognitive disability have had with the NDIS and accessing health care?

Since the rollout of the NDIS in Tasmania there have been a range of consistent problems that people with cognitive disability report. Essentially these challenges involve debate about 'who' (health versus disability) pays for support when it is required to ensure

- effective communication to facilitate understanding of proposed treatments; and/or
- targeted support to meet the needs of the individual within an unfamiliar environment.

Often, the persons NDIS package becomes a focus of bargaining for resourcing instead of an enabler of a positive outcome. This is a recurring issue and often relates to support requirements that may fall outside of the participant's agreed plan supports. At times, it seems there may be a reactionary predisposition from the NDIA that proposes utilising an individual's current funding 'now' with an informal intention to 'fix it later' through a plan review. This requires a 'leap of faith' from providers who are expected to provide supports *now* in the hope that a 'timely' plan review will address any funding shortfall.

A further issue occurs in the demarcation between State health funding and NDIS funding responsibilities. Each disability/health interface is now a complexity of bureaucratic obfuscation and policy misalignment. Li-Ve Tasmania shares the below vignette of a person it supports to exemplify this common issue and its impact on people we support...

This person requires cardiac surgery, has significant comorbidities and private health insurance coverage. Whilst finalising arrangements for booking the required surgery in private hospital, challenges were unveiled regarding 'who' would fund support for this lady whilst in hospital. It is recognised/agreed by all parties that this person would need supports in excess of the existing NDIS plan. These would be essential to assist her to cope in the unfamiliar environment, communicate her needs and support her to navigate her post-surgical recovery. Her disability (NDIS funded) staff know this person well and have expertise in regards to her communication support needs. Unfortunately the hospital will employ sitters, but not her disability support staff. This is problematic because she needs familiarity and continuity in care to get maximum benefit from the surgical intervention (by being able to communicate her experience, needs, pain, recovery support needs etc).

Protracted discussion about who will fund this variation in support ultimately led to the surgery being moved into the public system. As a direct consequence of the delay (to determine NDIS versus health service) and now the current Covid-19 situation, surgery has been postponed. This persons health is now described as 'serious risk' and her quality of life and opportunities to participate in life (? choice and control) are diminishing.

[Question 4: What do you think should be done to fix the problems people with cognitive disability have in getting health care? How could the NDIS and health systems work better for people with cognitive disability?](#)

In 2017 the Tasmanian NDIS-Health Advisory Group (TNHA Group) produced a paper comprehensively outlining the issues faced by people with an intellectual disability in the the acute health system. The TNHA Group noted six Policy recommendations and five Procedural Recommendations. Li-Ve Tasmania strongly endorse their findings, together with the Policy and Procedural recommendations (Appendix A – see attached).

Critically, Li-Ve Tasmania advocates strongly for the introduction of flexibility within individual funding packages via the NDIS which allows for the provision for additional resources if/when individuals with complex needs are required to go to hospital (public or private).

Professor David Gilchrist noted in his White Paper *Six Years and Counting: The NDIS and the Australian Disability Services System* that “We now have a significant body of evidence in 63 separate reports, primarily focused on the NDIS, written since 2013 relating to the problems and potential solutions across the system.”

The commitment to a dedicated proactive Acute Health Care Plan (AHCP) is a clear solution to this issue and will ensure that the most vulnerable people in our health care system can be sure to experience person centred, responsive and quality health care as they require it. Li-Ve Tasmania see opportunity for the Royal Commission to respond to this systemic issue with a clear framework that ensures that continuity of care, familiarity of place and people (including their chosen support workers) are recognised as critical elements to ensuring people with cognitive disability achieve positive outcomes for their healthcare concerns.

Simultaneously, there is a need to support Tasmanian health practitioners to gain clear insights into the lived experience of cognitive disability and the disability service setting. To build confidence and a capacity to deliver flexible, responsive, equitable care for all Tasmanians, regardless of ability or impairment.

Together, these solutions will ensure that outcomes for people with cognitive impairment are consistently enhanced and are experienced as positive for all involved.

