



Developing a Mental Health and Addictions Research Agenda for Ontario

LGBT Consultation Summary

September 13, 2010

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1. INTRODUCTION

On September 13th, 2010, the Ontario Mental Health and Addictions Knowledge Exchange Network (OMHAKEN) and Rainbow Health Ontario (RHO) partnered to sponsor a LGBT (lesbian, gay, bisexual, and transgender) consultation in Toronto as a special session of the Creating Together project.

OVERVIEW OF CREATING TOGETHER

The Creating Together project is sponsored by the OMHAKEN and is co-sponsored and supported by key funders and users of mental health and addictions* research. A list of partners is included in the figure below.

Figure 1 - Creating Together Partners



* Addictions is being defined to include abuse and dependence on substances (e.g., alcohol, drugs, tobacco), problem gambling as well as process addictions such as video gaming.

The goal of the overall Creating Together project is to involve key stakeholders in the creation of a research agenda for mental health and addictions in Ontario, focused on population health and health services. The project is a departure from past practice. The aim is to understand the knowledge needs of stakeholders, and from these needs inform the research agenda, rather than it being driven by funding bodies and researchers alone. An overview of the consultation process is included in Figure 2 below.

The results of the project will be used by Creating Together Co-sponsors and possibly other research funders to guide priorities in the allocation of research funds. The ultimate goal is that the research agenda and results will benefit consumers/survivors and family members by developing the knowledge to create a stronger mental health and addictions system.

The final report was completed in the Spring of 2011, in advance of the forthcoming Ontario Governments province-wide mental health and addictions strategy.

Figure 2 - Overview of Overall Consultation Process

| In-Person Consultations | | Video Conference Consultations | |
|-------------------------|-------------|--------------------------------|---|
| June 17 | Thunder Bay | June 18 | Northern Ontario - connecting with people |
| July 6 | Toronto | in: | <ul style="list-style-type: none"> • Kenora • Sault Ste. Marie • Timmins • Sudbury • North Bay |
| July 8 | London | July 26 | Southern Ontario - connecting with people |
| July 13 | Ottawa | in: | <ul style="list-style-type: none"> • Kingston • Cambridge • Hamilton • Niagara • Windsor |
| LGBT Consultation | | | |
| September 13 | | | |
| Web-Based Consultations | | | |
| Mid October | | | |

OBJECTIVES OF THE LGBT CONSULTATION

The LGBT session was a special consultation that was carried out as part of this project. This was jointly led by Rainbow Health Ontario and the Creating Together team at OMHAKEN. This special session was important due to the knowledge gaps with respect to the health status and disparities among the LGBT communities, both provincially and nationally. To the best of our knowledge, a mental health and addictions research consultation with the LGBT communities has never been conducted in Ontario.

The objectives of the LGBT consultation session were to:

- Understand research needs and perspectives on research gaps in relationship to mental health and addictions and the LGBT communities
- Identify research topics and knowledge exchange areas which would help to address these needs and gaps in the communities
- Identify priorities among areas for mental health and addictions research and knowledge exchange

This session was intended to place emphasis on specific issues and develop specific priorities relevant to the LGBT communities. A summary of this consultation will appear in the overall final report to demonstrate how the process can be tailored to specific communities. The products of the LGBT consultation will be circulated and used by Rainbow Health Ontario and others to help guide research and knowledge exchange activities.

The OMHAKEN and RHO teams worked together to conduct this consultation and develop this report.

| Creating Together Project Team |
|---|
| Health Systems Research and Consulting Unit, CAMH |
| Heather Bullock, Manager Knowledge Exchange |
| Dale Butterill, Dale Butterill Consulting Group |
| Paula Goering, HSRCU Co-Director (former) |
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PARTICIPANTS

The intent of this consultation was to engage a wide range of stakeholders representing different perspectives (see Figure 3).

Figure 3 - Consultation Participants



Potential participants were identified through the networks of Rainbow Health Ontario, OMHAKEN, local addictions and mental health system leaders, and members of the Expert Panel established for this project.

Seventy people registered and forty-nine people participated in the event.

