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STANDING COMMITTEE ON HEALTH AND COMMUNITY WELLBEING
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Submission Cover Sheet

Review of ACT health programs for children and young people

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HealthCare Consumers

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Review of ACT health programs for children and young people

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Health Care Consumers' Association

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Background

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.

In 2020 HCCA undertook a research project on behalf of the ACT Government, looking at the experiences and expectations of children and their family members in accessing interstate specialist care and identifying areas of success or failure within the system. Twelve families and four representatives from organisations as well as staff at the Canberra Hospital were interviewed as part of the Kids Interstate Shared Care Project. This submission draws on this research and the resulting final report.

You can access the full report online, either on the HCCA website or the ACT Health website:

- HCCA Website: https://www.hcca.org.au/wp-content/uploads/2020/11/HCCA-KIP-Project-Final-Report-ACT-Govt-Logo-and-Appendix-B-1.pdf
- ACT Health Website: https://cms.health.act.gov.au/about-our-health-system/planning-future/territory-wide-health-services/new-plan-childrens-health.

If you have any questions or wish to discuss our submission further, please do not hesitate to contact us.

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1. General comments

HCCA welcomes the opportunity to provide input into the "Review of ACT Health programs for children and young people." This submission will predominantly deal with issues relevant under 1a, 1c and 1d of the Committee's terms of reference. The 1d component particularly focuses on the issues arising for families having to seek interstate treatment for their children due to the limited number of paediatric specialists in the ACT. This submission will concentrate on the existing state of health care for children with long term or life limiting conditions who live in the ACT and who have had to access treatment interstate.

Canberra Hospital, the main campus of Canberra Health Services(CHS), is the largest regional teaching hospital in South East NSW and the Australian Capital Territory[1]. However, it remains a relatively small hospital, in terms of patient throughput compared to hospitals in Sydney and Melbourne. As a result, in some areas, and for some conditions, the number of people in the population needing specific services can be too small to support a subspecialty. This is especially the case for paediatric specialist care. Any examination of services provided in Canberra needs to take into consideration that even if some, or all, of the treatment can be provided in the ACT, often initial diagnoses and regular monitoring appointments still require care interstate. We see the key issues for health care consumers, in relation to children and young people in this situation, to be:

- Care coordination;
- Diagnosis challenges;
- Access to local paediatric therapeutic equipment and services; and
- Care navigation.

All public health services and private hospitals in the ACT are required to meet the National Quality and Safety Health Service (NQSHS) Standards to operate. NQSHS Standard 2, Partnering with Consumers[2], requires health services to demonstrate the action they are taking to understand and respond to the health literacy circumstances of their patients and communities. The findings from the Kids Interstate Shared Care Project demonstrate an urgent need for action by all health services in the ACT to improve their responsiveness to the care requirements and the health literacy circumstances of children and families who need care interstate - particularly in the areas of communication, information and system navigation.

HCCA's Kids Interstate Shared Care Project report goes into more detail around these areas of concern and the key issues listed above. The ACT Government, as part of their 2020 re-election commitments, has committed to implementing the recommendations from this report. We look forward to seeing the work in this area progress.

2. Care coordination

Care coordination and particularly communication between care providers across state lines is a huge challenge for families. In many cases ensuring high quality care for their children relies on families manually transporting hard copies of their child's scans, treatment records and other information between care facilities. These poor communication processes create gaps in the child's treatment history that are a massive problem for patient safety. They result in treating physicians not having a complete an accurate record of a child's condition which, particularly in emergency situations, can be life threatening. This gap also results in a lack of appropriately transferred acute care plans, palliative care plans and other vital alerts needed for appropriate treatment. Consumers highlighted a number of instances where this lack of care information resulted in inappropriate emergency care when the child presented at Canberra Hospital with acute symptoms.

> *"When we'd take her to emergency, that was our only option, to take her to emergency, they couldn't even put us in a private room. She was sitting next to a kid with gastro... And I'd have to get there, and I'd just have to fight and fight for everything. I said, 'She can't sit in emergency. She has brain cancer.'" – Consumer Participant HCCA Kids Interstate Shared Care Project*[3]

In one of the cases a child suffered a life-threatening event, but the emergency department did not have the appropriate information of file and were unaware of the specifics of the condition so refused to admit them. In this case it required the parents contacting the specialist in Sydney and them contacting the registrar at Canberra Hospital to tell them to admit the child. These sorts of delays are unacceptable in any life-threatening circumstances and they are completely avoidable. Even in cases where the parents are proactive in trying to coordinate a Canberra based interdisciplinary team with the Sydney treating team to help manage things like post-operative recovery, they have been singularly unsuccessful because the child is not considered to be a current patient at Canberra. This makes it incredibly difficult to maintain a child's continuity of care in shared care situations or to ensure that a child who has complex post-operative needs can have the post-operative care provided as close to home as possible.

