Tufts Medical Center

Psychotropic Medication Oversight among Youth in Custody of State Child Welfare Systems

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Psychotropic Medication Use among Youth in Child Welfare Custody

"It [mental healthcare] is really important. If I don't have the help that I need, then I won't be able to get my medicine and stuff. I need my medicine. If I don't have my medicine, I have real bad blow-ups I try to hurt people or hurt myself, or I destroy stuff. So I really need my medicine for that."

-Youth formerly in foster care

(Leslie, Mackie, et al, 2011)

Psychotropic Medication Use among Youth in Child Welfare Custody

"They told me if it ever made me sleepy then they'll take me off of the [antipsychotic medication]. Cause I'm a school person. I like to go to school. I like to learn and for the simple fact it was making me fall asleep in school I just felt like you're just taking the fun out of my life because I love school, you're just taking the one thing I love out of my life. And I would tell the doctor the medications is making me fall asleep in class and my teachers would tell them she's falling asleep a lot in class and they still wouldn't take me off the medications."

-Youth formerly in foster care

(Leslie, Mackie, et al, 2011)

Learning Objectives:

Our objectives for this presentation are:

1) Summarize recent rates of mental health need and psychotropic medication use among youth in child welfare custody;
2) Describe five overarching components for psychotropic medication oversight for youth in foster care, prioritized by Health and Human Services (HHS), and variation across states; and
3) Provide resources, linked in these slides and available on the 3BI thumb drives, for each of the five components prioritized by HHS.

LEARNING OBJECTIVE 1

- Summarize recent rates of mental health need and psychotropic medication use among youth in foster care;

Relevance? Child Welfare/ Child Protective Services System (CW)

- America's Children: A Snapshot
  - U.S. child welfare population under 18 in 2010: 408,425
  - More than a quarter of a million children entered foster care (i.e., removal from home and placement into an out-of-home setting) between October 1, 2010 and September 30, 2011
  - White children under 18 in 2010: 41%
- Children in Child Welfare
  - U.S. referrals possible child abuse/neglect in 2009: 702,000 children
  - 78% suffered neglect
  - 18% were physically abused
  - 10% were sexually abused
  - 8% were emotionally or psychologically maltreated
  - 2% were medically neglected
  - Estimated 10% experienced other types of maltreatment (e.g., abandonment, treats of harm, congenital drug addiction, etc)

(Children's Bureau/ACF, 2010; US DHHS, 2011)

Mental Health Needs of Youth in CW

- Rates of emotional or behavioral disorders range from 37-80% of children in foster care (point prevalence rate) vs. 11-25% community-based rate *(Landsverk et al, 2006; Halfon et al, 1995; U.S. Public Health Service, 2000; Burns et al, 2004)*
- Rates of emotional or behavioral disorders range from history of adverse childhood experiences including:
  - Abuse
  - Neglect
  - Domestic violence
  - Poverty
  - *In-utero* and environmental drug exposure
  - Genetic loading?

(Battistelli, 1996; Hurlbert et al, 2004)

Foster Care Alumni

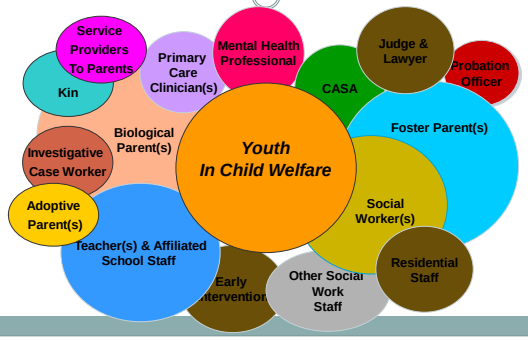
- Lifetime prevalence of mental health disorders among adults who experienced stays in foster care exceeds the incidence rate of the general population
  - PTSD 30% Alumni vs. 7.6% Gen Pop
  - Major Depression 41.1% vs. 21% Gen Pop
  - Panic disorder 21.1% vs. 4.8% Gen Pop
  - GAD 19.1% vs. 7% Gen Pop
  - Drug dependence 21% vs. 4.5% Gen Pop

(Northwest Alumni Study, Pecora et al, 2005)

Exacerbated by. . .