APPROACH

Prior to the consultation, the project team developed a draft list of knowledge themes and topic areas drawn from a scan of provincial policy, planning and research documents and a discussion with an Expert Panel established for this project. The list of topics focused on the mental health and addictions system, health systems/services, and population health/public health related topics. It was not LGBT specific. The themes and topics were drawn broadly from mental health and addictions. The three major themes were:

- Social determinants of health
- Health systems/services research
- Research resources

This list of specific topics is shown in Figure 4 below. The purpose of the list was to help but not limit participants in thinking about knowledge needs for the LGBT communities, that could be addressed through research or knowledge exchange.

Figure 4 - Draft Knowledge Theme and Topic List

| Theme | Topic |
|--|--|
| <p>1. Social Determinants of Health</p> | <p>These are the social factors (e.g., housing, employment, income, and income distribution) that affect health and well-being.</p> <p>A. Vulnerable populations may include but is not limited to: Gay/Lesbian/Transgender/Bisexual people, people with HIV/AIDS, Aboriginals, Francophones, vulnerable groups of men and women.</p> <p>B. Risk and Resilience: Understanding what places people at risk and what constitutes resilience that enables people to deal with uncertainty, change and risk across the lifespan.</p> <p>C. Stigma and Discrimination: Reducing the barriers to service use and community inclusion.</p> <p>D. Other?</p> |
| <p>2. Health Systems/ Services Research</p> | <p>This is research that tells us how services and systems are working, how well matched they are to the needs of people who use them, and their abilities to access them.</p> <p>A. Performance Monitoring: The routine collection of information on the system, e.g., number of emergency room visits, length of stay.</p> <p>B. Health Economics: Tells us what the costs and benefits are of services.</p> <p>C. Health Human Resources: The right people in the right place at the right time with the right skills and values.</p> <p>D. Continuity of Care: The journey through the systems and transitioning out.</p> <p>E. Integration: The organization of the systems, e.g., the absence of silos and creation of organizational linkages.</p> <p>F. Program Evaluation: Learning about how to achieve better outcomes.</p> <p>G. Health Promotion and Prevention: What we need to know to improve health, wellness and to prevent mental health, addictions and/or gambling problems.</p> <p>H. Other?</p> |

| Theme | Topic |
|-----------------------|--|
| 3. Research Resources | These are resources that better the conducting and use of research. A. Data Quality/Analysis: Accurate, accessible, relevant information for research. B. Knowledge Transfer and Exchange: Conducting research that is relevant, gets to users for action and is informed by user needs. C. Capacity Building: Training and other activities that support research uptake. D. Other? |

PARTICIPANT INPUT

Participants were asked to respond to two questions in consideration of this list:

1. What knowledge would help you to be more effective in your work and in your relationship with the systems with which you interact?
2. In your opinion, what are the topics where better use of existing knowledge by mental health, addictions and problem gambling stakeholders would be of greatest benefit to consumers, families, policy developers and decision-makers?

2. CONSULTATION RESULTS AND IDENTIFIED PRIORITIES

OVERVIEW

Participants provided input in response to the questions and the draft theme and topic areas. A revised, summary list of the themes and topics was then created for people to respond to in selecting their priorities. In the priority setting exercise, participants were asked to identify the primary role they play in the community (e.g., consumer and family member; service provider; allied profession/sector; policy maker, system planner, provincial organization; researcher; or other) and to indicate their top five priorities for research and knowledge exchange from among the various topics identified through the consultation discussion.

The top three research areas for future focus for the LGBT communities, according to the highest number of votes in the prioritization exercise were (N = 147¹):

1. Program evaluation 20/147
2. Stigma and discrimination 18/147
3. Vulnerable populations 17/147

The overview of the data has been organized according to the most highly rated priorities to the lowest priorities identified by the group. It is worth noting that there is not a huge difference between the items at the top of this list, and those at the bottom of the list (20 votes vs. 2 votes respectively). This speaks to the need for mental health research with LGBT communities in many areas. The top 3 rated areas, are reflective of the need for basic information about LGBT communities and the impact of discrimination on mental health and access to services and support.

¹ N = 147 as some participants left prior to the exercise, some did not want to participate and others only included a few priorities instead of 5.

1. RESULTS

The input below is organized below by overall highest priority as voted by participants.

