CAMH

Summary of the External Review of the CAMH Gender Identity Clinic of the Child, Youth & Family Services

January 2016

Background

The Gender Identity Clinic (GIC) of the Child Youth and Family Services (CYF) in the Underserved Population Program (UPP) at CAMH has engaged in clinical, academic and research activities for over 30 years. The GIC is recognized as one of the few clinics of its kind in Canada and internationally.

In January 2015, a well-established community based group presented to CAMH a number of concerns pertaining to the GIC and the belief that its present practice model was out of step with emerging practices. In response to the concerns raised, CAMH undertook an external review to assist in ensuring that GIC practices reflect the current evidence base.

The external review was conducted by:

1) Dr. Suzanne (Sue) Zinck from Halifax; a Child & Adolescent Psychiatrist with expertise in gender identity and gender variance, who has practiced for 10 years within a Canadian context.
2) Dr. Antonio (Tony) Pignatiello, a local Child & Adolescent Psychiatrist with 23 years of expertise in systems of care with children and youth presenting with complex needs.

The reviewers were asked to do the following:

1. Assemble an independent review of the clinical pathways associated with the clinic,
2. Review the literature on best practices and clinical guidelines with this population
3. Assess the extent to which the workings of the GIC were in accordance with those guidelines as well as national and international practice.

The review process was undertaken between June and November 2015. A systematic review of the relevant literature was completed including a review of the World Professional Association for Transgender Health (WPATH) Guidelines. Community stakeholder focus groups were conducted and information was obtained from former patients and family members. A chart audit of GIC clinical records was also conducted. CAMH participants included current members of the Gender Identity Clinic at CAMH, CAMH Empowerment Council, the leadership of Underserved Populations Program.

Presented here is a summary of the final report's key findings, the recommendations of the reviewers and the CAMH action plan in response to the review.

Summary of Key Findings

The reviewers noted that the GIC has demonstrated exceptional research productivity and has led in raising global awareness of concepts of gender identity, variance and transgenderism. However, in the course of this review, two predominant themes emerged as areas of concern for the reviewers: firstly, the GIC appears to operate as a insular entity within CAMH and the community at large, and secondly, the GIC appears to be out of step with current clinical and operational practices. The feedback to the reviewers reflected the very polarized views in this field, indicating that client and community stakeholder feedback was both positive and negative regarding the clinic. Some former clients were very satisfied with the service they received while others felt the assessment approach was uncomfortable, upsetting and unhelpful. The professional community recognized the academic contributions of the clinic while some community stakeholders voiced concerns with regard to the present model of care.

The following is a summary of feedback provided by the reviewers:

- Research knowledge and clinical guidelines have evolved, particularly in the last five years, and society's understanding and acceptance of the diversity of gender expression and identity have changed. There appears to be a mismatch between literature research findings (including those from GIC itself), and clinical practice and approach.
- Clinic assessments are long and, at times, appear to be clinically inappropriate for the child's age. Questions were raised by the reviewers about the information shared regarding participation in research as documentation suggested that consent obtained may not have been fully informed.
- The Clinic describes its approach as a model that employs play therapy, cognitive behavioural therapy or a combination of both as part of its treatment paradigm. Play and combination therapy do not reflect current approaches to the treatment of anxiety, a primary condition of many of the clients seen by the GIC and thus this practice may be outdated.
- Feedback from families indicated that the clinic supported families very differently. Some families reported that services or referrals were not offered to them despite requests while other families reported receiving exceptional supports for long periods of time. In some instances, the reviewers expressed concern regarding the possible over-involvement of parents in a child's treatment planning.
- GIC is viewed by some as being overly-conservative in its patient referral times. A concern was raised with regard to the GIC criteria for diagnosing readiness for referral for gender-affirming hormones and the inherent risk of delays to referral.
- It was noted that access to GIC is limited due to long wait lists. As the clinic tends to operate in separately from other CAMH supports and community providers, there is an issue with regard to timely and efficient transition of care to and/or from the community or to adult services.

Summary of Key Recommendations

In following the extensive review process, the reviewers made seventeen (17) recommendations which focus on future service models as the reviewers recognized the tremendous need for specialty services for this community. The recommendations made by the reviewers are:

1) The current assessment and treatment approaches need to be revised. Gender variance versus gender dysphoria should be distinguished and explained. The aim to reduce suffering can be achieved with a client-centred and family supportive approach. To move towards this goal, it is recommended that WPATH, CPATH & AACAP guideline-informed care paths be utilized, across the age spectrum. Some specific examples include, but are not limited to:
    a) Explain these at the start of assessment (informed consent/harm reduction/client-centred)
    b) Refrain from treatment of the child that targets reduction of gender-variant behaviors or use of language that pathologises these.
    c) Refrain from allowing parent alone to choose the treatment path
    d) Educate parents and children about gender expression, gender identity, gender variance across the lifespan
    e) Assist all families with communication and acceptance within and outside the family
    f) Liaise with schools to provide advice on inclusion and obtain collateral about social adjustment and any protection needs
    g) Refer teens taking hormone-blockers for gender-affirming hormone treatments when ready and eligible in collaboration with endocrinologists involved.
    h) Staged sexual history interview using suggested approach:
        i. Age-appropriate questions (pre-pubertal sexual history is not required)
        ii. One may rule out paraphiliae with 2 screening questions: “How do you feel about yourself when you dress in your preferred clothing?” Follow-up, if unclear, “Does it affect your sexual confidence or your overall self-confidence?”
        iii. Inquire about attraction and whether sexually active late in the assessment
        iv. Inquire only about safe sex practice use at assessment
        v. Inquire about details of sexual practices only when assessing for treatment that can affect sexual function and inform patient about the reason for these questions (informed consent).

