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

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Policy to Practice Dialogue: Making it Work in Child Welfare
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Learning Objectives:

At the end of this session, the learner will:

1) Know recent rates of psychotropic medication use among youth in foster care;
2) Describe recent efforts to develop approaches to psychotropic medication oversight in foster care;
3) Profile Tennessee as a case study; and
4) Consider practice implications for this vulnerable population of youth.

Youth in Foster Care

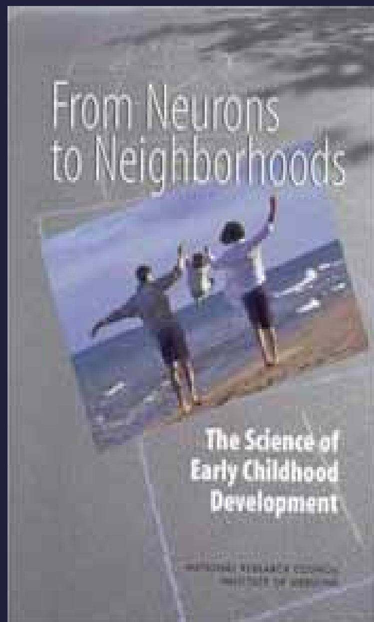
- Large proportion of youth
  - 3.5 million reported to CW each year
  - Approximately 423,000 children in foster care on any given day *(Children's Bureau, 2011)*

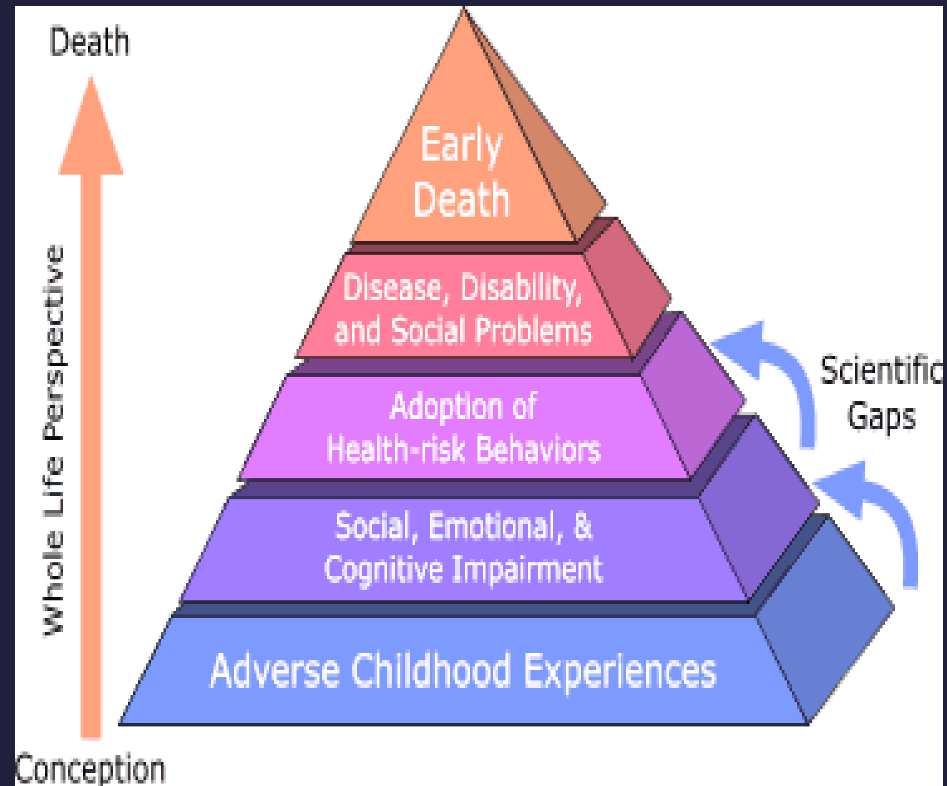
- Unique vulnerabilities of this population
  - "At risk" for developmental, behavioral, educational problems
  - Subpopulation: High needs and costs to child welfare, medical, mental health, education systems
    - Almost 50% score at or above the clinical cutoff on the CBCL, even 12 months post removal *(Burns et al., 2004; Leslie et al., 2004; Leslie et al., 2005)*
    - About one-fifth of children > 4 years in special education *(Lambros, Leslie, et al., 2010)*

Mental Health Needs of Youth in Foster Care

- 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; McMillen et al, 2004; Halfon, Mendonca, and Berkowitz, 1995; U.S. Public Health Service, 2000)*
- 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?

