

Family & Person Centered Care in Early Psychosis: Making Real Change

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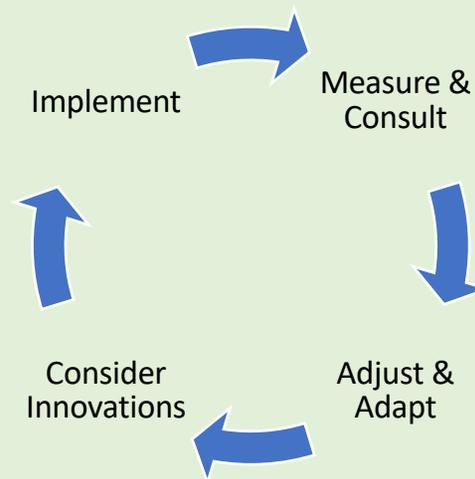


Definitions

- Institute of Medicine : *“care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensur[es] that patient values guide all clinical decisions”*
- Gerteis et al (1993): *“an approach that consciously adopts the patient’s perspective as to what matters”*
- Pat Deegan: *“I would argue that we also need to grapple with the question of how to pass on, not just knowledge and skills, but wisdom. Wisdom doesn’t scale so easily. How do we teach the spirit of the work? How do we teach staff to see beyond the disease or diagnosis to the person in the context of their life? How do we teach clinicians to shift the focus from what’s the matter? – to what matters to you?”*

Patient Centered Care, Shared Decision Making & Evidence Based Medicine

- EBM  algorithmic rule following (follow a manual, don't do anything else)
 - Greenhalgh: *“Real evidence based medicine has the care of individual patients as its top priority, asking, “what is the best course of action for this patient, in these circumstances, at this point in their illness or condition?” It consciously and reflexively refuses to let process (following manualized protocols) dominate outcomes (the [collaboratively] agreed goal of management in an individual case).”*
- Organizational/leadership support
- Feedback Loops



Psychosis-Specific Issues & Challenges

- Insight, capacity & patient autonomy
 - Involuntary Treatment
 - Agency during/after episodes
- Entanglements of voices/delusions with:
 - Religious & spiritual beliefs
 - Trauma/difficult life events
 - Personal interests/goals/aspirations
 - Culture
- Developmental Stage
 - Psychosis & 'identity'
 - Stigma/prejudice



Caveats & Considerations

- Language of person-centered care, recovery, shared decision making ubiquitous
 - Language/mission statements \neq concrete changes in practice
 - One touch trainings \neq concrete changes in practice
- Sounds simple but meaningful PCC & Shared Decision Making is really hard!!

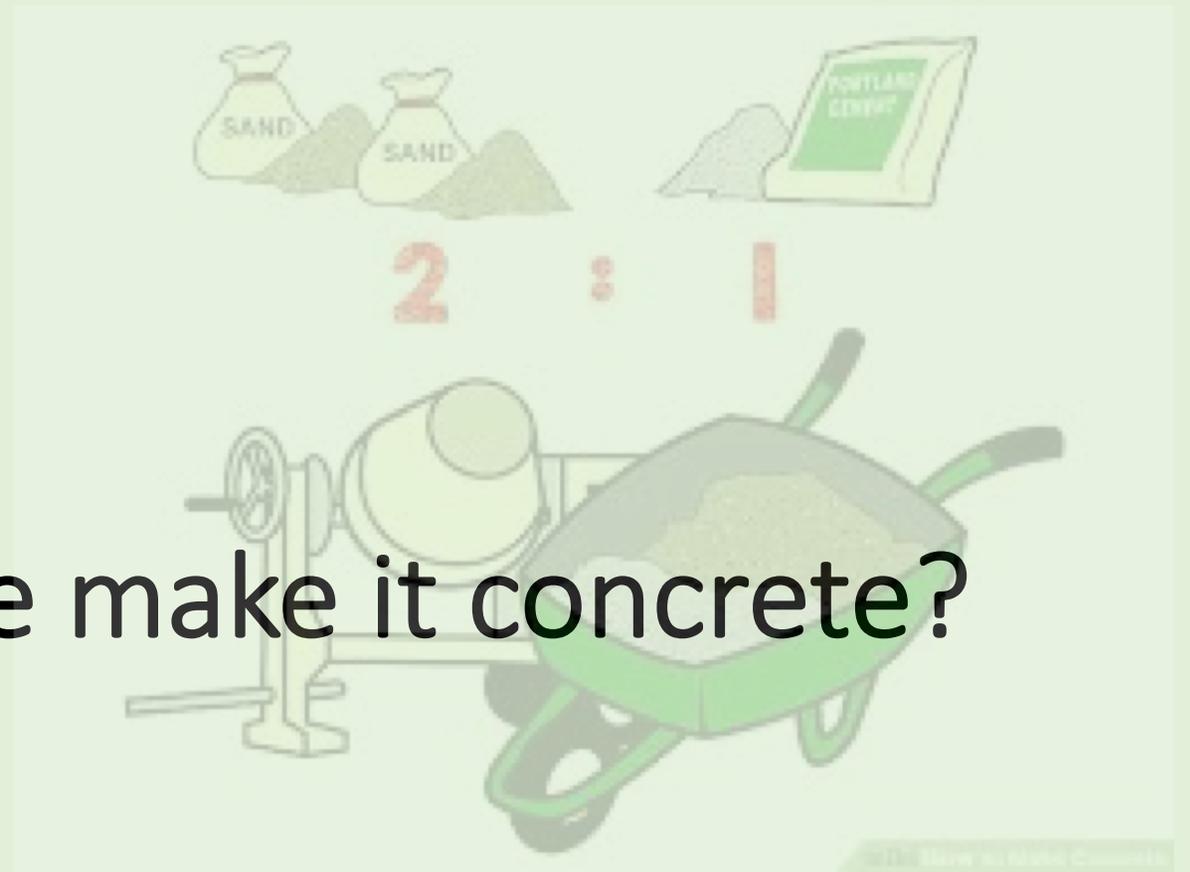
What *are* essential elements of patient centered practice in EIP?

