Youth engagement in the design of services and research for youth mental health and addictions services: Innovative projects and key youth contributions

**Chair:** Kristin Cleverley  
**Discussant:** Michelle Munson

**Presenters:** Jessica Rong, Kristin Cleverley, Jackie Relihan, Joanna Henderson
Overall Symposium Objectives

• Recognize the important role of youth engagement to optimize research projects using a wide range of research designs

• Become familiar with methods of engaging youth as expert consultants and co-designers

• Understand the specific effects youth can have on project design and implementation.
Presentations

• Engaging youth in the co-design of an instructional video for an online Delphi survey to prioritize core components of child to adult mental health care transitions.

• Youth engagement in a pragmatic randomized controlled trial: integrated collaborative care teams for youth mental health and addictions

• Youth friendliness in mental health and addictions settings: A scoping review of the literature
Engaging youth in the co-design of an instructional video for an online Delphi survey to prioritize core components of mental health care transitions

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Transitions from CAMHS to AMHS

Risks of poor CAMHS-AMHS Transitions

- More severe and enduring MH problems
- Improper medication monitoring
- Increased involvement in justice system
- Dropping out of care
- Increase in risky behaviours
- Jeopardizes other developmental life trajectories
- More vulnerable & less resilient over time

Davis, Geller, and Hunt, 2006; Davidson and Cappelli, 2011; Gulliver, Griffins and Christensen, 2010; MHCC, 2015
Existing issues in Research and Practice

• Lack of psychometrically sound instruments to evaluate transition interventions
• Little existing research evaluating transition interventions
• No reliable and valid set of core components to assess quality of transition
• No consensus among experts as to which core components are important and feasible in the evaluation of transition programs
• No authentic engagement of youth and caregivers in the development of core components
Building Consensus on Core Components of CAMHS to AMHS Transitions: A Delphi Study

• **Delphi**: a multi-staged online survey designed to achieve consensus among experts on an important issue

• **Purpose**: to authentically engage youth, parents/caregivers, clinicians, and administrators/policy-makers as experts in a Delphi study to come to consensus on core components that can be used to improve the quality of CAMHS-AMHS transitions
Delphi Study Details

• Selection of Experts: 4 expert panels with equal numbers of youth, parents/caregivers, clinicians, and administrators/policy makers.

• Recruitment: nation-wide, invite sent out via youth, parent networks

• Data collection: Two online survey rounds, ratings based on importance and feasibility

• Analysis:
  • Core components refined/added/dropped based on consensus within each expert group
  • Consensus within and between groups examined to understand key commonalities and differences
Delphi Video Creation Process

June
• EAC Meeting
• Brainstorming general information to include in the Delphi video

July
• Youth + Research team meeting
• Review and give feedback on draft script (written by RA)
• Consensus on definition of key terms, narrative flow, principles of video graphic design

Aug
• Youth, Research team, and Graphic Designer Meeting
• Review and give feedback on draft video
• Consensus on revisions: aligning script content and visuals, representations of youth, survey walk-through

Oct
• EAC Meeting
• Review and give feedback on completed video
• Consensus on minor edits for finalization
Patient Engagement

• **Strategy for Patient-Oriented Research Patient Engagement Framework:** research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes

• **Expert Advisory Committee (EAC):** Youth, family members, and knowledge users provide guidance and feedback at all stages of the research process

• **EAC feedback:**
  • Need for supplemental materials for youth and parents/caregiver experts to make decisions in the Delphi.
  • Video co-created with the youth to introduce the study, provide an overview of the instructions, and be embedded in the introduction of the online survey
Youth Engagement throughout the Project

The Youth Engagement Initiative (YEI) Team is made up of four Youth Engagement Facilitators (YEFs) and a Youth Engagement Coordinator and is based out of the McCain Centre for Child, Youth, and Family Mental Health at CAMH.

The Youth Engagement Facilitators bring their perspective as youth with lived experience into research and program activities related to youth mental health and substance use.
Video Creation
Youth Engagement throughout the Project

• It is crucial to ensure that a study is easily accessible to this population in order to receive valid results.

