The Gordian knot for rural and remote mental health services: developing Early Intervention Psychosis services for Ontario’s north

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Outline

• Context
  ◦ Psychosis and EPI
  ◦ Rural EPI programs
• Project 1: Implementing and developing EPI programs
• Project 2: Tale of two rural EPI models
• Project 3: Evaluation of training program
• Project 4: (currently underway) North BEAT
Objectives

• The challenges and successes of program implementation and development from the perspective of program decision-makers
• Evaluation of an education and training program with the aim of increasing capacity among (non-medical) mental health workers in northern and remote rural regions
• Pilot outcomes data of two different models of rural EPI practice in Ontario
Context
Psychosis

- Severe and persistent mental illness
- Common sub-types are schizophrenia and bipolar affective disorder
- Effects psychosocial and cognitive development
- WHO ranks the burden of mental illness as one of the most disabling in the world (2008)
- Leading cause of years lost to disability among youth ages 10 to 24 years (Gore, et.al. 2011)
Youth Mental Health Services

- “orphan of the orphan” (Senator Kirby, 2006)
- Adolescence is often time for onset of mental disorders
- Transition-age youth (16-24 years) esp at risk of falling through gaps
- Youth with psychosis at double disadvantage
  - Need early identification, access to services and early intervention
- How do you do this in rural and remote areas?
What is Early Psychosis Intervention (EPI)?
EPI in Context

• EPI (early psychosis intervention) developed in early 1990’s in Australia, UK, Netherlands
• Client and family centered
• EPI is specialized services including psychiatric assessment, medical treatment, education, family support and psychosocial rehabilitation
• May involve intervention for a period that ranges from one to three years
• EPI is founded on the principles of hope and recovery
Goals of EPI

- Improve early detection, access to services
- Decrease duration of untreated psychosis (DUP)
- Promote recovery
- Improve long-term outcomes
- Research suggests that EPI may improve outcomes, especially if duration of untreated illness is minimized (Malla 2005, Marshall 2006, McGorry 2007)
EPI In Ontario

• Over $100 million annual accord money spent on mental health over 4 years in 2004
• Significant proportion invested in Early Psychosis Intervention (EPI)
• 5 original EPI programs based in large urban academic centres in Ontario
• Over 35 new programs, expansion of original sites
• Most have an outreach or rural component
• Provincial standards for EPI programs released in 2010
Literature on Rural EPI Services

• Welch et al 2007 SER
  ◦ Australia: Southern Area First Episode (SAFE)
  ◦ Canada: South Fraser Area Health (BC)
• Updated search
  ◦ Kelly et al 2007: commentary
  ◦ Stain et al 2008: New South Wales, Australia
  ◦ Wilson 2007: New South Wales, Australia
Literature Key Messages

• Distinct differences from urban challenges
• Increased role of primary healthcare
• Specialist within generalist model
• Longer DUP and decreased access
• Increased monies needed for similar services
• Role of social network
• Vital role of adequate education, training, ongoing supervision
Original Best Practice Model: EPPIC Service Model

EPPIC Service Model:
The Original model from which most EIP programs were based

- Referral from external agencies
  - Youth Access Team (YAT): Referral gateway to EPPIC. Mobile assessment, crisis intervention, and brief community treatment
  - Personal Assessment and Crisis Evaluation (PACE) clinic: Identification and treatment of young people at risk of developing psychosis

- Referral from external agencies

- Early Psychosis Prevention and Intervention Centre (EPPIC) outpatient case management
  - Specialist comprehension programme for young people 15-29 years with psychosis.

- EPPIC Inpatient Unit (16 beds)
  - Family Work: Multi-family groups and individual family sessions
  - Group Programmes: Tailored, group-based interventions
  - Accommodation: Housing and Support Services
  - Research Programmes
  - TREAT/STOPP
  - Vocation

- EPPIC Statewide Services
  - Assist external agencies to incorporate an early psychosis focus into clinical programmes

- Prevention Promotion and Primary Care (PPP) Programme
  - Prevention and promotion activities; facilitating partnerships with community service providers; development of early intervention programmes

Key:
- Dotted line: External referral pathway
- Solid line: Internal referral pathway

