



Health Consumers Tasmania

Building a Consumers Health Voice in Tasmania

Ms Anita Dow MP (Chair)

House of Assembly Select Committee on reproductive, maternal and paediatric health services in Tasmania

Dear Ms Dow,

Health Consumers Tasmania welcomes the opportunity to provide a submission into the House of Assembly Select Committee on reproductive, maternal and paediatric health services in Tasmania.

Health Consumers Tasmania's submission is premised around quotes from everyday Tasmanians which we find is a more powerful way of ensuring Tasmanian voices are heard in these forums and enquires. It also includes the contributions from the Tasmanian Birth Trauma Peer Support Group which Health Consumers Tasmania facilitates, some members of which have also chosen to make their own submissions. We thank them for their incredible contribution to this work.

We welcome the opportunity to discuss these issues with you and your Select Committee in person.

Yours sincerely,

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1 Health Consumers Tasmania

Health Consumers Tasmania (HCT) draws on the lived experiences of Tasmanian health consumers and broader feedback from the Tasmanian community and not-for-profit sector.

The content for our response to the terms of reference comes from a number of sources:

- Tasmanian Birth Trauma Peer Support Group
- Consultations with patients, carers and community workers
- Online survey regarding Tasmanians key health priorities (July 2023)
- Kitchen table discussions with health consumers – over 86 kitchen tables have been undertaken involving more than 490 consumers in group discussions or one on one interviews
- Specific research into:
 - Cost of living pressures impact on health
 - GP access in rural and remote areas including the Central Highlands; and Dover, Geeveston and the far South
 - After-hours access
 - Consumer perspectives on Virtual Healthcare

Health Consumers Tasmania (HCT)

HCT is a Company Limited by Guarantee, funded by the Tasmanian and Commonwealth governments (Department of Health and Primary Health Tasmania respectively) and reporting to an independent board. HCT has established a community of interest of over 800 people and has been formally involved in over 15 partnerships or national/state-wide health related committees to-date.

HCT has been formed to provide health consumer advocacy, which it does in a number of key ways:

- Facilitating consumer engagement by placing health consumers on committees and workshops to inform government decision-making in service delivery design, program and systems reviews and evaluations
- Collecting community views and using this evidence to advocate for a health system that better meets the needs of Tasmanians
- Providing training to health consumers on how to engage with the health system, and to health staff on how to engage with individual consumers or community groups
- Facilitating community-led placed based solutions to local healthcare services with a number of regional and remote communities

Health Consumers Tasmania is not an industry or union-based body and therefore does not represent the commercial interests of any one group or body. Rather, HCT is a facilitator for Tasmanian health consumers to express their views into the health system, and the views of the community more broadly.

2.0 Consumer Perspectives

The six key points this submission raises are that women and parents need:

1. Better access to services, especially in rural Tasmania
2. Continuity of care
3. More affordable access to care
4. To be listened to, have their concerns heard, and their experience respected
5. To exercise their right for autonomy and be an active partner in decision-making
6. More and better choices for models of care and service providers that relate to their specific needs.

These key themes are based on a summary of a wide range of consumer perspectives and are broadly relevant to the topics of reproductive, maternal and paediatric services. However, specific issues relating to one or more topics have also been raised.

Due to the wide range of topics within the scope of this Select Committee, HCT recommends that consumers with relevant lived experience should be engaged further when the Select Committee considers drafting recommendations from this enquiry.

Any quotes included in this submission were collected from consultations and surveys with communities about health care access across Tasmania between 2020 and 2023 and from members of HCT's coordinated Birth Trauma Peer Support group.

1. Women and parents have trouble accessing the services they need in pregnancy and for their children, especially if they live in rural areas.