[Question 5: Why do people with cognitive disability experience violence, abuse, neglect or exploitation in health care? What are the causes?](#)

Hospitals and health care facilities can be intimidating and for people with a cognitive impairment who are probably unwell or in pain, scared, confused, effective communication and understanding will at best be challenging. There are a myriad of triggers that may result in people with cognitive impairment to be more vulnerable in this environment, including (but not limited to):

- Symptoms
- Unfamiliar environment, people, system, tools, practices
- Not being well prepared for the appointment
- Cognitive impairment – impact on ability to process, recall, interpret information, environments, expectations on them and others, self-esteem,
- past experience
- person’s ability to communicate pain and/or emotion

[Question 6: Is the violence, abuse, neglect or exploitation that people with cognitive disability experience, different in Doctors or GP’s surgeries, medical centres, hospitals, specialists or consultants? Is it different in public, private or not-for-profit health care?](#)

Li-Ve Tasmania note that the ‘setting’ for care often determines the opportunity for a quality outcome for the person with disability. That is, a doctor’s surgery is typically a familiar place in terms of the physical environment, the staff at the reception area, the doctor and the overall consultation experience (arrive in specific area, seating to wait in another, eventually enter the

consultation room) is typically the same process each time we visit. Often too, the person is able to have one treating physician whom they can build a sense of trust and relationship with. When maximised to its potential, this setting can achieve positive health care assessment and provision of quality care because there is opportunity to ‘invest’ in forward thinking and planning based on knowledge of the patient. This setting is conducive to person centred care.

In contrast an appointment at a hospital is, by virtue of the setting, not able to offer such personalised attention, flexibility regarding wait times, familiarity with which room, and in fact, which physician the patient may see. Hospitals are bigger institutions, they require navigation of complex and new spaces, often deliberately apply more rigid systems (out of necessity to manage volume and finite resources) and therefore there are often much bigger expectations on the patient to navigate these variables. There is an inherent need to be able to cope with fluid detail (i.e. please arrive at 7am, be prepared to wait for several hours before your appointment). For people living with cognitive impairment, these challenges can be problematic and can trigger issues unrelated to the health care needs.

In an acute setting, the care required has to conform to the service model of the setting. It is more likely to be rushed (getting people in/out of consultations), staff may be more likely to use a directive tone, the consultant may not be afforded time for a true consultative approach, and may be interpreted as “impersonal”. Such process and time constraints will typically result in the person with cognitive disability feeling pressure, feeling overwhelmed by the many and fluid variables and it may result in negative and low value healthcare.

Different health care settings also provide different opportunity for disability support staff to prepare and support the person prior to and following a consultation. However, despite the setting, Li-Ve Tasmania conclude that when the disability support staff’s skill, expertise and knowledge of the person is utilised proactively, the consultations and outcomes are more positive and more likely to lead to improved health and well-being for the person with the cognitive disability.

Private hospitals response to supporting people with cognitive disability vary from site to site however some commonality exists where:

- the support solution is often to bring in a ‘sitter’ who has no knowledge or experience with the person and whose role it is to simply call the nursing staff (who also don’t know the person) if the person requires support
- they claim insurance issues prevent them from allowing disability support staff – the staff familiar with/to the participant – to ‘work’ within their hospital environment. This view has prevailed even when Li-Ve Tasmania has demonstrated its insurers will cover our employees in the acute setting
- Elective surgery can be ‘at risk’ of cancellation as protracted negotiations take place over support arrangements in respect of the persons disability
- a person with disability is likely to exhibit ‘challenging behaviour’ in the acute setting and the proposed solution is to transfer them to the public system if they ‘play up’. The obvious mitigation is to have staff support who are familiar with and to the person so that a proactive, person centred approach can be utilised, drawing on the strength of their knowledge and history with the person with disability.

