Understanding Barriers to Service Access for Children with FASD: Presentation of LEND Capstone Project

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FASD within a BioPsychoSocial Model

Biological
- Prenatal Exposure
- Physical Health
- Metabolism
- Nutrition
- Genetics

Psychological
- Executive Function
- Cognitive Ability
- Adaptive Skills
- Mental Health

Social
- Provider Knowledge
- Intervention
- Stigma
- Policy
- Community Resources
- Violence
- Poverty
- Trauma

Engel (1980)
Social Influences: How to Capture These?

Confusion and changes in terminology

- Allostatic Load
- Complex Trauma
- Chronic/Toxic Stress
- ACEs
- Child Traumatic Stress
- Developmental Trauma Disorder
Adverse Childhood Experiences (ACE) Study:

People who reported ACEs had increased physical health, mental health, and social problems.

ACEs are common:
- Nearly 2/3 reported at least 1 ACE
- 1 in 5 reported 3 or more ACEs

Researchers described a cumulative effect:

Women experience 2+ ACEs at a greater rate than men.
Adversity ↔ Neurodevelopment

ACE Study, updated understanding of adversity:

Some ACEs are more potent than others

Potency of ACEs varies by gender:
- Boys: Poverty
- Girls: Sexual abuse

Synergistic Effects:
- Interactions of certain ACEs have an exponentially greater impact
- Boys (3+ ACEs): Poverty X sexual abuse, parental substance abuse, loss of a parent
- Girls (2+ ACEs): Sexual Abuse X DV, crime victim, poverty, parental mental illness, loss of a parent

Putnam, Harris, & Putnam (2013)
Adversity ↔ Neurodevelopment

At greater risk for maltreatment:
- Young children
- Children with special needs

Children who experience adversity exhibit developmental differences:
- Gain, then lose skills
- Slow or no progress

Hertzman & Boyce (2010)
U.S. Department of Health and Human Services, Administration on Children, Youth and Families, Children’s Bureau (2016)
Adversity Neurodevelopment

Protective Factors!

Findings are less robust:
- Fewer studies
- Unclear pathways of influence on child outcomes

Proposed:
- Early Intervention
- Permanency of placement
- Stable housing, nutrition
- Provider knowledge/specialty training in intervention

Neurocognitive Assessment Clinic (NCAC) ACEs Study

Principal Investigator: P. Kodituwakku, PhD

ACEs measured:

1. Maltreatment
2. Parental Mental Health
3. Parental Substance Abuse
4. Witness to Domestic Violence
5. Loss of a Parent (death, incarceration, deportation)
6. Disruption in primary attachment figure (CYFD involvement, multiple home placements)
NCAC ACEs Study

Methods:
- Chart abstraction
- Single reviewer, no inter-rater reliability

Sample:
- All patients seen in NCAC for FASD diagnostic evaluation or neuropsychological evaluation in 2016
- Exclusions:
  - No FASD diagnosis
  - n = 91
NCAC ACEs Study

Results:

Patients Seen in 2016 by Gender (n=91)

Boys: 54%
Girls: 46%
NCAC ACEs Study

ACEs Reported by Caregivers during NCAC Clinic Visits in 2016 (n=91)

Results:

<table>
<thead>
<tr>
<th>Number of ACEs</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 ACE</td>
<td>18.51%</td>
</tr>
<tr>
<td>2 ACEs</td>
<td>22.22%</td>
</tr>
<tr>
<td>3 ACEs</td>
<td>44.44%</td>
</tr>
<tr>
<td>4 ACEs</td>
<td>14.81%</td>
</tr>
</tbody>
</table>
NCAC ACEs Study

Discussion:

- Validity Issues:
  - Small Sample
  - Caregiver under-reporting
  - Inconsistent method of data collection
  - No inter-rater reliability in chart review

- While percentage values may not be absolutely accurate, the trend is informative:
  - Children with FASD commonly experience 2+ ACEs
  - Children with FASD experience 3+ ACEs at a substantially greater rate than the general population surveyed by the CDC

- Proportion of boys to girls seen in NCAC:
  - Reflective of gender-based attitudes towards behavioral health- behavioral markers of FASD are largely externalizing behaviors (more often associated with boys)
  - Given updated understanding of the relationship between gender and adversity, girls may be under-served in NCAC

- Children with FASD experience substantial rates of adverse life experiences that can be viewed as barriers to accessing diagnostic and intervention services.
Problem Statement

“There is so much information out there about how to diagnose these kids, and what they look like. But I never find anything that talks about what kind of services are helpful for them. And besides, they seem to have so many other problems- you know, with their parents and home lives.” – School Social Worker

Understanding the social factors that contribute to positive developmental, social, and economic outcomes for children with FASD will improve present functioning and prevent future negative outcomes.
Planned Study

• Survey study to establish baseline information

• Research Questions:
  • What services are children with FASD accessing?
  • What do caregivers identify as barriers to service access?
  • What do caregivers identify as supports in accessing services?
  • Is there an effect of gender on service access?

• Methods:
  • Target sample: caregivers of children who received an FASD diagnosis from NCAC between 2013-2016
  • Telephone survey, expected length 30 minutes
Next Steps

• Methods (cont’d):
  • Measure: questionnaire designed for this project
    • A mix of close-ended and open-ended questions
    • 2 sections: accessing diagnostic services, accessing intervention services (historical and present access)
    • Questions written at 8th grade reading level, administered verbally
    • Sample questions:
      • How old was your child when you first became concerned about them?
      • Who was the first person you talked to about your concerns?
      • What services is your child receiving now? (yes/no response to list of options, including “other” option)
      • What has made it difficult for your child to get services?
      • Are there services you think your child needs that they are not getting?

• Apply for IRB approval (PI: P. Kodituwakku, PhD)
Next Steps

• **Plan for Data Analysis:**
  • Descriptive findings
  • Analysis of variance by gender

• **Publish findings**
References