1. Program Evaluation (20 votes)

General Comments:

- Intake forms can be a useful source of data (if they ask questions about LGBT identities)

| Research Needs |
|--|
| <ul style="list-style-type: none">• More research on what actually works (promising practices)• Comparative research: LGBT programs compared to general programs (especially around accessibility); comparative research on interventions for LGBT communities; comparative research into user designed programs vs. standard programs;• Conduct literature review on client self-directed care to determine how much knowledge is available• Research on the effects of service users controlling their own care• Evaluation of school-based training related to LGBT via improving/preventing mental health and addictions issues (e.g. Toronto District School Board)• Evaluate experiences of LGBT clients receiving services to refine overall system• What is the effectiveness of services for substance using women? |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none">• No identified areas for knowledge exchange |

2. Stigma and Discrimination (18 votes)

General Comments:

- Holistic approach to layered stigma and discrimination
- Complexity of stigma and how it compounds discrimination

| Research Needs |
|---|
| <ul style="list-style-type: none">• Exploring the nature of systemic discrimination and the relationship to mental illness• Stigma and discrimination within LGBT/by LGBT communities; Stigma of mental health problems within LGBT communities; Racialized communities within LGBT communities;• Stigma and discrimination outside the LGBT communities: Trans discrimination in health system and residential services; Homo/transphobia among frontline staff• Poverty as compounding factor for stigma and discrimination• Explore the link between homophobia and Post Traumatic Stress Disorder |

| Existing Knowledge Exchange |
|--|
| <ul style="list-style-type: none"> • No identified areas for knowledge exchange |

3. Vulnerable Populations (17 votes)

| Research Needs |
|--|
| <ul style="list-style-type: none"> • Children & Youth (and kids of LGBT); LGBT youth addictions; Mental health and youth - LGBT left out • Identity intersection • Separating L-G-B-T - communities decide unit of research • Immigrants, refugees & newcomers (adults and youth) and/or LGBT youth of colour • Low income & homeless people • Seniors and older adults • Sex workers • Mental/Physical Disability |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none"> • Plain language summaries of existing research/knowledge |

4. Risk and Resilience (13 votes)

| Research Needs |
|--|
| <ul style="list-style-type: none"> • Identification of risk takers and the reasons why they engage in risk taking behaviours • Increase knowledge individual factors related to risk and resilience: Need more research on the role of individual strengths; Trauma/Posttraumatic stress disorder (PTSD) in relation to putting people at risk; first psychotic break as it relates to: concurrent conditions and coming out and risk and resilience • Increased knowledge of the social determinants of health and their role in risk/resilience: Role of community in building strength/resilience; Understanding resilience in the context of poverty; Isolation as a risk factor • The role of geography in risk and resilience: Rural & small cities - resilience and vulnerability for LGBT • Relationship with the justice system and associated risks • More longitudinal studies and qualitative research |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none"> • No identified areas for knowledge exchange |

5. OTHER - Theme 2: Health Systems/Services Research (13 votes)

| Research Needs |
|--|
| <ul style="list-style-type: none"> • Longitudinal studies to understand long term outcomes • Housing (youth) • Safer use sites • Standards of care across mental health and addictions services • LGBT fertility & healthcare as it relates to mental health • Comparative study of different models of positive space • Peer involvement in research role of self-identification both for people & service providers • LGBT inclusive in-take forms & screening assessments |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none"> • Best practices for services and positive space |

6. Data Quality/Analysis (11 votes)

General Comments:

- Reach more agencies to recruit participants
- More research partnerships are needed for cross-fertilization
- More funding for community-based research
- Researchers need ways to reach transient LGBT communities and other populations not represented

| Research Needs |
|--|
| <ul style="list-style-type: none"> • More multi-method, longitudinal designs and more qualitative research • Ontario Common Assessment of Need - does this new tool being rolled out for community mental health programs in Ontario fit LGBT needs? • Statistics Canada should ask about gender identity • Separate data for LGBT • Best practices for services and positive space |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none"> • Better access to data for lay people |

7. Capacity Building (10 votes)

General Comments:

- LGBT communities in calls for proposals
- More knowledge exchange practices were identified rather than research needs for capacity building

| Research Needs |
|---|
| <ul style="list-style-type: none">• Research into how to build on existing work and improve peer-led opportunities• Research on benefits of training of medical professionals on LGBT health |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none">• Join existing webinars & teleconferences• Education topics for clinicians to access info on LGBT• Have structured meetings (ongoing re: LGBT, health issues, research, etc.)• Mentoring and funding for students• Curriculum development at post-secondary level• Better systems/mechanisms for partnerships |

