**Background and Purpose**

Early intervention (EI) improves developmental outcomes for children with ASD (Dawson et al., 2010; Kasari, Freeman, & Papaarella, & Jahromi, 2008), yet access to EI is contingent on screening. In 2006, fewer than 10% of PCPs screened for ASD (Doonsie, Weiner, Johnson & Newschaffer, 2006). The American Academy of Pediatrics (AAP) now recommends ASD screening for all children at 18 and 24 months of age (Johnson & Myers, 2007). Understanding the views of PCPs on early screening for ASD and what factors contribute to acceptance and use of screening tools might facilitate wider implementation of the AAP guidelines.

The purpose of the focus group study was to gather information from PCPs to inform a revision of the First Year Inventory (FYI; Baranek, Watson, Crais, & Reznick, 2003), and to explore the utility of using an ASD screener between 12-18 months during well-child visits in pediatric, family-practice, and family medicine department settings in North Carolina. The FYI is a parent report screening tool used to detect risk for autism in 12-month olds. Results of a recent longitudinal study in a community sample suggested that the FYI had strong predictive validity and showed promise as an ASD-specific screening tool (Turner Brown, Baranek, Reznick, Watson & Crais, in revision).

**Methods**

### Focus Group Questions

- **Think back...to young children...you suspected of having autism.** What are some of the issues that you feel are important to consider when screening for ASD in young children?
- **What specifically would you be looking for in a screening tool for 12-month olds?**
- **What would enable your practice to use a screening tool like this?**
- **What are the challenges to using a screening tool like this?**

### Provider Focus Groups n=61

<table>
<thead>
<tr>
<th></th>
<th>MD</th>
<th>Nurse</th>
<th>*Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Health</td>
<td>16</td>
<td>19</td>
<td>6</td>
</tr>
<tr>
<td>Family Practice</td>
<td>1</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>Private Practice</td>
<td>8</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>35</td>
<td>1</td>
</tr>
</tbody>
</table>

* Other: Administrative staff, Physician’s Assistant, Resident, Social Worker

### Conceptual Framework Coding Scheme

**Tool Design**

- Cost
- Format
- Length
- Literacy Level
- Age range
- Social validity
- Writing of items

**Ethical Moral Dilemmas**

- Procedural
  - Current Practice
  - Desired Practice
  - How administered?
  - Training Related Issues
  - Who administers screen?
  - Who scores it?
  - Who scores results?
  - What happened at WC visit?
  - What didn’t happen at WC visit?

**Interpersonal**

- How do you know autism when you see it?
- Need for clear evidence
- Intra office procedures and communication

**Context**

- Culture/SES
- Early Intervention System & Resources
- Hispanic context
- Insurance billing
- Medicaid system

### Results: Example Codes and Quotations

<table>
<thead>
<tr>
<th>Theme</th>
<th>Definition</th>
<th>Illustrative Quotations</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethical Moral Dilemmas</td>
<td>Dilemmas that providers face in practice (e.g. falsely alarming parents, limited resources with regard to services).</td>
<td>“I think one of the things for me is just apprehension as to how the family is going to respond when I mention a term like autism that has such a stigma.”</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“… even today I had a patient who had some delays and no one could answer for me what I would be looking for if I needed to refer her on further for some issues, which was kind of frustrating for me...or whether or not we should screen her for autism...and she’s four years old.”</td>
<td>27</td>
</tr>
<tr>
<td>Interpersonal</td>
<td></td>
<td>Include professional’s uncertainty about screening for autism at 12 months OR whether behaviors that they are observing during well child visits are cause for concern.</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I want to see data that it works. It’s not a useful... screening tool, I’m not going to spend the time.”</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I think it’s important but I would be concerned about how accurate it is at 18 months for autism.”</td>
<td>20</td>
</tr>
<tr>
<td>Need for clear evidence</td>
<td>Include comments about provider’s need for clear evidence of early behavioral markers at 12 months of age in order to consider screening at that age.</td>
<td>“Another thing is sort of belief that the system is really going to GET these kids, cause it’s one thing for us to screen at 12 months old, but if the system is overwhelmed, and we have all public patients so it’s ALL going to the same few agencies, you know there is TIME CAPACITY...”</td>
<td>11</td>
</tr>
<tr>
<td>Culture/SES</td>
<td>Include comments about cultural and SES diversity, and need for sensitivity to these differences in views of screening, accessing, and use of resources.</td>
<td>“…it just depends on the level of education of the parent and how sophisticated they are... Some of my parents don’t read very well, so some of the questions on there are difficult for them. And then some of my patients are Spanish speaking so it’s not appropriate...”</td>
<td>11</td>
</tr>
</tbody>
</table>

**Discussion**

- The code “Ethical/Moral Dilemmas” had the highest overall frequency. PCPs concerns included the “risks” of over- or under-referral and the impact on families, the “stigma” of the term autism, and weighing the benefits and risks of early screening.
- PCPs also had questions about how do you know what to look for in infants, what is “typical”, and where’s the evidence for early identification of ASD?
- PCPs were apprehensive about the capacity of the EI system and the lack of follow-up from EI agencies once children were referred.
- PCPs were concerned about cultural bias of screening tools and their own limitations in understanding perspectives from families of other cultures.
- PCPs wanted a tool that was: quick (e.g., 5 questions) and a two-tiered system (general & at-risk screens), Medicaid approved, electronically available, and culturally sensitive. PCPs also debated who should complete the tool (parent and/or PCP).

**Future Directions**

- Focus groups on screening for ASD with diverse group of parents- results to be shared
- Currently surveying PCPs about screening practices in NC
- Developing models of effective screening practices
- Translational professional development for PCPs
- Assessing effectiveness of referral tracking
- A further revision of the FYI is underway and will be informed by the current project.

**References**


Tanner-Brown, L., Barnek, G. T., Reasmick, J. J., Watson, L. R., & Craig, E. R. Prevalence Validity of the First Year Inventory to Age Three Years. (in revision).

**Acknowledgements**

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http://www.med.unc.edu/pears

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