# Shaping the Future of Transitional Mental Health & Addition Services for Young People

Mario Cappelli, Ph.D., Director of Psychiatric & Mental Health Research, CHEO



## Acknowledgements:

#### Research Group:

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### Partner Organizations:

 University of Ottawa, Youth Services Bureau, Canadian Mental Health Association, Dave Smith Centre, Royal Ottawa Mental Health Centre, Queensway-Carleton Hospital, Montfort Hospital, Children's Hospital of Eastern Ontario, Ottawa Hospital

#### Funding Support:

- Champlain LHIN, Ontario Centre of Excellence for Child and Youth Mental Health, CHEO RI, CIHR, CHEO Psychiatry Associates Research Fund, & the Mental Health Commission of Canada
- Colleagues: Simon Davidson, Melissa Vloet, & Jenny Carver

## Guiding Principals:

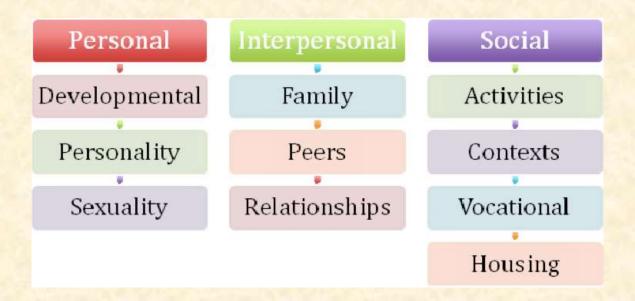
- Evidence Based: Existing or Create
- Best Clinical Practice: Expert Opinion
- Inclusionary: Young People, Family Members, Providers, Policy Makers
- Develop Local but Think Global

## Presentation Outline

- Brief Background
- Highlight the outcomes of each of the deliverables
- Conclude with most recent work
- Caveats: focus largely on Mental Health and only a small "A"; excluded Dual Diagnosis

# Not just about Mental Health & Addiction

Multiple transition factors (interface between institutions, community and individual factors)



## Definition:

Transition: (Blum, 1993)

Purposeful, planned movement from child-centered to adult-oriented health care systems

Care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive

Transfer: (Burke et al., 2008 as cited in Singh et al, 2010)

Termination of care by a children's health provider which is re-established with an adult provider

## Background:

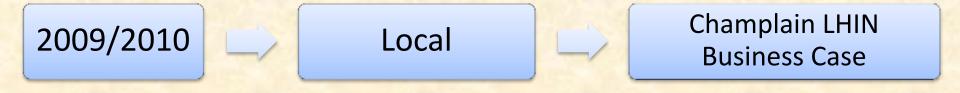
- 70% of mental health problems begin in childhood or adolescence (Statistics Canada, 2002)
- 60% of known cases, young people with enduring mental health & addiction concerns and continuing needs disengage from service during the transition
- Re-engagement is usually crisis driven
- Vulnerable youth, e.g. socially isolated males with a high level of service needs, are the most likely to disengage
- Untreated children and adolescents with mental health & addiction concerns become "more vulnerable and less resilient" with time

# Statement of The Problem (McGorry, 2007):

"Public mental health services have followed a pediatric split in service delivery, mirroring general and acute health care. The pattern of peak onset and the burden of mental disorders in young people means that the maximum weakness and discontinuity in the system occurs just when it should be at its strongest"

