Standing Committee on Health and Community Wellbeing
ACT Legislative Assembly
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HCCA Submission:

Inquiry into Raising Children in the ACT

Thank you for the opportunity to contribute to the Inquiry into Raising Children in the ACT.

HCCA is aware of significant and growing challenges families experience accessing health care for their children in the ACT. This applies to all types of health care for both acute and chronic conditions.

Accessing specialised or complex care interstate is a known issue for ACT families and the risks and pressures of this are only beginning to be addressed. In addition, there are other emerging challenges to accessing timely and affordable care (including primary care), which need to be recognised and responded to.

ACT families have a right to access the health care their children need when they need it.

There is also significant scope to improve the support available to parents with disability or illness. The ACT must move past a reliance on child removal and instead look for consumer centred solutions to specific challenges. We can and must do better.

Yours sincerely,

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HealthCare Consumers

SUBMISSION

Inquiry into Raising Children in the ACT

April 2024

About HCCA

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a Health Promotion Charity registered with the Australian Charities and Not-for-Profits Commission.

HCCA's approach to this submission

HCCA is a member-based organisation and we draw on the views and experiences of our membership and networks to advocate for consumers of health care (all of us!).

In preparing our response to this Inquiry we have drawn on the knowledge and experiences of our members and community. We received feedback on access to, and experience of, health services supporting children and their families in the Canberra region.

The priority for consumers is safe, high-quality health care that is accessible in a timely way and integrates diagnosis, treatment and support for ACT children and their families.

Consumer feedback has been collated and contextualised here to address the Inquiry's Terms of Reference below. We have responded in depth to Terms of Reference F and G due to their specific relevance to health care:

> F) Availability of health services including access to paediatric specialists and screening; and
>
> G) Support and advice for prospective parents with a disability and/or significant health issues.

We did not receive feedback relating to Term of Reference H) Fertility issues and the accessibility of affordable fertility treatments and so have not addressed it in this instance despite its specific relevance to health care access.

Specific Comments addressing the Inquiry's Terms of Reference

F) Availability of health services including access to paediatric specialists and screening

Access to suitable and timely health care is an ongoing and significant issue for ACT families. There are challenges in access to both primary and specialist care including important diagnostic services from which medical and non-medical support may flow (including access to appropriate interventions and supports in schools, or NDIS funding for therapy and supports).

With long delays and difficulties in accessing medical services, including general practice, primary care and specialists, there is a need to ensure that parents have more access to services like the Walk-in Centres for their children. There is also a need to prioritise specialist services through community health centres, rather than hospital-based outpatient clinics, which have very long waiting lists and often cannot see children.

Access to primary care

There is a need for better medical primary care models in the ACT where patients can access GP services without co-payments and have access to more collocated and integrated primary care services provided by nurses, psychologists, physiotherapists, pharmacists and social care services etc. The existing Aboriginal Community Controlled Health Organisation model used by Winnunga Nimmityjah is an example of this model.

The Walk-In Centres or Urgent Care Clinics can provide some of these services, however, they do not provide continuity of care for patients with chronic conditions, which often require on-going and integrated health care across a range of professional disciplines.

Accessing support for both acute and chronic health issues is a challenge in the ACT. HCCA urges consideration of innovative models of care to meet families' needs for health care in a more timely and integrated way.

Families tell us about their challenges navigating limited services, lengthy wait times, weighing up the benefits, challenges and costs of seeking care privately or seeking care interstate.

Consumers have responded positively to the expansion of services offered by WiCs (such as medical imaging available at Weston Creek) and to the potential for further expansion of this model of care under the Commonwealth's Urgent Care Clinic funding. Consumers were encouraged by the potential for improving multidisciplinary team care, hoping that this could help reduce pressure on limited primary and acute care services, and improve consumer access to some health services without out-of-pocket costs, at a time when cost of living increases have been significant.

