Assuring Comprehensive Care through Enhanced Service Systems for Children with ASD and ID/DD
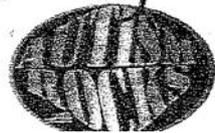
A project of the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN)

R Nickel MD (nickelr@ohsu.edu)

Kim Miller – the Violinist

Art by People with Autism – Part of your world

ACCESS Project

- State autism implementation grant funded by the US Maternal and Child Health Bureau

- Administered by the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN)

- Follow-up to project funded by the Oregon Commission on ASD (OCASD) and the Centers for Disease Control

5 Components

- Assure project fidelity with existing OCASD State Plan (**Advisory Group**)

- Increase state and local community capacity for the identification for young children with ASDs/other DDs **(Autism Identification Teams)**

- Improve screening, referral and management of children with ASD and other DDs in a medical home (**Enhancing the Medical Home**)

- Support family-professional partnership in all levels of the project **(Parent Partners)**

- Develop effective coordination of complex services and systems

ASD Identification Teams

Goals:

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.

Decrease the wait time for a comprehensive team evaluation

Outcomes: improved family and provider satisfaction, decreased age at entry to ASD services, decreased cost to health plans/CCO's

Rationale

- Currently in Oregon, children may receive a medical diagnosis but not educational eligibility for ASD services and vice versa
- Certain agencies do not accept educational eligibility as a diagnosis, e.g., Developmental Disability services, Social Security Administration
- Different process in medical vs. educational settings: *for example,*
  - prescribed timeline to complete evaluation in education and long wait lists for a medically-based team evaluation

  - use of DSM criteria by medical teams and not by educational teams

OCASD Screening Identification and Assessment (SIA) Committee's Recommendations for Identification

- Consistent process across medical and educational settings including use of DSM criteria

- Interdisciplinary Team evaluation based on DSM criteria

- Specific Components for the evaluation

- Specific Competencies for team members

http://www.orcommissionasd.org/images/uploads/OCASD_2010_Report_FINAL.pdf

Recommended Components of the Identification Team Evaluation

- Diagnostic interview based on DSM
- Standard observation using research-based, autism-specific tool (e.g. ADOS 2)
- Observation of individual in unstructured activity
- Developmental assessment
- Hearing testing
- Once identified, reports to caregivers and "starter pack" on next steps and resources to families

Developmental Assessment

- A 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

Recommended Competencies to be Possessed by the Identification Team

Ability to assess and/or conduct:

- Typical and atypical child development
- Differential diagnosis (what looks like ASD but isn't)
- Formal and informal assessment practices
- Specific assessment tools and methods for accurate identification of ASD and other disorders
- Characteristics of ASD
- Family and environmental dynamics/systems
- Knowledge re common co-occurring medical and mental health conditions and resources

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Who is on the Team?

- Health care professional
- Mental health provider
- Educational staff
  - Autism specialist
  - Speech pathologist
  - School psychologist
  - Other staff as needed, e.g., Occupational Therapist
- Parent of child with ASD
  - Connects with parent before and 1 month after evaluation, present at team and family conferences

Where We Are Now

- 8 Communities:
  - Initial 4, Astoria/Seaside, Coos Bay, Salem and the Dalles
  - Recent additions, Medford, Grants Pass, La Grande and Albany
- Teams meet monthly, all have mental health representative as regular member of the team or as consultant
- Process
  - Concurrent and sequential medical and educational evaluations (all teams do initial evaluations together)
  - Review of results by medical and educational staff, completion of DSM 5 checklist
  - Joint review of results with families
  - If disagreement, referral to IDD/CDRC for further evaluation (to top of waiting list)

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TA/Supports Available to AIT/s through OCCSYHN

- Initial training for all team members
  - Characteristics of high performing teams
  - Characteristic behaviors (online videos from Natl Professional Development Center, First Signs/Autism Speaks, CDC)
  - DSM 5 vs DSM IV
  - Differential Diagnosis
  - DSM Interview, ASD questionnaires
  - Medical issues of children with ASD
  - Interpreting information to families ("Breaking the News")
  - STAT (Screening Test for Autism in Toddlers) for health care members

On-going TA/Supports

- Site visits
- Webinars/conference calls
- Information, Materials (including materials developed by AAP/CDC) and Resources
- Sakai
- Online discussion group