- Multiple placements *(Battistelli, 1996)*
- Reliance on Medicaid/public mental health providers; potential access issues *(Iglehart, 2003)*
- Lack of a single designated and consistent individual (e.g., parent, worker, clinician) to monitor care *(Battistelli, 1996)*

Care (Dis-)Coordination



Effect on Child Welfare Systems

- Problems & reunification
  - Young children with developmental problems 2x as likely to remain in foster care than be reunified *(Horowitz et al, 1994)*
  - Externalizing problems in older youth 2x as likely to remain in foster care 18 months after entry *(Landsverk et al, 1996)*

Cost of Mental Health Care

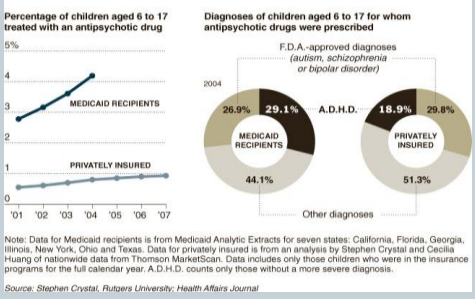
- Mental health expenditures for children in foster care on average ($2082) were just over 10 times the cost of children not in foster care ($181) *(Harman et al, 2000)*
- FY 2004, over half of the Medicaid expenditures for children in foster care, within one state, were for antipsychotic medications alone *(Strayhorn, 2006)*

Psychotropic Use among Youth in Foster Care

- High rates*
  - Foster Care: 13-52%
  - General population: 4%
- Polypharmacy (Use of 3 or more medication over 30 days)
  - Foster Care: 5.3%, with range at state-level from .5% to 13.6% *(Rubin et al, 2012)*
  - Foster Care prescribed at least one psychotropic medication in one state: 41% *(Zito et al, 2008)*
  - Youth with autism in foster care: 5 to nearly 50% across 28 *states (Rubin et al, 2009)*
- Geographic Variation:
  - Rates of medication use varied: 0%-40% (a 40-fold variation) across catchment areas, nationally *(Leslie et al, 2011)*

*(dosReis et al, 2001; Kansas Health Policy Authority, 2008; McMillen et al, 2007; Office of Texas Comptroller, 2007; Olfson et al, 2002; Raghavan et al, 2005)

Health Policy Implications: Insurance Type



As cited in NYT (12/11/2009): Crystal et al, 2009

Setting the Context

- NPR:
  - Foster Kids Given Psychiatric Drugs at Higher Rates (2011)
- PBS:
  - The Watch List: The Medication of Foster Children (2011)
- ABC:
  - 20/20: Overmedication in Foster Care (2011)
- GAO
  - HHS Guidance Could Help States Improve Oversight of Psychotropic Prescriptions (2011)
  - Concerns Remain about Appropriate Services for Children in Medicaid and Foster Care (2012)

Federal Policy Context

PL 105-89: *"The Adoption and Safe Families Act" of 1997*

Included 'well-being' as an element of the mission for child welfare agencies

PL 110-351: *Fostering Connections to Success and Increasing Adoptions Act of 2008*

Required plan for oversight and coordination of health and mental health services for children in foster care

PL 112-34: *Child and Family Services Improvement and Innovation Act*

Required protocol for psychotropic oversight by July 2012

1997 **2008** **2011**

(Mackie et al, 2013)

LEARNING OBJECTIVES 2 and 3

- Describe five overarching components for psychotropic medication oversight for youth in foster care, prioritized by Health and Human Services, and variation across states; and
- Provide resources, linked in these slides and available on the 3BI thumb drives, for each of the five components prioritized by HHS.