Canberra Health Services' document *Consultation: Expansion of the Walk-in Centres to include Urgent Care Clinics,* noted that:

> "Assessment against the guidance material issued by the Commonwealth on UCC [Urgent Care Clinics] indicates the current WiC model meets 95% of potential scope of UCCs. What is currently not provided in the WiCs is:
>
> - Whole of life age span – WiCs currently see over 1 year old's
> - IV antibiotics and fluids
> - Advanced Life Support
> - Point of Care pathology testing.
>
> In discussions with the Commonwealth, it has been agreed that these items are not required in the ACT context, given the proximity to emergency departments, and the desire to ensure WiCs do not extend their treatment times, subsequently resulting in increased waiting times."

While HCCA is supportive of ensuring reasonable waiting times for people accessing WiC services, we are concerned that this limits the utility of WiC's for young families who are otherwise forced into untenable waits in the Emergency Department.

Accessing specialist services

We hear from consumers all the time about the difficulties accessing specialist paediatric clinical services. Many specialised services are not available in the ACT and those that are often have substantial waiting lists that can impact on the quality of life of children waiting. In addition, treatments can be time sensitive. Sometimes optimal treatments are not viable if the wait to commence is too long, risking worse long-term health outcomes.

This issue becomes more frustrating for families when they are prevented from accessing interstate care due to nominal availability in the ACT, which does not exist in practice. Families need greater transparency around available services and waiting lists and the ACT needs to be more proactive in setting up alternative avenues for patients to access care when it is oversubscribed or made unavailable due to changes in staffing.

One consumer told us:

> *'We needed to see an orthopaedic specialist for scoliosis. We got a run around of referrals of Sydney specialists to see in Sydney or maybe in Canberra. It ended up being practically impossible to see someone in the public system in Canberra – in the middle of the year we were told there were no appointments that year and that appointments would not yet be taken for the following year, and to call back in the new year. For a condition where timing is imperative for treatment, we had to look into private specialists after also being turned away from public services in Sydney due to apparent availability of services in Canberra. It is very frustrating when you cannot access the care that you need'.*

HCCA notes that guidance in *Healthpathways* on scoliosis has not been tailored to the local region so it is of limited assistance to GPs in figuring out who/where to refer patients to. This is true for a range of conditions and contributes to waits to identify and access the right service for a child needing non-routine care. When the pathways for care vary widely by condition, this sort of resource is vital.

Consumers complain that they are not provided appropriate estimates of waits, how to escalate concerns over a triage decision, or alternative pathways to care which may be timelier – for example accessing care interstate, be it in a capital region town or travelling to Sydney.

Some waiting times are extreme as this consumer reflects:

> *I know someone whose child is waiting for paediatric gastroenterology, is listed at Category 1, and has been waiting for more than 12 months for an initial appointment in the public system. It seems very concerning that patients in the most urgent*

> *category are unable to be seen in the ACT, and not informed about wait times or alternate pathways?*

This is not an acceptable situation and transparency with consumers and collaboration and candour with interstate services is required.

Support for families accessing health care

In 2020, HCCA published the *Consumer and Family Experiences and Expectations of Accessing Interstate Specialist Care: The Kids Interstate Shared Care Project*[1], this report set out the challenging experiences of families of very unwell children managing inter-jurisdictional health care and disruptive and expensive travel.

Some recommendations from this report have been implemented and are already having a positive impact on the experiences of families accessing care interstate. The Paediatric Liaison and Navigation Service (PLaNS) has been developed through a rigorous co-design process and is providing navigational support to families. So far, feedback on PLaNS has been positive, however the service has been impacted by staff attrition and is reaching capacity. HCCA would like to see this valuable service appropriately resourced to meet the scale of need and staffed in a way which prioritises optimal continuity of care for families.

