A Future for Early Intervention

Lessons Learned and the Potential Transformation of Specialized Early Psychosis Services

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INTRODUCTION

**Section Topics**

- Introductions
  - CCOR Research: Who do we least serve?

- Gaps
  - Current gaps (research & practice)

- Vision

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**INTRODUCTION**

**PRESENTERS**

**RESEARCH PROJECT**

**DRIVERS OF DISENGAGEMENT**

**DRIVERS OF POOR OUTCOMES**

**WHO WE LEAST SERVE**

**VISION**

**CONCLUSION**

**GAPS**
INTRODUCTION

Presenters

Nev Jones
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Asha Passalacqua
Anthony Vasquez
INTRODUCTION

Our Research

• Systematic coding of clinical records & assessments for 282 discharged early intervention in psychosis clients
• Goal: to better unpack factors contributing to sub-optimal outcomes & disengagement in EIP

ETHNICITY/RACE

- White: 26%
- Latino/a: 37%
- African American: 20%
- Asian American: 15%
- Middle Eastern/Arabic: 1%
- Samoan/Pacific Islander: 1%
INTRODUCTION

Outcomes & Disengagement

GOALS MET AT DISCHARGE
- No goals met
- Goals partially met
- All goals met

DISENGAGEMENT
- Engaged Until Discharge
- Disengaged/Withdrew

Vision

Drivers of Poor Outcomes

Who We Least Serve

Presenters

Research Project

Drivers of Disengagement

Gaps

Conclusion
### Drivers of/Contributors to Poor Outcomes

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency All Goals (n=60)</th>
<th>Frequency No Goals (n=70)</th>
<th>Fisher’s Exact Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual Trauma</td>
<td>25; 41.7%</td>
<td>54; 77.1%</td>
<td>.000***</td>
</tr>
<tr>
<td>Structural Adversity</td>
<td>27; 46%</td>
<td>55; 78.6%</td>
<td>.000***</td>
</tr>
<tr>
<td>Physical Abuse Only</td>
<td>7; 11.7%</td>
<td>12; 17.4%</td>
<td>.459</td>
</tr>
<tr>
<td>Sexual Abuse Only</td>
<td>2; 3%</td>
<td>14; 20%</td>
<td>.006**</td>
</tr>
<tr>
<td>Does not concur with diagnosis/clinical interpretation of problems</td>
<td>2; 3%</td>
<td>14; 20%</td>
<td>.003**</td>
</tr>
<tr>
<td>Rejects EIP model/therapy/meds</td>
<td>2; 3%</td>
<td>15; 21.4%</td>
<td>.006**</td>
</tr>
<tr>
<td>Psychosis</td>
<td>0=4; 1=15; 2=21; 3=18 (58)</td>
<td>0=1; 2=9; 3=34; 3=24 (68)</td>
<td>.096</td>
</tr>
<tr>
<td>Depression</td>
<td>0=13; 1=24; 2=13; 3=6 (56)</td>
<td>0=8; 1=23; 2=24; 3=10 (65)</td>
<td>.184</td>
</tr>
<tr>
<td>Substance Use</td>
<td>0=28; 1=15; 2=5; 3=3 (51)</td>
<td>0=23; 1=18; 2=18; 3=6 (65)</td>
<td>.055</td>
</tr>
<tr>
<td>Family Support</td>
<td>50; 83.3%</td>
<td>35; 50%</td>
<td>.000***</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
<td>.001**</td>
</tr>
</tbody>
</table>
## Drivers of/Contributors to Disengagement

