Future Directions for Coordinated Specialty Care
Embracing Transformative Change

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Future Directions

Sustaining benefits for more people over the long term

Leveraging & centering lived experience

Attention to adversity, race and culture

Transformative change
Empirical motivation

• Most the benefits of early intervention programs are lost by 3 - 5 years post-follow up (Nordentoft)
• Outcomes & engagement with services are profoundly shaped by class, race and social disadvantage
  • An estimated 60-80% of those with schizophrenia diagnoses will be unemployed or under-employed 10-14 years following an initial episode (Morgan, Stralin)
• In models including social & structural disadvantage, level of symptoms had only a tiny impact on engagement & outcomes (Jones et al 2019)
• Persistant disparities/inequalities affecting African-American clients & families (Jones et al 2020a,b; Oluwoye et al, 2020)
• Lack of career mobility, career options, low wages within the peer workforce (Jones et al 2019, 2020)
• Approximately 40-50% of CSC clients disengage or are discharged within the first year of treatment (Mascayano et al 2020)
  • Early discharge predicts poor outcomes
Transformational times ask for transformational change

To stop replicating the past we need 'vision guided' system innovation.

Landscape  
Exploring pathways

Regime  
Analysing the system

Niche  
Experimenting

Assessing

Translating

Pre-development  Take-off  Acceleration  Stabilisation
The hard questions

• How can we adequately attend to the intersections of race, poverty, welfare benefits, arrest/incarceration, disability and recovery?

• How can we give young people what they want and need in a way that brings about sustained change?
  • During CSC and after

• What would our systems, programs and policies look like if truly co-produced & co-led by those who experience psychosis and their families?
Asking these questions at both the micro and macro level.

"...we as a nation must undergo a radical revolution of values. We must rapidly begin the shift from a “thing-oriented” society to a “person-oriented” society. When machines and computers, profit motives and property rights are considered more important than people, the giant triplets of racism, materialism, and militarism are incapable of being conquered...True compassion is more than flinging a coin to a beggar; it is not haphazard and superficial. It comes to see that an edifice which produces beggars needs restructuring. A true revolution of values will soon look uneasily on the glaring contrast of poverty and wealth...A nation that continues year after year to spend more money on military defense than on programs of social uplift is approaching spiritual death."

—Martin Luther King Jr. (April 1967)
Asking questions in ways that address epistemic justice

- Service users/patients & families, including those from diverse racial/ethnic communities, as sources of input & information
  - vs individuals with the power to directly shape services & provide cross-cutting expertise

“...people’s participation...is allowed, and their contributions are in fact used for knowledge production and knowledge-transmission purposes; but nonetheless, they are not treated as subjects of knowledge or “epistemic agents”—but only as sources of information—that is, as objects”

- Jose Medina
1. lived experience

• If we want to engage young people
• If we want to improve services
• If we want to improve outcomes
  • It all begins with a deep understanding of service users’ experiences, priorities & needs
  -> sustained engagement with these experiences
  -> and the integration of staff/leaders with lived experience
Which does not mean

**Status & Compensation**
- Administrative Leadership
  - Psychiatrist(s)
  - Team Leader/Manager
  - Case Manager
  - Supported Ed/Emp
  - Peer Support

**Decision Making Authority**
- State/Oversight
  - Agency Leadership
  - Program Leadership
  - CSC Team

or

**Client Advisory Board**
instead

User Experience
- Deep engagement with what the user experience actually is: QI, evaluation, research, consultation

User Insights
- What from the perspective of end users and families would actually work and why
- Innovation/ideas from former service recipients, the peer movement, activists

User Leadership
- Experientially grounded roles & leadership
- Researchers, clinicians, prescribers, support staff with personal experience
- Co-production processes
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transformative change
Sustaining benefits/change

- The long-term view: Sustained versus temporary change

- Self Endorsed
- Autonomy
- Choice Full
- Congruent within yourself
- Whole Hearted
- Essential to Wellness
- Our 3 Basic needs are...
- Feel Connected
- I matter to others
- A sense of belonging

- Mastery of things important to competence
- All about the environment
- Maker Space
Autonomy
Actions/behaviors are self-aligned
Doing X because I want to

Competence
Belief in one’s abilities
I can do X

Relatedness
Belief that one belongs & is included; positive social identity
Doing X has social meaning/value

psychosis?
autonomy, autonomy support & the example of medications

“I really liked my psychiatrist and therapist, so I took meds while I was in the program, but yeah, I was waiting until I left so I could go off them”

“it was really never on the table to discontinue and so I did so as soon as I left”
competence, work

parent: “the [CSC] program was amazing...they did sort of try to help with a job but honestly we see no way...he’s just not capable of working”

Former client: “I’m not really sure about myself anymore... I was working a part-time job when I left, but then I lost it after I ended up back in the hospital”
relatedness, belonging

former client: “you know, the stigma, I don’t think anyone wants to be known as someone with schizophrenia”

former client: “f**k that sh**: psychiatry is the genocide of black people; I don’t belong there”

former client: “I don’t actually have psychosis, that was a mistake”
structural barriers to autonomy, competence, belonging

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<tr>
<th>structural &amp; institutional</th>
<th>interpersonal</th>
<th>individual</th>
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<tbody>
<tr>
<td>• welfare policy</td>
<td>• stigma/prejudice</td>
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<td>• healthcare coverage</td>
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<td>• accommodations in work/school</td>
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<td>• criminal justice history checks</td>
<td>• family relationships/support</td>
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timescales

Career Development

18-24

24-28

28+

Work? Entry level job?

School? Grad school?

Field or majors?

Clinical work?

Policy?

Consolidated career

CSC
TRANSFORMATIONAL TIMES ASK FOR TRANSFORMATIONAL CHANGE

To stop replicating the past we need ‘vision guided’ system innovation

- Exploring pathways
- Envisioning
- Analysing the system
- Experimenting
- Assessing
- Translating

Pre-development → Take-off → Acceleration → Stabilisation
References & grounding research