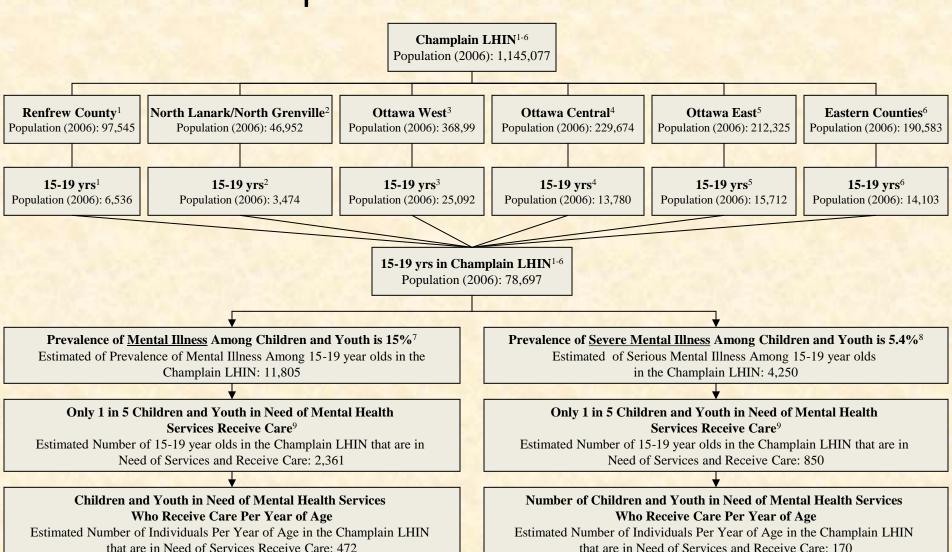
## Time & Context Overview:





The purpose of this study was to identify the organizational factors that facilitate or impede effective transition between CAMHS and AMHS. The objectives of this project included: 1) estimating the numbers of transitional youth/young adults in the Champlain LHIN with mental health disorders and 2) identifying barriers and facilitators to achieving successful transition.

## Estimation Model - Youth Distributed by Champlain Counties for 2006



# 2<sup>nd</sup> Objective: Sources of Information (TRACK measures)

Participants	Method
Team Leaders and Program Managers	Survey
Service Providers	Focus Group
Youth	Focus Group
Parents	Focus Group

# Findings from Team Leaders Questionnaire

#### Lack of Policy/Direction Indicated

"Process is much more half hazard – if youth do not fit the criteria ... unfortunately, patients are often sent back to their family physician without their appropriate follow up arrangements"

#### **Barriers to Achieving Successful Transition**

"Different approach (philosophy) in providing services through the life span. (E.g. in child and adolescent psychiatry, the work involves a partnership with the family, the school, CAS while in adult services, the work is mostly done with the patient only"

"Stringent criteria in adult specialized programs in which many youth do not fit."

## Findings from Youth Focus Group

#### Theme 01: Difficulties Accessing Services/Retaining Care

"I didn't feel better inside I felt like what am I suppose to like do something horrible to myself to make you realize that I'm actually not doing well"

#### Theme 02: Poor Transitional Planning

"you're in the middle of a crisis and you're in the hospital and because your birthday comes while you're in there they'll wheel you away. And that terrified me so as I got older I would panic."

#### Theme 03: Philosophical Differences

"CAMHS it's more of a lean on me we'll walk down this road where out of CAMHS its kind of like take a hike, there's the road that's all you get. You have to depend on yourself a lot more and that can be hard when you don't have a lot of trust in yourself.

## Youth Goals for Transitions

#### **Youth Driven**

"Important thing is respecting the patient's wishes of what is transition to them. Working with the patient to figure out what the transition plan is for them instead of like saying it to them and saying this is what you're going to do. Asking like, what do you think would be helpful? I felt like that wasn't really done."

#### Supportive, Coordinated and Planned

"Maybe if they know you're going to be transferred to AMHS maybe bringing you there with somebody, seeing the place, kind of getting more comfortable instead of just poof you're there."

#### **Communication/Shared Care**

"More communication between CAMHS and the AMHS when you're being transferred ...your chart is so thick that... on the first day and your having an anxiety attack they don't have time to go through it to see that X drug is not good for her system."

## Findings from Parent Focus Group

#### Theme 01: Accessing Services

"The wait time is excruciating. I essentially advise parents to mortgage their house and go get private care."

"... there are services but they're fractured throughout the community."