<table>
<thead>
<tr>
<th>Category</th>
<th>Disengaged (n=85)</th>
<th>Engaged (n=149)</th>
<th>Fisher’s Exact Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual Trauma</td>
<td>55 (64.3%)</td>
<td>71 (52.3%)</td>
<td>.347</td>
</tr>
<tr>
<td>Structural Adversity</td>
<td>65 (76.5%)</td>
<td>82 (55%)</td>
<td>.002**</td>
</tr>
<tr>
<td>Sexual Abuse Only</td>
<td>13 (15.3%)</td>
<td>7 (4.7%)</td>
<td>.005**</td>
</tr>
<tr>
<td>Incarceration at or prior to baseline</td>
<td>11 (13%)</td>
<td>5 (3.4%)</td>
<td>.007**</td>
</tr>
<tr>
<td>Immigrated to the US as a child or adolescent</td>
<td>17 (20%)</td>
<td>12 (8%)</td>
<td>.012*</td>
</tr>
<tr>
<td>Severe Baseline Symptoms</td>
<td>Absent 56 (65.9%)</td>
<td>Absent 93 (62.4%)</td>
<td>.388</td>
</tr>
<tr>
<td>Baseline Substance Use</td>
<td>54/77 (70%)</td>
<td>64/119 (54%)</td>
<td>.063</td>
</tr>
<tr>
<td>Clinician perception that client has “Minimal Insight”</td>
<td>25 (29.4%)</td>
<td>16 (10.7%)</td>
<td>.000***</td>
</tr>
<tr>
<td>Baseline “Motivation for Treatment/Recovery”</td>
<td>16 (18.8%)</td>
<td>68 (45.6%)</td>
<td>.000***</td>
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<tr>
<td>Family Support</td>
<td>45 (53%)</td>
<td>115 (77.2%)</td>
<td>.000***</td>
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Who does EIP least well serve?

Young people with multiple intersecting disadvantage, differing interpretations of their experiences and a lack of compensatory supports or resiliency factors:

- Are members of minority groups
- Immigrated to the US as children, parents do not speak English
- Have experienced significant background adversity
  - Foster care, past homelessness, incarcerated family members, undocumented, living in dangerous inner-city neighborhoods, poverty
- Individual trauma
  - Sexual abuse, physical abuse, emotional abuse, witnessing domestic violence, losing a parent to suicide, witnessing a homicide, bullying
- Do not agree with a medical explanation of their challenges
One of the most significant risk factors for developing psychosis is trauma. Some types of trauma include:

- Sexual and physical abuse
- Bullying
- Neighborhood violence
- Early disruption of relationships with primary caregivers

Many forms of trauma experienced after (or stemming from) a diagnosis can significantly shape the experience of voices, psychosis and/or distress, such as hearing the voice of an abuser. These include trauma experienced due to involuntary treatment, discrimination and/or social exclusion.

A significant ‘risk factor’ for disengagement.
GAPS—A REVIEW OF THE BROADER LITERATURE

QUALITATIVE EXAMPLE

- family is low SES & have limited resources
- parent is a day laborer and undocumented.
- housing is tenuous
- housing is in an area impacted by gangs.
- entire family is homeless
- parent is an alcoholic.
- experienced sexual and physical abuse from people in his family.
- currently lives with mother and sister who physically abused them.
- relatives of the family struggle with depression and suicide.
- physical and verbal abuse from his father and his sister and has experienced sexual trauma from a third sibling. removed by police for getting in a fight with brother and involuntarily hospitalized.

TRIUMA

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Structural Adversity

Structural discrimination significantly increases the risk of developing psychosis.

Types of Adversity

- Racism
- Neighborhood Disadvantage/Neighborhood Violence & Crime
- Poverty/Socioeconomic Stressors
- Homelessness & Housing Instability
- Criminal Justice System Entanglements/Police Profiling

The attributable increased risk for psychosis from childhood adversity is 33% (Varese et al., 2015).
family is low SES & have limited resources
parent is a day laborer and undocumented.
Housing is tenuous
housing is in an area impacted by gangs.
entire family is homeless
parent is an alcoholic.
experienced sexual and physical abuse from people in his family.
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GAPS—A REVIEW OF THE BROADER LITERATURE

**POVERTY**

Low SES/poverty impacts

**Families**
- Ability of families to provide financial and emotional support
- Ability of family/client to engage

**Communities**
- Higher crime/’neighborhood ‘blight’
- Increased drug use/drug trafficking
- Decreased quality of schools, access to education
- Quality and stability of housing

**Individuals**
- At greater risk for individual trauma, other forms of adversity
- Victimization/exploitation
- Second-hand exposure to violence (e.g. gang shooting)
Rates of psychosis are significantly higher in certain ethnic minority groups because rates of childhood adversity are higher (Berg et al., 2015).

