

Moving Beyond Trans-Sensitivity: Developing Clinical Competence in Transgender Care (the Trans Care Project)

Project Summary and Analysis

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a collaboration between Transcend Transgender Support & Education Society and Vancouver Coastal Health's Transgender Health Program, with funding from the Canadian Rainbow Health Coalition's Rainbow Health – Improving Access to Care initiative

Trans Care Project: Summary and Analysis

Context and Background

Trans people in BC experience multiple barriers to accessing health and social services. The top three reported barriers – financial expense of services, lack of service availability, and waitlist for services (Goldberg, Matte, MacMillan, & Hudspith, 2003) – point to a scarcity of services available within the publicly funded health and social service systems.

The longstanding difficulties faced by trans people in accessing competent care were complicated in 2002 by the closure of the Gender Dysphoria Program (GDP) at Vancouver Hospital. The GDP, established in the early 1980s, focused on the assessment and treatment of people who met DSM criteria for “Gender Identity Disorder”. The GDP offered endocrinological, urological/gynecological, psychiatric, psychological, and social services, and was the sole gatekeeper for public health coverage for transition-related surgeries. In May 2002, as a result of provincial cuts to health transfer funding, the GDP was closed.

Vancouver Coastal Health (the health region responsible for funding the GDP) agreed to work with the trans community to create a new service. Following a review of models in other regions, interviews with key service providers, and a community survey, one year after the GDP closure Vancouver Coastal Health adopted a decentralized, community-based, peer-driven model of care that was intended to address both the transition-related needs of transsexuals (the focus of the GDP) and also the broader health issues faced by transsexuals, crossdressers, bi-gender and multi-gender people, androgynous people, and others within the umbrella term “transgender” (which had never before received attention). The new system, based on the report *Recommendations for a Transgender Health Program* (Kopala, 2003), moved away from direct delivery of care. Instead, the program would coordinate training and referrals to a network of community-based family physicians, nurses, social workers, counsellors, and other clinicians working with the trans community.

For two decades community-based clinicians had relied heavily on the GDP to provide trans care. To make a community-based network viable, substantial training and support would be needed for community-based clinicians with little trans care experience. Accordingly, the framework for the new THP (Kopala, 2003) included five recommendations related to clinical training:

- Develop clinical guidelines for all practitioners to ensure professional competence in the various specialty transition/crossdressing services.
- Encourage the adoption of a harm reduction approach to hormone prescription and maintenance.
- Educate primary care providers about cross-gender hormone use, and provide sample protocols and a list of endocrinologists with expertise in transgender medicine.
- Provide ongoing, continuing medical education in the area of transgender medicine.
- Develop specific educational materials for family doctors.

In the first year of the program’s development, the Transgender Health Program (THP) identified approximately 180 community-based service providers with an interest in general and specialty trans care. Thirty-three introductory workshops were delivered to clinicians in both rural and urban locations to improve understanding of trans issues and lay the foundation for sensitive, respectful care. But sensitivity/awareness building was not enough: more advanced training was needed to ensure that care was not just trans-positive, but also clinically competent. With funding through the Canadian Rainbow Health Coalition’s *Rainbow Health* initiative, supplemented with additional funding by Vancouver Coastal Health, the Trans Care Project was created to address these needs.

Project Description

Scope and limits

This project focuses on the identified service and training needs in BC. Regionally-specific issues in health governance, health service delivery, and the history/demographics of trans communities are extremely important, and some of the information cannot be readily used by clinicians, educators, and community activists in other regions. Some of the clinical issues (e.g., techniques used to raise voice pitch, care following SRS, recording of “M” or “F” on lab requisition forms) are not geographically-specific and can be readily adapted for use outside BC.

In keeping with the *Recommendations for a Transgender Health Program* (Kopala, 2003), it was agreed that the Trans Care Project would focus on two areas of trans care: specialty transition/crossdressing services and primary care. Sufficient clinician resources were available to proceed in seven topic areas: adolescent health, hormones, mental health, primary medical care, social and medical advocacy, speech/voice care, and surgery. We had originally hoped to include information about hair removal, but attempts to identify local hair removal experts who could participate in the project were unsuccessful.