#### Theme 02: Difficulties with Transitioning

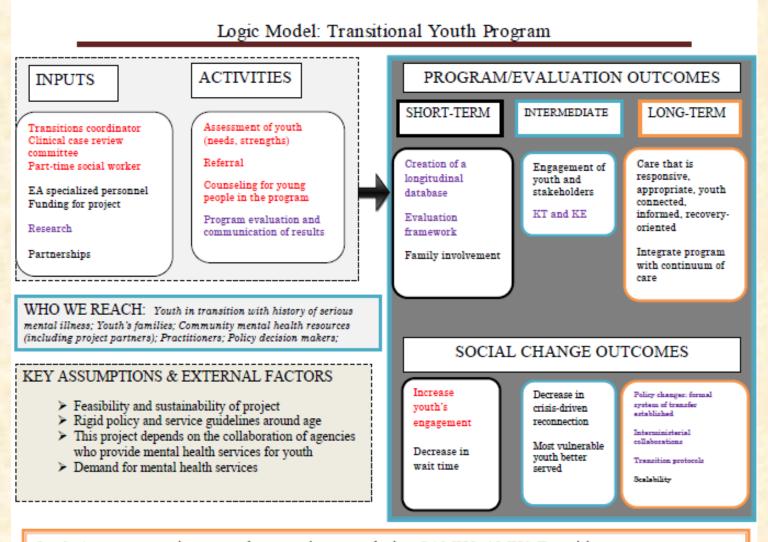
(at point of transition) "Now we're figuring out where her treatment goes. There's a lot of shuffling, to figure out where her clinic work will go and which doctors will prescribe meds. So it's very confusing. She's (daughter) been worrying about it for over a year."

"There's no communication there. That's the biggest thing; it's not a collaborative thing. They did not listen."

## Parent Goals for Transition

"We need to have transition workers who are aware of the different issues. We're all dealing with the need for respite; we're all dealing with the need for continuity of care; safety; we all need some form of education and some part of assisted employment and assisted living. We all need these things."

## Recommendations lead to the development of the Ottawa Transitions Program



Goal: Access to continuous and appropriate care during CAMHS-AMHS Transition







Provincial Policy Paper -Centre of Excellence

- Explore three sources of data: scientific publications; published guidelines and protocols; and mental health service program websites.
- The purpose: to outline the current barriers and facilitators to service delivery during this transition of care phase from child and youth services to adult services as well as examine best practice guidelines in this area.

# Provincial Policy Ready Paper: Ontario Centre of Excellence for Child and Youth Mental Health

 In order to meet the objectives of this paper, the research team will meet with key policy makers in Ontario to understand their needs and once the review of literature is complete to ensure policy implications are being included in the final document.

## Facilitators to Effective Transition

- Empirically informed practice guidelines
  - 1. An active, future-focused process
  - 2. Young-person-centered
  - 3. Inclusive of parents/care-givers
  - 4. Starts early
  - 5. Resilience framework
  - 6. Multidisciplinary, inter-agency
  - 7. Involves **pediatric** and **adult** services, in addition to **primary care**

## Facilitators... Cont.

- 8. Provision of coordinated, uninterrupted health care
  - Age and developmentally appropriate
  - Culturally appropriate
  - Comprehensive, flexible, responsive
  - Holistic medical, psychosocial and educational/vocational aspects
- 9. Skills training for the young person in communication, decision-making, assertiveness, self-care, and self-management.
- 10. Enhance sense of control and interdependence in healthcare
- 11. To maximize life-long functioning and potential

## Identifying Transitional Models

Reciprocal Service
Agreements (BRIDGE
& TRACK Studies, UK)

Having agreements to direct the transition helps clarify roles and responsibilities

Protocols must be realistic given the context of the service and they must be used to be effective

Often relies on chronological age

Standalone Transition
Service Providers (e.g.,
"Orygen" & "Headspace" in
Melbourne, Australia,
"Youthspace" in UK)

Prioritizes the transition for youth

Targets youth from 12-25

Considers developmental age

Costly and contingent upon stakeholder buy-in at multiple government and community levels.