- Participants : 125 EIP/CSC providers (20 US states, Canada, UK, Australia)

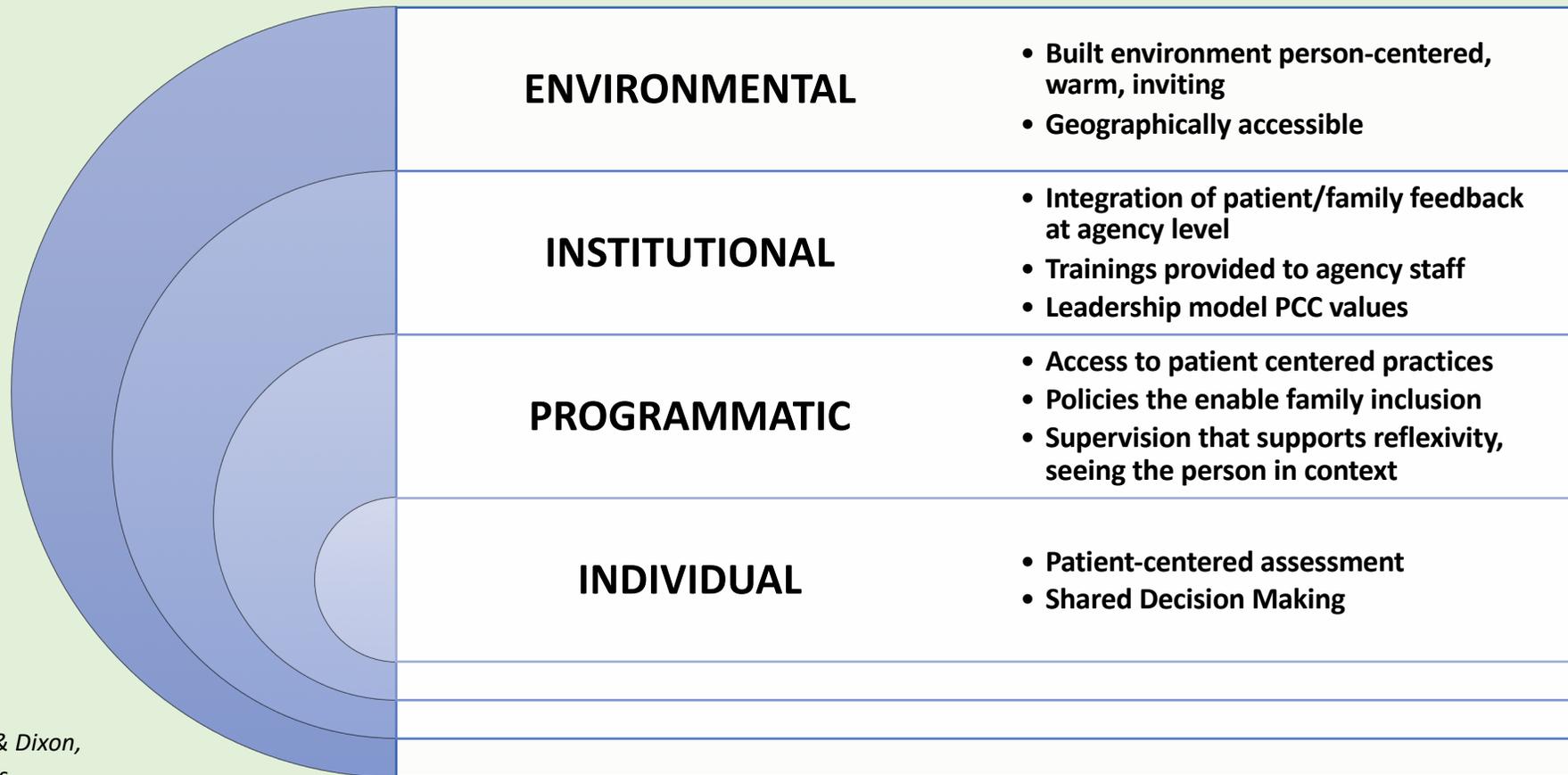
Question	Yes
All clinical staff receive targeted training on working with trauma in the context of early psychosis	30.43%
We have implemented specific trauma informed care policies or procedures	40.87%
We use a structured tool (e.g. cultural formulation interview) to better understand clients' cultural backgrounds	20.69%
Since launching, program has made specific policy or program changes in order to address culture-related issues or emergent ethnic/racial disparities	24.35%
We have brought in members of ethnic/cultural minority communities to consult or contribute to improving practices	31.30%
Peer specialist as a member of the team?	31.9%
Supported education & employment specialist?	52.45%
Family-peer/Family partner?	15.7%

