Development and Piloting of the Parent Perceptions of Autism Spectrum Disorder (PP-ASD) Survey

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Early Intervention is important
Identification is delayed
Longer delays in culturally and linguistically diverse communities
Parents play important roles
Purpose

Develop and pilot a survey that describes parent perceptions surrounding ASD and identification.
Survey Development

1. Literature review
2. Feedback interviews
3. Pilot – Parent Perceptions of ASD (PP-ASD)
3 Aims of PP-ASD

1. Barriers and facilitators to obtaining an identification of ASD

2. Parent perceptions and knowledge of (a) causes of ASD, (b) identification, (c) intervention

3. Information sources parents turn to
PP-ASD: 5 Parts

1. Perceived causes
2. Identification (Barriers and facilitators)
3. Intervention
4. Information sources
5. Demographic questions
Participants: Caregivers of children with a clinical or educational determination of ASD (N = 205)

Sex

- Female: 57%
- Male: 43%
Race

- Caucasian: 76%
- Black
- Asian
- Other
Education

- Post-sec Degree, 61%
- < High School

High School
Most parents hold positive perceptions of identification.
85% of parents agree that it is important for their child to be identified as early as possible.
82% and 88% of parents trust what (a) healthcare professionals and (b) teachers say, respectively.
81% and 75% of parents agree that (a) healthcare professionals and (b) teachers were helpful in getting their child evaluated, respectively.
50% of parents think an identification of ASD could harm their child.
Who initiates an ASD evaluation matters for age of identification.
<table>
<thead>
<tr>
<th>Initiator</th>
<th>$\beta$</th>
<th>SE</th>
<th>$t$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept (Parents)</td>
<td>4.568***</td>
<td>0.356</td>
<td>12.827</td>
</tr>
<tr>
<td>Healthcare Professional</td>
<td>1.782***</td>
<td>0.513</td>
<td>3.476</td>
</tr>
<tr>
<td>Teacher</td>
<td>2.208***</td>
<td>0.506</td>
<td>4.366</td>
</tr>
<tr>
<td>Family or Friend</td>
<td>0.432</td>
<td>0.695</td>
<td>0.622</td>
</tr>
<tr>
<td>Other</td>
<td>0.245</td>
<td>1.031</td>
<td>0.237</td>
</tr>
</tbody>
</table>

*Note. $R^2 = 0.111. F(4, 196) = 6.086.$  
*p < .05. **p < .01. ***p < .001.*
Parents report, on average, 6 barriers and 8 facilitators.
Barriers

- Lack of Trust of H. Professionals: 36
- Dismissal of Concerns - H. Professionals: 37
- Parents did not ASD diagnosis: 41
- Long Evaluation Process: 45
- Parent Lack of Knowledge of ASD: 48

Background

Methods

Results

Conclusions

Next Directions

Questions
### Facilitators

<table>
<thead>
<tr>
<th>Factor</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents Doing Research</td>
<td>65%</td>
</tr>
<tr>
<td>Media Exposure</td>
<td>67%</td>
</tr>
<tr>
<td>Parent Knowledge of ASD</td>
<td>73%</td>
</tr>
<tr>
<td>Parent Knowledge of Child Devel.</td>
<td>77%</td>
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<tr>
<td>Parent Persistence</td>
<td>87%</td>
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</tbody>
</table>
Age of ID v. Sum of Barriers/Facilitators

- **Facilitators**
  \[ r_s = .342, p < .001 \]

- **Barriers**
  \[ r_s = -.025, p = .724 \]
Results point to importance of preparing parents to be advocates.
Extend to immigrant-refugee communities
Questions?
Appendix
There are **significant** differences in age of identification based on type of identification.
Age of Identification

- Overall: 6
- Educational determination: 6.8
- Clinical diagnosis: 6
- Both: 4
75% of parents know the difference between an educational determination and clinical diagnosis.
<table>
<thead>
<tr>
<th>Comparisons</th>
<th>Mann-Whitney Test (U)</th>
<th>$p$</th>
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</thead>
<tbody>
<tr>
<td>Educational Determination v. Clinical Diagnosis</td>
<td>2198.5</td>
<td>.024</td>
</tr>
<tr>
<td>Educational Determination v. Both</td>
<td>556.5</td>
<td>&lt;.001</td>
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<tr>
<td>Clinical Diagnosis v. Both</td>
<td>1213.5</td>
<td>&lt;.001</td>
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<tr>
<td>Variable</td>
<td>$r$</td>
<td>$p$</td>
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<tr>
<td>-----------------------</td>
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<tr>
<td>Number of Barriers</td>
<td>-.025</td>
<td>.724</td>
</tr>
<tr>
<td>Number of Facilitators</td>
<td>.342</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
## Barriers

### Service Shortages
1. Lack of Services: 31%
2. Long Eval: 33%
3. Long Waitlist: 45%

### Resource Challenges
4. Language Barriers: 19%
5. Financial Barriers: 21%

### Poor Relationships
6. Comm - Teachers: 22%
7. Comm - H. Professionals: 20%
8. Trust - Teachers: 23%
9. Lack Trust - Profs: 36%

### Negative Perceptions
10. Not Want Label: 41%
11. Stigma: 31%
12. Denial: 24%

### Lack of ASD Knowledge
13. Pub Awareness: 33%
14. Teachers: 31%
15. H. Professionals: 34%
16. Parents: 48%

### Dismissal of Parent Concerns
17. Fam/Friends: 35%
18. Teachers: 26%
19. H. Professionals: 37%

### Identification Errors
20. Screeners - No Detect: 18%
21. Different Diagnosis: 25%
Facilitators

Specialized Training
1. Teachers - 47
2. H. Professionals - 56

Parent Knowledge
3. Importance ID - 63
4. Child Devel - 77
5. ASD - 73

Concerns Identified
6. Fam/Friends - 56
7. Teachers - 60
8. Prof - 54
9. Screeners - 58

Awareness
10. Media Exposure - 67
11. Know Someone w/ ASD - 52

Action
12. Persistence - 87
13. Doing Research - 65