

Before we get started...

- Do you think peers/families have a unique contribution to make?
 - · Really?
 - How deep or superficial a contribution?
- Do you think the system is basically okay, or requires transformative (deep, structural) change?



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Introduction

- Disclosure & lived experience are core components of EIP and so...
 - Disconnects between clients & administrators
 - Intrinsic & instrumental value
 - Transformative potential
 - Commitment/loyalty to real impact

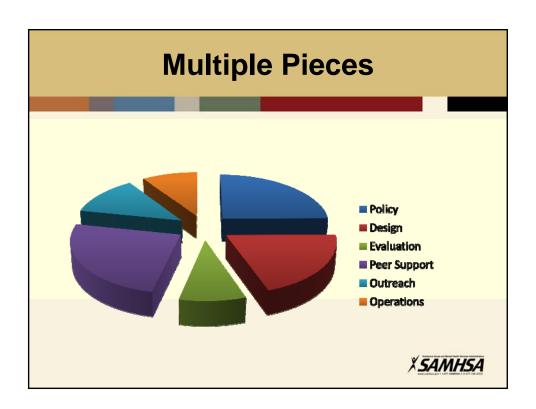


Orienting Framework

Transformation & Transformative Change •Peer/YA* involvement driving second order change:

- Paradigm shift vs. incremental improvement
- Foundational re-structuring of programs
- Services "transformed" through peer involvement & leadership should look and feel fundamentally different

*includes family-peers/family-support



More About Values

- Client-centered planning, design, and evaluation are increasingly central to domestic & international initiatives
- For success, programs must:
 - · Appeal to clients & families
 - · Center upon clients' and families' needs
- Difficult or impossible if clients & families themselves are not meaningfully involved



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Client & Family Perspectives

"The therapy and other supports were fine, they're good, but at a certain point what you really need is someone else who gets it, not because it's their job, or because they studied psychosis in school or whatever, but because they've experienced it. The peer I worked with was the only person, I felt, who really got it, all of it, the confusion, the pain, the complications, and lots of other stuff you just generally don't talk about."

—former EIP client



"I remember talking to psychiatrist and care workers who repeatedly reassured us that it wasn't our fault, my husband and myself, and that was well intentioned of course, but I just don't think professionals without this experience can even begin to comprehend the pain, the guilt, the fear...not just that one's child has developed schizophrenia, but all the decisions from meds they don't want, to forcing them to go to the ER. Do they really get that pain and guilt? That you just don't know if what you're doing is right? The first time I met other parents there was just this flood of tears and relief and a lot that was exchanged that didn't even involve words."

More About Barriers

Attitudinal Barriers

Leadership or staff do not believe that peer involvement actually makes a differences

Leadership or staff believe that peers pose a threat (e.g., are likely to transgress clinical boundaries; will contribute to non-adherence)

Leadership or staff do not believe that peers have a fundamental contribution to make (E.g., "we're all peers")

Leadership or staff are willing to go through the motions but not invest in deeper organizational change

Operational Barriers

Program does not have the funds or resources to invest in positions, training &/or organizational culture

Program structure (e.g., distribution of resources, staff roles/responsibilities) does not allow for meaningful integration & no structural adjustments are made

Roles are unclear or :

- •Peers seen as infringing on others' scopes of work
- •Peers positioned as catch-all workers for tasks others don't want

Barriers Specific to EIP

- Core team roles & responsibilities already established
 - Peers later "added in" without structural adjustments
- Minimal guidance/resources relative to other components of EIP
- Billing/reimbursement challenges





Best Practice Principles

- Leadership models respect
- Program structure facilitates involvement
- Program values facilitate involvement
- Trainings support involvement
- Concerns proactively addressed
- Investment in ongoing development & support

1. Modeling

Remember the Bobo Doll?

 Social learning theory holds that we internalize interactional behaviors by observing others, including how others treat people or things



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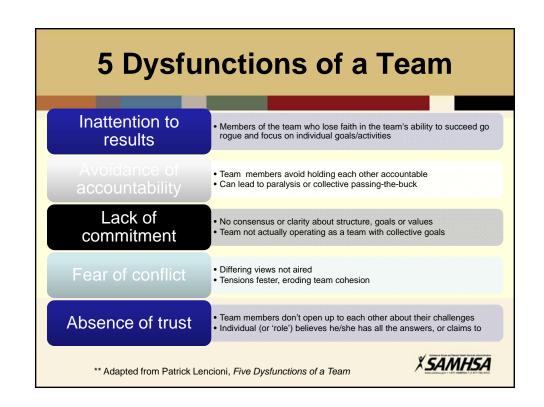
Organizational Leadership

- Never underestimate the power of:
 - Program leaders who model deep respect for clients/family members, including unique insight & expertise
 - Or consequences of the reverse
 - Paid program consultation with peer experts
 - Not just about peer support
 - Leaders/executive staff who disclose lived experience of psychosis

2. Program Structure Facilitates Involvement

- For each CSC role:
 - Clear scope of work
 - Distinct peer/family role(s)
 - Clear performance expectations
 - e.g., peer specialist meets with each new client (unless declined) within first month of services
- Clear roles within team
 - e.g., case conference or team meetings
 - Other staff have a clear sense of when to involve peers
 - · e.g., crisis situations, medication discontinuation
- Team functions as a team





Serving the client is what ultimately matters Results Team accepts collective responsibility for failures, collective success · Actions not in line with goals/plans swiftly addressed • Individual team members willing to accept responsibility for problems · Accountability not focused on blame/shame, but on end-goals Commitment is not to meeting individual goals or 'being right" but to meeting the needs of client Commitment All team members fully on board with team-based ethos Value the triangulation of diverse perspectives · Differing views on a particular client aired All members open to learning from each other • Team leader facilitates, practices neutrality Conflict • Majority of decisions consensus based Peers trust that other team members respect their views **Trust** Other team members humble/open to learning from lived experience Other team members also trust that their contribution will be recognized