Pathways to care in early intervention differ along racial/ethnic lines.

African Americans have poorer access to mental health services than do whites in terms of service utilization and the quality of service received.

Ethnic minorities diagnosed with schizophrenia are more likely to disengage from treatment.
Conceptualization of psychosis as one or more distinct neuropsychiatric disorders did not take hold until the 19th century. Often do not map onto the experiences described by clients.

Unusual experiences associated with psychosis are typically connected to an individual’s personal and cultural histories, and their dynamic relationship to identity.

Cultural competency requires a motivation towards understanding the ancestral, cultural, and/or religious context of an individual’s experience.

Gender identity and sexual orientation are also significant factors that are intimately connected with an individual’s experience of psychosis.
Cultural/Religious Context for Experience:

Content
Cultural context can influence the particular content of anomalous experiences that are considered psychosis.

Cultural Orientation
Western perspectives traditionally invite a pathological orientation, i.e., Hearing Voices.

Other possibilities for psychosis-like experiences that are socially integrated and culturally understood (Luhrmann et al., 2014)

Religious/Spiritual Perspectives
Personal religious or spiritual context also have significant roles in determining the content, interpretation, and response to experiences of psychosis. i.e., Spiritual Emergence/emergency
Diagnosing queerness

Homosexuality wasn’t removed from DSM until 1973.

Effects of ‘diagnosis’ in experiences of Gender Dysphoria.

How do these attitudes infiltrate contemporary practice in EIP?

Danger of stigmatizing of queer/trans youth through pathologizing of unique gender experience.
**INTERRUPTIONS TO FILL THE GAPS?**

- Focus to date on symptoms/symptom focused intervention
  - Including cognitive remediation
- Work on integrating IPS (supported employment)
- Family work mostly centered on multi-family psychoeducation/multi-family groups
- Preliminary interventions components with different focus:
  - TRIPP (Melbourne, AU): trauma focused therapy in EIP
  - Intensive case management for high risk clients (Melbourne, AU)
  - Housing supports for EIP youth (Montreal, Canada)
  - Youth/service user driven engagement/clinician training & supports (Sussex, UK; EYE Project)
  - Youth involvement/leadership (Platform Team, Melbourne; Headspace, Jigsaw)
  - Third sector linked peer supports (Mind, UK)
  - Supporting students with early psychosis in higher education (NASMHPD toolkits)
  - Family work centered on multifamily groups
  - Family work centered on family support groups: Recovering Our Families (Krista MacKinnon)
A VISION FOR THE FUTURE

Section Topics

- healing
- the workplace
- welcoming space
- peer support
- engagement

INTRODUCTION

VISION

CULTURE OF INCLUSION

WELCOMING SPACE

ENGAGEMENT

PEER SUPPORT

THE WORKPLACE

HEALING

CONCLUSION
Equipping programs to respond to structural adversity

- Training: increasing provider capacity

- Competencies
  - Cultural
  - Structural
  - Trauma-informed care
  - Recovery-orientation/recovery culture

- Flexibility to respond to young people from disadvantaged backgrounds
- Proactively target forces driving poor outcomes and disengagement
A VISION FOR THE FUTURE

WELCOMING SPACE

The physical space of your program is participants first impression of you, your colleagues, and the perceived openness of the services.

A welcoming space includes:

- The sharing of spaces, including restrooms and communal areas
- Participant contact with people, rather than walls or other barriers
- A sense of home -- art, plants comfortable seating, wide selection of books and art
- Creating hospitality -- warm and welcoming environment, food, tea and coffee, printed resources
A VISION FOR THE FUTURE

ENGAGEMENT
Connection is the key to engagement
- Be real, authentic
- Be human
- Be honest

Understanding the power dynamic.
- Are you giving them choice or do they feel forced or coerced to comply with your treatment suggestions?
- Don’t impose frameworks, invite dialogue instead!

