Disparities in Familiarity with Developmental Disabilities among Low-Income Parents

Katharine E. Zuckerman MD MPH; Alison E. Chavez, B.A.; Carolina Regalado, Olivia J. Lindly, MPH; Julie A. Reeder, PhD MPH CHES

Funded by the National Institute of Mental Health, Award K23MH095828
Background

- Developmental disabilities (DDs) affect 1 in 6 children in U.S.
- Early diagnosis and treatment:
  - Improved developmental outcomes
  - Improved family coping with condition
  - Possible cost savings
- Low-income and minority children at risk for under-identification and treatment of DDs.
  - These children less likely to participate in Part C Early Intervention and other early childhood services.
Background: This project

• Differences in parents’ awareness of DDs and their early signs may contribute to disparities in DD identification.

**RESEARCH GAP:**
Little is known about low income and minority parent information about and experience with DDs in early childhood

**APPROACH:**
Community samples of low-income parents

Insight into what parents of children with DDs understand in early childhood, prior to diagnosis
Study setting: Oregon WIC Program
(Special Supplemental Nutrition Program for Women, Infants and Children)

WIC provides:
• Nutrition and health screening
• Nutrition education and breastfeeding support
• Supplemental foods
• Referrals
• Appts with families 4 times/year

WIC serves:
• Pregnant women and children age 0-5
• Families with incomes <185% Federal Poverty Level (75% below 100% FPL)
• Nationally
  • 42% Latino,
  • 20% African American
  • 4% Asian/PI
  • 5% Native American
Research Questions

1. How knowledgeable are WIC participants and WIC staff about signs of a potential development delay?

2. Does parent knowledge differ by race/ethnicity or English proficiency?

3. What role do WIC staff play in making critical developmental observations and connecting parents to community services?
Survey Administration – Parent Survey

• Face-to-face (waiting room intercept) parent survey at 7 of Oregon’s 34 WIC agencies.
  – Selected agencies with larger percentages of Latino participants.
• Self-administered survey
• Oral administration available in English or Spanish
• 79% of parents approached completed the survey (n = 539).
Survey Administration – Staff Survey

Online survey of Oregon WIC clinical staff

- Staff survey assessed:
  - Knowledge of child development
  - Frequency of parent asking about concerns and staff noticing concerns
  - Staffs’ perceived connectedness with Early Intervention and pediatric medical providers
Knowledge of Early Signs

1. Imagine your friend’s son just turned two years old. Your friend tells you she has concerns about her son and is wondering if you agree. Would you be Concerned or Not very concerned about the following?

Put an X to mark if you are concerned or not very concerned.

<table>
<thead>
<tr>
<th></th>
<th>No. Not very concerned</th>
<th>Yes. Concerned</th>
</tr>
</thead>
<tbody>
<tr>
<td>The child does not walk well.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He does not use one finger to point to show interest in something.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He does not talk at all.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He is not potty trained.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He cannot pick up a small object, like a raisin or a Cheerio, with the tips of his thumb and fingers.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He does not like to share toys with other children his age.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He does not respond to his name when his mom calls.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He cannot feed himself a cracker or a cookie.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He does not take an interest in other children (watch, smile, or go to them).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He cannot drink out of a regular cup (no lid) without spilling.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He does not recognize any letters or numbers.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Knowledge about Developmental Disabilities
Final Sample

**Parent Survey**

- 539 parents at 10 WIC clinic sites (7 LA’s)
  - 30.0% non-Latino white (NLW)
  - 10.7% non-Latino other race (NLO)
  - 19.4% Latino, English proficient (L-EP)
  - 37.0% Latino, limited English proficient (L-LEP)

**Staff Survey**

- 153 clinical staff (80% of all eligible staff)
  - Represented 33 of 34 agencies
  - Mean yrs in WIC: 12.5
  - 72.5% worked at WIC for >5 years
  - 88% White, 24% Latino
  - 39% bilingual
Results