Collaborators: Sarah Kamens, Marc Manseau, Oladunni Oluwoye, Michelle Jamiesen

So how do we make it concrete?



Levels of PCC/FCC



Specific Practices & Processes

- Patient & family centered assessment practices
 - Getting to know the person vs. checking boxes
- Team roles (peer specialist, family partner, SEE)
- Peer and family involvement in programmatic decision making
 - Advisory councils
 - Collaborations with family & peer run orgs/advocacy groups
- Patient centered outcomes (PCO)/PCO-driven care
- Training, supervision & ongoing support for providers
 - Trauma, culture, socioeconomic disadvantage, indigenous communities
 - Instill deep appreciation for the importance of making meaning from experience
- Continuous quality improvement/innovation transfer
 - Patient and family driven
 - Include (track & evaluate) involvement & satisfaction

Planning & QI: Using a Process Tool

- Marc Ragins' Recovery Based Progress Report Card
 - Process, not outcome
 - Internal desire for QI versus evaluation imposed by funder
 - Allows individualized areas of focus/improvement
- Lived Experience integration & involvement
 - Core program manuals include peer role/contribution
 - Trainings reflect equal value of peer/youth involvement
 - Effective peer specialist integration
 - Collaboration with external peer/youth advocacy organizations
 - Peer/youth involvement in program decision making

	Not yet explored	Exploring	Emerging	Maturing	Excelling
Core program manuals include peer role/contribution		Adjunctive/incidental mention of potential peer support role	Peer support manual/scope of work, but no integration across program materials/manuals	Some integration of peer support/youth leadership component in program manuals/materials but not fully integrated	Initial program manuals/materials have been completely revised and rethought to fully include peer support and youth/peer inclusion; persons with lived experience hold key roles in the revision process
Trainings reflect equal value of peer/youth involvement		Basic training for peer specialists	Basic peer training + some integration of information regarding the peer role in all trainings	Trainings all include well-integrated information on peers as well as material on youth/peer involvement and leadership in other ways (e.g. role of youth advisory board)	Trainings not only seamlessly integrate and provided dedicated coverage of all team roles, but also often feature speakers/trainers with lived experience; supervisors receive dedicated support or training regarding the integration of peer specialists & effective supervision

CSC Adaptation of Mark Ragin's MHA Village Recovery Based Progress Report Card (see: <http://mhavillage.squarespace.com/section6/2011/12/6/a-recovery-based-progress-report-card-2009.html>)

	Not yet explored	Exploring	Emerging	Maturing	Excelling
Collaboration with outside peer and youth organizations		Flyers for local groups posted in a waiting area; agency occasionally hosts speakers	Program leadership know and have met with local leaders, open lines of communication but no direct collaboration	Program works with a local peer or youth org on at least one collaborative event a year, regularly invited leadership to share ideas/perspectives, active bi-directional referrals	Program has active partnerships with at least one peer or youth organization, with activities or projects co-sponsored by both parties; staff are regularly encouraged to attend the peer/youth organizations events, and peer/youth staff participate in the program's advisory board
Peer/youth involvement in program decision making		Internal discussions about a youth advisory board	Youth/peer advisory board with sporadic meetings but no direct influence over policy or practice	Youth/peer advisory board with active projects & some direct influence over programming; program actively explores additional ways of involving peers in program development such as focus groups or townhalls	Youth/peer involvement is woven into multiple aspects of the program, including an advisory board, active youth/peer led projects and multiple involvement mechanisms; dedicated coordinator for engagement work

holding ourselves accountable /
ensuring change is real

How do we know how our programs are actually doing? Is it patient centered care?

- Analyze utilization data, performance data, outcomes
- Client and family surveys
- Focus groups & townhalls
- Informal feedback

- Tailored fidelity tools
 - Are we actually following/implementing the changes we planned to?
 - Include concrete operationalization of PCC/FCC

- 'Negative case analysis' – learning from those not doing well, not aligned with current practices

- Adapt/make (further) changes if necessary

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Questions???