• Youth participation in research is important, as it can provide a perspective that is commonly forgotten.
Youth Engagement throughout the Project

**Recruitment Consultations**

- **Recruitment strategies should not be an afterthought**, they require frequent updates.

- **Meet youth where they are at.** Often youth may not feel comfortable entering the academic realm. When researchers make an effort to be accommodating and welcoming, youth are more likely to be genuinely engaged.

- **Highlight the benefits for youth**: i.e. the potential to be a part of social and structural change, honorarium, etc.
Youth Engagement throughout the Project

Youth Networking
What is Youth Engagement

“Youth engagement is a whole community approach to mental health care and an active and ongoing process that embeds youth voice at all levels. It is a set of practices that offer youth opportunities to develop meaningful relationships with adults, learn skills, work on issues they're passionate about and contribute to social change.”

The Ontario Centre of Excellence for Child and Youth Mental Health
Youth Engagement throughout the Project

• Meet regularly over the course of the project to guide:
  • recruitment strategies;
  • development of supplemental Delphi study materials;
  • development of the study website;
  • interpretation of findings;
  • development of knowledge translation goals and strategies;
  • dissemination of the project findings to knowledge users
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YouthCan IMPACT

Youth engagement in a pragmatic RCT: Integrated collaborative care teams for youth mental health and addictions

Jackie Relihan; Joanna Henderson, PhD, CPsych; Lisa Hawke, PhD; Gloria Chaim, MSW, RSW; Kristin Cleverley, RN, PhD
A Collaborative Project!

Principal Funders:

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- Marilyn & Charles Baillie

Other Funders:

- SKYLARK
- east metro youth services
- LOFT
- The Sashbear Foundation
- Margaret and Wallace McCain Centre for Child, Youth and Family Mental Health
- The Anne Johnston Health Station
- South East Toronto Family Health Team
- Michael Garron Hospital
- Sunnybrook Health Sciences Centre
- SickKids
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Integrative Collaborative Care Team (ICCT)

• ICCT funded by CIHR and OSSUs (3 year RCT)
• Collaboration between
  – SickKids, CAMH, TEGH, Sunnybrook
  – EMYS, Skylark
  – LOFT, Sashbear, Anne Johnston Health Station, South East Family Health Team
• First RCT of an “Integrated Service Hub” model worldwide
Objectives

To address MHA system gaps...

• Work with youth, families, and stakeholders to test the benefits of ICCTs for youth with MHA challenges
  – Develop model in partnership with community agencies, adolescent psychiatry hospital departments, and family health teams (FHTs)
  – Engage youth and families in all phases of the project to ensure that services are responsive to their evolving needs

• Provide rapid access to MHA services, system navigation, evidence-based interventions matched to level of need
A group of youth who access services went through a list of values they would like to see guiding the YouthCan IMPACT service providers.

A group of youth who access services went through a list of values they would like to see guiding the YouthCan IMPACT researchers.
Method

1) Phone Screen

2) Consent & Assessment

- 500 Youth aged 14-18
- 250 ICCT
  - 3 service centres
- 250 TAU
  - 4 hospitals

- 6 month Assessment
- 12 month Assessment
A nurse practitioner is a medical professional who can support you with your physical and mental health.

You may meet with the nurse practitioner once and then return back to your family doctor for follow-up, or you may want to schedule more appointments with the nurse practitioner.
Nurse practitioner's name:

Contact for booking and cancellations:

You can easily schedule an appointment with a nurse practitioner through your walk-in clinician.

What might the YouthCan IMPACT nurse practitioner do to support you:

- Order tests, prescribe medications, and help you better understand your mental and physical health concerns better.
- Help you with things like sleep, sexual health, healthier food choices, and other physical health concerns.
- Set goals with you for your health and provide follow-ups.
- Refer you to a psychiatrist if appropriate.
- Collaborate with your psychiatrist and family doctor to help you in planning your care.

If you're unsure about seeing a nurse practitioner or have any questions, please talk to your clinician.
Walk in therapy is offered by clinicians at all YouthCan IMPACT sites. In walk-in therapy an evidence-informed solution-focused brief therapy (SFBT) approach is used. Staff are non-judgmental, validate your concerns, and will work collaboratively with you.

Walk-in counselling sessions can last between 45-60 minutes.