As in all projects, time and funding limited the specific issues that could be covered in each area. We recommend that future work prioritize:

- a) clinical guidelines and training frameworks: addiction treatment, trauma care, employment/vocational services, hair removal and hair loss treatment, assessment and treatment of dysphoric children age 12 and under, expanded work on counselling needs of loved ones
- b) consumer education: safety issues (e.g., dealing with harassment/violence, disclosure of trans status, general safety planning); sexual health; body image; materials for prisoners, youth-in-care, street youth, and people in long-term residential care facilities

Project products

The Trans Care Project involves a partnership between clinicians and trans community members to create three tools for education:

1. Clinical best practice guidelines
2. Frameworks for clinical training
3. Consumer education materials

Clinical best practice guidelines are important in helping promote consistent and high-quality care. It is not possible or desirable to create a “one size fits all” approach to care: care must be flexible, with consideration of an individual’s preferences, values, physical needs/limits, psychosocial capacity to participate in treatment, and response to treatment (James, 2005). However, as a starting point it is useful to have a basic template that outlines guiding values, principles, and a baseline protocol that can then be adapted to meet the patient’s needs.

Clinical training frameworks include discussion of the core competencies in various areas of trans care and projects/strategies to increase clinician knowledge, awareness, and skill at basic, intermediate, and advanced levels of practice. At a basic level, the practitioner is sufficiently aware of trans issues to be able to interact effectively with the trans individual or loved one in non-trans-specific care (e.g., responding appropriately to disclosure of gender concerns, making referrals to

trans specialty services as needed). At an intermediate level, the practitioner has not only awareness but also clinical competence in trans-specific issues relating to general care (e.g., screening for sex-specific disease such as cervical or prostate cancer). At an advanced level, the practitioner is able to provide clinical feminizing/masculinizing services (e.g., speech/voice change, assessment of hormone readiness, hormone maintenance, pre- and post-surgical care)

Consumer education materials have two functions. By translating best practice guidelines into lay language, they assist the transgender person to understand options for care and to assert their rights with practitioners. They also provide a tool for education of health and social service providers who need introductory information or who are unwilling to devote the time to read a more detailed manual on care.

Clinician-community partnerships

Increasing trans access to care requires not only increased clinician awareness of and sensitivity to trans health concerns, but also assertive and persuasive recruitment of public health professionals to be actively involved in care. Trans community advocacy is vital in creating change; clinician champions are also needed. In particular, clinician involvement is essential in making training materials and practice guidelines maximally relevant and accessible, pushing colleagues to come forward as being willing to provide care to trans people, and sustaining advocacy with health professional associations, post-secondary training programs, and health governance bodies. From its inception the project was intended to foster a sense of ownership by local clinicians, and to model clinician-community partnerships as a guiding principle for trans health care reform.

Nine clinicians from various disciplines who had demonstrated a commitment to improving trans access to care and also a commitment to the THP's guiding values (client-centred care, harm reduction, etc.) were recruited to serve as clinical advisors to the project. This group – expert in adolescent health, counselling, endocrinology, medicine, nursing, psychiatry, social work, speech/voice care, and surgery – agreed to provide overall input on the project's development and also clinical advice on draft documents.

The project's original design included an Advisory Team of two trans people (one FTM and one MTF, each representing the organizational partners) and a tenth clinician with an outstanding history of involvement in LGBT health advocacy and clinician training. This team would work closely with three project staff (research coordinator and two research assistants) to keep the project on track. When the coordinator quit after four months on the project, the two trans representatives on the Advisory Team agreed to split the coordinator responsibilities, with the clinician joining the Clinical Advisory Group to provide more general project guidance.

Trans community input was provided by the staff of the program (four trans individuals – two with strong research experience and two with strong community experience), trans people on staff at the Transgender Health Program, and lay members of the THP's Education Working Group (created to oversee the development of educational initiatives within the THP). Additional feedback was sought from trans members of the THP Advisory Group and organizations in and outside BC that create trans peer education materials.

Development of materials

The balance of community/clinician involvement varied depending on the nature of the documents. For the clinical guidelines, clinicians were contracted to co-write with the project's research coordinator; for the consumer education materials, the two trans research assistants worked with the research coordinator as co-authors. The peer review was similarly weighted (with more clinical input

than lay input on the clinical guidelines, and more lay input than clinical input on the consumer education materials).