Research on the Effects of Abuse and Neglect



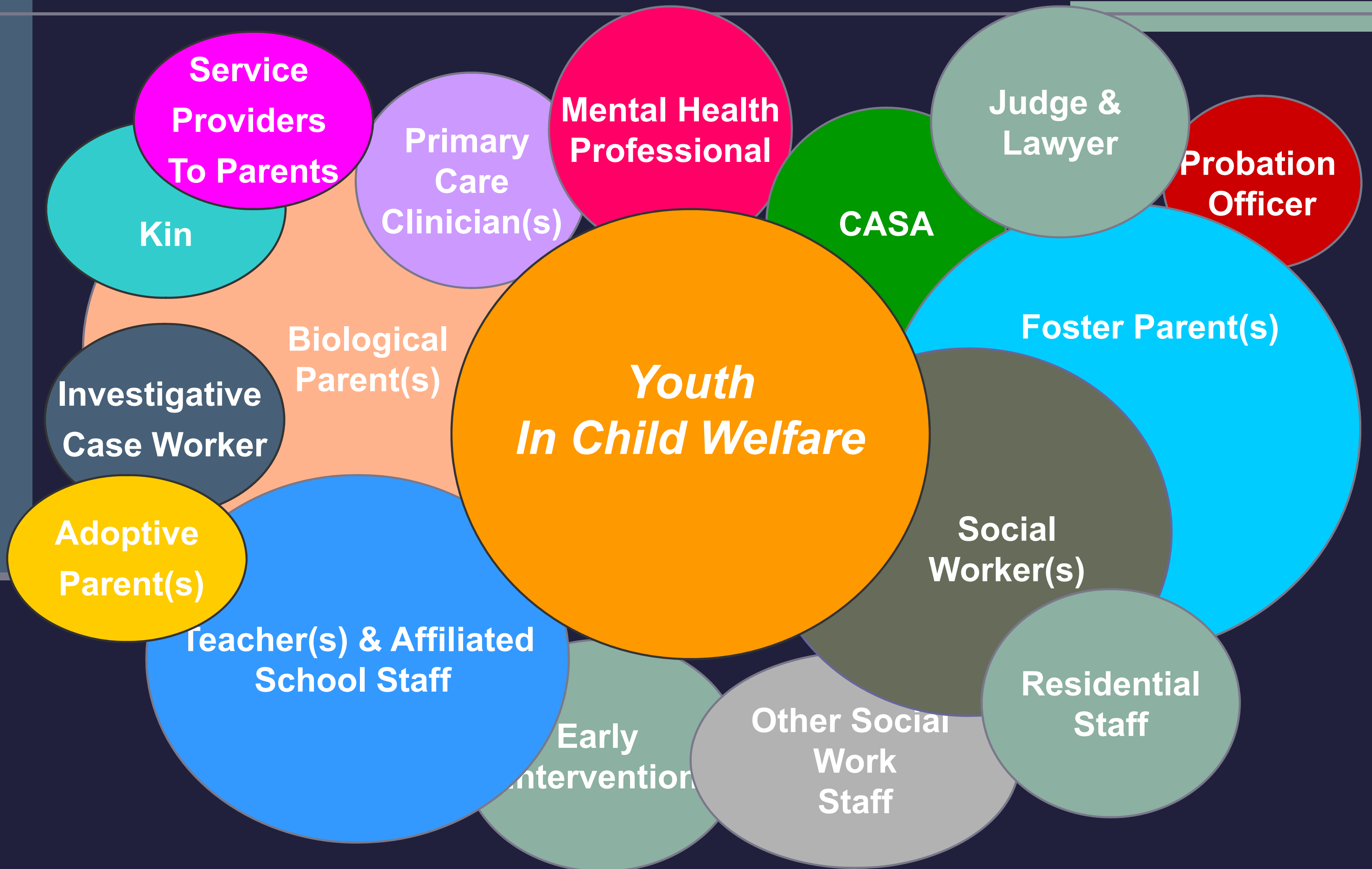


http://www.acestudy.org/aboutacestudy.php

Exacerbated by. . .

- Multiple placements *(Battistelli et al., 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 et al., 1996)*

Care (Dis-)Coordination



Effect on Child Welfare Systems

- 20% of placement changes related to behavior problems *(James et al., 2004)*
- 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)*

Medication Use among Youth in Foster Care

- In general, youth population during last decade:
  - Psychotropic medication use increased 2-3 fold *(Olfson et al., 2010)*
  - Polypharmacy increased 2.5-8 fold *(Olfson et al., 2002)*

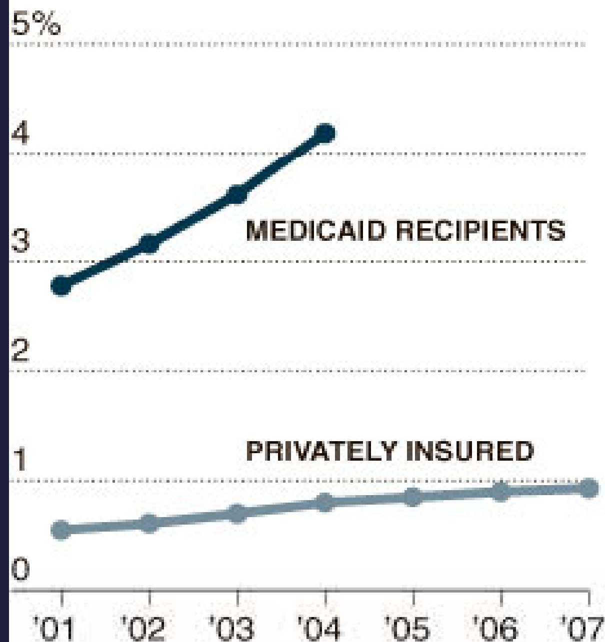
Medication Use among Youth in Foster Care