Antenatal care and delivery:

While all Tasmanians are eligible to receive free antenatal care, women and birthing people living in rural and regional areas across Tasmania cannot access adequate local maternity and birthing options. People in rural communities, including the Huon Valley, Scottsdale, East Coast, Tasman Peninsula, and Ulverstone have all expressed that increased access to midwifery, birth, antenatal care was a key priority:

"[When asked what their priority for services is] Local birth centre. I do not want to have to drive to Hobart for birth and all my midwife appointments ... Also, in the case of an emergency what are we meant to do? You can't get in to see the doctor with less than two weeks notice. It seems Cygnet used to have a birth centre, and they had local doctors and nurses who could help people in the community. Everything is getting more centralized now and it's harder to access in rural areas.", Huon Valley

“I have found it hard to get appointments for standard stuff, so I sometimes put them off. I couldn’t get the care that I needed during my pregnancy [locally], so I had to drive to Hobart services.”, Far South

Not having access to local support is particularly stressful for women in labour and when they are planning for their labour:

“Don’t close down essential hospitals e.g. Latrobe – just to meet state budget requirements. This will help avoid stress for people like my pregnant daughter who was in labour – who had to go to Burnie from Kimberley (80kms) – then was told she was too soon – and told to go home. She rushed off to Launceston and she gave birth straight away. [It was] very stressful.”, Ulverstone

“Also, we need ambulance access when giving birth – My last baby came in 30mins! I was pushing in the car driving to the hospital! Access is about travel time, preparation, thinking about what happens if you don’t make it to the hospital.”, Huon Valley

After-hours services:

While not a child-specific service, many people who seek care after-hours, do so for their children. In fact, many consumers say that they would wait for care if it was for themselves, however, when they are pregnant or seeking care for a child they will not delay care. Therefore, adequate after-hours care is a particular priority for parents of young children:

“We need healthcare services locally that bulk bill or have a minimal fee for after-hours care especially for concession card holders. The main one would be doctors or midwife services to eliminate the need to go to A&E without costing you an arm and a leg. Having a doctor that can come to you without a large delay would be great for young families. I think there should be more in person care offered to postnatal (midwife, doctor physio, in home help etc).”, Launceston

As young children are high users of after-hours and urgent care and have different needs to adults, people suggested having facilities which cater for children and families:

“[When asked for a solution to after-hours access] A GP clinic that is open 24 hours and has the ability to do basic xrays and ultrasounds and is designed to cater for children with high needs, for example a sensory room and quiet spaces.”, Launceston

“We need an A&E for children.”, Launceston

Specialists:

Access to paediatricians and other specialists is particularly poor across the state. Time and time again, we hear from consumers who cannot access paediatricians and other specialists.

Wait times for outpatients through the publicly-funded systems can be abysmal and for those parents who can afford to go private the situation is not much better:

“Private paediatricians have shut their books in Tasmania. There is a 3 year wait at the RHH for a paediatrician. I have absolutely nowhere in Tasmania to get my son assessed for ADHD/Autism, even though his school teacher has requested it. I might have to go to Melbourne (which we can’t afford).”, Hobart

“I can’t access a child psychologist, there needs to be funding in this area. There also needs to be Autism funded programs. I’m waiting 4-7 months to get into a child counselling service...We need Speech Pathologist availability for children that have issues as well as those that are borderline having issues, it is always prioritized for those that have major issues and those that have minor problems get left by the wayside.”, Ulverstone

“We need more availability of children's mental health [services]. My boy needed to see one after witnessing his brother choking and turning blue, it affected his ability to eat because he was so scared, and it took 11 months to get him to see someone and in that time he lost a heap of weight because we couldn’t get him to see anyone sooner.”, Ulverstone

“There’s no paediatrician and a lack of experience and information with complex problems. We need everything above a general practitioner. It’s hard to even access that. You just put up with it because that’s your only option. When your doctor is on holiday or sick you can’t get the support you need.”, Huon Valley

Child-specific services:

Good child-specific services are very well valued, especially in the initial time after birth. People with young children often express the desire for increased services that visit in the home.