* You can access these services with or without a health card.
How does a YouthCan IMPACT Walk-In session work?

- When you arrive at the site let the receptionist know that you're there for a walk-in session and they will give you a form to fill out. This form gives the team basic information about you and what you may want the clinician to know about why you came in. All the information that you provide is confidential.

- After you complete the form you will meet with a clinician. Together you will talk about what's on your mind that day.

- The focus of this session will be on abilities, resources, and skills that you have or want to further develop. Together you and the social worker will target a priority and co-develop a plan that you feel comfortable with.

- If at a later time you feel you need more help, you can come back to the walk-in during walk-in hours and continue another conversation about what's on your mind.
Primary & Secondary Outcomes

- Reduced wait times
- Improved satisfaction
- Reduced family burden
- Greater patient/family engagement

Clinical Outcomes
- Enhanced functioning
- Reduced symptoms

ICCT vs. TAU

Service Outcomes

Implementation Outcomes
- Strong community uptake
- EBP fidelity

Economic Outcomes
- Lower treatment cost
- Cost-benefit improvements
Youth Engagement in YouthCan IMPACT

• Co-designed the project website
Youth Engagement in YouthCan IMPACT

- Create resources for youth and researchers
  - What is Research?
  - Recommended Apps List
Youth Engagement in YouthCan IMPACT

• Review and contribute to manuscripts
  • A review of youth-friendliness in mental health and addiction services
  • Practical recommendations for research staff to engage youth in research planning, design and execution
Do’s and Don’ts of Youth Engagement

**DO**

- **HAVE CLEAR EXPECTATIONS**
  Know your goals and objectives and share them with your youth partners; be clear about the youth’s role and contribution

- **BE PARTNERS**
  Integrate youth voice into decision-making and identify environmental barriers to engagement

- **CHECK IN**
  Act as an adult ally by listening to youth feedback and offer mentorship where appropriate

- **GIVE TIME**
  Allow time for reflection; pre-brief and debrief sessions can clarify and build confidence

- **RECOGNIZE DIVERSITY**
  No single youth represents all youth perspectives; diverse voices deserve to be heard, respected and considered

- **VALUE CONTRIBUTIONS**
  Compensate youth for their participation in projects by providing a wage or honoraria

**DON’T**

- **DOMINATE THE CONVERSATION**
  Youth can feel intimidated or uneasy participating in meetings or on projects that don’t make space for their participation

- **BE TOKENISTIC**
  Ensure that youth voices are heard and acted upon; value youth perspectives and representation as stakeholders in your work

- **PRIVILEGE ONE FORM OF KNOWLEDGE**
  The purpose of collaboration and consultation is to have a diversity of voices at the table

- **DISREGARD FEEDBACK**
  Make space in the project timeline for consideration of feedback and follow up on the outcomes

- **STEER YOUTH**
  Allow youth to guide the conversation towards the issues and ideas that are most important to them
Trainings for Staff

• Staff training on Apps List
• Research staff training on things to consider when they are working with youth

“Have fun with it...Acknowledge that the assessments will likely be crappy and that you're there if there are any questions or if they just want to take a break to chat.”
Youth Engagement in YouthCan IMPACT

• Implementation Guidebook for Youth Hubs

Designing Your Service System:
What do youth want?

What types of services should be offered? Are there services youth have accessed that they would want to see continued? Are there any services that youth have accessed that have not been helpful?
Summary

• ‘One-stop shop’ community mental health centers
• Collaboration with hospitals, community service providers, youth, families
• Different types and levels of youth engagement throughout the project
For more information:

www.youthcanimpact.com

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Tweet #YouthCanIMPACT
What makes mental health and addictions services youth friendly?