Information Memorandum (5 Components)

1. Screening, evaluation and treatment planning
2. Shared decision-making and informed consent
3. Medication monitoring
4. Mental health expertise and consultation
5. Information sharing

(U.S. Department of Health and Human Services, 2012)

Tufts/ICH Research Team

- 2 national studies:
  - 2009-2010 (Charles H. Hood Foundation)
    - Examine state policies and best practices and disseminate to child welfare agencies
  - 2011-2013 (William T. Grant Foundation)
    - Identify types of information states using to develop plans
    - Investigate monitoring approaches
  - 2012-12 (Agency for Health Research and Quality)
    - Document state approaches to monitoring psychotropic medication use in all 50 states, and DC.

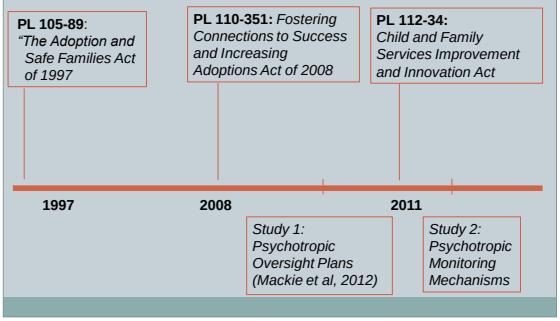
Methods

- **Tools:** Semi-structured qualitative interviews and surveys to validate and update state data
- **Samples:** Key informants
  - Child welfare
  - Collaborators in youth-serving systems
- **Document review:** Policy and protocols available on child welfare website or provided by key informant
- **Analytic approach:** Coding consensus, co-occurrence, and comparison

Samples

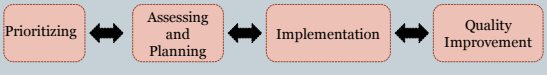
- 2009-2010 (Charles H. Hood Foundation)
  - 47 out of 50 states and DC (response rate: 94.1%)
  - Key informants, n=58
    - Governor's Office (n=1)
    - Medicaid (n=1)
- 2011-12 (W.T. Grant Foundation)
  - 51 out of 50 states and DC (response rate: 100%)
  - Key informants, n=72
    - State and county-administered child welfare agencies (n=58)
    - Medicaid (n=7)
    - Judiciary (n=2)
    - Contracted academic partners or consultants (n=5)
- 2012-2013 (AHRQ)
  - 46 of 50 states and DC (response rate: 90.2%)

Federal Policy Context

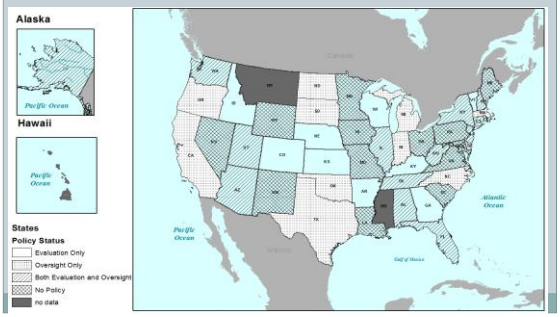


Implementation Stage

- For each component, states are at different stages of development:



Psychotropic Oversight Policies (2009-10)



Component One

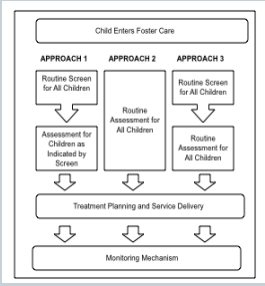
SCREENING, ASSESSMENT, AND TREATMENT PLANNING

Component 1: Screening and Assessment

- Initial Health Screen (24-72 hours)
- Comprehensive Assessment (30-60 days)
- Sensitive to the unique needs and experiences of youth in child welfare custody
  - Trauma related to maltreatment and trauma secondary to removal from home and placement changes
  - *In-utero* environmental drug exposure
  - Genetic loading

(AAP District II Task Force on Health Care for Children, 2001; AACAP/CWLA, 2002; Jensen et al, 2009)