“In the early days of bringing your newborn child home from hospital, the most crucial service was the “Extended Midwife Service” that runs out of the Mersey. This service is a game changer, especially for a first-time mum. My 2 children were born privately in Launceston, however, the service is automatically booked in when you are discharged from hospital, to align with the NW Coast service. To have an experienced midwife come to your house whenever you need in the first couple of weeks is amazing, especially as you don’t even have to go in the car (or have got out of your nightie) to get their help and advice. Awesome service, beautiful caring nurses that just love caring for mums and bubs.”, Ulverstone

However, some women and parents struggle to access family health services they need (eg. CHaPS) and other postnatal care that meet their needs. Once again, this is even more pronounced for people who live in rural and regional area of Tasmania.

“My main concern is Family health. This is not fully covered adequately in Bicheno at the current time. I had issues during my pregnancy which meant that I had to seek appointments elsewhere. There is a current baby boom in Bicheno which means that there is a need for midwife support locally. Ongoing care of children is

important – especially for blood tests, etc. Family and child health and mental health care are all important. I suffered from Post-natal depression, at a time when there were no appointments available for six weeks with psychologists. The currently situation has improved, but there are only monthly visits from psychologists.”, East Coast

“[We need] More availability of CHAPS nurses and appointments, they feel so rushed and with limited days available right now it’s difficult to fit them into your schedule when you have young children.”, Ulverstone

“[We need] More GP’s and Child Health nurses, or a change of structure like quick book-in or drop-in clinics on a certain day of the week where maybe trainee doctors get a whole day paediatric experience checking out children 0-5 years in the morning and 6-12 years in the afternoon, just for 5-10 minute appointments, or a service like this at the Doctors clinics or Child Health Clinics or a nominated Pharmacy.”, Ulverstone

“We need child and maternal care. There is no one representing Breastfeeding Tasmania locally. Another woman to speak to talk through issues was really helpful. More support is important. One child health nurse services vast area. The service is not useful. It’s good to see you for first 6 months but after that you are on your own. CHaPS is important in connecting relevant services particularly for new mums unfamiliar with services and needs. We need access for women in rural communities above and beyond GPs. Someone who is all about babies and mums not just general medical issues.”, East Coast

Coordination of services:

Women and parents want to experience timely, co-ordinated and integrated service provision for themselves and their young children across the primary care sector (incl. GPs) as well as child- and maternity-specific services. The lack of coordination causes significant frustration and leads to delayed access to healthcare when consumers have to wade through service after service or are bounced between referrals, having to retell their story over and over again.

The lack of integration between sectors also affects people’s ability to know about, be referred to, and access services they are eligible for:

“Two years postpartum I am still getting a formal diagnosis for my pelvic floor injury. This was due to not knowing where free services were because of the disconnect between hospital care and outpatient services and the lack of coordination with other specialised services. Lack of knowledge from GPs on what birth trauma is and how to refer and really just a basic lack of trust in health system to help me.”

Recommendation 1 – All levels of government to work in collaboration with consumers across Tasmania to design and implement local reproductive, maternal and child health services, which meets consumer needs and are accessible to all Tasmanians regardless of their locality.

2. Women and parents in Tasmania want continuity of care from their healthcare services, but do not always receive it.

Many parents struggle with having continuity of care in primary care for their children, as many practices rely on locums, or they cannot access a regular GP practice. Coupled with limited record sharing, this means parents have to retell their “story” time and time again, which can lead to irregularity in treatment and delays in receiving appropriate care. Consumers who have sought services as a result of a traumatic event or who have experienced birth trauma, have conveyed that this can be particularly damaging.

