

**Submission for *Our Healthcare Future (THS)*,
Inquiry into Disability Services in Tasmania (Legislative Council), and
*Inquiry into Rural Health Services in Tasmania (Legislative Council)***

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Dear Chairs of the *Our Healthcare Future*, *Inquiry into Disability Services in Tasmania*, and *Inquiry into Rural Health*,

Thank you very much again for the opportunity to contribute to your important works. I have been privileged to meet some of you before in a range of circumstances and present in person to a previous Legislative Council inquiry. My particular comments now and previously relate to ways to optimize healthcare for Tasmanian adults with intellectual disability, and I believe, are relevant for all three Inquiries.

Though my comments have previously been received courteously, at this point there is little in the way of practical change in disability (non-NDIS and NDIS) and health sectors and still a complete absence of interface between the sectors, which work to substantially reduce both the well-known preventable poor health outcomes experienced by adults with intellectual disability when they are unwell and the associated high preventable inefficiency in costs of disability support and health care. There are still all too frequent examples where Tasmanian adults with intellectual disability do not receive standard treatments for particular health conditions received by Tasmanians without intellectual disability either because they are not offered the treatment by health professionals/ systems and or they do not have adequate levels of disability supports required for them to participate in and access the required healthcare treatment. The end result is that adults with intellectual disability die unacceptably prematurely compared to their peers without disability and experience preventable suffering from inadequate healthcare treatments and or disability supports to help them obtain those treatments.

Our future healthcare in Tasmania must embrace means by which adults with intellectual disability of all ages, NDIS participant or not, city, regional or rural living, can have access to and participate in the best possible healthcare that is available to Tasmanians

without disability to extend their length of life as well as quality of life. Fundamentally, this means that both current provisions of disability supports and health services must undergo some adjustments. To define and design these alterations, disability support services, health services and people with lived experience of intellectual disability (people themselves with intellectual disability, their families and close friends) must work together. I am proposing:

establishment of a formal collaboration between Tasmanian disability (NDIS and non-NDIS funded) services, health services and people with lived experience of intellectual disability to oversee a progressive positive interface between health and disability services and professionals in relation to disability supports and healthcare for adults with intellectual disability of all ages and across all geographical regions with the tasks of:

1. the design and implementation of reasonable adjustments to mainstream health care access, delivery and quality assurance systems to ensure that adults with intellectual disability are offered and provided best possible treatments available to people without intellectual disability who have that same medical condition,

2. the design and implementation of specific person-centred disability supports plans for adults with intellectual disability to facilitate their access to and participation in primary, secondary and tertiary level healthcare, and clarification of the funding of those disability supports,

3. provision of evidence of effectiveness of collaboration in cross fertilization of health and disability sector and professionals' values, processes, policies, understanding, sharing, innovations, problem solving, showing ability to modify professional demarcations, contributing to a culture of continuous improvement in shared care for adults with intellectual disability,

4. for design and implementation of specific further adaptations to tasks 1 to 4 above so as to be applicable for adults with intellectual disability, disability and health services set up in city, regional, or rural areas of Tasmania,

5. provision of evidence of continuously improving of health outcomes among all Tasmanian adults with intellectual disability living in all geographical settings from city to remote and regardless of disability support funding model,

6. setting a time frame of 5 years by which the first cycle of design and implementation phases are completed, the first signs of positive Collaboration impact are being seen, and lessons to be learned are collated for the process of continuous improvement.

Achieving the outcomes requires the foresight of current planning for future improvement within health services and among health professionals especially doctors in understanding what it is like living with intellectual disability and it requires an acknowledgement by the disability sector that they do indeed have a responsibility and place to continue disability support for their clients when they are unwell in any healthcare setting or require disability supports for healthy living at home.

The suggested collaborative approach requires establishment of a dedicated formal process using a person-centred approach, having input from people with intellectual disability and their families, having input from public and private health senior representatives in active clinical life, having specific pragmatic consideration of the impact of geographical isolation from people who live in those areas, having consideration of the implications of being an NDIS participant or being outside of NDIS eligibility age limits on funding and resourcing disability supports, and having input representation from government and non-government disability sector professionals. The outcomes of this collaboration must satisfy adults with intellectual disability and their families, must comply with ethical and human rights

frameworks, both health and NDIS Quality and Safety Commission codes of conduct and quality standards, and Tasmanian state and national regulatory and legislative standards. In respecting contemporary disability values, outcomes of collaboration must work towards improved access to mainstream health services rather than designing a separate healthcare system and service for adults with intellectual disability. Importantly, the outcomes must work towards equalizing quality healthcare outcomes from our mainstream services for Tasmanian adults with intellectual disability wherever they live and whichever model of disability support funding they obtain with Tasmanian adults without intellectual disability.