Source:
Northwestern Ontario

Population: 234,599

Land Mass: 406,819.56 km²

Population Density: 0.6/km²

% Urban Population: 61.6%

% Rural Population: 38.4%
Northeastern Ontario

Population: 551,691

Land Mass: 395,576.72 km²

Population Density: 1.4/km²

% Urban Population: 71.5%

% Rural Population: 28.5%
Gordian knot:

How do we adapt an urban high density population model of care

• for Northern Ontario?
• and be true to the model
• and provide good quality care
Implementing and developing early intervention programs
Matryoshka Project

• System Enhancement Evaluation Initiative
• 3 year, multi-site project
• Purpose:
  ◦ to examine the effects of new investments in community mental health programs on continuity of care
• Research lead by Dr. Carolyn Dewa
• (Centre for Addiction and Mental Health)
Wave 2 Interviews

• Wave 2 qualitative interviews with EPI program decision makers
• Purpose:
  ◦ To understand how EPI programs were developed
  ◦ To understand key influences on program development
  ◦ To discuss how service model was adapted

• Cheng et al 2011, Early Intervention in Psychiatry
Methods

• Design based on grounded theory
• Purposive sampling of program decision makers - 7 interviews across 6 programs
• Questions based on interview guide
• Interviews were recorded and transcribed
• Double independent coding
• Analysis through discussion and consensus
Findings
Findings – Key Influences

- Clinical mentors and perceived experts
- Local and provincial EPI networks
- Front-line observations and grassroots movement
- Champion/leader
- Commitment and passion for EPI
Key Influences

• “what I found myself doing of course and like other EPI managers is calling one another. Luckily we had the [provincial network] right …and so through there I had mentors…”
Challenges

• Lack of program/clinical guidelines
• Early funding restrictive
• Lack of skilled EPI service providers
• Adapting traditional hospital services to the community (ie: clozapine)
• Overcoming geographical challenges
  ◦ Population density
  ◦ Balancing differing needs in same region
Challenges

• “I think one of the things that has uh really shifted is around the staff complement…and that had to do with funding…It was very limited and there were all sorts of different things that money had to pay for…so while the proposal might have called for 2 nurses, more social workers, OT’s…The agency has gone with more generic kind of case managers…in making the money spread a little wider”
“our initial proposal the first thing that happened to the dollars was they were cut in half... So instead of a [full-time] worker it was .5 of a worker... the money squeaked out of the envelope year by year... It’s difficult because then you are trying to implement half of everything[.] It really compromised us.”
Successes

- Innovative partnerships and collaboration
- Quality clinical service; able to engage hard to serve clientele, families
- Collegial, coherent, enthusiastic team
- Decreasing resistance to EPI model and change
- Shift existing mental health system
  - Transitional age youth, early rehabilitation, homeless youth, youth in trouble with law
Successes

• “I think the successes the family work we have been able to do and the families themselves have really helped us to be successful in intervening in the lives of the youth.”

• “So our successes would be...a high degree of earlier identification and compliance with best practices...simply put.”
Findings – Regional Adaptations

- Each program unique
- Building from what existed, instead of emulate “Cadillac” model
- Thinking “outside of box”
- Adapting ideologic model
Policy Implications

• Program development was influenced by network, champions, mentors
• Adapting ideologic model to practice shaped by funding stipulations
• Funding and human resources were major challenges
• Successes in outcomes, client/family satisfaction
• Absence of provincial standards allowed innovation
Two rural service models
Tale of two rural areas

- Northern (west) Ontario
  - Size of France (~550,000 km²)
  - 45% of Ontario’s landmass
  - 2% of Ontario’s population
  - ~250,000 people
  - Density 0.4/km²

- Southern (east) Ontario
  - Smaller area (~10,200 km²)
  - 2% of Ontario’s landmass
  - ~4% of Ontario’s population
  - ~264,000 people
  - Density 25.9/km²
EPPIC Hub-Spoke Service Model

SAFE Project SPOKE (NSW)

EPPIC Services Hub (Melbourne)

District Center

District Center
Rural Ontario EPI Service Models

Northwest: Specialized Outreach

Southeast: Hub and Spoke
Rationale

- In rural regions, services challenges are accentuated
- Youth in rural areas have:
  - Increased mental illness, higher rates of suicide & addictions (Boyd 2006, CMHA-Ontario 2009)
- Youth with psychosis in rural areas have:
  - Increased DUP, decreased access to services (Stain 2008)
- EPI services have shown to reduce
  - Hospital admission, length of stay
  - (Chen 2005, Bertelsen 2008)
- What if different models produce different outcomes?
Methods