Consumers have commented that they have been pleased to see the beginnings of a truly collaborative approach with Sydney Children's Hospitals. And continuity of staffing in the PLaNS team will contribute further to building relationships and improving communication and collaboration between health services. As Canberra Health Service staff become more aware of PLaNS' functions, these established lines of communication can be leveraged to impact positively on the care of all children accessing care interstate.

Not all consumers recognise that there may be benefits, in terms of safety and quality, in the development of a deliberate and conscious shared care arrangement for those children and adolescents needing complex care. That said, HCCA understands that some specialist services cannot be appropriately delivered in a small jurisdiction like the ACT. While shared care may be the expedient solution to ACT residents accessing care for rare or complex conditions, this does not negate the risks inherent in this approach.

HCCA believes that the ACT Government needs to be more intentional in the way this model is structured and provide better support to patients who need to access health care this way. Where the ACT is unable to offer timely or appropriately specialised services through hospitals or community services, families should receive maximal assistance to access interstate services in a timely and integrated way.

The *Child and Adolescent Clinical Services Plan*, launched last year, focuses on clinical care. HCCA believes there would be benefit from also addressing some key non-clinical components which impact on the consumer experience of clinical care. This is particularly important where some aspects of the Plan commit to approaches which can have other, non-clinical impacts on patients and their families or guardians.

The Plan reflects analysis that the most appropriate structure is the formalisation of the use of interstate specialists rather than recruitment of specialists and development of models of care locally. While HCCA accepts the rationale for this approach, and supports the approach in principle, we would like to see greater consideration of the impacts of this approach on families. There needs to be mitigation of the financial and social pressures experienced as a result of travel to access the health care a child needs.

To this end, we would like to see the Plan include measures to support the cost and time burden of this travel on families. While IPTAS[2] goes some way to addressing this, consumers feel it does not offer sufficient support. Families are required to cover costs up front and this is not feasible for everyone. In addition, the subsidy available does not cover all expenses and it does not recognise the specific needs of families in this situation (who may need to travel with other children, for example). Consumers also tell us that the administrative burden of IPTAS is significant and onerous for families under acute stress.

There are no other appropriate subsidies or housing arrangements to support families who are unable to access the care they need in the ACT. It is not appropriate to rely on the Ronald MacDonald House Charities to provide this support. Their services are valued and important, however capacity is an issue and charitable generosity is not a solution when the need extends from a deliberate government policy approach. These families have a right to accesses appropriate health care and should not be placed under undue financial pressure in doing so.

We urge the implementation of all recommendations of HCCA's *Consumer and Family Experiences and Expectations of Accessing Interstate Specialist Care: The Kids Interstate Shared Care Project.*

Screening, diagnostic and support services for neurodevelopmental conditions

Another area of concern for ACT families is access to screening and diagnostic services for neurodevelopmental concerns. Families are aware that early diagnosis provides access to early intervention and additional supports which can be protective of mental health and reduce severity of distress in children and their families.

The long delays and substantial costs associated with obtaining a diagnosis place significant strain on children and families seeking support to manage the symptoms of neurodevelopmental conditions which negatively impact their daily life.

Consumers shared that:

> *Even the children getting diagnosed, it is happening when they're 10/11/12. It is not happening earlier. Once they realise they need it, it is years until it actually happens.*
>
> *You've got families who are literally having to make a decision. Well, who gets diagnosed first? Who can we afford? Who needs to prove it to the people who have to accommodate their needs most?*

While the *Child and Adolescent Clinical Services Plan* addresses some of these issues, consumers provided suggestions for how the ACT may be able to provide timely, best practice care for children and adolescents with neurodevelopmental needs. We would like to see an integrated model where diagnosis and intervention are provided seamlessly.

> *We need a diagnostic and intervention centre.*

Consumers have commented that they would like to see this care occur in community settings.

> *There is a screaming cry from consumers for paediatric, community-based services.*

Some consumers feel there has been a deterioration in early intervention services since the disbandment of Early Intervention Preschools, which were disbanded upon commencement of the NDIS. Consumers expressed concern that a reduction in community based early interventions has compounded the issues around delays in accessing diagnostic services.