Component 1: State Approaches



	n (%)
Approach 1	35 (73)
Approach 2	12 (25)
Approach 3	1 (2)

Component 1: Self-Reflection (2)

At the systems-level:

- Is a **standardized** "tool" employed (trauma-informed and evidence-based)?
- How will the **cost** be reimbursed to recruit appropriate clinicians?
  - e.g., foster care-risk adjustment
- Are there **available services** once needs are identified?
- Can we **track** receipt of services?
  - e.g., information system

Component 1: Self Reflection (1)

At the practice-level:

- Before initiating pharmacotherapy, was an evaluation of physical and mental health employed and medical history obtained?
- What **type of mental health evaluation** was provided?
  - e.g., as needed, screen/assessment, assessment
- Does the approach address the **unique needs** for mental health evaluation of youth in child welfare custody, including trauma, *in utero* exposures, and potential genetic loading?
- **When** was the screen (24-72 hours) and assessment (30-60 days) conducted?
- **Who** conducted the evaluation?

Resource: California Evidence Based Clearinghouse

Component 1: Resources

Sponsor/ Author	Guideline
American Academy of Child and Adolescent Psychiatry (AACAP)	Position Statement on Oversight of Psychotropic Medication Use for Children in State Custody: A Best Principles Guideline
AACAP	Policy Statement on Psychiatric Care of Children in the Foster Care System
AACAP; and Child Welfare League of America (CWLA)	Policy Statement on Mental Health and Use of Alcohol and Other Drugs, Screening and Assessment of Children in Foster Care
American Academy of Pediatrics	Fostering Health: Health Care for Children and Adolescents in Foster Care
Jensen PJ, Romanelli LH, Pecora PJ, Ortiz A.	Mental Health Practice Guidelines for Child Welfare

Component Two

SHARED DECISION-MAKING AND INFORMED CONSENT

Component 2: Definitions

- **Consent:** The process of a:
  - Clinician providing information to the child, family, and state-assigned decision maker about the treatment options, targeted symptoms, and course of treatment; and
  - State-assigned decision-maker provides an informed decision regarding which treatments are in the best interest of the child.

  (Romanelli et al, 2009)
- **Assent:** A 3-part process that includes the youth:
  - Understanding (to the best of his/her developmental abilities) treatment options,
  - Voluntarily choosing to undergo treatment options, and
  - Communicating this choice.

  (Bartholome, 1995)

Component 2: Consent and Child Welfare

- Child welfare agency, acting as *in loco parentis* or "in place of the parent," assumes legal responsibilities and functions of the parent when child enters custody
- Informed consent and shared decision-making:
  - A process, both at time of initiation and ongoing, by which the child welfare agency or its designee consents to the use of mental health services, including psychotropic medications, for children in custody.

Component 2: Process

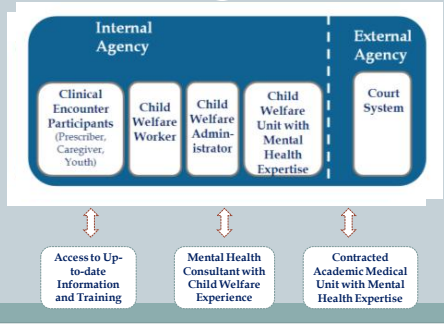
INFORM → MAKE → AUTHORIZE → NOTIFY

(Leslie, Mackie, et al, 2010)

Component 2: *Who Makes the Decision* to Consent

(Leslie, Mackie, et al, 2010)

Component 2: What additional resources are available?



Component 2: Self Reflection

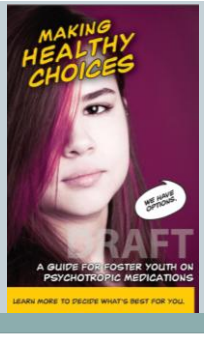
At the systems level:

- How can we ensure meaningful informed consent and shared decision-making?
- What are the policy/legal considerations specific to our state that need to be considered?