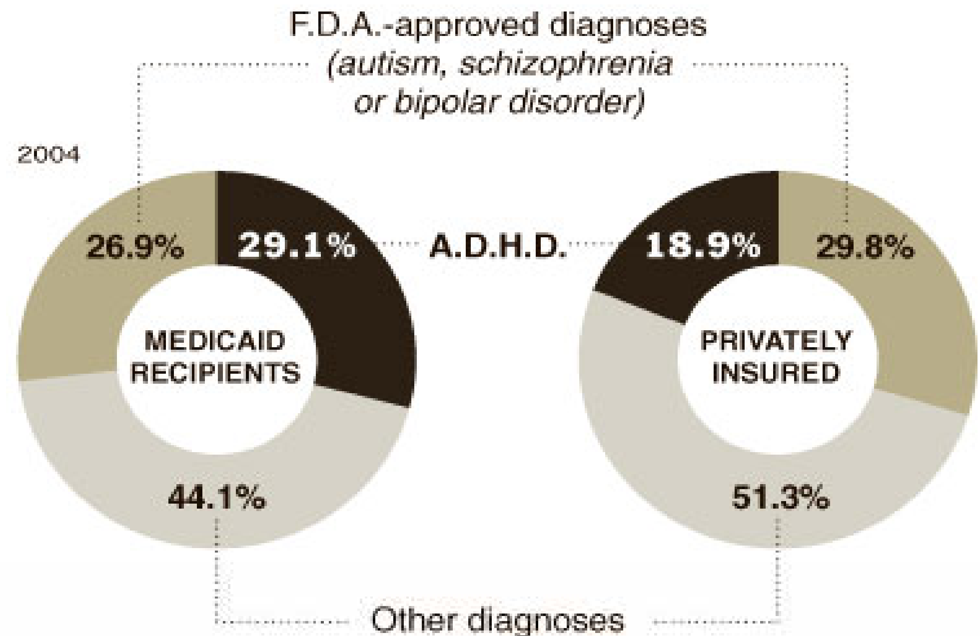
- Estimated rates of medication use for youth in foster care range from 13-52% as opposed to 4% in general population. *(dosReis et al., 2001; Kansas Health Policy Authority, 2008; McMillen et al., 2007; Office of Texas Comptroller, 2007; Raghavan et al., 2005; Zima et al., 1999)*

Medication Use among Youth in Foster Care

- Study on polypharmacy for youth in foster care *(Zito et al., 2008)*
- Random sampling of 472 youth in foster care in Texas prescribed psychotropic medications
  - Found 41% received three or more psychotropic drugs concomitantly

Health Policy Implications: Insurance Type





Note: Data for Medicaid recipients is from Medicaid Analytic Extracts for seven states: California, Florida, Georgia, Illinois, New York, Ohio and Texas. Data for privately insured is from an analysis by Stephen Crystal and Cecilia Huang of nationwide data from Thomson MarketScan. Data includes only those children who were in the insurance programs for the full calendar year. A.D.H.D. counts only those without a more severe diagnosis.

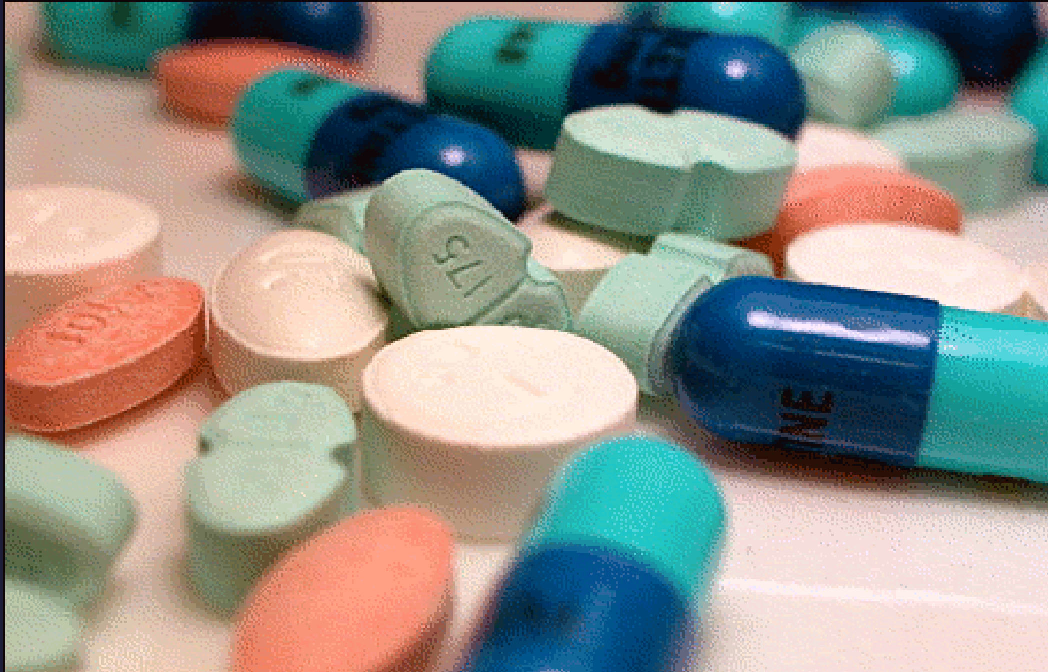
Source: Stephen Crystal, Rutgers University; Health Affairs Journal

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

Implications: Geographic Variation

- Significant geographic variation in rates of psychotropic medication use among youth in child welfare:
  - National Study on Child and Adolescent Well-being (NSCAW): 15% of children reported taking psychotropic medication,
  - Rates of medication use varied: 0%-40% (a 40-fold variation!) across catchment areas *(Leslie et al., in press)*
  - State-variation in concomitant use of 3 + psychotropic medications for children with Autism Spectrum Disorder in foster care *(Rubin et al., 2009)*

Congressional Hearings 2008



P.L. 110-351

- “Fostering Connections to Success and Increasing Adoptions Act,” October **2008**
  - http://www.fosteringconnections.org/
- State child welfare systems must develop health and mental health plan for foster care
  - Collaborate with Medicaid, pediatricians, and other experts
  - Include health and mental health screening, continuity of care, oversight of medication

PL 110-351 Guidance

- Released guidance in Spring 2010
  - http://www.fosteringconnections.org/
- Mandates a schedule for “health screening that meets standards of medical practice.”
  - Specifies identification of mental health needs.
  - Mental health screening process needs to mirror or incorporate professional guidelines.
- Encourages agencies to pay particular attention “to oversight of the use of psychotropic medicines in treating the mental health care needs of children.”

