



## **Submission Regarding The Guardianship and Administration Amendment (Advance Care Directives) Bill 2020**

This submission was authorised by Leanne Groombridge on 16 October 2020. For further comment, please contact [ceo@yoursaytas.org](mailto:ceo@yoursaytas.org)

Advocacy Tasmania Inc. (AdvoTas) is an independent, client-directed service that provides support to people with disabilities, older persons, people living with mental illness, and people who use alcohol and other drugs. The matters raised in this submission are directly informed by the reported experiences of our clients with disabilities in relation to substitute decision making.

AdvoTas contributed to the Tasmanian Law Reform Institute (TLRI) inquiry into Tasmania's Guardianship Laws, and strongly supports the recommendations to modernise and align these laws within a comprehensive human rights framework. We regularly work with people who experience substitute decision making under the Guardianship and Administration Act (Act), and see the wide range of impacts this Act has on the rights, choice and control of our clients. We believe there is an urgency to reforming the entire Act, which is currently incompatible with fundamental decision-making and human rights of people in Tasmania, including both those with and without disability.

We are of the view that implementing some aspects in relation to Advance Care Directives (ACD) in isolation is likely to create unintended consequences within the Act. The potential consequences include deepening inequality between People with Disability and other people in Tasmania and inconsistencies between various provisions of the Act.

By way of background, the UN Convention on the Rights of Persons With Disability (UNCRPD) was signed up to by Australia in 2008, and fundamentally changed the focus from viewing People with Disability as objects of charity, protection and treatment to being people with rights; people who can enjoy those rights, and make decisions about their own lives, be active members of society and receive support to exercise those rights.

The Act does not currently reflect the approach of the UNCRPD and routinely overrides the rights, freedoms and choices of People with Disability in Tasmania. In our experience, the Act also does the same for people that have legal decision-making capacity, as a lack of this capacity is not required for involuntary orders under the Act. Our view is that the Bill also does not implement the UNCRPD and continues many of the issues our clients are experiencing under the current Act.

A fundamental issue with the Act that also relates to this Bill is the definition of disability. This definition leads to inconsistent interpretations of meaning and application. We regularly work with

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*Note 1: Case studies in this document have been anonymised, and therefore have some details changed to prevent identification and/or may be a combination of multiple clients' experiences.*

people who have decision-making capacity, who are nevertheless subject to substitute decision making under the Act. These issues are particularly salient when it comes to the Emergency Provisions under the Act, which have an incredibly low threshold, low bar of evidence, and lack of effective review process. We believe there is a substantial incompatibility between the proposed ACD provisions and Emergency Orders, as they are trying to achieve fundamentally different outcomes. Namely, to empower those with decision-making capacity to make decisions about the future, compared with trying to protect and act in the best interests of people who make ‘unreasonable’ decisions in the views of the medical profession.

Conversely, some of our clients have also expressed concerns to us that they are worried they may be unduly influenced to sign “do not resuscitate” orders, whereas other clients have expressed concerns that their capacity to make ACDs will not be respected.

Many of the issues with the Act and the Bill come down to the definition of disability used:

*“disability means any restriction or lack (resulting from any absence, loss or abnormality of mental, psychological, physiological or anatomical structure or function) of ability to perform an activity in a normal manner”*

This definition undermines the human rights of People with Disability as equal members of the community. Guardianship and Administration orders apply to the making of decisions, and therefore “*physiological or anatomical structure and function, and ability to perform an activity*” other than the activity of making of decisions, are not relevant considerations. In practice, this definition captures people that are fully capable of making decisions, but those decisions are not respected by others due to attitudes towards disability more generally. This is a fundamental issue that the TLRI recommendations more broadly were seeking to address.

Advance Care Directives, on the other hand, are definitionally made when a person does not have significant impairment in their decision-making capacity and therefore already expand the scope of the Act to apply to people who do not have disabilities of any form.

The current structure of the Act leads to abuses of the Guardianship and Administration Act whereby People with Disability who have no impairments in their decision-making capacity are put under orders, restricting their ability to make decisions about their own bodies and lives and denying them the autonomy and dignity of risk afforded to other Tasmanians.

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### **Case Study 1: Jennifer**

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*Jennifer has moderate mobility impairments associated with her condition, but no identified impairments in her mental or decision-making capacity. She sought advocacy support when, after a stay in hospital to recover from an injury resulting from a fall, she had been denied the right to discharge herself from the hospital to return home.*

*Jennifer reported that when she had requested to leave, she had been put off repeatedly by the hospital doctors, who said they would “organise things”. When she asked for her discharge papers, Jennifer was assigned a “sitter” by the hospital to ensure she did not leave.*

*Jennifer and her advocate were told Jennifer was under a “duty of care order”. The advocate sought urgent legal support for Jennifer, which determined that Jennifer was under no legal orders at that time and that she had the right to be discharged.*

