Translating Research Evidence Into Systems Change: Actionable Policy Recommendations from Foster Care Alumni

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We are change agents "Motivating others through voices of experience"
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PUBLIC/ACADEMIC PARTNERS
STAKEHOLDER ENGAGED, PATIENT CENTERED RESEARCH

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UNDERSTANDING ENGAGEMENT

PCORI Engagement Principles
- Reciprocal Relationships across all aspects
- Co-learning
- Partnership
- Transparency, Honesty and Trust

Youth MOVE Model for Engagement
- Builds upon peer connections & unites voices
- Promotes learning & growth
- Developed partnership and collaboration
- Identifies service and support gaps
- Seeks to improve access and quality of services

Both studies asked similar questions, with different approaches

PCORI Foster Care

What Helps What Harms
COMPARATIVE EFFECTIVENESS OF STATE PSYCHOTROPIC OVERSIGHT SYSTEMS FOR CHILDREN IN FOSTER CARE

Project Overview

Aim 1
- Review of state oversight mechanisms
- Key informant interviews with state policymakers

Aim 2
- Gather perspectives of individuals from multiple stakeholder groups through individual and group interviews

Aim 3
- Compare effectiveness of state policy interventions through state data analysis
QUALITATIVE RESEARCH IS **ITERATIVE**
PEOPLE’S PERCEPTIONS: “THE LIVED EXPERIENCE”

- PCORI Team Reviewed and Coded Transcripts
  - Keeps us “open and honest”
- Summarized Recurring Themes
  - Powerfully Illustrated of a Personal Example
- Intention to Engage Youth to Support System Improvements
Alumni Participants offered recommendations for systems change

“Actionable” recommendations provide tangible suggestions for system improvement
- Example: Increase Trauma-Informed Care

“Actionable” recommendations guide advocates to craft evidence-based policy proposals
ACTIONABLE POLICY RECOMMENDATIONS:
CHANGING THE RULES: A GUIDE FOR YOUTH AND YOUNG ADULTS WITH MENTAL HEALTH CONDITIONS WHO WANT TO CHANGE POLICY

- Defining an issue or problem that you want to change;
- Making connections with partners;
- Carrying out the action plan
- Implementing the change.

Changing the Rules, Portland State University, 2017. Available at: https://www.pathwaysrtc.pdx.edu/changing-the-rules
NOTABLE THEMES

- Always Provide “Trauma-Informed Care”
- Ensure Youth Understand the Risks and Benefits of Mental Health Treatments
- Use a Team Approach to Plan Mental Health Care
- Respect the Youth’s Right to Refuse Medication
“So the trauma needs to be identified and dealt with at its root cause and it may take untraditional paths to do that. Um, there are some traumas that people not in foster care will never admit to the day they are dead. Unless those traumas are acknowledged and sort of dealt with, and all we are doing is treating symptoms of a cancer.” – Alumni Participant

“I guess to make sure that there’s always a trauma-informed approach when dealing with foster youth, knowing the difference between behaviors of trauma and mental illnesses and what it looks like when a child is traumatized from the situation. Even just being removed from a parent’s home can be traumatizing.” – Alumni Participant
ENSURE YOUTH UNDERSTAND THE RISKS AND BENEFITS

Prioritize Youth’s Comprehension

“...I had no idea of what the doctors were saying. I had no idea what the big terms were.”
   – Alumni Participant

“I think that there just needs to be way more emphasis on explaining like even if in the interim before any decisions are made that would give youth in foster care more control over medication and prescription and things like that but even before that I think there needs to be emphasis on explaining what the medication is and what it does and what it’s for.”
   – Alumni Participant
Youth Voice Front and Center

“I mean just having the youth involvement is big. Like if you are considering putting them on medication discussing the side effects and everything with them, like, ‘hey this is what this is, this is what could happen,’ and just having them informed.”
– Alumni Participant

“So I personally think that the youth should work in conjunction with the doctor, kind of like a psychiatrist... So just having like a full disclosure about everything about it, um, and the doctors, from when I was in care, were under pressure to push certain kinds of meds. So I actually kind of retract what I say about having, um, about the doctor having the final decision, I think it really should be with the young person and the doctor if the caregiver can't even be part of the conversation.” – Alumni Participant
“And as far as anything else, um, services because I feel like, you know, you can't really make a decision on anything with just one or two people or three people, you need like a team.” – Alumni Participant

“I think in the end it's like not one real sole person can say what’s going to be the best practice... I mean in some cases, kids are going to be able to make really good decisions and some cases they are not. Some cases parents are, um, biological parents, foster parents, group homes or even the workers... I mean like I guess everything is checks and balance and it’s kind of hard to decide or figure out how you check and balance that.” – Alumni Participant
RESPECT THE RIGHT TO REFUSE TREATMENT

Respect Youths’ Rights to Refuse Medication

“I would think her right is to say no more... I would think it's a basic human right to be able to say no.” – Alumni Participant

“The doctor doesn’t know how her body feels, doesn’t feel what her body feels so the direct person who’s taking it should definitely have the right to say I don’t wanna take this anymore.” – Alumni Participant
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