Continuity of care is recognised nationally as essential for optimal birthing outcomes for women¹, however in Tasmania women struggled to receive continuity of care when they are pregnant:

“I found it [continuity of care] was problematic when I was pregnant as well. It’s recognised that across the country and across the world that having continuity of care improved outcomes, like having the same midwife, or GP throughout your pregnancy. But in Tasmania... I asked for that, it was an option you could ask for, but they were just like, too bad, we don’t have enough staff. You will just see a different person every time and just have to explain everything again every single time. It was really frustrating, to give an example I had really, really low iron which is a problem I have in general, but it was exacerbated in pregnancy and I kept asking for an iron infusion because it’s something I have had in the past and they always said, we’ll talk about this next time. We’ll see if it is worse. But then the next time would be a different person and they would say the exact same thing. And I was like, but you said this last time and so I never got any help, I was just tired the whole time.”, Hobart

Recommendation 2 - State and Federal governments establish industry wide formal healthcare protocols in conjunction with consumers to ensure women, children and families are able to receive continuity of care across and within services and sectors, as it is known to result in better health outcomes and consumer satisfaction.

3. Women and parents have trouble affording care for themselves and for their children:

While antenatal care is free for Tasmanians, many primary care and other additional services are not. Out-of-pocket costs for private specialists can be very high and the number of bulk-billing GPs is declining, even for young children. In addition, people have to pay for parking fees for appointments (especially for outpatient appointments) as well as the cost of travel and accommodation, which affects rural families in particular.

“I need to go to Hobart for many of these [services for special needs child] including podiatrist for my child, varying specialist such as ENT in the past and learning support. On top of this I am on a single parent income and am not able to claim any rebate on these appointments, you have to cover travel costs, all because we don’t have many services down here. People with multiple children or multiple health issues travel many times to Hobart for short tests, or just Sorell if you’re lucky.”, Tasman

Mothers and children who have complex conditions, poor mental health or adverse events from childbirth find themselves having to pay for many aspects of care, as their needs are not always met by free services.

In addition, treatments and medications can be very expensive. We know that the affordability of healthcare is declining with the growing cost-of-living crisis, which is causing more and more families to struggle to budget for unexpected costs associated with ill-health.

“My daughter woke with a rash in February... \$80 at the chemist to buy panadol, antihistamine, creams etc then it cost me \$120 out of pocket to see her GP (I did receive the partial rebate but still had to have the \$120 there...) So, it cost me \$200 in the space of two hours for a kid with a viral rash.... there are so many mothers out there who cannot pay this. Just because you don't have a healthcare card doesn't mean this is affordable.”

Reproductive services are also not always affordable or accessible:

“I have had to wait 3 months for a contraception change and then to have them changed over again I must wait a further 3 months. Whilst trialling these I also have to pay exuberant amounts of money, just to prevent for falling pregnant. This should be a free service.”, Ulverstone

Recommendation 3 - Women, children and families should be able to afford the healthcare that they need without experiencing significant hardship – a review of existing financial support mechanism available is necessary to stop this group falling behind.

4. It is imperative that women and parents feel listened to and respected by health professionals. Women in particular experience biases based on being female (or non-male), which affects their treatment, their care outcomes and their trust in services.

Women often experience not being believed, or not taken seriously about their health complaints. They tell us of having their pain dismissed in childbirth as well as with other reproductive concerns, for example pelvic pain and endometriosis. This leads to unnecessary suffering, prolonged diagnoses as well as poor outcomes in labour. One of the leading causes of trauma associated with birth is the

feeling of not being listened to (coupled with lack of control)². The disregard of mother's rights and loss of autonomy can lead to obstetric violence.

"As women the health system seems to believe that we have no knowledge or idea about what is best for our own bodies and baby. I was often ignored and labelled as moody or difficult when I sought advice and assistance with my post-partum care."

"The anaesthetist was only called back because I was dissociated and stopped pushing or responding to anyone, not because of my pleas. My words didn't matter....I felt profound despair that my partner and the people caring for me wouldn't address my pleas and that no help was possible. Then, suddenly, the message changed and pain relief and intervention became possible when [the obstetrician] advised that we were going to theatre. That decision wasn't made because of my begging, but rather because they felt I'd been pushing for too long. My wishes had no place in any part of the process."