8. Health Promotion and Prevention (8 votes)

General Comments:

- Suicide prevention programs are needed

| Research Needs |
|---|
| <ul style="list-style-type: none">• Research into the role of social determinants of health in health promotion and illness prevention• Health promotion and prevention needs of the various LGBT communities: Sexual health for LGBT females; Impact of Gay Straight Alliance programs in schools on LGBT youth• Research on targeted health promotion and prevention programs• Research into health promotion and prevention needs across life span• Research on role of community support - anti-bullying as a health promotion strategy |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none">• Plain language material for health promotion and available in multiple languages |

9. Continuity of Care (6 votes)

General Comments:

- Where do LGBT youth go after transitioning/coming out?
- What mental health and addictions services exist within justice system?

| Research Needs |
|---|
| <ul style="list-style-type: none">• Connect systems to track clients• Further research into disclosure issues: ongoing coming out/disclosure of sexual orientation/gender identification; Self identifying when pregnant (not respected)• Which services commit to being inclusive for LGBT and what does it mean? I.e. whether LGBT is specifically mentioned in program materials, and whether the program model takes account of LGBT needs and issues (discrimination and its effects, safe space, community building etc)• Research into how family health teams can increase their ability to deal with more complex cases/issues• Impact of coordination of care on continuity of care |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none">• Disseminate and implement best practices in housing, shelters & other residential services |

10. Other - Theme 3: Research Resources (6 votes)

| Research Needs |
|--|
| <ul style="list-style-type: none">• Power dynamics with community-based research |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none">• Where to find funding dollars for research priorities• More access to technology (i.e. webinars, electronic journals, etc.) |

11. Performance Monitoring (5 votes)

General Comments:

- LGBT inclusive intake forms and waiting rooms;
- Report back to communities of interest should occur with performance monitoring;
- Suicide services for LGBT are missing.

| Research Needs |
|---|
| <ul style="list-style-type: none"> • Conduct user satisfaction research with services • Sex designation: Develop more descriptive sex designation (within the different databases - standardized); Electronic health records - categories need to be developed; How many services ask about sex orientation/gender in assessment (develop best practices in asking about gender) • Evaluate effectiveness of treatment for LGBT communities • Research the relationship between LGBT & Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) diagnoses • Gather baseline stats of LGBT communities within mental health and addictions services • Is Ontario Common Assessment of Need (OCAN) an effective tool for LGBT communities? • Research on different languages of service providers (i.e. addictions vs mental health sector) |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none"> • No identified areas for knowledge exchange |

12. Health Economics (5 votes)

General Comments:

- Increase health info for LGBT (e.g. cost of smoking)

| Research Needs |
|--|
| <ul style="list-style-type: none"> • Research around waitlist & costs associated with them • Specialized versus generic services: Are LGBT mandated services cost-effective and/or preferred?/Cost benefit of dedicated services vs general services; Cost/benefits of collaboration & integration of mental health and addiction services • Economic benefits of harm reduction & safe use sites • Comparative study on access & cost of mental health and addictions for LGBT communities in urban vs rural settings • Assess costs and benefits of health promotion/illness prevention approaches e.g., what is the impact on service use? |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none"> • No identified areas for knowledge exchange |

13. Health Human Resources (5 votes)

General Comments:

- Standards of care are needed for LGBT communities
- The way the current mental health and addictions systems operate makes it hard for LGBT individuals to be open
- LGBT staff not supported to be out

| Research Needs |
|---|
| <ul style="list-style-type: none">• Areas for service provider related research: does gender make a difference?; What is the effect of having LGBT staff serve LGBT clients?; what services are accessible to LGBT?; Research is needed on capacity, support, safety of LGBT staff in mental health and addictions settings.• What is the effect of lack of standards for services serving LGBT individuals? |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none">• No identified areas for knowledge exchange |

14. Integration (4 votes)

| Research Needs |
|--|
| <ul style="list-style-type: none">• Service integration: Research into how to integrate LGBT into bigger programs?; Do other integration models (e.g. clinical decision support system work for LGBT) assess impact on LGBT individuals being served through mainstream mental health and addictions programs. How to integrate culturally competent services for LGBT people within mainstream services?• How best to deliver culturally appropriate LGBT care and services?• Are the LHINS improving mental health and addictions services for LGBT population?• How accessible are mainstream mental health and addictions services for the LGBT population?• How best to integrate different ministerial programs? |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none">• Communities of LGBT practice to enable research & discussion |

