Raise Your Voice!
Shared Decision Making about Psychiatric Medications with Children and Youth

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Learning Objectives:

1. Identify strategies to enhance informed consent processes and shared decision making among youth considering psychotropic medications

2. Articulate the roles of supportive allies in the medical informed consent process

3. Describe the imperative need and value for youth engagement and voice in all aspects of mental health care for youth

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Comparative Effectiveness of State Psychotropic Oversight Systems for Children in Foster Care

Aim 1
- Review state oversight mechanisms and interview 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
Improving the Mental Health Clinical Encounter: Perspectives from Stakeholder Participants

- Qualitative Methods
  - Foster Care Alumni participated in web-based discussion groups (n=8)
  - Prescribers participated in individual semi-structured phone interviews (n=33)
- Participants provided recommendations for changes on two levels
  - The clinical encounter/direct service
  - The mental health system
#1 Identify strategies to enhance informed consent processes and shared decision making among youth considering psychotropic medications

Medical Informed Consent

- Understanding Risks and Benefits of Psychotropic Medications
- Permission – Consent and Assent – to prescribe and administer the medication
- Assent: Agree to, approve and participate in treatment

Shared Decision Making

- Collaborative planning
- Involves youth, families, and community member in ongoing medical planning
- Voluntary and confidential
- Young people are at the center of the process
Emerging Best Practice: Shared Decision Making (SDM)

• SAMSHA defines SDM as the way “youth work together with their providers to make the best plan for their own needs and situation”

• Agency for Children and Families (ACF) calls for “Authentic Inclusion” where each person – including the youth – actively and openly discusses treatment decisions and come together to decide on the best course of action.
Learning Objective #1:

Identify strategies to enhance informed consent processes and shared decision making among youth considering psychotropic medications
Key Findings: Barriers to Informed Consent and Shared Decision Making

Clinical Encounter-level & System-level

- Multi-layered oversight process & multiple players
  - Many people involved in state oversight
  - Provider of consent may not be present at appointment

- Risks and benefits
  - Complicated information to comprehend and consider
  - Inadequate time to process treatment information

- Lack of continuity
  - Frequency of change to foster home placements and clinical care
  - Absence of accurate medical history, including past medications

- Developmental considerations
  - Children and youth have an individualized cognitive and developmental status, impacting their role in the shared decision making process
  - Issues of age and maturity have to be considered when determining a child or youth’s role in shared decision making
Recommendations from Foster Care Alumni

• Ensure youth understand the risks and benefits of mental health treatments
• Use a team approach to plan mental health care
• Always prioritize youth voice
• Always provide trauma-informed care*
Alumni Recommendation: Ensure youth understand the risks and benefits of mental health treatments

Development and dissemination of educational materials for youth and families to prepare them for active role in the shared decision making process and understanding risk and benefits of medication.

- Understand the purpose of medication
- Monitoring side effects
- Ensure appropriate allotted time is available to discuss risk and benefits of medication
- Provide youth and family enough time to make a informed decision related to medication
- Provide resource materials that are youth and family friendly
Alumni Recommendation: Use a team approach to mental health care

Care coordination is a strategy used in some oversight and monitoring programs. Which allows case managers to support families and youth with proper evaluations, access to psychosocial services which may reduce the need for medication.

- Minimizes burden on family to coordinate care among multiple providers
- Team approaches facilitate communication across multiple state agencies and services providers
- Multiple perspectives can support the youth and families with understanding treatment options that work best for them
Alumni Recommendation: Always prioritize youth voice

Youth guided means that young people have the right to be empowered, educated, and given a decision making role in the care of their own lives as well as the policies and procedures governing care for all youth in the community, state and nation.

