



## **INITIAL REPORT: Transgender and non-binary young people and their families - A qualitative investigation of experiences of clinical care**

Professor Damien W Riggs and Dr Clare Bartholomaeus, Flinders University, South Australia, and Professor Annie Pullen Sansfaçon, University of Montréal, Canada

### **Background**

Internationally, an increasing number of young people are disclosing that they are transgender or have a non-binary gender, and are presenting to gender services (Telfer et al., 2015). This diverse population of children, when compared to their cisgender (i.e., non transgender) peers, report higher rates of negative life experiences, often due to discrimination (Clark et al., 2014; Jones & Hillier, 2013; Strauss et al., 2017), including in the context of service provision (Guss et al., 2019).

Emerging evidence demonstrates that family support is a protective factor in reducing negative outcomes and promoting overall well-being for transgender and non-binary young people (McConnell et al., 2016; Olson et al., 2016). There is, however, little research on how transgender and non-binary young people and their families seek out and experience support in the form of specialised clinical care.

Moreover, qualitative studies that offer an in-depth understanding of the experiences of transgender and non-binary young people who undergo puberty suppression and/or hormone therapies and their families/caregivers are scarce. Whereas quantitative studies have considered outcomes (i.e., with regard to treatment protocols and outcomes, see Tollit et al., 2018),

they do not provide an in-depth understanding of the realities faced by transgender and non-binary young people and their families in terms of accessing clinical care. This more in-depth understanding is critical to ensuring that optimal care is provided to the increasing numbers of transgender and non-binary young people presenting for clinical services internationally.

The research summarised in this initial report sought to explore the experiences of Australian transgender and non-binary young people and their families who access clinical care during their pre-pubertal, pubertal and post-pubertal stages of development. The research constitutes the Australian component of an international study exploring experiences of clinical care for transgender and non-binary children and young people and their families. Data have already been collected in Canada (see Pullen Sansfaçon et al., 2019 for an overview of the protocol used across all countries) and Switzerland, with plans for data collection in other countries. This project will produce comparable qualitative data between countries on the experience of transgender and non-binary children and young people and their families in terms of experiences with clinical care.

### **Project Overview**

Transgender or non-binary young people aged 11-17 and their

parents were interviewed together to explore their experiences of clinical care. The use of dyadic interviews allowed for similarities and differences in perspectives between young people and their parents to be considered. Interviews were conducted with participants living in either South Australia or Victoria.

The Royal Children's Hospital (RCH) in Melbourne is the most comprehensive gender service for young people in Australia (Telfer et al., 2018). In South Australia, an informal gender service exists through the Women's and Children's Hospital (WCH). Both the RCH and WCH have reported significant increases in referrals for transgender and non-binary young people seeking services.

10 interviews were conducted, 5 in Victoria, 5 in South Australia, constituting a sample of 21 participants (i.e., 10 young people and 11 parents: 1 young person was interviewed along with both parents). Participants needed to have previously or currently be in receipt of clinical services (e.g., ) mental health services, paediatric services, endocrinology, or any other service specific to their gender diversity. Participants did not need to have attended the RCH or WCH.

### **Initial Findings**

Interviews explored a number of key areas in relation to clinical care, including pathways to care,

and both positive experiences and challenges associated with clinical care.

### ***Pathways to clinical care***

Most of the parents interviewed worked to educate themselves about clinical care options. This included accessing online private parent groups. Participants identified the need for parents to listen to their children, be supportive, be proactive, and advocate for the needs of their children in terms of clinical care. A typical journey to care involved a child disclosing information about their gender to their parents, and the parent(s) then seeking assistance.

Most participants reported long wait times for an initial appointment at a gender service, often more than 6 months after being referred. This led to some parents seeking additional support from outside gender services whilst awaiting an initial appointment. This meant that for some families, children had already socially transitioned before seeing a dedicated gender service. Yet despite such progressive steps made by parents, time was still a significant issue for many of the young people in terms of a need to access medical treatments in an expedient fashion.