15. Knowledge Transfer and Exchange (4 votes)

General Comments:

- Most of what is gathered below pertains to knowledge transfer and exchange practices and not research needs for knowledge exchange

| Research Needs |
|--|
| <ul style="list-style-type: none"> • Research on effective knowledge transfer and exchange (KT) for LGBT communities |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none"> • Best practices for dissemination/engagement with communities (making it sexy!) • Increase access of literature re: discrimination on sexual orientation/gender identity & effect on mental health • More KT on treatments • More KT on HIV & concurrent disorders & safe sites • Plain language - what exists • More user friendly KT • Increased access for LGBT communities to: journals for agencies; to databases & concurrent LGBT research; free access to academic papers • Teaching database on research skills |

16. OTHER - Theme 1: Social Determinants of Health (2 votes)

| Research Needs |
|--|
| <ul style="list-style-type: none"> • Social Determinants of Health: Education; Employment; Supportive housing specific to LGBT • LGBT communities: Empower LGBT service users; effects of power dynamics within LGBT communities; Violence in LGBT communities - how it relates to mental health and addictions; target LGBT youth • System issues: How "phobia" impacts research; Traumatized by the system, how do you engage? LGBT rarely accounted in forms; Intersectionality approach, beneficial but expensive practice • Trauma • Family dynamics |
| Existing Knowledge Exchange |
| <ul style="list-style-type: none"> • No identified areas for knowledge exchange |

3. PRIORITIES BY STAKEHOLDER GROUP

The top priorities by the primary role groups (consumer and family member; service provider; allied profession/sector; policy maker, system planner, provincial organization; researcher; or other) were:

- 1. Consumer and family (N = 20)**
 - Health Systems Research - Other - 4/20
 - Stigma and discrimination - 2/20
 - Continuity of care - 2/20
 - Health promotion and prevention - 2/20
 - Data Quality/Analysis - 2/20
 - Research Resources - Other - 2/20

- 2. Mental health and addictions service providers (N = 67)**
 - Program evaluation - 15/67
 - Risk and resilience - 9/67
 - Vulnerable populations - 6/67

- 3. Allied professions and sectors (N = 22)**
 - Vulnerable populations - 7/22
 - Stigma and discrimination - 3/22
 - Performance monitoring - 3/22
 - Health Systems Research - Other - 3/22

- 4. Policy makers, system planners, provincial organizations (N = 15)**
 - Stigma and discrimination - 2/15
 - Health economics - 2/15
 - Health human resources - 2/15
 - Program evaluation - 2/15
 - Health promotion & prevention - 2/15
 - Health Systems Research - Other - 2/15

- 5. Researchers (N = 23)**
 - Stigma and discrimination - 6/23
 - Data quality/analysis - 4/23
 - Capacity building - 4/23

- 6. Other (N = 0)**

4. CONCLUSIONS

There are many areas where knowledge is needed and can be addressed through both research and knowledge exchange.

It is clear that participants are concerned about the gaps in knowledge and skills in serving LGBT people within mental health and addictions programs. The consultation cited multiple issues in connection with this view - lack of education in professional schools, lack of continuing education, and failure to recognize the different needs of LGBT people and the sub-groups (diversity) within this community.

The issue of stigma and discrimination came up in relation to mental illness or addictions but also clearly in relation to the stigma that some LGBT people feel about their sexual orientation and gender identity and also the widespread discrimination and social exclusion that they experience. Many participants suggest that this be recognized as a causal factor or a contributing factor in mental health and addictions problems. There is some research on this but not much that is Canadian and little knowledge exchange of these ideas.

The significant focus on health service evaluation suggests that participants want to know how adequately (or inadequately) the mental health and addiction system is performing in relation to LGBT people. For example, is it providing welcoming and safe environments? Are the opportunities to discuss the unique issues and stressors that affect LGBT people? Are links being made to issues such as anxiety, depression and suicidality as well as alcohol and drug use?

From the results, it can also be interpreted that topics such as continuity of care, integration and health economics received fewer votes because service geared to LGBT people are still in such a preliminary stage of development and these might be issue to look at a later point.