Youth encounter two transitions: at entry and exit.

#### Transition Teams

Better coordination of care

Shared Management Model

Assists in the management of responsibility concerns.

CAMHS-AMHS Team Collaboration

Costs associated

Requires buy-in by service providers.

Untried in mental health

# 2<sup>nd</sup> Objective: Meeting in Toronto April 2010 with Policy Makers

Name	Position	Ministry
Charlotte Moore	ADM	MOH
Darryl Sturtevant	ADM	MCYS
Aryeh Gitterman	ADM	MCYS
Marian Mlakar	Director	MCYS
Grant Clarke	ADM (A)	EDU
Barry Finlay	Director (A)	EDU
Nancy Naylor	ADM	MTCU
Ellen Passmore	Director	MTCU
Nancy Lum-Wilson	Team Lead	MOH
Susan Paetkau	Director	MOH

## Key Messages

- 1. Clear channels of communication to be established between Ministerial leadership bodies.
- A. Make mental health transitions from CAMHS to AMHS a priority.
- B. Facilitate the adoption of a model of care that is informed by best practice guidelines and research on transitional planning for youth.
- C. Align the ministries with the shared goal of adopting a model of care and monitoring outcomes of the selected model.
- D. Encourage inter-ministerial collaborations for CAMHS to AMHS transitions at the policy level.
- 2. The selected model of care to maintain a youth-centered approach where transitional planning is completed proactively rather than reactively
- A. Be collaborative, involving multidisciplinary perspectives and communication between CAMHS and AMHS agencies. This will need an holistic approach that emphasizes the importance of a number of variables, including medical and psychosocial factors.
- B. Provide care that is coordinated, comprehensive and seamless. This care needs to be flexible and should be driven by the needs and developmental age of the youth.
- C. Acknowledge resilience factors and encourage the inclusion of parents and caregivers while balancing/fostering a sense of independence and responsibility in youth.
- 3. The transition program that is selected should be guided by current evidence in knowledge translation and implementation science
- A. Enhance levels of knowledge of health team leaders and healthcare providers within a developmental context.
- B. Encourage all allied health professionals to recognize that acting to improve mental health transitions is a priority.
- C. Facilitate future uptake of the program along with the monitoring and evaluation of outcome data.



Vloet, M., Davidson, S., & Cappelli, M. (2011). We Suffer from Being Lost": Formulating Policies to Reclaim Youth in Mental Health Transitions. <u>Healthcare Quarterly</u>. 14(2), 32-38



#### International

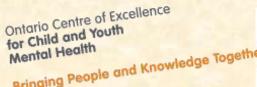


CIHR International Symposium,

### **Objectives of Meeting**

- Establish a collaborative network of national and international researchers studying youth mental health transitions
- Develop a consensus statement describing a gold standard of transitional care for youth
- 3. Create a framework (i.e., a common evaluative, outcomes-based platform) to study the efficacy of transitional practices
- 4. Use this framework as the foundation for future research initiatives including studies aimed at identifying evidenced-based practices for youth mental health transitions