Trans health research is in its infancy and there are insufficient data to generate purely empirically-derived, evidence-based guidelines for care. To supplement existing research, ten clinicians who are known to be expert in areas of trans care with very little published information were interviewed to determine their clinical practices. Simultaneously, a library of over 1000 clinical articles was created and the relevant literature reviewed and summarized.

The training frameworks are based on a review of existing undergraduate, graduate, post-graduate, and continuing education in BC, as well as interviews with clinicians who provide trans-specific training in other regions. To ensure compatibility with existing local training and to obtain additional feedback, local clinicians involved in clinician training provided feedback on framework drafts.

The consumer education materials were based on the practice guidelines, as well as a review of peer education materials developed in other regions.

Dissemination of project materials

This project was designed as part of trans health care reform currently taking place in BC. As discussed earlier, the primary audience is local – BC clinicians, training institutions, and trans people/loved ones. However, some of the project findings are applicable in other regions. Accordingly, some dissemination strategies are specific to BC, while others are intended to reach a broader audience.

General dissemination (all project documents)

PDFs of all documents are available to the general public via the Transgender Health Program website (<http://www.vch.ca/transhealth>), with links from other participating organizations. Hard copy of all documents are available via to the THP at no cost to people in BC and at cost to others (with complimentary copies for all clinicians involved in project).

An announcement about project materials was sent to all clinicians/agencies listed in THP resource guide (180+ local services), all member groups of Trans Alliance Society, all BC-based transgender listservs, and the Harry Benjamin International Gender Dysphoria Association clinician listserv. The Canadian Rainbow Health Coalition will further promote the project as part of its dissemination relating to the initiative that this project was part of.

It has been recommended that Vancouver Coastal Health support clinicians to present findings at professional meetings (including local rounds, symposia, and association meetings) and primary care/public health conferences. Trans people involved in the project should also be supported to present to transgender organizations and at transgender health conferences.

Dissemination of specific products

1. Guidelines for care and literature reviews

BC clinicians are the primary audience for these documents. They may also be of interest to clinicians with an interest in trans care in other regions, and to professional associations.

To reach BC clinicians, condensed versions are being created for submission to local clinical journals, with the full text of the guidelines used as reference materials in clinical training provided by the Transgender Health Program. Local websites that provide information about clinical standards of

care and practice protocols (e.g., health professional associations, health governance bodies) will be encouraged to link to the online versions of the documents, as will the Harry Benjamin International Gender Dysphoria Association.

The literature reviews and expanded guidelines are being revised for submission to the *International Journal of Transgenderism*. If submission to *IJT* is not successful, alternative opportunities for publication of the set of guidelines as a book will be explored, with the aim of getting copies into public and university libraries.

2. Training frameworks

Vancouver Coastal Health, as the funder of the Transgender Health Program, is the primary audience for the training frameworks. The frameworks may also be of interest to professional associations, post-secondary institutions, and other health policy/governance bodies. Targeted information will be sent to post-secondary institutions and professional organizations that provide training to health professionals. An article is under development for submission to the *International Journal of Transgenderism*.

3. Consumer education materials

Transgender people in BC are the primary audience for the consumer education materials. Non-transgender loved ones are also consumers in terms of counselling services. The consumer education materials may also be of interest to health and social service professionals, teachers, community workers, and others who are seeking introductory information (rather than the more detailed clinical guidelines). Copies will be printed and distributed at transgender peer support meetings and consumer libraries throughout BC (e.g., libraries at community health centres, Out on Shelves at The Centre, public library system).

Some of the information in the consumer education materials is specific to BC. Transgender organizations in other regions will be encouraged to use and adapt the material to fit local needs. Announcements will be sent to transgender groups throughout Canada, and an article submitted to <http://www.trans-health.com>.

Ten Lessons Learned From the Trans Care Project

Lessons about trans health

1. The research done thus far is too weak to confidently state what is evidence-based “best practice” guidelines in many areas of trans care.

