

Dear Ms Lewis

Thank you for the opportunity to provide feedback to the Disability Inclusion Bill 2023.

I was surprised not proactively approached by the Community and Disability Services Community Partnerships and Priorities Division to contribute feedback to the draft Bill. **My first suggestion is a proactive by your group to approach to leaders involved in mainstream services, as well as those leaders in disability, to invite them to contribute comments.** People are very busy everywhere and it is possible that they may have missed other notifications of the draft Bill and invitation for commentary.

As you are aware, my experience and skill is particularly in the mainstream health-disability interface. The barriers experienced by people with intellectual disability in accessing and participating in hospital level health care are very well described. These barriers contribute to the also well-documented higher than usual rates of preventable mortality and morbidity in hospital experienced by people with disability. These experiences result in even more disability and preventable earlier death. Better health care outcomes is one of the top priorities expressed by people with disability and their families. The draft Bill is relevant for potential obligations for mainstream health services for people with disability accessing their services. **Relevance of the draft Disability Inclusion Bill in relation to mainstream health services is the main focus of my commentary to you.**

As well, it is documented that health workers have sub optimal understanding of what it is like living with disability, of the importance of appreciating that disability in the delivery of their healthcare, of the importance of working with patients' disability supports and of the regulatory aspects of the disability sector and their interface with those in health. The Australian Commission on Safety and Quality in Health Care has more recently begun to acknowledge the necessity in development and implementation reasonable adjustments to its National Safety and Quality Health Service Standards, which aim to fundamentally address the barriers experienced by people with (intellectual) disability when seeking health care at the hospital level. In Tasmania, neither in public or private health systems is there any formal work on such reasonable adjustments. Having said that, at Calvary Lenah Valley Hospital the Director or Mission, the Quality and Safety Manager and I have started some preliminary work on the development of reasonable adjustments to usual care for our patients with intellectual disability. Calvary hospital has also adopted a Charter of Rights acknowledging the Code of Conduct of the NDIS as being applicable by health workers in their care of patients who are NDIS participants. There is no oversight of whether or not the code of conduct is adhered to and furthermore, it differs from the health code of conduct. As I read the draft bill, The Disability Inclusion Bill has relevance via potential legislation to ensure that mainstream hospitals have in place systems and processes to ensure that people with disability receive the same quality and safety of health care as their peers without disability. I can confidently inform you that mainstream hospitals have a long way to go before their access is truly inclusive for patients with intellectual disability. I expect that it will take years and years before anything happens. For example, in NSW, the

NSW Ombudsman reports on data about deaths among people with disability have reported the same unacceptably high numbers of preventable deaths and morbidity among this population across decades, despite identifying causes, and offering remedial actions. Health has such a long way to go in terms of understanding disability values and reasonable adjustments, attitudes, that educational access perhaps via the Disability Inclusion Advisory bodies must be considered. **Somewhere in the Disability Inclusion Bill, formal, spelled out, sustained mechanisms for supports, education, legislation requirements, feedback to enlighten those mainstream services in their obligations in service provision to people with intellectual disability need to be present, and a sensible timeline for achievement of these. Improving the disability awareness within the health sector will not occur “naturally”. Any such collaboration must, however, also include an inherent respect for and understanding of the way the health sector and its professionals work, and how they necessarily differ from paradigms within disability sector. To be effective the proposed Disability Inclusion Advisory body may require membership from mainstream services, and not only disability representatives.**

The draft Disability Inclusion Bill reads nicely and contains all the ethical values but in my view, in relation to its relevance to mainstream health, requires incorporation of an even stronger requirement for proof of inclusion policies are developed (e.g. by reasonable adjustments) and then implemented, and additionally, proof that such inclusion policies by presentation of data have improved health care outcomes for patients with intellectual disability using that mainstream health service. The Bill should also outline the assessment of compliance of “inclusion” and the prospect of penalty, and its nature, if certain inclusion policies are not made, are not effective, and are not undergoing continuous quality improvement. **The pragmatic measures of compliance with or breaches of the legislation need to be spelt out to mainstream services. .**

The draft Disability Inclusion Bill does not clearly state the scope of the mainstream health services to which it would apply. It would seem that the Tasmanian Health Service would be legally required to adhere to the Disability Inclusion legislation. What about its clout with respect to private **hospitals, community based or solo GP practices, private entity GP practices, allied health professionals, dentists?** Are they also required to adhere to the legislation?