This communication breakdown also affects the transition of care between child/adolescent specialist care and adult care:

> *"If you are a teenager, who is seeking to move to an adult neurologist in Canberra, the doctors will probably have not had contact with Sydney Kids Hospital. Sydney Kids Hospital will help as much as possible but the experience of patients is that the information does not seem to make it to the ACT doctors." – Stakeholder Participant HCCA Kids Interstate Shared Care Project*[4]

Handovers and transitions of care within an institution are already fraught with technical and communication issues that can compromise patient safety[5], this is especially so between in and outpatient services[6]. These challenges are only complicated further when trying to manage this across institution and state boundaries. These communication breakdowns are not specific to the ACT alone, however consumers highlighted that it is the transition between out-of-territory care and care back home in the ACT that is particularly difficult. It is important to be aware that these communication break downs can have severe health implications, in some cases delaying necessary treatments and/or follow ups.

> *"… the sleep study wanted the tonsils and adenoids out, and I told the ENT doctor that and they said, no, we do the sleep study first. And I said, well, no, that's not my understanding. And as a result of that, my sleep study for my son got cancelled and so did the surgery because they were both waiting on each other to do their thing first." – Consumer Participant HCCA Kids Interstate Shared Care Project*[7]

3. Diagnosis challenges

GPs, who should be central to the coordination of a child's care in Canberra, were notably absent from the experiences of the people interviewed for the project. Where they did feature it was usually in a negative light as a barrier to diagnosis. They were noted for not listening to the parent's concerns or ordering diagnostic tests that were incorrect e.g. a blood test for paediatric brain cancer.

> *"We were following up with doctors for about six months before she got diagnosed. We saw the GP several times. We saw the home doctor several times, just because she'd vomit, and we would say it's not a tummy bug because none of us have it... At six months beforehand, she started having severe behavioural changes... so I went to the GP and I said this isn't right. She's lashing out at her little brother, who was only probably nine months then. The GP put it down to she's upset because you've had a new baby." – Consumer Participant HCCA Kids Interstate Shared Care Project*

GPs are an important part of a child's care however they must listen to families' concerns. Parents and families know their children best and are in a better position to notice subtle signs that would indicate that a child's condition is changing or unusual. This is particularly true for young children who may not have the capacity to clearly articulate what is happening. GPs need to be appropriately trained in consumer-centred care to ensure that they listen to the parents, children and families, as well as being aware of and using the appropriate referral pathways for children in the ACT.

Parents also reported that children in Canberra are often seen by adult specialists when there are no paediatric specialists in that area. In some cases this worked; however in others the delay in seeing a paediatric specialist resulted in long delays in diagnosis. It is important to ensure that if an adult specialist is unable to help that the child be given the appropriate interstate paediatric specialist referrals in a timely fashion.

4. Access to local paediatric therapeutic services and equipment

There are limited paediatric physiotherapy options in the ACT. Children with rare conditions who need specialised facilities or support e.g. hydrotherapy pool access, often struggle to get appropriate and affordable access to these services. Children who need post-operative physiotherapy either end up going to Sydney, or they must use a local private paediatric physiotherapist, which can be expensive.

There is the potential for the auxiliary health services to support children with neuromuscular conditions through the University of Canberra Hospital, however at present referrals must be done specifically through Canberra Hospital, even though they are both CHS services. For children who receive diagnosis as well as the majority of their treatment through specialists in Sydney, this can make accessing rehabilitative therapies in Canberra difficult.

Parents also reported issues when trying to access specialist therapeutic equipment. Some families needed specialist accessibility equipment which was not available in paediatric sizes. Others were prescribed equipment in NSW (due to the specialist care being provided there) and were then unable to access the appropriate equipment through the ACT system.

> *"… it was a sleep doctor in Sydney that prescribed it, but because we didn't live in New South Wales they couldn't give us one, so we had to hire one for $750 a month until the ACT Government could put through their process to get us the machine funded. That took several months to get that." – Consumer Participant HCCA Kids Interstate Shared Care Project*

5. Health care navigation

While improving care coordination will go a long way towards improving the experiences of children and their families, navigating the health care system in the ACT also presents a challenge for consumers. This is especially the case for families with a child who has a complex or life-limiting condition. Some of the larger hospitals in Sydney appear to have dedicated staff to liaise and co-ordinate care within the NSW system, but the Canberra arrangements appear more ad hoc and the communication links between the two systems, as mentioned previously, are often poor.