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## Over 50 Participants



- 1. <u>Suzanne Archie</u>, **McMaster University**, Hamilton, ON
- 2. Max Birchwood, **Youthspace**, Birmingham, UK
- 3. Gary Blau, Center for Mental Health Services; Washington, US
- 4. <u>Pamela Brown</u>, **Ministry of Children and Youth Services**, Toronto, ON
- 5. Sarah Cannon, Parent Participant, Niagara, ON
- 6. Mary Ann Davis, University of Massachusetts, Boston, MA
- Sheree Davis, Ministry of Health & Long-term Care, Toronto, ON
- 8. <u>Aaron Goodwin</u>, Youth Participant, Halifax, NS
- 9. <u>Ashok Malla</u>, **McGill University/Douglas Hospital**, Montreal, QC
- 10. Steve Mathias, University of British Columbia, Vancouver, BC
- Patrick McGorry, Orygen/Headspace, Melbourne, Australia
- lan Manion, Ottawa Centre of Excellence for Children and Youth Mental Health, Ottawa, ON
- 13. <u>Kwame, McKenzie</u>, **University of Toronto, Centre for Addiction and Mental Health**, Toronto, ON
- Moli Paul, **University of Warwick**, Warwick, UK
- David Pilon, Capital District Mental Health Program, Halifax, NS
- <u>Cathy Richards</u>, **National Health Service Lothian**, Edinburgh, Scotland
- 17. Swaran Singh, University of Warwick, Warwick, UK
- Janet Walker, Portland State University, Portland, OR

# An International Perspective on Youth Transitions: Outcome

Unable to meet the objectives of the meeting:

- Tension between models: Transition Teams versus
   StandAlone Programs
- Transition Models: Ottawa Transitional Program, Lothian's
   Joint Mental Health and Wellbeing Program, TRACK/Bridge

   Program
- StandAlone Programs: Youthspace, ORYGEN, Headspace

# An International Perspective on Youth Transitions: Outcome

#### **VISION STATEMENT**

"Our goal is to foster confidence and self-determination throughout transitions to help young people and emerging adults move toward their visions of success. Mental health and addictions care will be resiliency focused and propelled by the needs AND strengths of young people, families, and communities."



Commission de la santé mentale du Canada

2013/2014



**National** 



MHCC Policy Ready Paper





- Transition Services outlined in The Mental Health Commission of Canada's (MHCC) National Mental Health Strategy
- 2013 RFP rewarded to the Children's Hospital of Eastern Ontario (CHEO) to write a national report on the current status of services for youth transitioning into adult mental health services (Emerging Adult)



# Taking the Next Step Forward: Building a Responsive Mental Health and Addictions System for Emerging Adults

prepared by

Jenny Carver, Mario Cappelli, Simon Davidson,

Warren Caldwell, Marc-André Bélair, Melissa Vloet

"This is a Magnum Opus which will be of great use as a resource to the field", Patrick McGorry

#### What did we do?

- Consulted with up to 50 experts from around the World
- Integrated available literature from peerreviewed studies
- Gathered and compared relevant policy documents from across Canada and internationally
- Input from provincial, and national leaders in policy and program development





## Input for Ontario LHINS

LHIN	MH Lead Contacted	Title
Central	Ashley Hogue	Senior Planner
North West	Brent Maranzan	Senior Consultant
Erie St. Clair	Dawn Maziak	Health System Design Manager
Mississaug a Halton	Ed Castro	Mental Health & Addictions Lead
Hamilton Niagara Haldimand Brant	Heather Riddell	Advisor, Health System Transformation
Central East	Jai Mills	Mental Health & Addictions & Aboriginal Strategy Lead
Waterloo Wellington	Patricia Syms Sutherland	Senior Manager
Central West	Suzanne Robinson	Director, Health Systems Integration

## **Provincial & Territorial Leaders**

Province	Lead Contacted	Title	Note:				
ВС	Deborah Saari	Director CYMH Policy	Monica Flexhaug also in attendance				
АВ	Shelley Birchard	Manager, Addictions and MH Branch	Sandy Nickel, Denise Salanski, Jodi Lane also in attendance				
SK	Joe Kluger	Mental Health & Youth					
MB	Leanne Boyd	Director - Policy Development, Research and Evaluation	Marg Synyshyn also in attendance				
ON	Mary Manella	Manager, Mental Health Programs Unit	Pamela Brown also in attendance				
QC	Dr. André Delorme	Directeur de la santé mentale					
NB	Yvette Doiron	Director, Child and Youth Services Director					
NS	Patricia Murray	Special Advisor to the Associate Deputy Minister on Mental Health and Addictions	Francine Vezina also in attendance				
PEI	Bobby Jo Flynn	Mental Health Programming Lead					
YK							
NT	Andy Langford	Director of Community Wellness and Social Service					
NU							

#### What is the current process for ensuring successful transition from CAMHS to AMHS?

What is the cut-off age or criteria for the end of CAMHS and starting age or criteria for take up into adult mental health services?