*When Jennifer attempted to leave the hospital, accompanied by her advocate and under legal advice, hospital security was called, and Jennifer was threatened with a Code Black (physical and chemical restraint). Jennifer was unwilling to risk being physically and chemically restrained and elected to wait, at which point the hospital applied for an Emergency Guardianship Order.*

*Despite no previously identified impairments in Jennifer’s decision-making capacity, the low evidence bar for medical evidence for Emergency Guardianship Orders in Tasmania meant that the 28-day order was granted, and Jennifer was restricted from leaving the hospital.*

*Jennifer attempted to appeal the emergency order, but was unable to access the appropriate Supreme Court mechanisms to do so within the 28 days of the Emergency Guardianship Order.*

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In Jennifer’s case, an attitude was prevalent in which a person with disability of any sort was likely to fall under the scope of the Guardianship & Administration Act, and it was simply assumed that her physical disability meant she also had impaired decision-making capacity. Under the current framing of the Act, the Board had no obligation to investigate, assess, or require an appropriate external expert to assess, Jennifer’s decision-making capacity- either before making the Order, or once the Order was in effect.

We are deeply concerned that under the proposed amendment to s65, the Board would be given the power to override a person’s ACD, again with no obligation to undertake further investigation or review of the circumstances once the “reasons for urgency” had passed. In practice, we believe this would routinely lead to ACDs being overridden, as the wishes and preferences of those who may have decision-making capacity are under the current Act.

AdvoTas has observed disturbing trends in the current use of emergency orders, in how those orders are requested, what evidence is required for an order to be put in place, what powers are granted under those orders, and the accountability of guardians and administrators (including the Public Guardian and Public Trustee) in ensuring the will and preferences of persons under orders are fully considered and respected.

This trend also extends to standard and the requirements that a guardian/administrator must consult with the person and take into account their wishes are practically unenforceable. In our experience, the obligation for administrators to act to assist the person to become capable of self-administering is further functionally not being implemented by the Public Trustee.

The fundamental issue here is that the Act does not depend on decision-making capacity, whereas ACDs do. There will often be people who meet the requirements to make an ACD, while at the same time also meeting the requirements for full substitute decision making under the Act. We believe this inconsistency is likely to lead to fundamental harm for people subject to the Act, and that it can also be addressed by the full Act being urgently and fulsomely reviewed.

## Case Study 2: Andrew

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*Andrew has a number of medical conditions that restrict his mobility and frequently require him to attend hospital for treatment. Andrew has very high intellectual capacity and no impairments to his decision-making capacity; at age 21, he experienced a medical event requiring life-saving emergency treatment to be undertaken.*

*Prior to the event, Andrew had frequently communicated to his treating practitioners that, should he require life-saving emergency treatment, he wished to refuse treatment. His practitioners acknowledged Andrew's wishes and stated that they understood, but reminded him there was no legal protection for Advance Care Directives.*

*When the event occurred, Andrew was subjected to the life-saving measures he had specified he did not wish to receive. When asking afterwards why his wishes were not respected, Andrew states that he received a strong impression that medical staff did not respect his capacity to make decisions on the basis of his physical disability. Andrew states that because he uses a wheelchair, it is extremely frequent for people- including medical professionals- to assume he also has an intellectual disability.*

*Under the proposed amendment to s65, even if Andrew had a formal Advance Care Directive in place, it would be possible for the Board to order that Andrew receive life-saving measures due to the "reasons of urgency". Andrew has stated he is fearful that even with a formalised Advance Care Directive, he will again be subject to medical interventions he does not want to receive, on the basis that people will assume his disability automatically equates to an inability to make informed decisions.*

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Andrew's case highlights the currently existing issue wherein the framing of the Act around "disability" leads to assumptions that People with Disability do not have decision-making capacity. The extremely low bar of evidence, investigation, and review of emergency orders, as demonstrated in Jennifer's case, has created a disturbing trend of people with disability being placed under emergency orders where they have no decision-making impairments. The ability for emergency orders to override ACDs will therefore only deepen inequality for People with Disability in Tasmania unless the existing flaws with the Act, particularly around emergency orders, are addressed.

## Case Study 3: Jeremy

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*Jeremy lives with his parents, who provide 24/7 care. Jeremy's disability means that he requires support with many aspects of life, including mobility; Jeremy has complex communication needs but can express his will and preferences. His capacity to give informed consent to medical treatment is variable.*

*Jeremy was admitted to hospital for planned surgery and had a complex care plan which detailed how medical staff could communicate with Jeremy.*

*Jeremy's parents report that before the surgery, they were pressured to consent to Jeremy's surgical sterilisation as a "preventative measure". When Jeremy's parents asked what the sterilisation would prevent, they state that medical staff cited "testicular torsion" but could not articulate why Jeremy should have a significantly higher risk of this than any other person with a mobility impairment. At no point did medical staff attempt to communicate with Jeremy to allow him to express his will and preferences on the matter.*