Parents, especially mothers, feel like they have to justify bringing their young children in to seek help for urgent and emergency care. Sometimes, they feel like their decision about whether or not to seek help rests on whether or not they have enough proof to be able to be believed:

"And again, it's happened to me so many times, you know, I have my second born, when and when I took her and she was only about four months old, the same kind of situation where I felt like I was being judged. Because she's a very energetic child, she was happily chatting along to everyone, even though she hadn't eaten anything drunk anything for two days. And the young doctor that was there was sort of like, you know, you can tell you're a very caring mother, but you could sort of hear in the undertones tones that he thought I was exaggerating. Yeah, so I think what I'm trying to say here is when I'm considering whether or not I'm going to be believed, because I feel like I'm not. It took for a doctor, a second opinion, because I asked for one, to measure her blood sugars that were dangerously low for them to admit us. And for me, I just feel like it shouldn't have had to come to that. For me it's like: what proof do I have that my child is sick? What proof do I have that I'm sick?," Hobart

Women should be listened to and respected as experts of their own lived experience and of their children's experience. This acknowledgement of expertise underpins shared decision-making. If women's experiences are not heard, trust is lost.

"I had a Doctor ask me why I would want to Xray my young child when he was unable to bear weight. I convinced the doctor and it was broken. On another occasion I went to the emergency room the doctor was an asshole. I told him my children had some needs and don't feel pain and they doubted me, and I have lost all faith in the Hospital.," Launceston

"[I want to be able to] See a GP when we need to and be heard and responded to when we approach the GP. Twice I have had to convince medical services that

illnesses are serious enough to get attention. Children's health issues are serious and require a dedicated response and not to be fobbed off. Twice I have had to rush to hospital because I left it too long. I shouldn't need to feel that my issues are not important by my doctor. I need to get confidence that the medical service providers that I have access to respect me and respond to my needs.", East Coast

Women also feel the same about their own health concerns, which can lead to tragic outcomes:

"With regard to myself, sometimes things have been very serious but I told myself I was just being dramatic and so I didn't seek help. I should have sought help. My first baby might not have been stillborn if I had. I think women are often told they are being dramatic or are just too sensitive, so they don't seek emergency help for themselves when they really should.", Hobart

Recommendation 4 – The government should co-design strategies and protocols with consumers and healthcare staff to ensure women are listened to and not subjected to gendered bias when seeking help for themselves or their children. Consumer complaints of being dismissed, bullied and belittled should not be ignored. Developing better tools for staff and consumers to understand healthcare rights and complaints processes is imperative to meaningful change.

5. Women and parents should be able to exercise their rights for autonomy in healthcare settings, however they are not always able to:

Health ethics and policy state that consumers have the right to being an active partner in their care, to be a part of informed decision-making and to give consent to any procedure or interventions (Reference?). However, this is not always a reality in practice in many different health settings:

"[When asked about health service priorities] We need GP's that are non-judgemental of people that may seek alternative solutions to healthcare. I have been shamed and bullied about some of the well-informed decisions I have made for my children. This has resulted in the avoidance of using the local GP service and either not seeking medical help, or having to travel to the city. We need a space where we feel supported, assisted and respected, not judged.", Tasman

Standard hospital procedures and routine interventions may be developed due to evidence of best practice as well as to ensure consistency and safety of care, however the implementation of these must be balanced with patient autonomy. Feeling a lack of control is a one of the two primary cause of birth trauma (coupled with not being listened to)². Women can lose autonomy over their own care and for many 'routine procedures', consent can become an afterthought. During labour, giving true informed consent is difficult, and this is exacerbated by the lack of continuity of care throughout pregnancy.