Study Objectives

- Through a national study:
  1) Examine state policies and best practices regarding psychotropic medication oversight;
  2) Identify promising practices to disseminate to child welfare agencies; and
  3) Determine implications for clinical care, research, and policy

Sample and Measures

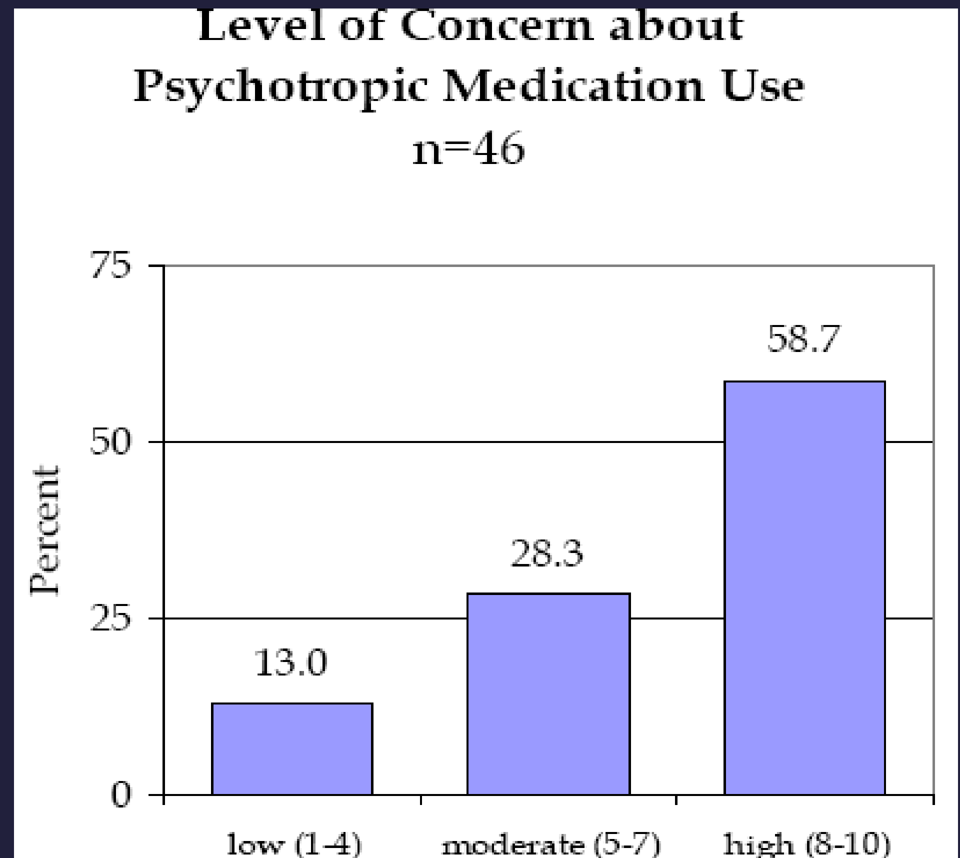
- Phone surveys conducted with key informants (n=48/51)
  - 64 questions concerning oversight of psychotropic medication use
  - 94% response rate
- Document review of existing state policies and guidelines, either available on public websites or provided by key informants
- Mixed methods approach

Components of an Oversight System: Recognition

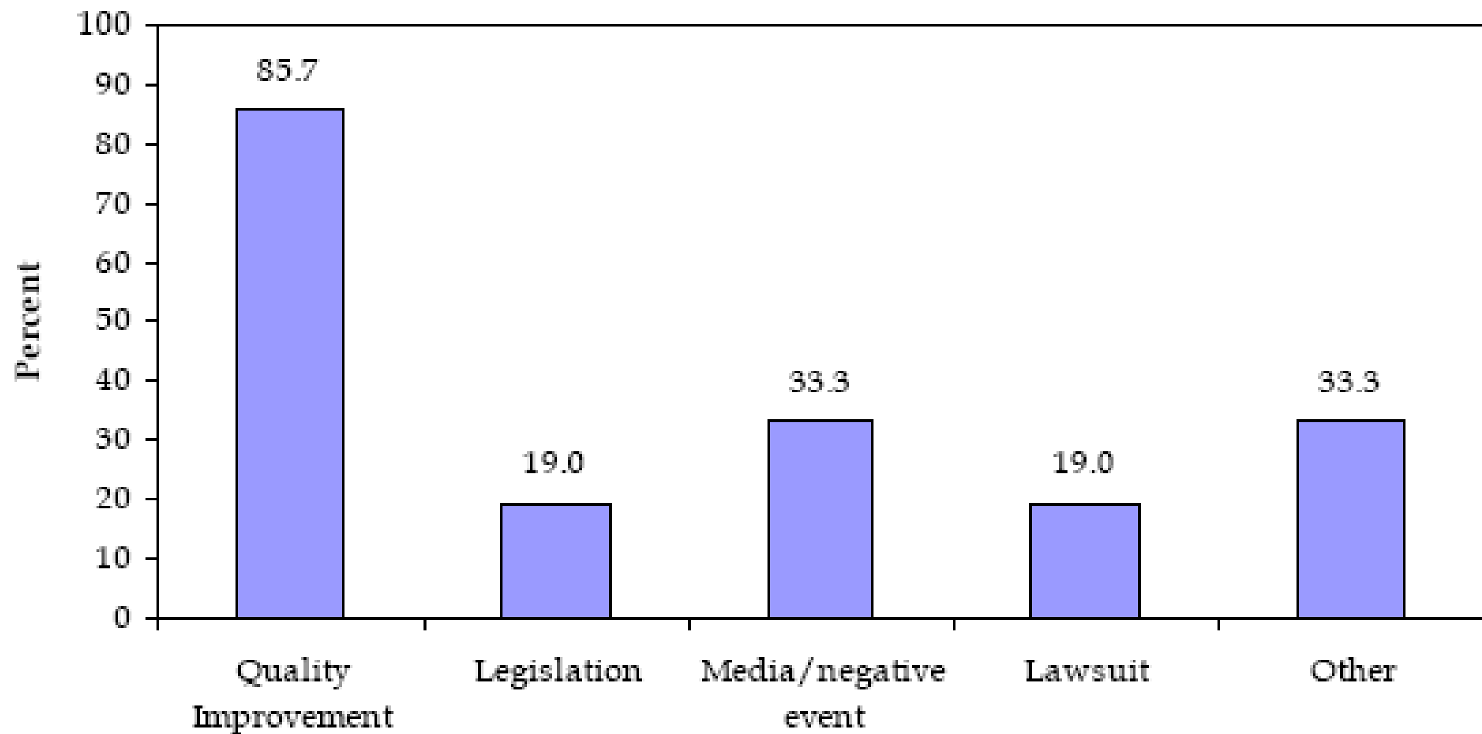
1. Recognition that psychotropic medication use is a systems problem
2. Collaboration among youth-serving organizations and stakeholders
3. Access to up-to-date guidelines on clinical practices
4. Mechanisms for identifying who needs psychotropic medication
5. Informed decision-making/consent and medication monitoring
6. Involvement of biological parents and youth in decision-making
7. Oversight program for monitoring population trends
8. Presence of a feasible and employable policy/guideline
9. Fiscal, human, and technological resources
10. National approach for psychotropic medication oversight