What services are available to service users/carers during transition?

Range of services?

Geographical boundaries?

Links to voluntary organizations?

How do the range and availability of services meet user/carer needs? Availability of policies and guidelines to staff to inform the process of transition?

#### How are services currently organized to achieve successful transition?

Organizational structures? Management systems? Model?

Collaborative decision making?

Communication of decisions to support transition?

Resources to support transition?

Adequate funding? Sources?

What human resources are involved? Are they organized in teams? What shortages exist? Use of temporary staff?

Access to information and computer equipment?

Is there an evaluation component to assessing your transition program(s)?

#### What are the greatest challenges to achieving successful transition in the way services are currently organized?

Most common three?

Why do you think these barriers exist?

How can these be reduced or overcome?

What would help you to overcome them?

#### How do you manage/promote inter-agency work during transition? Between...

Child and Youth Services

Community and Social Services

**Justice** 

Schools (college + university)

Adult health services

How is decision-making accomplished when multiple agencies are involved?

#### How does this impact on achieving transition?

Please give examples based on your experience

### **Current Landscape**

#### National

 Limited policies being implemented for the provision of mental health services to EAs

#### Provincial

- All provinces identify 'children and youth' as a priority
  - No province utilizes a CAMHAS/AMHAS transitional protocol for EAs
  - No province is tracking EAs across the CAMHAS/AMHAS transition
  - No province has mandated <u>services</u> designed for the needs of EAs

#### Regional Areas

 Lack of <u>co-ordination</u> between agencies is a significant barrier to the provision of care to EAs



Commission de la santé mentale du Canada

Emerging Adult Service Framework



System supports to ensure accountability and performance

measurement

exchange

envelope

and protocols

## Proposed Report Recommendations: National Implementation

- Develop a National Action Plan for EA mental health and addictions
- Establish a National EA Advisory Group
- Establish a knowledge exchange policy for provinces to share information about EAs
  - Create an annual summary report card of National outcomes on EA mental health
  - Establish funding for a longitudinal tracking study to include youth transitions from CAMHAS to AMHAS
- Appoint a Canada Research Chair for Emerging Adults Mental Health

## Proposed Report Recommendations: Provincial Implementation

- Establish EA mental health and addictions as a provincial priority starting with the most vulnerable populations.
- Establish a premier-led interministerial cabinet committee to oversee EA outcomes
- Establish provincial/territorial EA Advisory Council
- Identify a single ministry to be accountable for EA outcomes
- Establish service delivery standards for EA services and evidence-based practices

## Proposed Report Recommendations: Regional Implementation

- Develop a strategic plan to enhance transitions between CAMHAS and AMHAS
- Document and report on CAMHAS/AMHAS transitions (Referral, wait times, engagement, satisfaction, success)
- Develop regional EA core services
  - Establish a Regional Lead for Transitions and Emerging Adult
     Mental Health

# Regional Core Basket of MH & A Services

- 1. Acute inpatient mental health beds
- 2. Community-based, comprehensive day treatment & high intensity clinical services
- 3. First episode/early intervention for all diagnoses including screening, assessment, treatment services
- 4. System navigators
- 5. Peer support/mentoring roles
- 6. Family engagement, education, and support
- 7. Transition team coordination resources



- Re-engaging Provinces & Territories
- Original provincial and territorial leaders offered opportunity to review and comment on the Report
- MHCC PTAG presentation

