Disparities in Services between Latino and Non-Latino White Children with ASD and Next Steps

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Research on disparities

- Disparities in diagnosis of autism among Latinos are well established.
- Discrepancies in classification have been found among Latino children.
  - Assessments often do not take into account language barriers and assessment tools not validated for Spanish speaking populations.
Research continued

- Early intervention programs in states with higher African American and Latino children are less able to meet increased demand of serving children with autism.
- Age of diagnosis: Latinos and African Americans later than non-Latino whites.
- Latinos and African American children with ASDs have lower access to health care than non-Latino whites.
Research questions

- Do Latino and White children differ in
  - age of diagnosis?
  - ever receiving key public services (birth to three, preschool services, k-12 special education)?
  - the total number of services received and number of unmet services at time of interview?

- Do maternal education level and number of sources of knowledge about autism mediate the relationship between race/ethnicity and services?

- What are barriers to receiving services for Latino children?
Study

- Surveys: 105 total
- 46 Latina mothers
  - Data collected as part of larger study with in-home interviews
  - Recruited through service providers and support groups
- 59 non-Latino White mothers
  - Mail survey on service questions
  - Recruited through services providers and organizations
### Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Non-Latino White</th>
<th>Latino</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mom’s age</td>
<td>44.5</td>
<td>38.6*</td>
</tr>
<tr>
<td>HS or less</td>
<td>5.4</td>
<td>54.3***</td>
</tr>
<tr>
<td>Some college</td>
<td>19.6</td>
<td>23.9</td>
</tr>
<tr>
<td>College grad +</td>
<td>75</td>
<td>19.6</td>
</tr>
<tr>
<td>Mom employed</td>
<td>66.1</td>
<td>48.9</td>
</tr>
<tr>
<td>Married or living w/ part.</td>
<td>92.9</td>
<td>68.1**</td>
</tr>
</tbody>
</table>
# Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Non-Latino White</th>
<th>Latino</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-$29,000</td>
<td>5.5</td>
<td>56.5***</td>
</tr>
<tr>
<td>30,000-49,000</td>
<td>10.9</td>
<td>23.9</td>
</tr>
<tr>
<td>$50,000+</td>
<td>83.6</td>
<td>19.6</td>
</tr>
<tr>
<td>Child Age</td>
<td>9.8</td>
<td>9.4</td>
</tr>
<tr>
<td># of child behavior probs</td>
<td>4.80</td>
<td>3.79*</td>
</tr>
</tbody>
</table>
Age of diagnosis

- Age of diagnosis:
  - Age of first noticed:
  - Age told MD:
  - Age of DX:

- Comparison:
  - Latino
  - White
Age of diagnosis by age group

- 0 to 5
- 6 to 11
- 12 and up

- Latino
- White
When concerns brought to MD
When concerns brought to MD

ordered test  referred to spec  overall active response

white  latino
What did diagnosing professional do after giving diagnosis of ASD

<table>
<thead>
<tr>
<th>Action</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gave info on available services</td>
<td>58</td>
</tr>
<tr>
<td>Gave literature on autism</td>
<td>41</td>
</tr>
<tr>
<td>Spent time talking about autism</td>
<td>41</td>
</tr>
<tr>
<td>Referred to autism specialist</td>
<td>24</td>
</tr>
<tr>
<td>Referred to support group</td>
<td>21</td>
</tr>
<tr>
<td>Provided no additional info</td>
<td>12</td>
</tr>
</tbody>
</table>
Families learned about autism from:

- Friends
- Family members
- Books & Magazines
- Other parents
- Internet
- Education professionals
- Support groups
- HC professionals

The graph shows the distribution of information sources for white and Latino families.
Key public services in Wisconsin:
Ever received

<table>
<thead>
<tr>
<th>Service</th>
<th>White</th>
<th>Latino</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 3</td>
<td>80</td>
<td>50</td>
</tr>
<tr>
<td>Early child</td>
<td>90</td>
<td>80</td>
</tr>
<tr>
<td>Special Ed</td>
<td>90</td>
<td>90</td>
</tr>
<tr>
<td>Autism waiver</td>
<td>40</td>
<td>50</td>
</tr>
</tbody>
</table>
Services received at time of interview