Recognition: Priority

- Scale of 1-10, with 10 being high
- Human resources:
  - Medical Directors (n=16; 34%)
  - Mental Health Directors (n=24; 51%)
  - Other specialized mental health staff (n=32; 68%)



Recognition: Impetus



Recognition

- **Problem:** Not recognized as an issue by all members of child welfare agency
  - *"Identifying the problem - that is the stage we are at - not every one agrees that it is a problem."*
  - *"This issue has never been looked at on an organized basis. It has always been left up to the individual case workers."*
- **Solutions**
  - Gather data on rates of medication use-national and state specific
  - *"The challenges must be met at the system level."*
  - National response re: medications

Components: Collaboration

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Collaboration

- Variation existed in the extent of collaboration between youth-serving state agencies.
- Over half (55.4%) of key informants reported access to data sources located in other youth-serving agencies, such as Medicaid, Mental Health Departments, or Managed Care Entities.

Collaboration

- **Problem:** Lack of consensus across child-serving agencies and professionals
  - *“Typically, we don’t work together.”*
- **Solutions:** Collaborative process
  - *“It wasn’t until we made it a larger conversation that we made progress. Don’t develop policy-practice in isolation.”*
  - *“Include all of the stakeholders in the policy development - get them to voice their concerns and be a part of the process. Will likely lead to greater buy-in with the policy.”*

Components: Access

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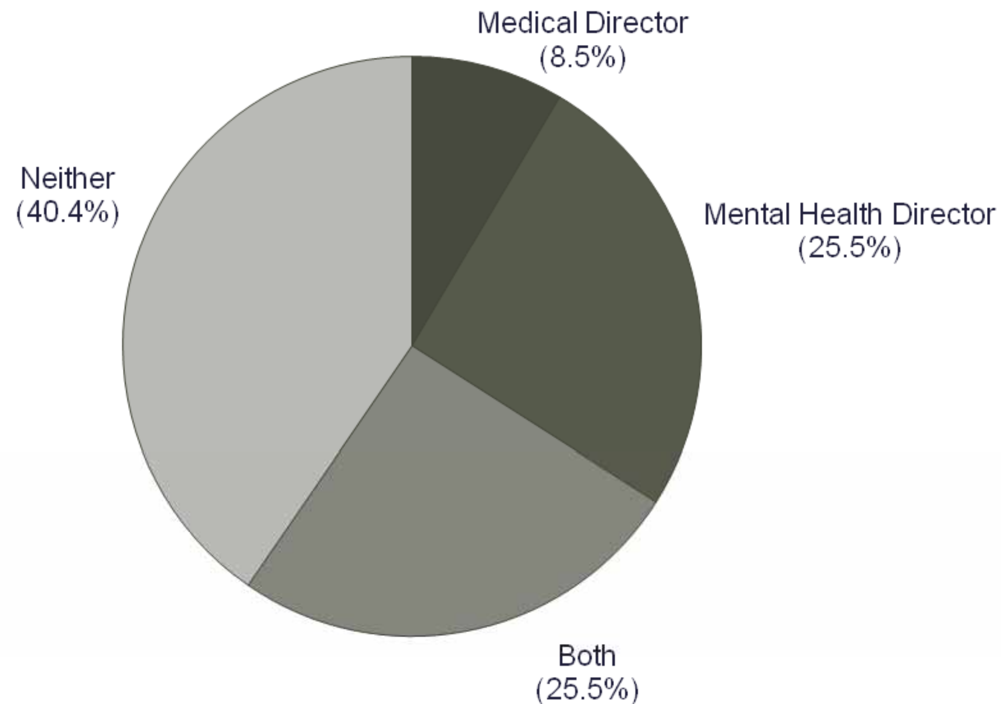
Access to Professional Guidance



Access to Professional Guidance

- Problem: Limited evidence and professional guidance available to inform development of psychotropic medication oversight system.
- Solution:
  - Consult Available Professional Guidelines
    - Example: AACAP Position Statement on Oversight of Psychotropic Medication Use for Children in State Custody: A Best Principles Guideline. See Appendix in *Tufts Study Report.*
  - Acquire Additional Expertise In Child Welfare Agency

Components: Identification

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Identification

- More than three quarters of the states completed **mental health screens** for children entering foster care (n=37 ,77.1%)
- Less than one quarter completed **mental health assessment** for children entering foster care (n=11, 22.9%)
- A forthcoming paper from our group suggests minimal adoption of professional guidelines for evaluation of mental health for children in foster care.