## PTAG Meeting: June 4<sup>rd</sup>, 2014

PT r	Representing		
Colleen Simms	Director, Mental Health and Addictions	NL	
Dr Rhonda Matters	Chief Mental Health and Addictions Officer	PEI	
Copy & alternate Heather Rix	Nursing Policy Analyst/Advisor	PEI	
Patricia Murray	Special Advisor to the Associate Deputy Minister on Mental Health and Addictions	NS	
Copy & alternate Lynn Cheek	Executive Director of the Mental Health, Children's Services and Addictions Branch	NS	
Gisele Maillet	Executive Director, Mental Health and Addictions	NB	
Sheree Davis	Director, Mental Health	ON	
Fran Schellenberg	Executive Director, Mental Health & Spiritual Health Care	MB & PT co chair	
Kathy Willerth	Director, Addictions and Mental Health	SK	
Silvia Vajushi	Executive Director, Addiction and Mental Health	AB	
Kacey Dalzell	Manager, Substance Use & Mental Health	ВС	
Copy Pamela.Liversidge	Executive Director, Substance Abuse and Mental Health	ВС	
Marie Fast	Clinical Manager, Mental Health Services	YK	
Sara Chorostkowski	Manager - Mental Health and Addictions	NW	
Lynn Ryan MacKenzie	Executive Director, Mental Health and Addictions	NU	
мнсс			
Jennifer Vornbrock	VP, Knowledge and Innovation	MHCC co chair	
Howard Chodos	Director, Mental Health Strategy	Strategy lead	
Francine Knoops	Lead, Strategic Policy and Stakeholder Engagement	Secretariat	
Vanessa Desjardins	Admin Assistant, Public Affiars	Secretariat	
Patti Robson	Director, Public Affairs		

### **Endorsement to Move Forward:**

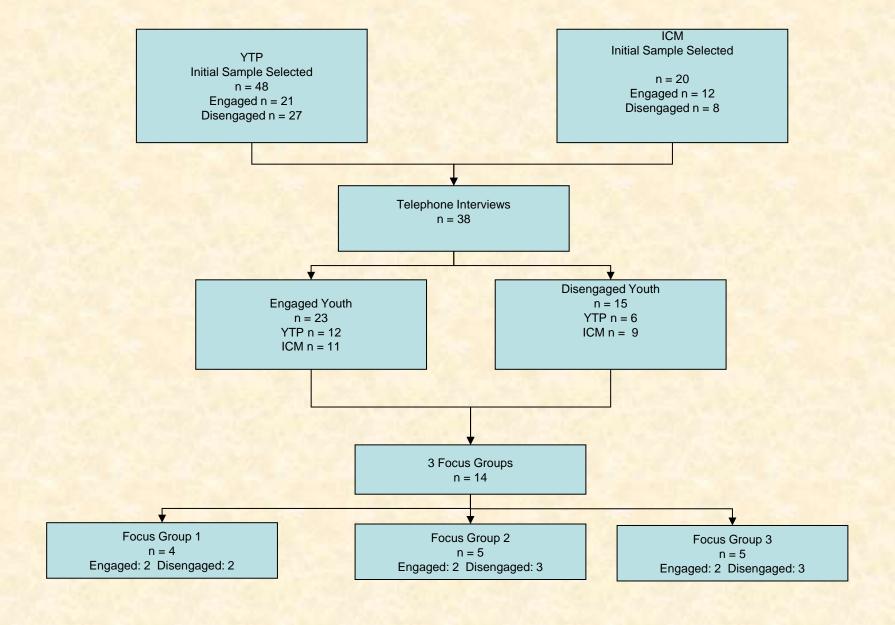
- 1) launch and disseminate the "Taking the Next Step Forward" policy report and companion reports
- 2) Video series
- 3) Engage various stakeholders (P/T champions, families & caregivers, Emerging Adults with lived experience) across Canada
- 4) ensure that key messages and action items that influence meaningful change have been communicated across Canada to diverse audiences