Scope of Work **Timing of involvement** Automatically upon entry into treatment? As suggested by primary therapist/case manager? By clients' request? **Group facilitation** Scope Peer support groups only? MFGs? Can anyone run any group? of 1:1 engagement Work · 'Therapy' vs. mutual support (reciprocal) **Case management** Who does what/is responsible for what? Social linkage (community involvement) vs. administrative linkage (SSI/SSDI, applying for benefits, housing) Administrative tasks Transportation? Record keeping? Photo-copying? X SAMHSA

3. Program Values Facilitate Involvement

- Messages communicated to staff when hired (implicit & explicit)
 - Program mission, ethos, goals
 - Program orientation
 - Trainings
 - Staff cliques
 - Views of leadership
- Characteristic language & word choice
- Programmatic hierarchies
 - Prescribers at the top, peers at the bottom?
 - · Pay scales?
 - Who has access to trainings?
 - Career ladders & promotion?
- Status of "expertise by experience"?



4. Trainings Support Involvement

- All staff need training, support & supervision on:
 - · Recovery in psychosis
 - Value of diverse perspectives
 - · Value of lived experience
 - Navigation of role boundaries, clinical boundaries
- Critical approach to 'expertise'
 - Very few 'facts' or absolutes in psychosis
 - Hugely variable, complex set of experiences
 - No one can dictate with certainty what the best treatment is for any given client
 - Collective humility in the face of tremendous uncertainty



5. Problems Proactively Addressed

- Beyond the team
 - Program or agency administration must be willing/able to take action
 - Make structural adjustments as necessary
 - Resolve tensions between staff/between roles

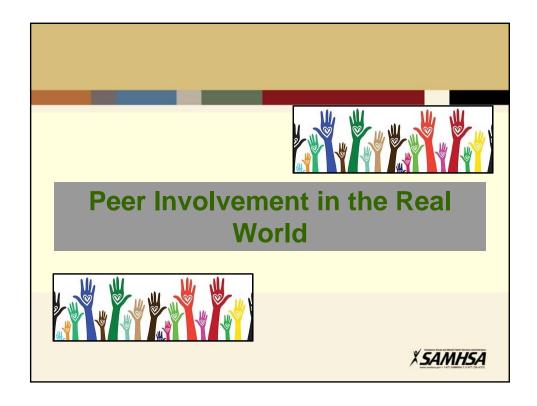


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6. Ongoing Support/ Continuing Effort

- Realities of public mental health require ongoing effort
 - Programs/teams constantly evolving organisms
 - Staff turn-over
 - · Changing skills & abilities
- Continuing education for all staff
- Direct reminders of value of lived experience
 - · Lived experience panels, events
- If things are going well, strive to raise the bar





Feedback from Peers

- Voices Outside Peers in EIP project
 - International survey of peers involved in EIP services in clinical, peer support, or leadership capacities
 - 25 respondents, most working in peer support roles in EIP, some in advisory or administrative capacity

What EIP Peers Had to Say

- "My view of early intervention services, at this point, is pretty bleak. There's a
 lot of rhetoric and very little substance behind it. I think the level of investment
 in peer leadership, at present, is minimal."
- "There are not enough of us. Our young clients could really benefit from more mentoring from peers in recovery."
- "Administrators and directors need to walk the talk. Inclusion of a single peer specialist means little if the larger program remains lodged in a medical model, centering on medication management and cognitive therapy."
- "I have been an advocate for several years on a state and local level. Without hearing voices from the trenches, we will not progress in providing adequate services in the field."
- "What happens on the ground seems to have little connection to the version of early intervention you read about in the manuals and newspapers. The ideas are there, but I found myself working in a leading national program where some of the staff appeared to not even believe in recovery, much less peer contributions."
- "The potential is huge. I stress 'potential."



U.S. EIP Programs	
Successes	Challenges
Client advisory or leadership boards	Boards not truly integrated with services & programs; indirect or minimal influence on core program design
Peer staff work as part of EIP team	Peer staff not truly accepted as valuable member of team, clinical insights devalued
Peer-led groups	Low participation rates, degree of penetration unclear
Client alumni as group facilitators	Concerns related to continued involvement in program, boundaries, etc.
Senior clinical or administrative leadership with lived experience	Individual may not be supported to explicitly draw on lived experience in senior role, if clinical, unable to disclose
Augmenting core EIP model or program with peer support	Position vis-à-vis other components unclear or under-valued; catch-all
Family-peer led MFGs	MFGs not a peer-led EBP by design; tensions with psychoed

Wrap-Up

- EIP/CSC represents a huge opportunity to fundamentally alter young people's lives
- Peer/family involvement central to this ambition
- Innovation, humility, openness to transformative change required

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Resources

- Guidance Manual: <u>Peer Involvement and Leadership in Early Intervention in Psychosis Services: From Planning to Peer Support and Evaluation.</u> (2015). NASMHPD.
- Experience Matters: A Youth Peer Support Training Guide in Early Psychosis. Orygen Youth Health, Australia.
- Training Family Peer Support Workers in an Early Intervention Mental Health Service. Orygen Youth Health, Australia.
- Youth Participation in Early Psychosis. Orygen Youth Health, Australia.

Thank you!

Questions?

[Note: A recorded archive of this webinar will be posted within 10 days at www.nasmhpd.org/webinars]