- Physical therapy
- Occupational therapy
- Speech therapy
- Social worker

For each service, the chart shows the number of units received by White and Latino individuals. The categories are represented as follows:

- **Physical therapy**: [Diagram with units]
- **Occupational therapy**: [Diagram with units]
- **Speech therapy**: [Diagram with units]
- **Social worker**: [Diagram with units]

The chart indicates the distribution of services received by White and Latino individuals.
Services currently received

- intensive autism therapy
- respite
- psychological services
- recreational programs
- medical assistance
Services and sources of knowledge

- # services
- # unmet services
- # sources of knowledge

Legend:
- Latino
- White
Barriers for Latino children for intensive autism therapy (waiver)

didn't know avail
service not app
wait list
child will not accept
other
not eligible
Barriers for Latino children for Respite

- didn't know avail
- service not app
- wait list
- child will not accept
- not avail
- other
- too expensive
- inconvenient
Barriers for Latino children for psychological services

- Didn't know availability
- Service not available
- No insurance
- Not satisfied
- No Spanish speaking
- Other
Barriers for Latino children for recreation services
Pathway to services

- Early Diagnosis
- Birth to Three
- Waiver Program: Intensive autism therapy
- Late diagnosis
- County DD Services right away
- Waiting list for County services
What do we do now?

- Clearly must get needed information about services to Latino families
- Agencies need to reach out to populations that lack access to knowledge, information, networks, etc.
- Information must be presented in a culturally and linguistically appropriate manner
New pilot intervention study in progress

- **Entendiendo el Autismo, Puedo Entender Mejor a mi Hijo (By Understanding Autism, I Can Better Understand My Child).**
  - Funded by UW Madison’s Institute on Clinical and Translational Research (ICTR)
  - Community Partner: Wisconsin Family Assistance Center for Education Training and Support (WI FACETS)
By Understanding Autism, I can Better Understand My Child
Advisory committee

- Latino parents of children with autism; local social service and medical professionals who work with Latino families; autism educator Emily Iland; research and FACETS staff
- Met several times to review and give feedback on program content
  - Will continue to meet throughout course of project
Advisory Board
Promotoras de salud

Program delivered by Promotoras de Salud (i.e. community health workers (CHWs))

- **Definition**: A lay health educator, or peer leader, indigenous to the target community who receives training to provide health education

- **Unique approach**
  - Hired 3 mothers of children with autism
  - Received intensive training in Spanish to review program content
  - Conduct home visits with participants
Promotoras de Salud
Ceremony for Completion of Program Training
Autism education for parents

- Program consists of 2 modules; each have 8 weeks of content
- 1 session administered/week
- Each session approximately 1 hour long
- Sessions includes activities, discussions and home work assignments
First module

- Focus on child development; understand an autism diagnosis; learning about available autism resources and services; and explaining a child’s behaviors to others.
First module sessions

- Session One: *Introduction and pre-test*
- Session Two: *Understanding Child Development*
- Session Three: *Understanding the Autism Spectrum and Your Child’s Needs*
- Session Four: *How to be an Effective Advocate*
- Session Five: *Advocacy in the School System*
- Session Six: *Talking About Autism and Building Social Support*
- Session Seven: *Stress and Depression*
- Session Eight: *Looking Ahead and Post-test*
Second module

- Focus on strategies parents can do to work with their child on enhancing social and communication skills and reducing problem behaviors
Second module sessions

- Session One: Introduction and Pre-test
- Session Two: Learning About Research-Based Interventions
- Session Three: Understanding Behavior Problems
- Session Four: Preventing and Reducing Problem Behaviors
- Session Five: Communication
- Session Six: Social Skills
- Session Seven: Play Skills
- Session Eight: Looking Ahead and Post-test
In conclusion

- Clear disparities exist for Latino children compared to non-Latino white children
  - In age of diagnosis
  - How families get information
  - Birth-to-three and intensive therapy
  - Number of services accessed and unmet service needs overall

- Need more programs to provide information in culturally competent ways
Acknowledgements

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  - Hilldale Student Fellowship Program
  - UW Institute for Clinical and Translational Research (ICTR)
  - Waisman Center
References