### ***Positive experiences and challenges when accessing clinical care***

Participants were, overall, glad to have been in receipt of clinical services, given young people required these for medical transition and mental health support. Positive experiences included 1) supportive, caring and informed clinicians, 2) clinicians who made a point of educating themselves, 3) a feeling of being heard and seen, and 4) appreciation that certain aspects

of gender transition were covered by public healthcare (e.g., puberty blockers).

However, participants also noted a number of challenges associated with clinical care. These included: 1) clinicians with insufficient experience working with transgender and non-binary young people, 2) significant amounts of time required to attend multiple appointments and to travel to appointments due to the location of services, 3) long wait times to accessing puberty blockers or hormones, 4) complex needs (especially with regard to mental health) often not attended to alongside a focus on gender, 5) limited support for wellbeing outside of assessment, 6) difficulty finding informed and supportive clinicians outside of dedicated gender clinics, and 7) the expense of services outside of the public sector.

### **Initial Recommendations**

Participants were invited to make comments about what might help to further improve clinical services in Australia. Suggestions made by participants included the need for:

- informed and affirming multidisciplinary teams
- clarity about pathways to care, alongside scope to tailor these to individual needs
- training for clinicians and front of house staff
- increased funding so that more staff are available and thus wait times are reduced
- additional supports for parents
- understanding that being transgender or non-binary is but one part of a young person's life
- Continued advocacy by clinical care teams for the rights of transgender and non-binary young people and their families

### **References**

- Clark, T. C., Lucassen, M. F. G., Bullen, P., Denny, S. J., Fleming, T. M., Robinson, E. M., & Rossen, F. V. (2014). The health and well-being of transgender high school students: Results from the New Zealand adolescent health survey (Youth'12). *Journal of Adolescent Health, 55*(1), 93-99.
- Guss, C. E., Woolverton, G. A., Borus, J., Austin, S. B., Reisner, S. L., & Katz-Wise, S. L. (2019). Transgender adolescents' experiences in primary care: A qualitative study. *Journal of Adolescent Health, 65*(3), 344-349.
- Jones, T., & Hillier, L. (2013). Comparing trans-spectrum and same-sex-attracted youth in Australia: Increased risks, increased activism. *Journal of LGBT Youth, 10*(4), 287-307.
- McConnell, E. A., Birkett, M., & Mustanski, B. (2016). Families matter: Social support and mental health trajectories among lesbian, gay, bisexual, and transgender youth. *Journal of Adolescent Health, 59*(6), 674-680.
- Olson, K. R., Durwood, L., DeMeules, M., & McLaughlin, K. A. (2016). Mental health of transgender children who are supported in their identities. *Pediatrics, 137*(3), e20153223.
- Pullen Sansfaçon, A., Temple-Newhook, J., Suerich-Gulick, F., Feder, S., Lawson, M. L., Ducharme, J., Ghosh, S., Holmes, C. & Stories of Gender-Affirming Care Team. (2019). The experiences of gender diverse and trans children and youth considering and initiating medical interventions in Canadian gender-affirming speciality clinics. *International Journal of Transgenderism, 1*-17.
- Strauss, P., Cook, A., Winter, S., Watson, V., Wright Toussaint, D., & Lin, A. (2017). Trans pathways: The mental health experiences and care pathways of trans young people. Perth: Telethon Kids Institute.
- Telfer, M. M., Tollit, M. A., Pace, C. C., & Pang, K. C. (2018). Australian standards of care and treatment guidelines for transgender and gender diverse children and adolescents. *Medical Journal of Australia, 209*(3), 132-136.
- Telfer, M., Tollit, M., & Feldman, D. (2015). Transformation of health-care and legal systems for the transgender population: The need for change in Australia. *Journal of Paediatrics and Child Health, 51*(11), 1051-1053.
- Tollit, M. A., Feldman, D., McKie, G., & Telfer, M. M. (2018). Patient and parent experiences of care at a pediatric gender service. *Transgender Health, 3*(1), 251-256.

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