> *"I would have loved for there to be someone who was like a key worker who just monitored us and helped us to liaise with everyone that was appropriate because half the time I didn't know. 'Should I ring the Sydney Children's Hospital social worker? Should I ring the Canberra Hospital social worker? Should we be having counselling, should we not be having counselling? What*

> *financial assistance can we get?'" – Consumer Participant HCCA Kids Interstate Shared Care Project*[8]

This kind of support is especially important in times of crisis or emergency when families may not have the emotional or mental capacity to navigate unnecessary barriers.

Patient Navigator programs are designed to help remove barriers that prevent a smooth transition between hospital(s) and the community[9], but they can also provide support in navigating the complexities within the health care system. Establishing dedicated support staff in the ACT that can act as a central point of contact for consumers as well as help them navigate the complexities of shared care arrangements, will go a long way in improving the experiences of the children and their families as well as improving the safety and quality of their care. Patient navigators can also help build the capacity of families in developing their own health literacy and coordinating information flow between care facilities.

6. Concluding remarks

This submission only briefly touches on a few of the key issues highlighted within The Kids Interstate Shared Care Project Final Report[10]. To give the Committee a better idea about the breadth of the work contained within the report we have included the report's recommendations for action below. These recommendations were informed by consultation with consumers, their families, advocacy and support organisations, as well as health care staff from CHS, specifically in Canberra Hospital.

Kids Interstate Shared Care Project Recommendations for Action

A. *Care Coordination*

1. Establish an ACT Paediatric Nurse Liaison Service.
2. Introduce Patient and Family Navigators.
3. Establish processes to ensure continuity of care across hospital services.
4. Improve access to integrated multidisciplinary team rehabilitation and disability related services.

B. *Information*

5. Develop and introduce an information pack and diary for parents including an online resource.
6. Provide access to diagnostic imaging for interstate specialists.

C. *Improving hospital and health care experiences for children and their families*

7. Improve acute incident processes.
8. Upskill local paediatric staff.

9. Establish paediatric outpatient nursing role.
10. Implement holistic approaches to care.
11. Rethink the role of GPs in shared care arrangements.
12. Train paediatric and ED staff on the importance of family centred care.
13. Review the model of care in paediatric palliative care and the role of the paediatric palliative care nurse.

D. *Supporting the family and the child beyond immediate care*

14. Improve current ACT Interstate Patient Travel Assistance Scheme.
15. Explore options to make more lower-cost accommodation near shared care hospitals available or to increase the IPTAS subsidy to a level reflective of the real costs.
16. Enhance the range of support services for families.
17. Improve support for schooling.

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[1] https://health.act.gov.au/hospitals-and-health-centres/canberra-hospital

[2] See the Australian Commission on Safety and Quality in Health Care NSQHS page on the *Partnering with Consumers Standard*: https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard

[3] Health Care Consumers' Association. (2020). Consumer and Family Experiences and Expectations of Accessing Interstate Specialist Care: The Kids Interstate Shared Care Project, Final Report. https://www.hcca.org.au/wp-content/uploads/2020/11/HCCA-KIP-Project-Final-Report-ACT-Govt-Logo-and-Appendix-B-1.pdf

[4] Health Care Consumers' Association (see note 3)

[5] Segall, N., Bonifacio, A.S., Schroeder, R.A., Barbeito, A., Rogers, D., Thornlow, D.K., Emery, J., Kellum, S., Wright, M.C. and Mark, J.B. (2012). Can we make postoperative patient handovers safer? A systematic review of the literature. *Anesthesia and analgesia*, 115(1), 102.

[6] Snow, V., Beck, D., Budnitz, T., Miller, D.C., Potter, J., Wears, R.L., Weiss, K.B. and Williams, M.V. (2009). Transitions of care consensus policy statement American college of physicians-society of general internal medicine-society of hospital medicine-American geriatrics society-American college of emergency physicians-society of academic emergency medicine. *Journal of general internal medicine*, 24(8), 971-976.

[7] Health Care Consumers' Association (see note 3)

[8] Health Care Consumers' Association (see note 3)

[9] Health Care Consumers' Association. (2018). A model for patient navigation in the ACT for people with chronic and complex conditions. https://www.parliament.act.gov.au/__data/assets/pdf_file/0011/1438895/A-model-for-patient-navigation-in-the-ACT-for-people-with-chronic-and-complex-conditions,-dated-7-September-2018-Prepared-by-the-Health-Care-Consumers-Association.PDF

[10] Health Care Consumers' Association (see note 3)