- Individual/service level
- Organizational level
- System/policy level

• To look at an individual in a different way.
• To assist the focus person in gaining control over their own life.
• To increase opportunities for participation in the community.
• To recognize individual desires, interests, and dreams.
• Through team effort, develop a plan to turn dreams into reality.
Alumni Recommendation: Always provide trauma-informed care

- Safety: Physical & Emotional
- Trustworthiness & Transparency
- **Empowerment, Voice & Choice**
- Collaboration and Mutuality
- Cultural, Historical and gender issues
- Peer Support
- Work with the youth to learn the cues he or she associates with past trauma
- Obtain a good history.
- Maintain a supportive, empathetic, and collaborative relationship.
- Encourage ongoing dialog.
- Provide a clear message of availability and accessibility throughout treatment.
- Access to trauma specific treatment

SAMHSA, 2014
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

Learning Objective #2:

Articulate the roles of supportive allies in the medical informed consent process
Key Findings: Supportive Allies in the Medical Informed Consent Process

- Relationships are at the heart of what youth need to learn, grow and thrive.
- Youth who do well had at least one stable and committed relationship with a supportive parent, caregiver or other adult.
- Supportive relationships are critical in development. They provide environment of reinforcement, good modeling, and constructive feedback.
- Supportive relationships enhance sensitivities, motivations, and skills involved in assisting and caring for others.

Search Institute, 2017
### Natural
- Parent/Caregiver
- Sibling
- Self-defined Family
- Foster Families
- Extended Family Member
- Peer
- Romantic Partner
- Supportive Adult

### Community
- Sports Coaches
- Faith Community
- Sponsor
- Education/Teachers
- Camp Counselor
- Employer/volunteer
- Mentors
- Big Brothers/Big Sisters
- Family Run Organization or Youth Run Organization

### Service
- Clinician
- Formalized Service provider
- Probation Officer, other program staff
- Parent Peer Provider
- Youth Peer Support Provider
- Pediatrician/Primary Care Doctor
- Foster Families

### Professional
- Youth Peer/Parent Peer
- Youth Peer/Case Manager
- Youth Coordinator/Project Director
- Youth Peer/Clinical Supervisor
- Youth Peer/State BH Department

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**Express Care, Promote Growth & Supportive, Young Adult Driven, Expand Future Possibilities**
Learning Objective #3:

Describe the imperative need and value for youth engagement and voice in all aspects of mental health care for youth
Key Findings: Youth Engagement and Voice in Mental Health Care

Young adults are recognized as having a valuable voice and are considered equals and experts in all areas of individual care and systems change work.

Young adults represent themselves and are the decision makers driving individual care plans, peer programming, and advocacy efforts. Young adults have the ability to determine personal outcomes. There is opportunity for young adults to initiate the process to create positive change.
Benefits of Engagement

- Identify potential areas of improvement
- Create services aligned to patient needs
- Improve communication between patient and providers
- Empower and ensure patients are fully participating in their health care
- Develop appropriate indicators to improve care
- Respond to patient and community needs
Informed Consent is challenging for youth in foster care.

Shared decision making is essential to informed consent but is difficult in brief clinical encounters.

Some environments better promote shared decision making.

A team-based approach to shared decision making is desirable.

Youth involvement and youth voice are a priority.

Notable Themes: Informed Consent and Shared Decision Making
Congruency with Prescriber Perspectives

Trauma-informed care
• Prescribers and Foster Care Alumni consider this necessary and important

Ensure youth understand risks and benefits
• Youth have to understand, as well as the legal consenter

Team approach
• Team members’ presence at appointments is important
• Prescribers may rely on team members for medical history

Youth Voice
• Developmental considerations influence youth involvement
• Youth buy-in is important for successful treatment
Provider Perspective

• I am only as good at my job as I can make a meaningful engagement with the youth and families I work with.

• Partnering in this work is essential, how else will I know:
  • Are the medications helping or harming?
  • What else are you trying that you may not tell me? Complimentary and alternative treatments? Licit and illicit substances (e.g. Marijuana as a medical agent)?
  • What am I missing in understanding the drivers of the symptoms we are looking to treat?
  • What else is needed? Meds don’t teach skills so we need to ensure meds are not being used in isolation of evidence-based treatments? Other services and supports?
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