Components: Informed Consent

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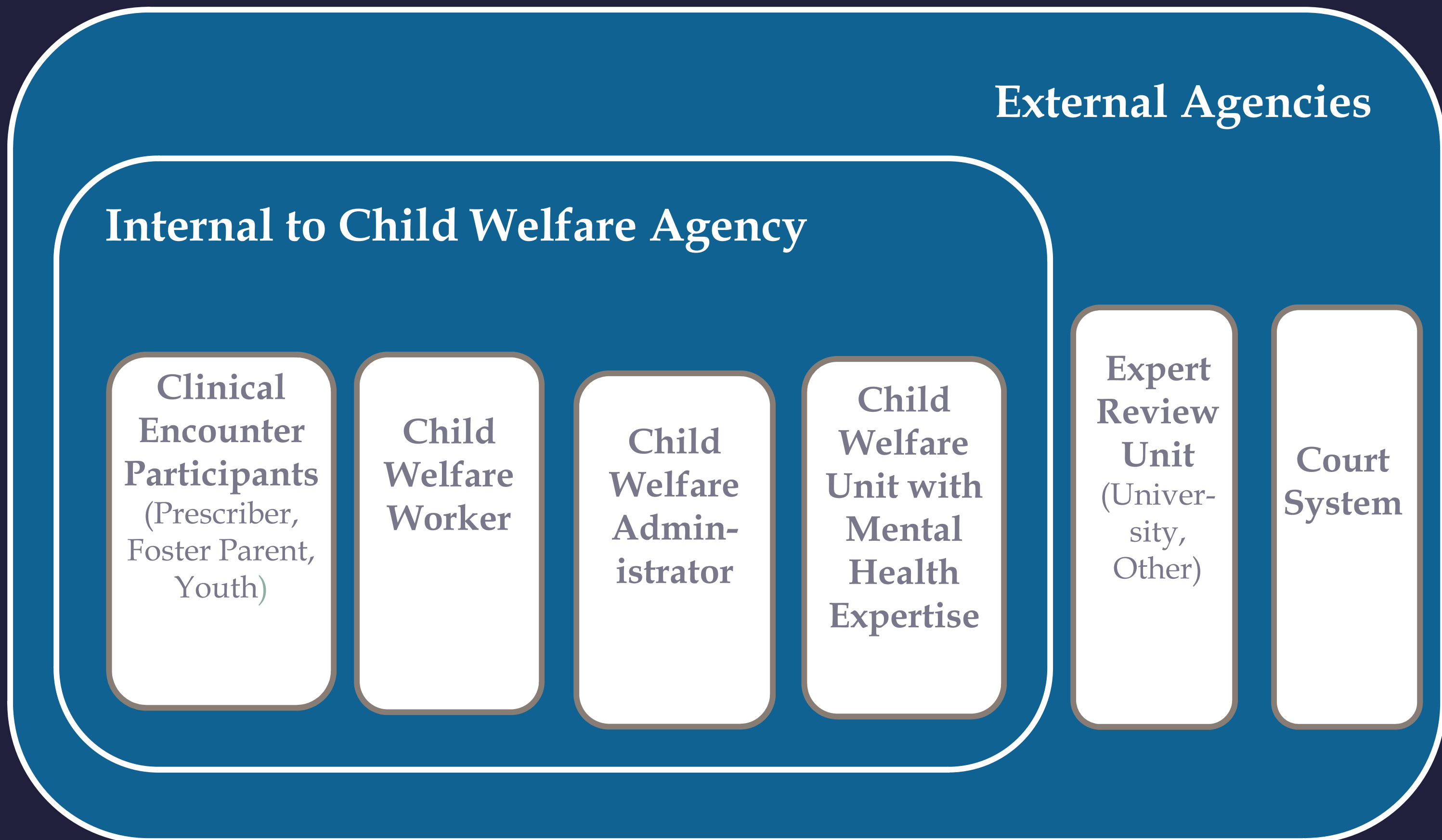
Informed Consent



Components: Consumer Engagement

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Consumer Engagement

- Engage youth: Youth in NY state foster care authored handbook for their peers about their rights and consent process for medication use
- Engage biological parents to become advocate for their child’s mental health needs and services