The Disability Inclusion Bill should incorporate more formally an interface between disability advisory resources and the mainstream service. In terms of health, this would provide means by which to problem solve issues of interface e.g. operational aspects of restrictive practices in hospital settings versus in the community, principles of interface as outlined in the NDIS COAG agreement 2015. The principles of interface between those services funded by NDIS and those funded by health are outlined in the November 2015 document, but operationally they remain grey, confusing, inefficient to sort out, resulting in people with intellectual disability not receiving the disability supports they require in hospital settings. In some cases, patients with intellectual disability are offered “sitters”, who provide a similar service to baby sitting. Disability supports for individuals with disability to access and participate in the health care they need when they are sickest (i.e. in the hospital setting) are professional services provided by people whom the person with disability knows- they do

not require baby sitters. Funding of the demarcation of NDIS versus health sources for disability supports in hospital settings needs addressing by both mainstream health and NDIS bodies. Such resolution may vary from State to State. **Any future Tasmanian Disability Inclusion Act needs to incorporate mechanisms whereby mainstream services can liaise with disability services and problem solve such matters of funding demarcation, as well as roles and responsibilities of disability and health professionals.**

Many of the protocols and service set-ups in mainstream hospitals pose barriers for people with disability, or ones that are set up are not adequately funded. It should be acknowledged that provision of optimal health services for adults with intellectual disability may initially cost more. As examples, the organisation of outpatient services in internal medicine at Royal Hobart Hospital is not person centred, so that it is hard for any adult with intellectual disability with multiple medical problems to be seen at an outpatient clinic, with the goals of preventing acute flares of chronic illnesses. An excellent service provided by anaesthetists includes organised clinical sessions for patients with disability to have necessary multiple tests/treatments under the one anaesthetic because they are unable to tolerate them without sedation, or frequent anaesthesia. This excellent service receives no extra funding and staff who run this service have added these quality reasonable adjustments of their own bat, with considerable work stress as a result. This means the service is a risk of failure and at risk of failure when those keys interested individuals leave work. **The Disability Inclusion Bill needs to be more specific about (a) funding to mainstream services for development and application reasonable adjustments to those mainstream services, and (b) the NDIS-health demarcation of funding for, and roles and responsibilities of the disability supports required by people with intellectual disability to access and participate in the health care they need.**

Other Tasmanian legislation can at times create barriers for people with intellectual disability getting the best health care possible or be confusing in terms of the health-disability interface. These can effectively exclude people with intellectual disability from best practice health care. For example, provision of opioids for people with intellectual disability with severe acute pain and their administration by funded disability support workers is prohibited, in many circumstances, by the Poisons Act 1971. This would mean that while the health sector and professionals have completed their diligent role in assessment of management of health care for severe pain management, the disability sector is prohibited from supporting their client in this way, leading to unnecessary suffering by the person with intellectual disability. Regulation around use of restrictive practices is also a grey area when applicable for patients with disability in the hospital setting. The regulations around their use differ across disability and mainstream health sectors. **The draft Disability Inclusion Bill should be amended to contain a section where it commits to proactively address State legislative barriers, sectoral conflicts between disability/NDIS and the mainstream health service where such issues effectively work to exclude people with disability the best possible health treatment and management.**

I can be contacted for more contribution or further clarification on my submission. Thank you again for the opportunity to contribute some feedback.

Yours sincerely,

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