COMMUNITY-BASED AUTISM IDENTIFICATION TEAMS:
Medical–Educational Collaboration to Identify Young Children with Autism Spectrum Disorder

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Introduction:
In Oregon, children may receive a medical diagnosis of an ASD but not educational eligibility for autism services and vice versa. This can be very confusing to families. There is a different evaluation process in medical vs educational settings. DSM criteria are used by medical teams and not by educational teams, and there is a prescribed timeline to complete educational evaluations but long wait lists for a medically-based team evaluation. In addition, certain agencies do not accept educational eligibility as a diagnosis, e.g., Developmental Disability services, Social Security Administration.

Objective:
Establish a single, valid and timely process in the local community that determines both educational eligibility for autism services and a medical diagnosis for children up to 5 years of age.

Description:
This project is one activity of our state autism implementation grant funded by the US Maternal and Child Health Bureau. This grant is administered through the Oregon Center on Children and Youth with Special Health Needs (OCCSYHN) at OHSU. This activity was initially funded by small grants from the Oregon Commission on ASD (OCASD) and the Centers for Disease Control.

Methods:
Evaluation Components: Our autism identification teams incorporate the following components for an inter-disciplinary team evaluation as recommended by the OCASD:
- Diagnostic interview based on DSM criteria
- Standard observation using research-based, autism-specific tool (e.g. ADOS 2)
- Observation of individual in unstructured activity
- Developmental assessment using the best available standardized tools for:
  - Cognition: thinking and reasoning
  - Adaptive functioning
  - Functional communication, including speech and language skills
  - Sensory processing
  - Social and emotional skills
  - Hearing testing
- Once identified, “starter pack” on next steps and resources given to family

Team Process:
a. Teams meet monthly
b. Concurrent and sequential medical and educational evaluations (all new teams do initial evaluations together)
c. Joint review of results by medical and educational staff including completion of DSM 5 checklist
d. Joint review of results with families
e. If disagreement, referral to Institute on Development and Disability at OHSU for further evaluation (to top of waiting list)

Who is on the team?
- A health care professional
- Mental health provider (as regular member or as consultant)
- Educational staff who are currently doing autism eligibility evaluations: Autism specialist, Speech pathologist, School psychologist or Special Educator and Other staff as needed, e.g., Occupational Therapist
- Parent Partner, a parent of a child with ASD, who connects with parents before and 1 month after evaluation and is present at team and family conferences

Where are the teams?
8 Communities (cities listed represent a local area served by an Educational Services District or ESD): Astoria/Seaside, Coos Bay, Salem, The Dalles, Medford, Grants Pass, La Grande and Albany (services started in September, 2015)

Training and supports provided to teams:
Initial 2 day training for all team members including training in use of STAT (Screening Tool for Autism in Toddlers and Young Children) (Stone, et al, 2004)
On-going technical assistance:
- Site visits, initial and as needed
- Every other month webinars, topics have included:
  - Team building
  - Breaking the News
  - Working with different cultural groups
  - ADOS and STAT scoring reliability checks
  - Case Studies, e.g., ASD vs ADHD, ASD vs 16p del

Information, Materials (including materials developed by AAP/CDC) and Resources, examples include:
- DSM 5 Family Interview (OHSU, 2012) revised
- “Starter Packet”
- Getting Started handout (Nickel, 2014)
- First 100 Days Kit from Autism Speaks
- Tip Sheets, examples include:
  - You are not alone (P McGin Smith)
  - Picky Eaters with ASD (Nickel, 2014)
  - Complementary and Alternative Medicine (CAM) and children with ASD (Nickel, 2014)
  - Tips for getting best behavior during administration of the STAT
- Autism Resources for Families (arranged by category, reviewed with parents on request by the team’s Parent Partner)

Experience to date:

<table>
<thead>
<tr>
<th># of children evaluated</th>
<th>65</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age when evaluated</td>
<td>Mean 3.8 years*</td>
</tr>
<tr>
<td>Referral source</td>
<td>Primarily from Early Intervention</td>
</tr>
<tr>
<td># with ASD identification</td>
<td>47</td>
</tr>
<tr>
<td># of disagreements</td>
<td>5</td>
</tr>
<tr>
<td># referred for CDRC team evaluation</td>
<td>4</td>
</tr>
<tr>
<td># other referrals</td>
<td>19</td>
</tr>
</tbody>
</table>

Team members and families highly satisfied with process

Lessons learned:
- Difficulty scheduling appointments: One solution - EI creates schedule of appointments to meet their timelines first, and gives it to parents and MD for scheduling MD appointments
- Giving of diagnosis/eligibility decision to family before meeting as a team
- Difficulty of Ei team members adjusting to new team concept that includes health care

Outcomes to date:
The Autism Identification Teams have increased state and local community capacity to identify young children with ASDs. They have also improved family and provider satisfaction. Data on possible decrease in cost to health plans and CCOs of team-based autism evaluations is pending.

For further information:
Contact Dr. Robert Nickel, nickelr@ohsu.edu and review the project’s web page at OCCSYHN.org and select “Community-based ASD Identification”