The ACT needs a holistic approach to neurodevelopmental services. These services must encompass mild/moderate presentations as well as acute/complex presentations and connect with education and disability support services.

Neurodevelopmental services should have strong connections with Mental Health services so that the specific needs of neurodivergent children can be met.

Families find the interplay of (public and private) health services and the NDIS difficult to navigate and suggest it contributes to a negative disconnect between diagnosis and support.

Families shared some of their experiences accessing services for their neurodivergent children. This consumer was advised to bypass the public system:

> *I have three [neurodivergent] children, and I have not been able to access public health paediatric specialists for any of them. I have been told by our paediatrician that the waitlist for autism/adhd assessment is 2 years and if you can afford to go private it's 3-6mo wait (or less). She also said that the public health specialists in this area tend to see the higher needs end of the spectrum (more like ASD3 with co-*

> *morbid conditions) so the lower to middle end of the spectrum like ASD1/ASD2 with ADHD will, in comparison to their regular patients, come across as needing no support. So, she basically said if you go on the public list you run the risk of waiting for a very long time only to get a less nuanced assessment that doesn't help access supports.*

This consumer found there were no public supports available to her son:

> *After [my son] was able to access the NDIS – the only option presented to me for OT, Psychology etc was private NDIS providers. It's like the NDIS basically by-passes any ACT based public or community programs.*

There are some services which consumers feel are meeting their needs but which are not well integrated into wider support structures. This family reflects on the federal EACH program[3] and the failure to integrate this into local supports as children age out of it:

> *The only Government service we have had success in using in a timely and helpful way is EACH, the NDIS partner for children under 9yo in this region. This is federal but they have proper timelines and budget to assess and see kids quickly to get them access to the NDIS Early Childhood Approach. Under 6yo do not have to have a diagnosis to be able to access supports and funding. After 9yo when you transition … it's an absolute disaster.*

Even when specialist neurodevelopmental public health services are available in the ACT they are unable to meet the scale of community need and provide suboptimal care as a result. This leads families to paying substantial costs to access safer and more timely care privately.

> *Due to my son's sensory needs related to autism – he is unable to access dental work in the 'dentist chair'. So we were advised by private dentist to access the ACT Health public dental service to go on the waitlist to have work done under anaesthetic in the public system as at that point his needs were not urgent and could wait 6-9mo. So, we accessed the public dental system and needed to have 2-3 appointments to get the proper assessment of his teeth done. Which was very difficult for him and annoying to take time off school etc as they just give you the appointment time they don't give you options. Then they told us the waitlist for dental work under anaesthetic was about 18mo. Basically the plan was to keep seeing him every 6 weeks (at an appointment time of their choosing) to wait until the problems got worse and he could be triaged up the ladder to more urgent to get in quicker. So basically, their idea was to wait until my child had dental abscesses and was in extreme pain until he could have work done. Needless to say, we went private – Paid $2500 and got in within 3 weeks to have all the work done at Calvary John*

> *James.*

HCCA explores in detail the issues impacting people with ADHD specifically in our submission to the Senate Inquiry into Assessment and Support Services for People with ADHD available here: Submission: Senate Inquiry into Assessment and Support Services for People with ADHD - HCCA[4]

While the stories shared here are specific to neurodevelopmental conditions, these sorts of stories are told across the health sector with families struggling to access necessary services in an affordable and timely way.

G) Support and advice for prospective parents with a disability and/or significant health issues

Parents with disability and significant illnesses face stigma in relation to accessing services to support themselves and their children. There are few health and other services (like Housing) in the ACT which truly understand and enact reasonable accommodation principles, which enable parents and children with disability to participate in our community. Even public schools are often inaccessible for disabled parents and children. As one consumer told us:

> *There is a child in my son's class that is now in a wheelchair. She can't access the classroom and they have to swap classes around to allow her to get to class. But what if there were other kids who also had mobility challenges, what if their parents do?*

The NDIS, while designed to supplement community-based assistance is not working as originally designed. In fact, many families now have no access to community based disability services, which have been replaced by private providers charging on a fee for service basis.