- Finish with the most recent Local Focus
- Transitioning Youth into Adult Mental Health and Addiction Services: An Outcomes Evaluation of the Youth Transition Project accepted for publication in the Journal of Behavioral Health Services & Research
- Mind the Gap: A Study of Youths' Experiences
   During the Transition from Child and Adolescent
   Mental Health Services to Adult Mental Health
   Services in the Champlain LHIN

## Mind the Gap: A Study of Youths' Experiences

- The objective of this study: to fill a gap in the current literature by explaining the challenges youth encounter during the transition from CAMHS and AMHS in the Champlain LHIN<sup>25</sup>.
- In order to achieve this objective, included the qualitative experiences of youth who both disengaged and remained engaged in care during the transition from CAMHS to AMHS.
- Include youth from the Ottawa Transition Program and ICM Program

	Total		Engag	Engaged		Disengaged	
	%	n	%	n	%	n	
Total	100%	38	60.5%	23	39.5%	15	
Age	M = 19.4		M = 19.4		M = 19.5		
Male	39.5%	15	43.5%	10	33.3%	5	
Currently Enrolled In school	50.0%	19	47.8%	11	53.3%	8	
Currently Employed	23.7%	9	30.4%	7	13.3%	2	
Currently has MH professional	47.4%	18	56.5%	13	33.3%	5	
Has Family Doctor	78.9%	30	87.0%	20	66.7%	10	
Highest Level of School Completed							
Elementary	13.2%	5	21.7%	5	0.0%	0	
High School	81.6%	31	78.3%	18	86.7%	13	
University	5.3%	2	0.0%	0	13.3%	2	
<b>Current Housing Status</b>							
On Own	39.5%	15	45.3%	10	33.3%	5	
Parental Home	26.3%	10	17.4%	4	40.0%	6	
Shared Accommodation	18.4%	7	17.4%	4	20.0%	3	
<b>Current Self-Reported Physical Health</b>							
Excellent	0%	0	0%	0	0%	0	
Very Good	18.4%	7	13.0%	3	26.7%	4	
Good	28.9%	11	30.4%	7	26.7%	4	
Fair	31.6%	12	34.8%	8	26.7%	4	
Poor	21.1%	8	21.7%	5	20.0%	3	



## Examples of Interview Questions:

Was there anything that helped or was unhelpful in preparing you for this move?

Thinking back, is there anything that would have been more helpful in preparing you for the transition

How would you describe your transition experience?

How would you describe your experience working with the transition team?

What are the strengths of the transition program?

Thinking back, is there anything that was not helpful or acted as a barrier in making the transition? (Prompts: transportation, availability and timing of appointments, etc.)

How could the transition program be improved?

## Recommendation: Development and distribution of transitions material

Based on feedback from the focus groups especially, youth suggested that having access to some reading material would be very helpful. This material should outline the transition process, including what to expect from start to finish, as well as provide a list of key contacts that youth and family can contact should questions or problems arise. While material should be available online, printed paper copies should also be available as some youth may not have regular access to the internet, and would require alternative means to access this information.

# Recommendation: Establish procedures for follow-up post transition

Once transition is complete, in that a youth has been matched to an adult service, procedures should be in place to follow-up with youth in order to ensure that the service matched for the youth is appropriate, being attended, and to offer any follow-up support that may be required. This will help reduce the incidence of youth who were matched to a service, but do not to attend due to systemic barriers such as availability of appointments, appropriateness of service, and accessibility

# Recommendation: Use of and access to primary care health services

Many youth reported not having access to a primary care family physician. Steps should be taken during transition to ensure that youth have both access to family physician and that their physical health needs are also being addressed, and to assist in the transition from a pediatrician to adult family physician.

# Recommendation: Ensure greater linkage to other services and supports

To ensure the greatest chance of success, a holistic approach to health and wellness should be taken. In addition to mental and physical health needs, addressed above, there are many social needs that may not be addressed during transition. Transition programs should assess the need for social services such as employment services, housing services, education, etc., and to ensure linkage between services to ensure a successful transition.

## Thank you!

Any questions?