*Jeremy was not under any Guardianship Order, as his parents retained parental responsibility at that time. However, sterilisation is specified as a Special Treatment under the Guardianship and Administration Act, for which parental responsibility is insufficient to legally grant consent- the matter must be brought to the Guardianship & Administration Board. There was no action at any time by medical staff to attempt to follow the current requirements of the Guardianship and Administration Act in this matter.*

*Jeremy and his parents expressed that they felt Jeremy's human rights were not respected by the hospital or its staff, either on an individual or a systemic level. They felt that staff had not regarded Jeremy as a real person with feelings and considered that his disability meant that automatically there was no need to involve him in medical consent decisions.*

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ACDs are fundamentally an issue of consent to medical treatment, which is a specific form of decision making. The proposed amendments specify how to determine a person's ability to make a decision in medical contexts, but there is no regulation of how the Board determines a person's ability to make decisions about other aspects of their life when making orders.

Definitions of "ability to consent" are heavily reliant on interpretation and therefore misuse, for example:

- What is "information relevant to the decision"? Who decides what is relevant and what is not? For example, it is common for individuals with lived experience of a particular medical treatment to consider some points of information highly relevant which are not routinely discussed by medical professionals providing advice.
- With the requirement to be able to retain information relevant to the decision, how long must it be retained? The amending Bill states that "*a [person] does not have impaired decision-making ability ... simply because ... the [person] can only retain information relevant to the decision for a limited time.*" For what period must a person be able to retain information to satisfy this requirement?
- Where a person is aged under 18, "sufficiently mature" is undefined and presents a major issue. People with Disability are commonly perceived as being "less mature" than they actually are – including through the problematic and harmful common practice of referring to people with intellectual disabilities as having a "mental age" different to their actual age (e.g. "He maybe 31, but he has a mental age of 10", wherein the person has an intellectual impairment, but obviously also has a lifetime of experiences and learning which a ten-year-old does not).
- Regarding the ability to "communicate the decision", to what extent is a practitioner obliged to facilitate a person's communication? For example, in Jeremy's case, medical practitioners did not facilitate his communication, and should have. What if his complex communication

plan had not been provided? He would still have the same ability to communicate, but practitioners would not know.

Many of these issues could be dealt with separately under a Consent to Medical Treatment Act, which has separately been recommended by the TLRI. While the current Act needs to be updated urgently to reduce the current human rights abuses People with Disability are being subjected to, particularly around medical care, we believe a Consent to Medical Treatment Act is a necessary future step in ensuring Tasmania meets its obligations under the UNCRPD for equal treatment of People with Disability.

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#### Case Study 4: Sadie

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*Sadie lived independently in the community with in-home support provided through a level 4 Home Care Package (HCP) until she had a fall and was admitted to hospital. An emergency Guardian and Administrator was appointed, and Sadie was moved to a Residential Aged Care Facility (RACF) on a permanent basis.*

*Sadie believed, at that time, she was only staying in residential care for a short period of time and so when she was asked by her HCP Case Manager if she wanted anything from home, she said no. Consequently, the Public Trustee arranged for Sadie's personal belongings to be sold or otherwise disposed of. With the support of an Advocate, Sadie eventually learned about the whereabouts of her personal belongings and was supported to lodge a complaint with the Public Trustee.*

*The Public Trustee responded they had difficulty verbally communicating via phone with Sadie about her situation, and emails show they took direction from her Case Manager and a hospital Social Worker, neither of whom had authority to make decisions on Sadie's behalf. Written correspondence between the Public Trustee and the Office of the Public Guardian demonstrates that both parties were aware of Sadie's belief that her stay in residential care was only temporary. Sadie did not receive written communication from the Public Trustee about their intention to relinquish her tenancy and sell her personal belongings, and so Sadie was left out of crucial decisions affecting her life. She feels if she had received a letter, she would have sought help sooner.*

*Contrary to requirements under the Guardianship and Administration Act 1995, Sadie feels her best interests were not taken into consideration by the Public Trustee as she is now left without an independent home and all her treasured items and personal belongings have been sold or disposed of. Sadie is furious that her rights were not respected, including her right to be fully informed, to be involved in decisions affecting her life, and to be treated with dignity and respect.*

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## Recommendations

### Recommendation 1:

*That the entire Act is urgently reviewed according to the TLRI recommendations, rather than Advanced Care Directives being implemented in isolation.*

### Recommendation 2:

*That the language of the entire Act, not just those sections pertaining to Advance Care Directives, be reframed away from “disability” to apply to all members of the community equally in accordance with the TLRI’s recommendations. Sections that are intended to apply only to people with impairments to their decision-making capacity should be framed in terms of decision-making capacity, not “disability”.*

### Recommendation 3:

*That valid ACDs are binding and are not able to be overridden for reasons of urgency or expediency, to prevent people’s decisions being routinely overridden in practice.*