Components: Monitor Trends

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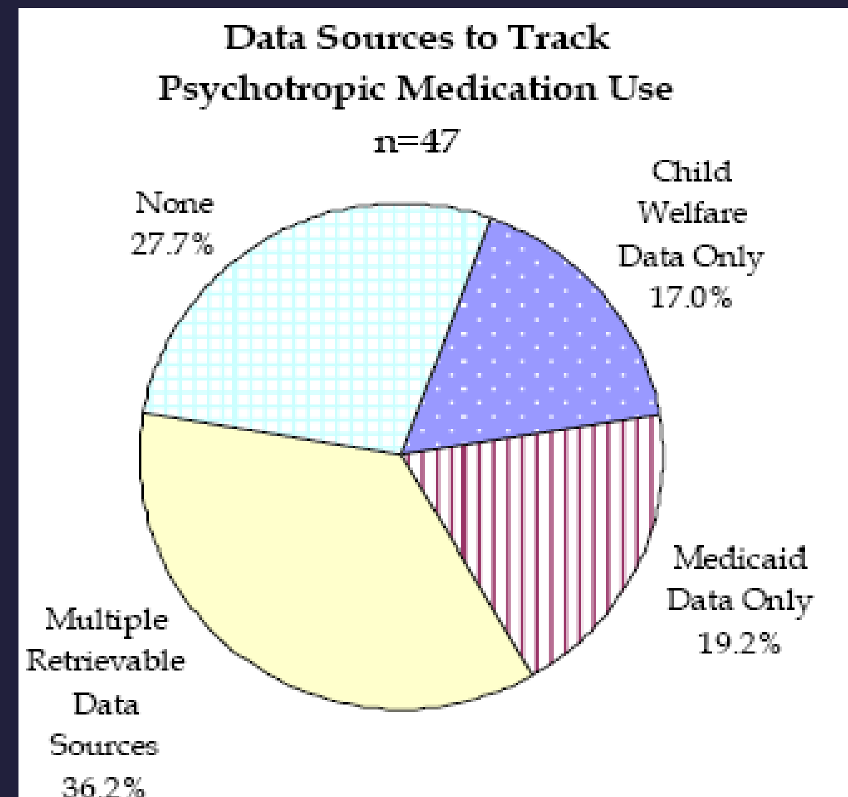
Monitor Trends

- Dimensions:
  - Variety of data sources
    - SACWIS
    - Medicaid
    - Mental health
    - Managed Care Plans
  - Population-level vs. individual case reviews or audits
  - Real time vs. periodic intervals
  - Merged databases



Monitor Trends

- Solutions:
  - Develop tracking system.
    - *“It is tedious to develop a policy but not really that hard. The hard part is implementation and tracking. Need to have people with specific skills to track and interpret the data.”*
  - Collaborate with Medicaid, mental health, and managed care plans to more accurately track trends via data sharing agreements
  - Require reporting by managed care plans

Monitor Trends: Secondary Review Process

- Look at prescription patterns for individual children and overall by utilizing:
  - Audits
  - Team reviews
  - Court hearings
  - SACWIS records
  - Child and Family Services Reviews process
  - Medicaid/mental health data reports
  - Pharmacy

Monitor Trends: Outliers

- Child taking more than three medications at a time
- Psychotropic medications in children <4 years**
- Prescribing 2+ meds in same class >30 days
- Dosage exceeds recommendations
- No documentation of risk/benefit discussion or informed consent paperwork
- In general, medications not used for a length at a time.
- Antipsychotic meds >2 years

Components: Pragmatic Oversight Plan

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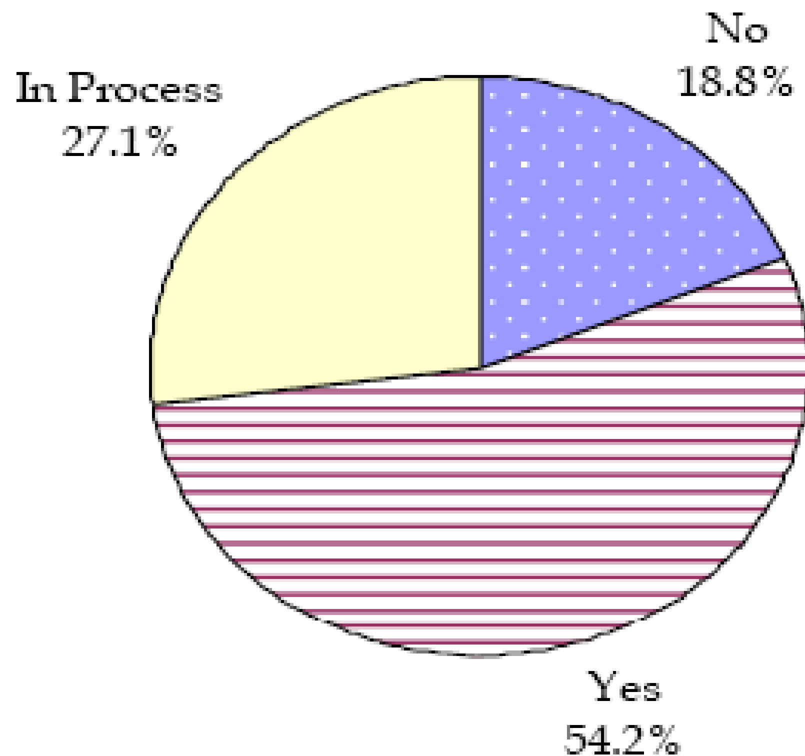
Pragmatic Oversight Plan



Pragmatic Oversight Plan

- Resources to develop a plan
  - *"We need to have resources who could guide this, especially technical assistance."*
- Fiscal resources for staff to implement plan
  - *"We recognize that given the fiscal situation, the big ticket items are not going to happen. We need to try to gather the best practice models and disseminate the info so it sticks at a local level."*
- Solutions: Braided/pooled funding, add to contracts, TA from federal government/academics, national model

Pragmatic Oversight Plan

- Develop Resources to Sustain
  - Braided/pooled funding
  - Add to contracts
  - Partner with academics
  - The advantage (?) of class action lawsuits
    - *“Funding is secure because we’re now under a consent decree.”*

Components: National Approach

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Component: Lack of National Approach

- Challenge:
  - No clear community standards and oversight for clinicians, particularly about the specific needs of this population
    - *"The medical community wants to prescribe meds because Medicaid will pay for them and child welfare staff are not qualified to challenge the doctors."*
    - *"Major challenge-getting a consensus between prescribers and child welfare about standards and expectations."*
- Solution:
  - Develop national approach to assist in identification of priority areas and use of promising approaches.