Evidence-based practice involves an integration of an individual professional’s clinical experience with the best available external clinical evidence (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). The aim of evidence-based research is to analyze and summarize existing studies – often via meta-analysis that grades studies according to levels of evidence – so clinicians have access to reliable, high-quality, up-to-date information (White, 2004). Levels of evidence are typically based on medical research and consider systematic reviews or meta-analyses as the most rigorous type of study, followed by randomized controlled double-blind studies, cohort studies, case control studies, case series, case reports, and expert opinion articles (in decreasing order).

Of course this dominant medical paradigm is not the only way of knowing or thinking, and it is limited in its applicability to counselling or other disciplines where the quality of care is more about the

quality of interpersonal interaction between clinician and client than about the “right” technique or tool. But given that medical clinicians (nurses, family physicians, endocrinologists, psychiatrists, surgeons) are a key audience for this project, we feel it is important to be aware that by medical standards, the studies we used as the basis for our guidelines would generally not be considered high-quality evidence. The best evidence we could find on many topics consisted of small case series of trans individuals (who rarely represented the diversity of the trans community), individual case studies, and clinical opinion of the professionals involved in the project. We also considered research with non-transgender people when that seemed logically supportable (although the validity of extrapolation from non-trans people to trans people is not proven).

The upshot is that the guidelines in this project do not represent an empirically derived set of “best practice” protocols. They represent the integration of our values, beliefs, and experiences with the limited evidence that is currently available. More research is clearly needed; in the interim, we need to do the best we can with the evidence that exists.

2. In the absence of clinical evidence that one approach is more effective than another, clinicians tend to have strong opinions that their way is right.

To paraphrase Asscheman & Gooren (1992), in the absence of empirical evidence about effective practice, trans care decisions tend to be guided by clinician belief/opinion, client beliefs and preferences, the beliefs/opinions of the client’s peer group, logistical realities such as cost and accessibility of a particular type of treatment, and local tradition.

Given this, at times the review process was, at times, almost comical in the vehemence and passion expressed by some of the clinicians. Hormone prescription, primary medical care, and mental health care were particularly contentious topics, with clinicians holding very strong opinions about the right (and wrong) way to practice, and little clinical consensus on any issue we tried to tackle. Some clinicians felt strongly that our suggestions were too “radical” or “soft”, while others felt we were overly “conservative”.

We tried to tackle this by presenting multiple perspectives on every contentious clinical issue, along with the reasoning behind our adoption of a specific position so clinicians (and consumers) could better evaluate our conclusions. We sincerely hope that clinicians who disagree with our recommendations will write and publish comments, critiques, and alternative viewpoints, so there can be more open discussion about the beliefs underlying “best” practice.

3. Publication in a scientific journal does not necessarily mean that information is accurate.

“Physicians have been using evidence to make medical decisions for over 50 years. The problem was that the research wasn't always good,” says Robert Flaherty, MD, a family physician at the Montana State University Student Health Service, who teaches courses in evaluating the medical literature. “People tended to assume that, just because something was shown by a research study and published in a journal, it was correct and could be used in practice. Instead, what we found was that the quality of the information from these studies was quite variable, and we stumbled around for many decades really not knowing the best way to do medical research.” (White, p. 52).

We were shocked by the poor quality of many of the published research articles that were reviewed for this project. Many of the studies lacked clear voluntary consent by participants, a key ethical violation that should have resulted in the study being refused Ethics Board approval. Some studies lacked methodological rigour or had faulty analysis of data; quite a few reported opinion as fact, cited old studies that have since been disproven, or were otherwise sketchy in their premise. While we

included some articles from before 1995, the bulk were published in the last five years, with numerous problems continuing in articles published in 2005.

It was particularly surprising that such deeply flawed articles were often published in high-quality medical and psychological journals. It is not clear why the threshold for publication of trans health research is lower than for research on other topics, or why poor quality research has escaped published comment. At minimum, clinicians should check a published study's methodology and data before drawing conclusions about the study, and not assume publication signifies accuracy. It is our hope that clinicians will go one step further than this, and actively work to create higher standards for trans health research.

4. Publication by a trans community group or individual does not necessarily mean that information is accurate.

We reviewed a number of publications by trans community organizations and individuals in the development of our consumer education materials. As with pieces written by clinicians, we were alarmed by the inconsistent quality of information published by community organizations and individuals, particularly online (where a wealth of misinformation exists in individuals' blogs, websites, articles, etc.).

