New South Wales

Special Commission of Inquiry into Healthcare Funding

Submission Number: 167

Name: Paediatric Urinary Incontinence Services, Children's Hospital Westmead

Date Received: 15/11/2023

the children's hospital at Westmead

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30th October 2023

Dr Gayathri Raman
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[redacted]

Mr Richard Beasley SC
Commisioner of the Inquiry
Special Commision of Inquiry into healthcare funding
NSW Health

Dear Commissioner,

Re: Current issues for Paediatric Urinary Incontinence Services

Thank you for the opportunity to address some of the issues facing the care of children with continence problems in NSW and some suggestions on how to improve management of these children. I am a member of the Medical Staff Council at Children's Hospital Westmead. I will first address the need for more multi-disciplinary continence services, and then specifically address the lack of paediatric pelvic and continence physiotherapy.

Issue 1: Statewide lack of public multi-disciplinary urinary incontinence clinics

I am a Paediatric Nephrologist and General Paediatrician and I manage the multi-disciplinary Bladder Clinic at the Children's Hospital Westmead. I run 2 clinic sessions a week and as part of the clinic, we have a Continence Nurse, a physiotherapist specialising in continence and a psychologist. We accept children with bedwetting from age 7 and above, any child with daytime urinary incontinence and developmentally delayed children who have the capacity

to toilet train. I would like to point out that there is no public multi disciplinary clinic service for constipation/bowel only incontinence at Children's Hospital Westmead and this is also a significant area of need.

Urinary incontinence is associated with recurrent urinary tract infections (2), stigmatization (3), depression (4) and lower quality of life (5), persisting in 0.5 to 2% of untreated adults (6).
Despite the strict criteria for referral to my clinic, the waitlist for this clinic is 18 months to 2 years. This is longer than the national wait times averaging 226 to 399 days. (1) As I am aware, this clinic is the only public multi-disciplinary continence service within NSW and I receive referrals from across the state. I even receive referrals from Sydney Children's Hospital as there is no multi-disciplinary service at that site. If any of the clinicians on the team take leave, especially myself or the physiotherapist, it is often difficult to find cover and this contributes to a long waiting list. The paediatric pelvic and continence physiotherapist in my clinic is planning to retire and I am struggling to recruit and train a replacement. This will significantly impact on service provision and waitlist times.

Many of these children are initially seen by primary care physicians and can be treated successfully. However, there is a need for more community-based continence providers so children can receive treatment whilst waiting on our waitlist or can avoid being referred to tertiary continence services. **There is also a need for more public multi-disciplinary clinics across the state.** Efforts should be made to upskill community-based providers and primary care physicians to treat simple continence issues in the community.

A relatively new innovation is the use of e-Health. An avatar based program called e-ADVICE has been trialed in the community to provide support to children waiting on a waitlist for an appointment with a tertiary continence clinic, with involvement of their primary health providers. A randomised controlled trial was performed to assess the effectiveness of this intervention. This study, which is awaiting publication, showed that e-ADVICE doubled the proportion of children who were dry at 6 months and improved their quality of life, whilst they awaited an appointment at a tertiary continence clinic.

Incorporation of this program in the community can reduce the need for review in the tertiary continence services and the number of visits within the clinic. Another benefit is indirect education of primary care physicians so they can feel more able to manage these children in the communities.

Other strategies include increasing educational opportunities for current providers in the community and support to increase the number of public multi-disciplinary continence clinics. **Sydney Children's Hospital in particular MUST have a multi-disciplinary service**.

Issue 2: Lack of paediatric pelvic and continence physiotherapists to support both urinary and bowel incontinence.

The paediatric pelvic and continence physiotherapist is an integral part of continence management. The physiotherapist can assist with evaluating and improving postural and body awareness for optimal voiding and defaecation, normalise pelvic/pelvic floor muscle

capabilities, teach relaxed voiding techniques and retrain muscle patterns to improve coordination for bladder/bowel emptying. The physiotherapist can also educate and train the child and family in using neuromodulation to treat bladder/bowel function including TENS for overactive bladder symptoms and interferential therapy for slow transit constipation.

Assessment and treatment for these conditions is specialised extended scope of practice which requires post-graduate training and mentoring. This includes the use of real time ultrasound, innovative and novel use of therapy and treatment options based on a sound and advanced level of understanding of child development, anatomy and physiology (particularly muscle structure and function), and a robust understanding of the existing evidence base and how to extrapolate that to the complex paediatric population.
Access to physiotherapy at CHW, in all caseloads, is via a specialist referral only.
Currently there is only 1 public paediatric continence physiotherapist in NSW and she also works across palliative care and the acute respiratory service. She is planning to retire soon, and we are struggling to train a replacement, both due to lack of staff and funding for training. There is no regular cover to support these patients when she is on leave, and she often returns to an increased workload.

Current physiotherapy funding and protected time exists for bladder (nephrology) patients:

- 9 hours/week to attend 2 x clinics. There is up to a 2 year wait list to get into MDT clinic, with only limited options for triage and advice ahead of clinic review.
- Very limited outpatient follow-up for patients once seen in clinic

There is **no specific funding or protected time for children with other pelvic conditions or bowel problems**, however these caseloads require the same level of expertise and confidence in order to treat successfully. These children are complex and have usually failed standard medical interventions and have had hospital admissions for management. These referrals come directly to physiotherapy from predominantly colorectal surgeons, but also from rehabilitation physicians, gastroenterology, gynaecology, urology and general paediatricians. On average, there are 20-30 complex referrals per year for this service.

With no dedicated funding or time available, these patients are managed ad hoc, usually to the detriment of other funded caseloads. The current goal is for these patients to receive their initial physiotherapy review within 3-4 months, however this is suboptimal clinical management and timing, demonstrated through repeat admissions and increased medical interventions for these children. This caseload requires access to timely, expert MDT involvement alongside the relevant referrers.

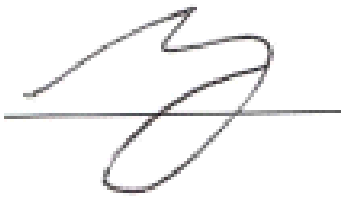
The physiotherapist working in these caseloads needs to have sufficient time available to upskill and mentor other health professionals to assess, monitor and treat these conditions, and to reserve time to treat the complex cases presenting to the tertiary MDT clinic. At the moment- we only

Recommendations:

1) Additional funding (8 hours/week) for an expert level 4 physiotherapist at CHW to provide above services in a tertiary evidence-based multidisciplinary setting.
This service needs to be sustainable and safe, allowing for increasing complexity with novel medical interventions, and increasing population numbers.
2) Funding to train other paediatric continence physiotherapists, especially at Sydney Children's Hospital and John Hunter Children's Hospital.

Please contact me if you need more information or want to discuss this further.

Kind Regards,



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