One State's Journey Towards Monitoring and Oversight: Spotlight on Tennessee

- Sued by NYC-based firm Children's Rights (same firm recently filed class-action lawsuit against MA DCF)
- Sought consultation from Child Welfare League of America, who asked Dr. Bellonci to provide consultation regarding behavior management and psychotropic medication policies
- Resulted in ~ 6 years of consultation for various projects related to these two areas

One State's Journey Towards Monitoring and Oversight: TN

- Department of Children's Services (DCS) seeks guidelines to advise staff on when to be concerned
- I recommend convening stakeholders meeting of prescribing community but relent and draft monitoring guidelines
- Guidelines meant to be utilized by DCS staff in their monitoring of psychotropic medications prescribed for children in care
- Guidelines *not* intended to dictate treatment decisions by providers

Placing Guidelines in Context

- *"…data on safety and efficacy of most psychotropics in children and adolescents remain rather limited and are in sharp contrast with the advances and sophistication of the adult field. In child and adolescent psychiatry, changes in clinical practice have, by far, outpaced the emergence of research data and clinical decisions are frequently not guided by a scientific knowledge base."* (Vitiello et. al., JAACAP, 38(5), p.501, May 1999)

Placing Guidelines in Context

- *"It is important to balance the increasing market pressures for efficiency in psychiatric treatment with the need for sufficient time to thoughtfully, correctly, and adequately, assess the need for, and the response to medication treatment."* (AACAP policy statement 09/20/2001)

Placing Guidelines in Context

- *"Anecdotally, the prescribing of multiple psychotropic medications ("combined treatment" or "polypharmacy") in the pediatric population seems on the increase. Little data exist to support advantageous efficacy for drug combinations, used primarily to treat co-morbid conditions. The current clinical "state-of-the-art" supports judicial use of combined medications, keeping such use to clearly justifiable circumstances."* (AACAP policy statement 09/20/2001)

- Polypharmacy should be avoided.

Framework for Guidelines:

- Every youth has unique needs - require individualized treatment planning
- At times, appropriate treatment for a specific child will fall outside parameters of guidelines
- Such cases should be considered for review by DCS consultants (e.g., Regional Centers of Excellence)
- It is the intent of DCS that children in care receive necessary mental health care, including psychotropic medications, in a *rational and safe* manner

Medication Integration

- Medication should be integrated as part of *comprehensive* treatment plan that includes:
  - Appropriate behavior planning
  - Symptom and behavior monitoring
  - Communication between prescribing clinician and youth, parents, guardian, foster parents, DCS case manager, therapist(s), pediatrician and other relevant members of the youth’s treatment team

Medication Guidelines

- Medication decisions should be:
  - Appropriate to diagnosis of record
  - Based on specific indications (i.e., target symptoms)
  - *Not* made in lieu of other treatments or supports that individual needs
  - Adjusted, over time, to minimum dose at which effectiveness remains and side effects are minimized
- Periodic attempts at taking off meds - if not, rationale for continuing meds should be documented

Medication Guidelines:

- Medication decisions should be based on adequate information, including:
  - Psychiatric history and assessment
  - Medication history
  - Medical history including known drug allergies
  - Consideration of individual’s complete current medication regimen (including non-psychoactive medications, e.g., antibiotics)

Medication Guidelines:

- Youth on 1+ medication from the same class (e.g., two anti-psychotic medications) should be supported by an explanation from prescribing clinician and may warrant review by a DCS consultant
- Youth on 3+ psychotropic medications should be supported by an explanation from prescribing clinician and may warrant review by a DCS consultant

Medication Guidelines:

- Medication dosages should be kept within FDA guidelines (when available)
- Clinical wisdom, “start low and go slow” particularly relevant when treating youth – helps to minimize side effects and to observe for therapeutic effects
- Any deviations from FDA guidelines should be supported by explanation from prescribing clinician and may warrant review by a DCS consultant
- Unconventional treatments should be avoided
- Medications that have more safety and efficacy data are preferred over newly FDA-approved medications

Medication Guidelines:

- Medication management requires informed consent of parents/guardians and *must* address:
  - Risks/benefits
  - Potential side effects
  - Availability of alternatives to medication
  - Prognosis with and without proposed medication treatment
  - Potential for drug interactions
- Risk vs. benefit of a medication trial needs to be considered and continually reassessed
- Justification should be provided when benefit of a medication comes with certain risks or negative consequences

Medication Guidelines:

- Children on psychotropic medications should be seen by prescribing clinician *no less than* once every three months – this is bare minimum
- Children in acute settings, displaying unsafe behavior, experiencing significant side effects, not responding to a medication trial, or in an active phase of a medication trial should be seen more frequently

Medication Guidelines:

- If laboratory tests indicated to monitor therapeutic levels of medication or to monitor potential organ system damage from medication, lab studies should be performed *at a minimum of* every three months (maintenance phase)

- If medication is being initiated, lab studies need to be performed more frequently until baseline is achieved

Questions?

For more information on the *Multi-State Study on Psychotropic Medication Oversight in Foster Care or the Rogers Examination*, please see the Executive Summaries for the respective studies.

For additional information about our work, please contact Christopher Bellonci (cbellonci@tuftsmedicalcenter.org) or Tom Mackie (tmackie@tuftsmedicalcenter.org).

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