“The institutionalism of birthing is loaded with so many gendered biases. In my experience I was treated like a vessel carrying a baby that needed to be successfully delivered regardless of my physical and mental wellbeing. I had so many procedures done to me, rather than decided with me, that I experienced severe physiological and emotional birth trauma. I was bullied and coerced into making decisions DURING labour that there really was no informed consent. When someone says NO once it is NO. This included vaginal examinations, augmentation, so many blood tests that both my arms were bloody and bruised. I didn’t even recognise myself afterwards.”

Recommendation 5 – The government to develop more robust mechanisms to check and review consumer complaints about being denied partnership in their own care and work with consumers to identify priorities and solutions to enable services to uphold women’s and parent’s autonomy in healthcare decisions.

6. Women and birthing people want to have choice in their service provider, however this is not always possible because of lack of providers or affordability:

In Tasmania, many/most pregnant women and people do not have a choice of who provides their service. Most receive care through their most local public hospital and are streamed into a service model. Some women may have some choice when it comes to models of care, but this can be limited depending on health and predisposing factors and place of residence. Most women and birthing people do not get to have any choice over the midwives or other health professionals involved in their care.

Many women want to be able to choose a homebirth and/or antenatal care provided in the home. This option is limited for many women due to the cost as well as the shortage of homebirth midwives:

“[I would like to see] Government subsidised Midwifery, for people who do not want to travel to the city, who may not be able to travel to the city for regular check-ups (heavily pregnant and car travel is an uncomfortable experience) or for those that are choosing homebirth. There have been and continue to be families struggling to pay the thousands of dollars to homebirth with a private midwife.

Homebirth is a safe option and is especially comforting for women in rural communities to know that they will be ready and supported to give birth in their homes (whether they have planned to or not).”, Tasman Peninsula

“I would love to homebirth, but cannot afford around five grand for homebirth midwives.”, Huon Valley

Compared to other States, especially metropolitan areas, a lack of choice also means that people are forced to use a particular service provider, even if they have had a negative experience with them in the past. If women have had a traumatic birth in that particular hospital or with a particular health professional, this affects their ability to receive subsequent care and even affects their decision to have more children.

Recommendation 6 – That women and birthing people have the opportunity to access person-centred care by being able to choose a service provider and/or model that meets their needs. Consumers must be involved in developing service model options.

Recommendation 7 – Telehealth criteria needs to be revised to allow women and birthing people to access a different service provider or GP without being required to have a face-to-face consult in the first instance when it relates to birthing.

3.0 Involving Consumers in Solutions

Perhaps most importantly, is for this Select Committee to ensure that any recommendations and consequent solutions are informed by consumers. Genuine consumer engagement is imperative to develop solutions to address the issues with reproductive, maternal and paediatric services in Tasmania.

Not doing this risk not only developing solutions that do not meet the needs of consumers, but also, in some cases might further harm consumers who have had negative experiences in health care. This is particularly important for women and children who have had traumatic experiences with health care and birth.

An example of a mistake which was made through not involving consumers in Tasmania, is that a group of women who had experienced birth trauma in a facility were offered counselling, but needed to access by contacting and being assessed through the same facility/personnel which caused the trauma.

Supporting consumers with relevant lived-experience to be involved in decision-making for proposed solutions will enable them to contribute their expertise for good decision-making at all levels of planning. Care must be taken to ensure that the way of engaging consumers is appropriate, supportive and trauma-informed (where appropriate).

Recommendation 8 – This Select Committee workshop any proposed recommendations it drafts with the HCT facilitated Tasmanian Birth Trauma Peer Support Group prior to finalisation and publication.

References:

1. COAG Health Council as represented by the Department of Health (2019) Woman-centred care: Strategic directions for Australian maternity services.
2. Hollander, M. H., van Hastenberg, E., van Dillen, J., van Pampus, M. G., de Miranda, E., & Stramrood, C. A. I. (2017). Preventing traumatic childbirth experiences: 2192 women's perceptions and views. *Archives of women's mental health*, 20(4), 515–523.
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