At the practice level:

- Whether or not at the age of consent/assent, how does the youth feel about taking this medication?
  - Consent/assent
  - Handbook (http://www.nrcpfc.org/publication-db/documents/psychmedyouthguide.pdf)
- Who informs, makes, authorizes prior to the child starting this medication?
  - Authorized consenter
  - Role of foster and kin caregivers and biological parents, whenever appropriate
- Is a second opinion warranted in this case?
- Who is notified of decision to start psychotropic medication use?

Resource: NRCPFC: Handbooks for Youth in Foster Care



Component 2: Resources

Sponsor/ Author	Resource
California	Foster Youth Help
Maine	Youth in Care Bill of Rights
New York	A Medical Guide for Youth in Foster Care
Oregon	Foster Care Questions
National Resource Center for Permanency and Family Connections	Resources to Promote Stakeholder Involvement
Child Welfare Information Gateway	Use of Psychotropic Medications
Patient Information Handouts	e.g., Dulcan, MK & Lizarralde, C. *Helping Parents, Youth and Teachers Understand Medications for Behavioral and Emotional Problems: A Resource Book of Medication Information Handouts* (3rd Edition)

Component Three

MEDICATION MONITORING AT THE CLIENT AND POPULATION-LEVEL

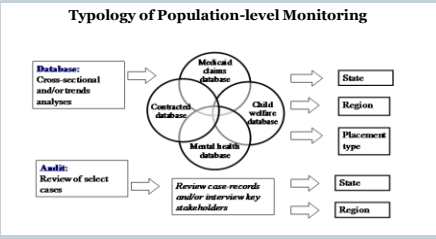
Component 3: Medication Monitoring (2012-13)

- Multi-level
  - **Client:** care coordination within and external to medical system, facilitate transitions, and identify red flag criteria to examine specific safety concerns
  - **Provider:** Provider feedback as QI tool, issued to the provider or hospital
  - **Population:** Needs assessment, policy-planning, monitoring problems and trends

Component 3: Medication Monitoring

- Multi-purpose
  - Descriptive
  - Consultative
  - Evaluative

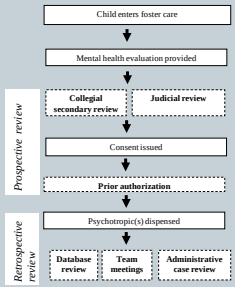
Component 3: Descriptive



Component 3: Consultative

- Cyber-medicine: On-line consultation
- Tele-medicine: Telephone consultation lines
- Co-located Consultation: In-person consultation

Component 3: Evaluative



Component 3: Self-Reflection

At the systems-level:

Descriptive

- What do we want to measure regarding psychotropic oversight and for what purpose?
- What data will be used and will linking data be necessary?
- What analyses do we want to distribute to what stakeholders? (State leaders? Clinicians? Case Managers? Parents? Youth?)
- What legal/policy barriers may exist to linking or disseminating data?

Consultative

- What stakeholders are in need of additional mental health expertise to ensure optimal psychotropic medication use?
- How can we provide a consultation service to support these individuals?

Evaluative

- What criteria/expectation/goal are you going to monitor (e.g., red flags)?
- How can key stakeholders be engaged in developing monitoring plans?

Component 3: Self-Reflection

At the provider level (based on our research and the AACAP practice parameters):

Descriptive

- What are the general trends in use of psychotropic medications among the population I serve?
- Are there concerning prescribing patterns for this population?

Consultative

- What systems are available for mental health consultations?
- Who can access these consultations?

Evaluative

- How will our practice-level system monitor the ongoing use of these medications?
- How often will the child or adolescent be seen?
- What are the possible side effects of this medication and how will they be identified and handled?
- What state or county systems, if any, evaluate optimal psychotropic medication use for youth populations that I work with?