[Question 8: What could prevent people with disability experiencing violence, abuse, neglect or exploitation in health care? What would make a person with cognitive disability feel safe when getting health care?](#)

The general principle for service enhancement here is one that focuses on person centred care. Ensuring that, where possible, people with cognitive disability will benefit from familiarity in unfamiliar/new environments (including procedures and unfamiliar clinicians). An approach that proactively considers the person, their involvement, their individual circumstances and need for support will always achieve a more positive experience for all concerned. Proactive funded planning is essential. To this end, it is essential to ensure people with disability can (if they want/need it) engage (pay) their staff who know them, and whom they trust to attend appointments to assist with translation, comprehension and retention of information which is critical for many people to feel 'safe'. 'Safe' that they are being treated with dignity, respect, can voice their questions/fears and can learn more about their rights, choices and opportunities for improved health care. In addition, this will allow for continuity within the persons chosen support network, ensuring that all staff have opportunity to receive and reinforce clear, concise messaging about health care and the person's choice/control.

Appendix B (attached) offers insight into the experiences from perspective of the parent of an adult person living with cognitive disability as they have interacted with the Tasmanian Health Service.

[Question 9: What would stop a person with cognitive disability reporting violence, abuse, neglect or exploitation in health care? What would make it easier for a person with cognitive disability to complain about violence, abuse, neglect or exploitation in health care?](#)

Many individuals with disability (and their staff and families) express concern with raising grievance, or wanting to query clinicians, systems and practices. Typically, this is related to feelings of anxiety and vulnerability that if they raise issues, they will receive less than adequate (or compromised) care. One parent of a person living with cognitive disability offered the following insight for us to include on this submission...

"we want justice and improvement but struggle to re-live the traumatic times through retelling the story and possibly upsetting institutions that still have our child in their hands".

Using the grievance process needs to be encouraged by staff. Examples of where learnings have been made following a complaint/report are an important tool, and the demonstration and consistent verbal reinforcement of a culture that welcomes and relies upon reporting and feedback from people about the care they receive to allow continuous improvement. For matters outside of business enhancement (i.e. matters constituting lawful intervention), the service outlet needs to clearly articulate what behaviours it does not tolerate/accept (violence, abuse, neglect, exploitation), what they may look like, who they may impact, why they are not acceptable and how people should report these. Similarly this information needs to be in clear, concise language, and supported by pictorial content.

Question 10: What else should we know?

In addition to the diverse and extensive practice-based wisdom in supporting people with cognitive disability, Li-Ve Tasmania is committed to improving the experiences and opportunities for this population (and those who support them) at end-of-life and when they are bereaved. In addition to maintaining services at an industry-leader level, Li-Ve Tasmania is highly committed to collaborating with like-minded sector leaders to achieve enhanced outcomes for people with disability at the end of life. It does this by:

- contributing its own practice-based wisdom to evidence-based research
- providing quality education to people living with disability (and those who support them) regarding the end of life and bereavement,
- developing evidence-based resources in end of life care for people with life-limiting illness and disability.

This suite of initiatives form the *Li-Ve Ability* program (APPENDIX C), dedicated to:

- recognition and value for the voice of lived experience - people with disability focus
- strengthening informal support networks - a families and carers focus
- building capacity and capability in our community - a disability and community sector focus.

In 2020, Li-Ve Tasmania enjoys a secure local and national profile as a leader in the field of disability and care at the end of life. It represents the voice of disability and shares its practice and evidence-based wisdom as a member of the Tasmania Bereavement Care Advisory Committee, Partners in Palliative Care Reference Group and specific disability and palliative care sector forums. In each of these opportunities, Li-Ve Tasmania is committed to working with mainstream healthcare services to enhance the experience of people with cognitive impairment and to reduce the incidence of violence, abuse, neglect or exploitation in health care.

Li-Ve Tasmania appreciates the opportunity to contribute to the Disability Royal Commission. It welcomes the opportunity to speak to the experiences of participants it supports and assist to achieve positive enhancement within health care for people with cognitive disability.

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APPENDIX A: TITLE (2017), Tasmanian NDIS-Health Advisory Group, 2017

APPENDIX B: Family reflection

APPENDIX C: Li-Ve Tasmania (2019) 'Li-Ve Ability' Paper