Consider their traumas or history of loss
- Have they been asked same “invasive” questions over and over?
- Understand the vulnerability that it takes for someone to open up to someone new.

Community building activities:
- movie screening and discussion
- public events
- picnics
- dinner
- speakers from other community resources
- involvement of family

Feedback, orientation, welcome packets, psychoeducation
Bring in a peer support specialist and/or education/employment specialist
A VISION FOR THE FUTURE

PEER SUPPORT

Essential for creating a culture of inclusion!

WHAT IS A PEER SUPPORTER?
PEER SUPPORT IN EIP?
WHAT CAN PEERS PROVIDE?
In the context of mental health a peer provider is someone with personal lived experience of the mental health system.

Considerations for EIP:
- Young Adult similar in age
- Lived Experience
- Family Member/Caregiver
- Lived experience of voices/unusual beliefs
- Similar backgrounds: trauma, racism, structural disadvantage
CONCLUSION

A VISION FOR THE FUTURE

Peer Support in EIP?

Non-hierarchical “real” relationship between participant and peer worker
  - Sensitive to participants’ need to connect on a human level versus a “paid expert”
  - Opens up possibility of different ways of exploring meaning and impact
  - Hope and inspiration that is tangible
  - Possibility of trust for those whose relationships have been repeatedly trust-breaking

Team impact
  - Serves to reinforce recovery culture
  - Breaks down us vs. them structures
  - De-clinicalizes – moves the conversations back to common humanity
  - Attention to social context
A VISION FOR THE FUTURE

WHAT CAN PEER SUPPORTERS PROVIDE?

➢ Inclusion of wellness, recovery and resiliency-based care
  A critical role in building and sustaining a welcoming space.

➢ First-hand knowledge of the healing process Mutual support and learning founded on 5 key principles
  - hope
  - equality
  - respect
  - personal responsibility
  - self-determination
  a person-centered model of resiliency

➢ Improved engagement
A VISION FOR THE FUTURE

THE WORKPLACE

➢ Critical reflexivity of:
  - Team hierarchies
  - Use of diagnosis and clinical language
  - Ability to work with clients’ own explanatory framework
  - What gets prioritized/deprioritized
  - Language used with participants but also in team meetings

➢ Introduction to entire team early on

➢ Intensive Team Training on Recovery/Recovery Culture
  - Including regular trainings led by youth/people with lived experience
  - Where possible trainings open to participants, families

➢ Community Building
  - Ceremonies and events for participants, families

➢ Flexibility
  - Mobile outreach
  - Easily Accessible Office on public transportation – Central location
  - Weekend and evening hours

➢ Client-driven/client-led care

➢ Attention to:
  - Potential to devalue the role of peer supporters, family supporters
  - Potential to prioritize symptom-focused therapy over functional goals
A VISION FOR THE FUTURE

HEALING

Staff center participants’ own explanations of their experiences
- Take this deeper through facilitated, open exploration
- Acknowledge impact of experiences on identity = “recovering identity”

Community Integration/Inclusion is the Center
- ‘Symptom amelioration’ takes a back seat to:
  Meaningful school or work
  Stable & independent housing
  Healing family systems
  Community involvement

- Experiences brought back into “culture”
  Connect experiences with history, the arts, religion/spirituality, science

Exploring Holistic approaches
- Offering somatic, mindfulness-based and/or energy oriented treatment
  (e.g. EFT, Qi Gong, Acupuncture, etc.)
- Role of soothing system / CFT
CONCLUSION

Main points to reflect on
CONCLUSION

QUESTIONS?

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REFERENCES


Outsider Art: http://www.outsider-art-fair.com

Jesse Reno - Where have you been, where are you now

Ken Law - Combustus

Marie Suzuki - ‘Nobody Can See’

Dion Hitchings – fudge packer