More specifically, my proposal and comments are relevant for *Our Healthcare Future*. As a health professional I want to contribute to a better health profile of all Tasmanians – in healthy living, in recovering from acute illnesses, in managing chronic illness, in living high quality and long length lives. My skill is particularly for adults with intellectual disability and their health. The data on their relatively poor mortality and preventable morbidity rates compared to peers without disability are robust, the analyses of causes and proposals for reversal of such disparities are well documented. Any healthcare future planning cannot ignore these appalling statistics especially when “fixes” are known.

My proposals and comments are relevant to the *Inquiry into Disability Services in Tasmania*. Although the life expectancy of adults with intellectual disability is (preventably) lower than people without disability, there is still a significant number of older adults with intellectual disability who, because of their age, are not eligible for NDIS and so receive a specialized funded government disability support in a community home. Many of these Tasmanian adults lived in the era of Willow Court, are now experiencing serious health problems, very likely in part related to their experiences of institutionalization years ago. The NDIS and the NDIS Quality and Safeguards Commission have established wonderfully strong regulatory and legislative standards of codes of conduct in relation to disability

support and ideally these could be applied to any Tasmanian disability services for adults with intellectual disability who are not eligible for NDIS. Of concern is an observed trend in Tasmania for disability service providers of this group of older adults with intellectual disability transfer or push for transfer of these older adults with intellectual disability into aged care instead of disability service funded supports, in part because of increasing needs and illness. This means that once again these adults with intellectual disability are yet again removed from their familiar community based homes, set up in institutions where they are still relatively young, and where they are unknown and their story is unknown. By now their parents may no longer be alive to advocate and assert for proper care for their ageing adult children. This means that opportunities for their optimal healthcare is even further reduced. These are examples of relevant issues for the proposed Collaboration within this Inquiry.

My proposal is relevant to the *Inquiry into Rural Health*. Improving the healthcare of Tasmanian adults is important no matter where they live. Solutions to and strategies for improving the healthcare of rural Tasmanians must also, in a dedicated purposeful way, include “reasonable adjustments” for those improvements as they apply for adults with intellectual disability also living in rural areas. Improvements in how the rural health sector and professionals interact with other services in rural areas, and how they interact with services in larger city centres in relation to residents and patients in rural and remote areas must also include adaptations to cater for those adults with intellectual disability who also live there.

My submission, then is about proposing to Chairs of all 3 inquiries, that a priority space is set within each of their committees for addressing improving healthcare of Tasmanian adults with intellectual disability of all ages, in all geographical settings and in all disability support settings. I have plenty more to offer to each specific group if invited, and

plenty more to share from my own collaborations, studies, and work with valued disability and health colleagues from Tasmania and elsewhere.

My background in both disability and health I feel humbly gives me credentials to make this submission. I have had a lifelong lived experience in disability with friends and family with intellectual disability, have studied disability and health at postgraduate levels gaining a PhD, and more recently Masters in Disability Practice, Graduate Diploma in Neuroscience, have provided a specialized medical consultancy service to adults with intellectual disability for more than 20 years, the last 10 years in Hobart. I have lived or worked in city and rural areas in Tasmania and elsewhere. I have been a board member of a disability service provider, am a current teacher of medical students and contributor to physician trainee curricula on intellectual disability training, am a board member of Internal Medicine Society of Australia and New Zealand and the Guardianship and Administrative Board where my experience and or advocacy in healthcare of adults with intellectual disability is called upon; I am a member of two current innovative Tasmanian advisory groups in aspects of healthcare for adults with intellectual disability both of which address aspects of the health-disability interface and geographical issues (palliative care and primary health). I continuously learn from a wide network of professionals across the disability sector in Tasmania, nationally and internationally, am still actively publishing papers on health and intellectual disability, am in regular discussion with colleagues about how to develop reasonable adjustments to their usual quality healthcare for their adult patients with intellectual disability. Around 2016-7, I established and chaired an (unfunded) Tasmanian NDIS-Disability-Health Advisory group addressing the interface in the hospital setting producing a position paper, and chaired a working party on NDIS for the Royal Australasian College of Physicians.

Thank you again for initiating these Inquiries, and for the opportunity to contribute to your important and valuable work for the Tasmanian community.

Yours sincerely

Robyn Wallace