- WIC staff have good knowledge of child development
- If staff observe a concern, likely warrants follow-up

Mean **staff** score: 82% correct

Staff scores not significantly different by staff position
Average parent score on child development questions by parent ethnicity, race, and English proficiency

Demographic Characteristics of Parent

<table>
<thead>
<tr>
<th>Demographic Characteristics of Parent</th>
<th>Average Correct Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Latino, white (NLW)</td>
<td>74.8%</td>
</tr>
<tr>
<td>Latino, English proficient (L-EP)</td>
<td>67.1%</td>
</tr>
<tr>
<td>Latino, limited English proficient (L-LEP)</td>
<td>66.1%</td>
</tr>
<tr>
<td>Non-Latino, other race (NLO)</td>
<td>59.7%</td>
</tr>
</tbody>
</table>

Mean parent score: 68% correct

*Indicates p<0.01 compared to NLW participants.
Self-reported knowledge about DDs

“How much do you know about these conditions?”

<table>
<thead>
<tr>
<th></th>
<th>Know a lot</th>
<th>Know a little</th>
<th>Heard of it but don’t know much about it</th>
<th>Never heard of it</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ADHD</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Intellectual disability</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ASD</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Non-Latino white
Non-Latino other race
Latino, English proficient
Latino, limited English proficient

*: Equivalent to 5 people
Community Contacts with DDs

“Do you have a family member or friend with…..”

- ASD: 44% White, 40% Other, 30% Latino-EP, 16% Latino-LEP
- ADHD: 64% White, 40% Other, 44% Latino-EP, 6% Latino-LEP
- Intellectual Disability: 22% White, 26% Other, 13% Latino-EP, 4% Latino-LEP

*p <0.05 compared to non-Latino White, on bivariate and multivariable analyses
How frequently do WIC staff field parent developmental questions or notice concerning behaviors in a child?

- **Never**: 1.3% (Parents) / 1.3% (Staff)
- **Less than once per month**: 17.1% (Parents) / 17.1% (Staff)
- **Between once per week and once per month**: 27.6% (Parents) / 54.0% (Staff)
- **More than once per week**: 39.5% (Parents) / 27.6% (Staff)

Graph: Percentage of Respondents

- **Parents asked staff about concerns (n = 153)**
- **Staff noticed concerns (n = 153)**

The graph shows the distribution of responses for both parents asking staff about concerns and staff noticing concerns. The percentages for each frequency category are indicated for both groups.
• Have you ever shared a concern about your child’s development with WIC staff?

- Of those who responded “yes,” NLO and L-LEP families were *more likely* to *share concerns* with WIC staff than NLW or L-EP families

35.4% of families          67.6% of families

Concerns were developmental, behavioral, nutritional, and health-related.

“[Staff] gave great pointers and advice.”       “Confirmed helpful people to talk to.”
WIC Staff Do Not Feel Well Connected to Providers

<table>
<thead>
<tr>
<th>Early Intervention</th>
<th>Pediatric medical providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>69.3% &lt; well connected</td>
<td>74.3% &lt; well connected</td>
</tr>
</tbody>
</table>
Conclusions & Implications

• Low-income families have unmet needs when it comes to child development information

• Low-income families, particularly Spanish speaking families want to talk about developmental concerns

• Spanish speaking families maybe less personally familiar with common developmental conditions
Conclusions & Implications

• Observation/discussion of potential developmental delays occurs frequently in WIC

• WIC staff do not feel well connected to providers who could further assess concerns

• There is little or no communication back to staff from pediatricians or E.I. about referrals they make

• There is a lack of continuity of care for families

• Early Intervention, Pediatricians, and Managed Care Organizations may want to *partner* with WIC to engage their shared patient population and decrease disparities in assessment and treatment
Thank you!

Contact:

julie.a.reeder@dhsoha.state.or.us
zuckerma@ohsu.edu