2) More careful delineation of who is the client: focus on any clinical distress associated with gender dysphoria in the child. The family members should become the focus as needed for education and any work toward acceptance of their child. Do not treat family members individually for mental health concerns, but rather, collaborate with other providers, where needed.

3) When assessing for comorbidity and psychosocial outcomes, correlates and their relationships should be examined in the context of the effects of gender dysphoria. These would include, but not limited to:

- Anxiety
- Depression
- Disruptive mood dysregulation
- Self-harm and suicide
- Substance use disorders
- Personality disturbances
- Work in the sex trade
- Underemployment
- Underachievement of academic potential

4) A review of the use psychological testing, even in research context with attention to:
    a. Option to decline
    b. Informed consent on use of IQ tests as not standard practice
    c. Separate consent for research and clinical use of all information
    d. Employ Gender-specific scoring of any psychopathology measures

5) File consent forms on chart and renew periodically (i.e. every 30 days for consent to share of information or annually for consent to treatment, in keeping with other CAMH forms and procedures). Forms should state option to revoke consent at any time and specify that clinical care would not be affected by the change in consent. This should include separate consent for any photographs, which generally should be requested only after careful reflection on the client's needs and with full informed consent from child and teen and parent.

6) Community engagement will be key in determining future directions (including physical location) of this specialty service. Whereas such a service need not necessarily to be housed at CAMH (in a hospital), it is imperative that it maintain an academic mandate.

7) Key organizations and institutions to consider for the engagement process could include Rainbow Health, Justice for Children and Youth, The Provincial Youth Advocate's Office, The Provincial Council for Maternal & Child Health, Children's Mental Health Ontario, LHINs, MCYS Lead agency/ies, as examples.

8) Collaborate with CAMH academic partners, resources, Chairs and Centres (i.e. The McCain Family Centre re Collaborative Care opportunities)

9) Develop a clear, implementable QI strategy, utilizing CAMH decision support as appropriate.

10) Update and create a governance model including an Executive and/or Advisory Committee (which should include as a minimum: clients (youth and/or family), CAMH Public Affairs, Legal, Ethics, community stakeholders, CAMH adult GIC, trainees)

11) Develop clearer, more streamlined processes for access to and flow through the clinic, and transfer to community resources and adult services, as appropriate. This should be consistent with Access CAMH, and CYF intake processes and procedures. Better collaborations/partnerships when dealing with crisis and

concurrent mental health situations are advised—especially so the burden of treatment does not fall onto clinic trainees.

12) Consider adding Social Work or other professionals with expertise in family therapy to the GIC team.

13) Community supports should be included in recommendations and psychoeducation to families and youth. These would include choice of services for hormone therapies, and surgery assessment, where appropriate, for example.

14) GIC staff to take training courses in more streamlined and efficient record keeping, chart organization and report preparation.

15) GIC team members are highly encouraged to review CAMH policies re: informed consent, and email correspondence with families.

16) When dealing with GIC controversies in a public forum, GIC members are encouraged to work with CAMH Public Relations to effectively deliver messaging which also considers reputational risk to the institution, and employs client-centred language. GIC staff may benefit from media training.

17) GIC and CAMH as a whole are encouraged to develop a campaign towards collaborative creation of "safe spaces" for transgender children, youth, families, and community caregivers.

CAMH's Action Plan

In response to the feedback and recommendations of this review, CAMH accepts that it is now time to update and improve the model of care within the GIC. In response to this, CAMH will move forward with a three step plan to:

1. Wind down the operations of the CYF GIC. Ensure the clients currently in care are provided with supportive ongoing care from appropriate care providers.

2. Engage key community organizations and institutions as well as clients, families and academic partners in a community engagement process with the goal of determining future directions.

3. Explore the best role for CAMH based on an assessment of the system's capacity for services for gender variant children and youth.

This is an opportune and somewhat natural time for re-visioning and modernization of the GIC. There is a tremendous need for specialty services such as this, clinically and academically. Knowledge of gender identity and expression has advanced significantly and society has also shifted in its understanding and acceptance of gender variance. Many of the children previously assessed and treated in the GIC and other similar services are now adults with their own voice, offering important insight to guide the development of services. At present, the political climate is palpable and this is an emotionally charged issue that would benefit from incorporating all evidence and voices.

CAMH wishes to thank all of those who participted in the review process. We apppreciate the candour and input of the stakeholders and clients who participated in this important review and look forward to leading a process that will allow CAMH to better address the needs of this important population.