In the past trans people and organizations have had to do substantial research to educate the clinicians providing our care. Certainly some trans individuals and groups have been conscientious about this research and have been cautious about the limits of their knowledge or ability to convey clinical information. Others are mistakenly confident about their understanding of clinical issues and are dispensing clinical advice to vulnerable people who do not have the resources to determine what is accurate.

As in all communities where there is a healthy skepticism of paternalistic approaches of "clinician knows best", trans people place high emphasis on peer knowledge and advice. Transgender organizations and individuals need to be careful not to offer clinical advice unless they are sure that advice is accurate and sound. Existing misinformation that is in circulation should be challenged, and capacity initiatives supported to improve consumer analysis of published health information.

5. Development of a reliable clearinghouse of materials reviewed for clinical accuracy should be a strong priority.

Community-clinician partnerships facilitate the mutual development of reliable, credible, and relevant information. Given the abundance of clinical misinformation already in circulation, we hope funding can be secured for a community-clinician partnership to:

- develop standards for ethical and methodologically sound trans health research
- develop standards for publication of clinical materials
- create an electronic clearinghouse of information that has been screened and verified as accurate/reliable by a team of clinicians and consumers
- create a group of reviewers able to work with journals and organizations to improve the quality and rigour of educational materials
- challenge inaccurate clinical and community reporting

Lessons about process

6. Aim high.

This project seemed impossibly ambitious – how could a project with a part-time coordinator pull together an international group of 71 individuals to develop 28 documents in under 16 months? While this project was by no means perfect and there are things we would do differently next time, it is a wonderful thing to have been able to pull it off. The sheer amount of work that needs to be done in the field of trans health can be daunting, but this project is proof that it is possible to aim high and succeed.

7. Build in mentorship and support for meaningful trans community involvement.

Some trans people have excellent skills and knowledge and are able to participate in complex projects without much support/mentorship. Others have experienced significant barriers to doing this kind of work and need more support, encouragement, and structure for their involvement to be meaningful.

When you're in a time crunch, it's easy to just go with the people who are the most experienced and hence more independent, but that leaves out important perspectives. We regret not having more time to have a broader range of trans people be involved in a substantive way. We would like to see future work include a stronger capacity-building component that includes training in health education writing, constructive criticism, and research skills, as few trans people have had the opportunity to work in these areas.

8. Assume you'll be working with half the time and funds you need.

There is never enough time/funds/energy to do everything that needs to be done. Every project has frustrating limits; unexpected things always happen that prevent the work from proceeding as planned. We knew this would likely happen but we still didn't build in enough of a time buffer at various stages to accommodate the glitches that are inevitable in this kind of collaborative work. The end was quite crunchy as a result, with quite a bit of stress for both the clinicians and the trans people to push through, and also insufficient time to have more than one round of review of draft materials.

The finances were also quite stressful at times. Although we committed a substantial portion of the funds to paying clinician contracts, we grossly underestimated the amount of time it would take for clinicians to be involved in writing and rewriting. As a result all of the paid clinicians went far beyond their contracted hours (as did the trans staff, who donated hours to the project to free up more of the budget for clinician payments). We were very fortunate to have generous clinical co-authors and also clinical peer reviewers; many refused honoraria, asking instead that the money be put into community work. We are grateful for the clinicians' generosity.

9. Be clear from the start about expectations, and realistic about the content knowledge required.

The original Project Coordinator resigned after four months on the job because he felt the project could not be done with the resources available. Having taken over his job, we can appreciate his overwhelm. This was a really daunting project for us even with our combined 18 years doing trans health work; asking someone with marvelous research experience but little trans expertise to coordinate this kind of project was unrealistic on our part. Trans health is substantially different than lesbian/gay/bisexual or intersex health, and it is not realistic to ask someone new to trans health to coordinate a relatively short project – there is not enough time for the inevitable learning curve. If

there are no local people with the capacity to do the job, then the project needs to be scaled back to a more manageable size to fit the capacity that is there, and work needs to happen to build the community capacity to do more work in the future.

We also lost a clinician partway into the project, due to changes in her life circumstances that prevented completion of her work. While we could not have anticipated this, in hindsight we wish that we had been firmer about expectations from the start, as it would have been better for the project to try to replace her – by the time it became clear that she would not complete the work, it was too late to find an alternative.