• Data from the Matryoshka Project
• Cross-sectional data between 2005-2007
• Only rural programs were included
• Rural = population density <100/km²
• General functioning in the community
  ◦ Multnomah Community Ability Scale (MCAS)
• Admissions to hospital, ER visits
  ◦ Structured interviews with clients’ case managers

• Cheng et al 2012 submitted
Specialized Outreach vs Hub & Spoke: clients serviced (enrolled) in each program
Specialized outreach vs Hub & spoke: Community functioning

- Outreach (n=15): 73.3% High Score, 26.7% Low Score
- Hub & Spoke (n=77): 70.1% High Score, 29.9% Low Score
Specialized Outreach vs. Hub & Spoke: Hospital Admissions

Admitted to Hospital in Last 12 Months (p<0.05)

- Outreach (n=10): 70.0% (No), 30.0% (Yes)
- Hub & Spoke (n=66): 31.8% (No), 68.2% (Yes)

Number of Nights in Hospital in Last 12 Months

- Outreach (n=7): 28.6% (30 nights or less), 71.4% (>30 nights)
- Hub & Spoke (n=21): 57.1% (30 nights or less), 42.9% (>30 nights)
Specialized outreach vs Hub & Spoke: Emergency room visits

**Emergency Room Visits in Last 12 Months**

Outreach (n=12): 58.3% No, 41.7% Yes
Hub & Spoke (n=63): 34.9% No, 65.1% Yes

**Number of ER Visits in Last 12 Months**

Outreach (n=7): 42.9% 1 ER Visit, 57.1% >1 ER Visit
Hub & Spoke (n=22): 40.9% 1 ER Visit, 59.1% >1 ER Visit
Successes

Specialized Outreach
• Education initiatives
• Shared care across region
• Fidelity to EPI model
• Quality, flexibility
• Service <16 yrs
• Consistent, regular psychiatry services

Hub & Spoke
• Regular training
• Use of videoconferencing
• Coordination across 10 agencies in 6 districts
• Local clinicians
• New EPI services in remote areas
• Formalized partnerships
Challenges

Specialized Outreach
• Providing EPI services equally across region
• Erosion of funding
• Wide scope of practice
• Psychiatric services dependent on “good will” of hospital

Hub & Spoke
• Variable access to GP/NP
• Variable access to psychiatric services
• No funding for psychiatry
• Part-time equivalent staffing
• Wide scope of practice
Policy implications

- Two different models of delivering specialized mental health services
  - hub-spoke, modeled after Australia
  - specialized outreach adapted after hub-spoke didn’t work
- Total numbers serviced in hub-spoke is double, why?
- Each trying to provide specialized services across vast region in equitable manner
- Need follow up research to determine why differences
  - is it due to inequitable access to services?
  - Is it because of the models of care?
Training and education to increase capacity
Rationale for Training in EPI

• EPI Tenet: increasing early detection and treatment
• Public awareness campaigns, educate professionals
• Prior evaluation of EPI training focused on GPs
  ◦ (Power 2007, Lester 2009)
• But:
  ◦ Shortage of primary care
  ◦ In-person seminars or workshops not possible
• Few have focused on training non-medical personnel
• (Few) have used distance education methods
Adapted EPI training program

• Adapted from curriculum developed in UK
• Train generalist service providers to detect, identify early psychosis
• Increase access to EPI services
• Goals:
  ◦ Help youth reclaim lives
  ◦ Eliminate need for long term mental health services/psychiatry through early intervention
  ◦ Keep youth in their communities
Evaluation Methods

• Goals:
  ◦ To evaluate the effectiveness of EPI training using video vs. in-person comparison
  ◦ To increase the capacity of mental health workers to identify early psychosis and access care
  ◦ To increase awareness of and access to EPI services
• 19 Participants: 7 on site, 12 remote
• Knowledge questionnaires pre, post, 3, 6, 9 mos f/u
• Focus group interviews at 6 mos post-intervention

• Cheng et al, 2012 under review, Early Intervention in Psychiatry
Stage 1: Groundwork