Joanna Henderson, Ph.D. C.Psych.
Jackie Relihan
Youth-friendliness in mental health and addictions services

- There are increasing calls to make mental health and substance uses services youth friendly
- Youth friendliness can be an opportunity to improve:
  - Service uptake
  - Engagement
  - Satisfaction

However…

- Youth-friendliness in mental health and addictions services is not clearly defined
- There is a lack of information about the characteristics that make services youth friendly
Objectives

1. What are the characteristics of youth-friendly mental health and substance misuse services?

2. What is the expected impact of youth-friendly mental health and substance misuse services?

3. How are youth-friendly mental health and substance misuse services defined?
Study Method

Records identified through database and grey literature search (n = 292)

Additional records identified through references of relevant articles (n = 22)

Records included for screening (n = 314)

Records excluded (n = 123)

Duplicates removed (n = 94)

Records screened for title and abstract (n = 220)

Full-text articles assessed for eligibility (n = 97)

Full-text articles excluded (n = 69)

Studies included for data extraction and synthesis (n = 28)
Characteristics of youth-friendliness

Four main categories:

1. Organization and policy characteristics
2. Environment characteristics
3. Service provider characteristics
4. Treatment/service characteristics
Stakeholder Consultations

Youth

Caregivers

Service Providers
Youth Engagement in Consultations

1. Development of the consultations
2. Recruitment for the youth consultation
3. Co-facilitator for the youth consultation
Youth-friendly Organization and Policy

Promote Services

Youth Engagement

Integrated Services

Safe Space

- Trauma Informed Lens
- Positive Interaction
- Mental And Physical Health
- Technological Platforms
- No Retelling Stories
- Conflict Resolution
- Substance Issues
- No Discrimination
- Positive Interaction

- Apply Youth Ideas
- Social Support
- Co-Located
- Social Media
- Designed Publicity

- Youth Incentives
- Vocational Support
- Transition Of Services
- Listen To Youth
Youth-friendly Environment

Youth engagement

Artwork

Non-clinical

Posters

Colorful

Youth-made brochures

Refreshments

High ceilings

Music

Open space

Couches

Wifi

Appealing

Couches

Comfortable

Computers

Magazines

Relaxed

Fidget toys

Bean bags

High ceilings

Music

Open space

Couches

Wifi

Appealing

Couches

Comfortable

Computers

Magazines

Relaxed

Fidget toys

Bean bags
Youth-friendly Service Provider

- Youth culture
- Explore expectations
- Consent
- Active listener
- Remember youth stories
- Right & Responsibilities
- Respectful
- Informal communication
- Genuine
- Clinicians & Support Staff
- Consistency
- Validate youth feelings
- Address current worries
- Clear up misconceptions
- Without interruption

- Non-judgmental
- Outside activities
- Use humor
- Confidentiality
- Clinicians & Support Staff
- Non-judgmental
- Outside activities
- Use humor
- Confidentiality

- Positive
- New paradigms
- Build trust gradually
- Release biases
- Peer counsellors
- Self disclosure
- Happy

- Smile
- Active listener
- Remember youth stories
- Right & Responsibilities
- Respectful
- Informal communication
- Genuine
- Clinicians & Support Staff
- Consistency
- Validate youth feelings
- Address current worries
- Clear up misconceptions
- Without interruption

- Youth engagement
- Non-judgmental
- Outside activities
- Use humor
- Confidentiality
- Clinicians & Support Staff
Youth-friendly Treatment/Service

- Informed decision
- Youth engagement
- Minimal waiting
- Recreational activities
- Inclusive
- Evidence-based
- After school
- Telephone consultations
- Informal first contact
- With or without family
- Art or music therapy
- Flexible times
- Accessible location
- Multicultural
- Free or affordable
- Text message reminders
- Smooth transition
- Traditional therapies
- Simplified assessment
- Superheroes metaphor
- Non-medical terms
- Wait time support
- Confidentiality and privacy
- Drop in visits
- Gender appropriate
## Expected Impact of Youth-friendly MHA Services

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<th>Increased</th>
<th>Decreased</th>
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<td>• Youth connections</td>
<td>• Stress</td>
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<td>• Youth empowerment</td>
<td>• Suicidality</td>
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<td>• Acceptable services</td>
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Definition of Youth-friendly MHA Services:

“A youth-friendly mental health and addiction service is one which is accessible, appealing, flexible, confidential and integrated, where youth feel respected, valued, and welcome to express themselves authentically, without discrimination of any kind; it is a developmentally and culturally appropriate service, that mandates youth participation in healthcare design and delivery, to empower youth and help them gain control over their lives.”
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Symposium Questions and Discussion