10. Support the development of regionally-specific guidelines.

We knew this project came out of a very specific context – the closure of a local gender clinic and the creation of a community-based network of care. And we knew that regional differences were very important in terminology and language issues. But we (naively) thought that it wouldn't take much to make our work useful to people across North America. We were surprised in the peer review process to have a couple clinicians/advocates say that they felt our work would be damaging in their geographic area. In further discussion with these reviewers it became clear that we underestimated the importance of regional specifics such as the structure of care, the extent of medical coverage for specific services, the local history/demographics of trans communities, and the local relationships between clinicians and consumers. The lesson for us is that there needs to be funding for each province to develop their own trans guidelines that take into account regional politics, cultures, and histories.

A key strength of this project is the combination of local clinicians and trans people with international experts. Thirty of the 53 clinicians involved in this project (Appendix A) work in BC. This project won't have as much oomph outside BC because there isn't the same kind of clinician investment.

Regionally-specific guidelines build in the local involvement that is necessary to ensure implementation beyond the life of the project. We strongly encourage funding of similar projects in all other provinces.

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Appendix: Trans Care Project Members

Community lay members (project staff, research interns, co-authors, and peer reviewers)*

- Jacqueline Allan
- Willow Arune
- Olivia Ashbee
- Fay Bamford
- Fionna Bayley
- Sam Bradd
- Debbie Beach
- Derek Eidick
- Jael Emberley
- Dianne Goldberg
- Joshua Goldberg
- Emily Hodge
- Rodney Hunt
- Sam Larkham
- Donna Lindenberg
- Rika Moorhouse
- Heather O'Shea
- Susanna Quail
- A. J. Simpson
- Lukas Walther
- Caroline White
- Nadine Wu

* Note: Community members include trans people, loved ones, and allies. Inclusion in this list should not be assumed to indicate that a person does or does not identify as trans.

Clinicians (advisors, co-authors, interviewees, peer reviewers)[§]

- Bronwyn Barrett, MSW
- Rosemary Basson, MB, BS, FRCP(UK)
- Katharine Blaker, MS, CCC-SLP
- Walter Bockting, PhD
- Cameron Bowman, MD, FRCS(C)
- Peggy Cohen-Kettenis, PhD
- Trevor Corneil, MD, MHSc, CCFP
- Georgia Dacakis, BAppSc, GradDipCommDis, MEd
- Marshall Dahl, MD, PhD, FRCP(C)
- Shelagh Davies, MSc, S-LP(C)
- Annelou de Vries, MD, PhD
- Henriette Delemarre-Van de Waal, MD, PhD
- Stacy Elliott, MD
- Jamie Feldman, MD, PhD
- Lin Fraser, EdD, MFT
- Peter Granger, MD
- Eva Hersh, MD, FAAFP
- Reinhardt Heuer, PhD, CCC-SLP
- Afshin Jaber, BSc(Pharm), RPh
- JoAnne Keatley, MSW
- Sheila Kelton, RN, BScN
- Gail Knudson, MD, MPE, FRCP(C)
- Lori Kohler, MD
- Marjorie MacDonald, RN, PhD
- Roey Malleson, MD
- Gerald Mallon, DSW
- Edgardo Menvielle, MD, MSHS
- Daniel Metzger, MD, FAAP, FRCP(C)
- Stan Monstrey, MD, PhD
- Murray Morrison, MD, FRCS(C)
- Fraser Norrie, MD, CCFP
- Megan Oleson, RN
- Brian Petty, MA, CCC-SLP
- Jorge Pinzon, MD, LMCC, ABP, FRCP(C)
- Melady Preece, PhD
- Rosemary Prentice, RN, MSN
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- Sandra Samons, PhD, DCSW
- Melanie Spritz, DO
- Lucretia van den Berg, MD
- Michael van Trotsenberg, MD
- Colleen Varcoe, RN, PhD
- Katherine Verdolini, PhD, CCC-SLP
- Catherine White Holman
- Wallace Wong, PsyD
- Kathy Wrath, RN
- Julian Young, PhD, RCC

[§] Note: Clinicians include trans and non-trans health and social service professionals. Inclusion in this list should not be assumed to indicate that a person does or does not identify as trans.