Northwestern Ontario

Sample size: 19

- Alkeldan: 3
- Fort Frances: 4
- Geraldton: 1
- Nipigon: 1
- Thunder Bay: 7
- Sandy Lake: 1
- Siksusk Lookout: 2

Planning, Funding, Ethics Approval

Stage 2: Workshop

This workshop took place
March 24/25 2011

- On-site attendance
- Remote attendance

Stage 3: Evaluation

- 3 month follow up questionnaire: June/July 2011
- 6 month follow up questionnaire & focus groups: September 2011
- 9 month follow up questionnaires: December 2011

Stage 4: Knowledge Exchange

Feedback to participating agencies; results shared at national and international EPI conferences; results to the development of training programs;
FINAL REPORT RELEASED MARCH 2012

Monitoring knowledge acquisition and EPI capacity as compared to baseline (pretraining)
Knowledge Acquisition

TRENDS IN KNOWLEDGE ACQUISITION: KASQ

% SCORE

PRE-WKSHIP  POST-WKSHIP  3M POST  6M POST  9M POST
Knowledge Acquisition themes

“It was important to hear [about EPI program] and get a clear understanding of how to access the services...after this training I feel really connected....and a lot more comfortable to call [Child & Adolescent Psychiatrist/facilitator]”
Referral to EPI program

PARTICIPATING AGENCY REFERRAL RATES

2010/11 2011/12

REFERRALS RECEIVED
- 2
- 8

REFERRALS ACCEPTED
- 2
- 6
Mode of training

KASQ: ON-SITE VS VIDEOCONFERENCING

% SCORE

PRE-WKSHP  6M POST  9M POST

ON-SITE  VIDEOCONFERENCING
Mode of training themes

“Videoconference allowed me to attend the workshop whereas I likely would not otherwise have been able to attend…I mean technology is technology and I guess that just comes with it, those glitches, so.”
Experience of Training and Evaluation

• “What I found nice, was [that] we were invested in our learning. But with the evaluations and the follow-up…lets [us] know that you guys were invested with our learning as well”

• “As a worker, it gives you more confidence in being able to assist somebody and knowing that you’re not alone in this…now you debrief with other people if you’ve got challenges. They can also challenge you…part of our role for each other is to move past our comfort zone for all of us to grow.”
Policy Implications

• Education and training workshop was of benefit
  ◦ New knowledge, innovative
  ◦ Professional relationships
  ◦ No difference between distance on on-site learning

• Knowledge acquisition didn’t change
  ◦ About high level of knowledge before workshop?
  ◦ About understanding EPI services and case detection?

• Consultation relationship between specialist and generalist improved, deepening collaboration
What’s next?
First Nations Youth

• Region has 20% self-identify as Aboriginal
• Poorer mental health and physical health
• Aboriginal suicide rate is much higher
  ◦ Females 8X higher, Males 5 x higher
  ◦ Nishnawbe Aski Nation territory one of highest in country
• 30% of youth in clinic
  ◦ Sicker when present, first to disengage
• Why?
  ◦ Culture? Social disparities? Remote access?
North BEAT
(Barriers to Early Assessment and Treatment)

• 3 year multi-site project, Aug 2012-July 2015
• Funded by Sick Kids Foundation, CIHR-IHDCYH
• Question: What are the mental health service needs of youth in Northern Ontario who experience psychosis
• Co-investigators:
  ◦ Dr. Bruce Minore    Ms. Mae Katt
  ◦ Dr. Jane Fogolin    Dr. Carolyn Dewa
• Collaborators:
  ◦ Regional Early Intervention Psychosis Program (NE)
  ◦ CMHA-Thunder Bay
  ◦ St. Joseph’s Care Group, Thunder Bay Regional Health
North BEAT

- Objectives:
  - to understand how youth in Northern Ontario experience first episode psychosis and services for psychosis
  - to describe the mental health of a subset of adolescents receiving mental health care
  - to specifically examine Aboriginal youth as a significant and vulnerable population in Northern Ontario, and to engage Aboriginal youth in a discussion about their service and access to mental health care needs
  - to understand what are the barriers to and facilitators for Aboriginal and non-Aboriginal youth receiving appropriate early psychosis intervention.
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Discussion, Questions?