In addition, we hear from our members that these families can be subject to discriminatory treatment by services like Child Protection. There is a sense that the ACT still routinely removes children from parents with disabilities at birth, without sufficient efforts to address alternatives that may enable families to stay together, and without attempting to put in place targeted supports appropriate for their circumstances.

One of the Actions from the ACT Disability Strategy is 'Supporting parents with disability to access services and to care for their children'[5]. We see this as essential to improve the situation for parents with disabilities. The priority needs to be development of effective family supports rather than the current reliance on child removal. The evidence shows that the removal of children from their families at the scale which occur in the ACT results in significant long-term harm to children, parents and the community[6]. Removal from family must be a last resort option, with much more appropriate wraparound assistance for families with children.

Discrimination against children with parents with disability is not addressed in the *Child and Adolescent Clinical Services Plan*. We received feedback that the Plan should include an individual advocacy approach for people with disability to act as a safeguard for children in families where parents have disability.

This would complement the role of the child & family centres in Community Services Directorate and measures in the Disability Health Strategy[7], with the aim of supporting these children and families as early as possible.

Consumers say they want more proactive intervention to set up supports in advance. When health or disability impediments to pregnancy, birth or parenting are identified, appropriate support structures need to be planned or put in place as soon as practicable. There needs to be health and disability service recognitions of risk factors and a collaborative approach taken to supports and risk mitigations. Currently consumers feel they have to figure this out independently.

As one consumer recommended:

> *Get supports in place early. Research how your health issues and disability may be affected by pregnancy – i.e. people with autoimmune conditions can have symptoms be exacerbated by pregnancy hormones. People with depression and anxiety or other mental health conditions can be adversely affected by pregnancy hormones. Check what medications you can and can't take in pregnancy and how this might affect your health condition.*

Midwifery continuity of care can make a significant impact here. Women receiving care under a continuity midwifery model of care have time to collaboratively identify challenges and work through interventions and accommodations. This clinician/consumer relationship has potential to set mothers with illnesses or disability up with the support necessary for birth and early parenting. Full commitment to implementing the Maternity in Focus[8] Plan will assist with ensuring this level of patient centred support is available when it is needed.

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[1] Health Care Consumers' Association. (2024). *Kids Interstate Shared Care Project.* https://www.hcca.org.au/wp-content/uploads/2022/06/HCCA-KIP-Project-Final-Report-ACT-Govt-Logo-and-Appendix-B-1.pdf

[2] Canberra Health Services. (2024). *Interstate Patient Travel Assistance Scheme.* https://www.canberrahealthservices.act.gov.au/__data/assets/pdf_file/0007/1985479/ACT-Interstate-Patient-Travel-Assistance-Scheme-Assessment-Guidelines.pdf

[3] https://www.each.com.au/

[4] Submission: Senate Inquiry into Assessment and Support Services for People with ADHD - HCCA

[5] ACT Disability Strategy 2024–2033 and First Action Plan

[6] Australian Institute of Family Studies. (20??). *Parental Disability and Threat of Child Removal*. https://aifs.gov.au/research/family-matters/no-51/parental-disability-and-threat-child-removal

[7] ACT Health. (2023). *Disability Health Strategy*. https://www.act.gov.au/directorates-and-agencies/act-health/strategies,-programs-and-reports/strategies-and-plans/act-disability-health-strategy

[8] ACT Health. (2022). Maternity in Focus. https://www.act.gov.au/directorates-and-agencies/act-health/strategies,-programs-and-reports/strategies-and-plans/maternity-in-focus