Webinars

- All team member webinars
  - Pertinent journal articles, new ASD information
  - Clinical issues, team process issues, special topics
    - Team building
    - Breaking the News
    - ABA based behavioral therapies
    - working with different cultural groups
    - Coding and billing
- Webinars on specific issues
  - ADOS and STAT scoring reliability checks
  - Developmental assessment
  - Case studies, e.g., ASD vs ADHD, ASD vs Anxiety Disorder
- Listserv/online discussion group

Information, Materials and Resources

- DSM 5 Family Interview
- "Starter Packet"
  - Getting Started
  - First 100 Days from Autism Speaks
- Tip Sheets
  - You are not alone
  - Nutrition and children with ASD
  - Increasing calories in the diet
  - Picky Eaters with ASD
  - CAM and children with ASD
  - Tips for getting best behavior during STAT
- Autism Resources for Families

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Experience to Date

- # of children evaluated - 44
- Age when evaluated (mean 2.8 years)
- Referral source (primarily EI)
- # with ASD identification - 32
- # of disagreements - 3
- # referred for CDRC team evaluation - 1
- # other referrals – 6
- Team members and families highly satisfied with process

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The Future: Sustainability for AITs

- Current activities re Sustainability:
  - Endorsement by OCASD and Screening Identification and Assessment (SIA) committee
  - Coding and billing by MDs/mental health provider
  - Meetings with CCO Medical Directors and development of case rate for CCOs (to include cost of Parent Partner and extra Education time)

The Future: Capacity

- Current activities re Capacity:
  - Issue for Medford and Salem teams
  - Identification of second mental health provider and 2 additional pediatricians for Salem team
  - Identification of second pediatrician for Medford team
  - Continue work on sustainability

Medical Home for Children with ASD and other Developmental Disabilities

Goal:

Enhance the care of children with ASD and DD in the primary care office

Objective:

Facilitate a quality improvement project in the primary care office (6 months)

Outcomes:

Improved family and provider satisfaction, improved access to needed services

Components of Medical Home for Children with ASD and DD/ID

- Identification
    - Screening and surveillance
    - Flagging of charts of children with ASD and DD/ID
- Pre-visit planning
    - Office Social Story/Visual Schedule
    - Pre-visit planning forms (one for the practice and one for parents)
    - Family-Centered Care Coordination Tool: Assessment of Care Needs
- Regular chronic condition management visit
- Care Coordination and Care Coordinator
- Care Plan and Next Steps Plan
- Care Partnership supports
    - (Materials, Resources, Self-management supports, Advocacy)

Methods

- Pre START survey
- START Autism 101 module
- Site visit with OPIP or ORPRN staff
- Complete Medical Home Index – RSF and key informant interview
- Review Medical Home for Children with DD including ASD outline
- Select components to address in QI program
  - Screening and Identification plus one other issue

Methods 2

- Collaboration with ORPRN (Oregon Rural Practice Research Network) and OPIP (Oregon Pediatric Improvement Partnership)
    - 2 Site visits
    - Monthly conference calls
    - Additional calls and emails as needed
    - Data collection
- Online discussion group through Sakai

Information, Materials and Resources

- Examples:
  - Hands in Autism Toolkit for MD's
  - Tips for a successful visit/Pre-visit Planning form
  - Family-Centered Care Coordination Tool: Assessment of Care Needs (AAP)
  - Next Steps Plan
  - Tip Sheets (as above)
  - Information on specific topics; e.g., Autism Speaks/ATN
  - Resources on visual schedules, First/Then pictures and Help/Break cards
  - Transition resources, e.g., www.gottransition.org

Parent Partners

- Parent Partners are OHSU employees and must complete new employee training that includes confidentiality and integrity training.

- Each Parent partner receives a Family Liaison Training manual and a copy of Words of Advice: A guidebook for families serving as advisors.

- A Two to Three hour formal training with the Family involvement coordinator is conducted that emphasizes team process, communication skills and confidentiality.

- Family Involvement coordinator will be present at the first Family meeting if team would like.

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On-going Supports to Parent Partners

- Monthly webinar trainings with all family network employees. (examples: quality improvement, cultural competencies, insurance information, policy and legislation information; autism specific information.)

- Monthly call with ACCESS parent partners to go over procedures: what is working and what needs improvement.

- Once a year, all family network employees including the parent partners, are required to attend a two day on site training conference.

- Family Involvement Coordinator is available for consultation for parent partners and all members of the team .