Component 3: Resources

Sponsor/ Author	Resource
Arizona	Psychotropic Medication Use Among Children in Foster Care in Arizona
California	Psychotropic Medication and Children in Foster Care: Tips for Advocates and Judges
Government Accountability Office	HHS Guidance Could Help States Improve Oversight of Psychotropic Prescription
Medicaid Medical Directors Learning Network (MMDLN)/Rutgers CERTs	Antipsychotic Medication Use Among Medicaid Children and Adolescents: Report and Resource Guide from 16 State Study
National Committee for Quality Assurance	Antipsychotic Medication Measures for Medicaid and CHIP
Texas	Psychotropic Medication Utilization Parameters
Washington	Partnership Access Line

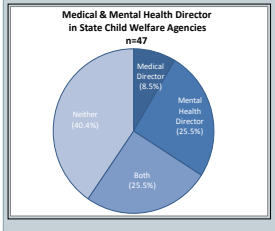
Component 4: Mental Health Expertise

- Mental health expertise
  - Child and Adolescent Psychiatrist
  - Pediatrician
  - Pharmacist
  - Psychiatric Nurse Practitioner
  - Registered Nurse

Component 4: Mental Health Expertise

- Mental health expertise may be available as:
  - Hired staff within the Agency
    - (e.g., Medical and Mental Health Directors)
  - Staff at partnering State Agencies; or
  - Consultants external to the State system
    - Formal and informal arrangements

Component 4: Medical and Mental Health Directors



Mental Health Expertise	n (%)
Medical Director	4 (8.5)
Mental Health Director	12 (25.5)
Both	12 (25.5)
Neither	19 (40.5)

(Leslie, Mackie, et al, 2010)

Component 4: Self-Reflection

At the system level:

- What skill set do we need in our system?
- Will we house expertise within child welfare, other public sector systems, or "contract-out"?
- How will we provide mental health expertise at the individual child level?
  - As-needed basis?
  - PRN consultation available?
  - Routine, required reviews?
    - Selected psychotropic medications/populations
    - All psychotropic medication/populations

At the practice level:

- Do you have mental health expertise available in cases where a second opinion is warranted?
- Do you have criteria for identifying cases in which a second opinion is considered appropriate?

Component 4: Resources

Sponsor/ Author	Publication or Tool to Support Mental Health Experts
AAP	Advocacy Guide: Training Modules
AACAP	State Advocacy Manual
AACAP	State Advocacy Toolkit
AACAP	Understanding Your State Legislature
AACAP	Advocating for Children and Adolescents with Mental Illnesses

Component 5: Information Sharing

- Information Sharing:

  As stated in the information memorandum, disseminating accurate and up-to-date information and educational materials related to mental health and trauma-related interventions (including information about psychotropic's) to clinicians, child welfare staff, and consumers (e.g., youth, family members, foster parents, and advocates)

Component 5: Self-Reflection

Systems- and Practice-level

- Where can we get accurate, up-to-date information?
  - Consult available professional guidelines
    - Example: AACAP Policy Statement on Psychiatric Care of Children in the Foster Care System. See Appendix in *Tufts Study Report*.
  - Consult Child Welfare Information Gateway
  - Acquire additional expertise in child welfare agency

Component 5: Resources

Sponsor/Author	Publication
NIMH	Mental Health Medications
NIMH	Treatment of Children with Mental Illness
NIMH	Treatment of Children with Mental Disorders
NAMI	NAMI Policy Research Institute Task Force Report: Children and Psychotropic Medications
AACAP	Psychiatric Medications for Children and Adolescents: Part I – How Medications are Used
AACAP	Psychiatric Medications for Children and Adolescents: Part II – Types of Medications

Questions?

- For more information on the *Multi-State Study on Psychotropic Medication Oversight in Foster Care*, please link here.
- For more information on a state evaluation of an approach to monitor antipsychotic medications conducted for the Office of the Child Advocate in the Commonwealth of Massachusetts, please link here.
- For additional information about our work, including our current study, please contact:

Tom Mackie (tmackie@brandeis.edu).

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