

The Medical Home for Children and Youth with ASDs and Other Developmental Disabilities

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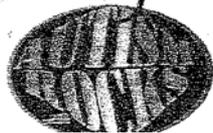
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Kim Miller - the Violinist

Art by People with Autism -
Part of your world



Assuring Comprehensive Care through Enhanced Service Systems for Children with Autism Spectrum Disorders/other Developmental Disabilities (ACCESS)

- State autism implementation grant funded by the US Maternal and Child Health Bureau
- Administered by the Oregon Center on Children and Youth with Special Health Needs (OCCSYHN)
- 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
- Increase state and local community capacity for the identification, evaluation and service delivery for children with ASDs/other DDs
- Improve screening, referral and management of children with ASD and other DDs in a medical home
- Support family-professional partnership in all levels of the project
- Develop effective coordination of complex services and systems

A Medical Home for Children with ASDs and Other Developmental Disabilities

Components:

- Quality Improvement team which includes one or more parents
- Identification
- Pre-visit planning
- Care Coordinator
- Regular well child visits and annual chronic condition management visit
- Care Plan and Next Steps Plan
- Resources and materials

Big Goals, Little Steps

- Family satisfaction
- Adequate time for care
- Planned visits
- Better co-management with specialists
- Help with referrals and resources
- Avoid duplications, errors
- Fiscal Viability
- Caution-Don't wait for consensus

Lail, 2011



Identification

- Developmental surveillance at all well child visits
- Regular developmental and behavioral screening as per AAP guidelines
- Use of a general developmental screen **and** an autism screen at 18 and 24 (30) months
- The M-CHAT R/F

[http://www2.gsu.edu/~psydlr/M-CHAT/Official M-CHAT Website files/M-CHAT-R F 1.pdf](http://www2.gsu.edu/~psydlr/M-CHAT/Official_M-CHAT_Website_files/M-CHAT-R_F_1.pdf)

Pre-Visit Planning

- Flagging of charts of children with ASD and DD/ID
- Tips for a Successful Visit
- Office Social Story/Visual Schedule
- Pre-visit planning form (to be completed by parents)
- Child and Family Strengths and Needs Assessment, e.g., Family Centered Care Coordination Tool (AAP)
 - What would you like us to know about your child, what does s/he do well, like, dislike?
 - What would you like us to know about your family?

Tips for a Successful Visit - MD

- Ask parents what works best for their child
 - Suggestions to consider
 - Office social story and visual schedule
 - Pre-appointment visit to the office
 - Scheduling appointment early, before or right after lunch or end of the day
 - Ask parents to bring favorite toy(s), beverage, and/or snack(s)
 - Limit time in waiting room , e.g., child/family can wait outside and come in when MD ready
 - Headphone use
 - Standardize the visit, same exam room, highly engaging and predictable toys in room
- (Michele Raddish MD, 2012)

Tips for a Successful Visit - Family

- Mention any special needs for the appointment and mention strategies that work
 - a longer appointment
 - a special time of day, e.g., at the end of the morning or first thing in the afternoon
 - limited time in waiting room (e.g., a child with autism who cannot tolerate long waits in unfamiliar places)
 - a time when few children or parents are present in the office
 - any sensitivities to light, sound or touch
 - notify office staff of your child's preferred method of communication

Tips for a Successful Visit - Family

Prepare for the visit:

- do pre-visit to the office or virtual visit online
- create a picture schedule or social story for the visit
- bring toys, snacks, visual supports from home as needed
- list the one or two important questions you would like answered
- think of 2 goals (e.g., functional skills, recreational activities) you would like your child to develop (or your older child would like to address) over the next 6 months or so.
- make sure you bring your child's care notebook
- bring copies of reports from specialists as well as any recent test results
- bring copies of school records and be prepared to discuss any school issues

How to use and construct visual schedules



Resources and Materials

- Disorder specific Information, materials and resources
 - Information for families of children with new diagnosis of ASD or DD/ID
 - Links to additional information on specific topics
- How to use and construct visual schedules and First/Then pictures
- Data monitoring log
- Transition resources including Life Skills Checklist and other materials at www.gottransition.org
- Next Steps Plan and supports (goal-setting and related training and supports for specific issues)

Information for families of children with new diagnosis of ASD or DD/ID

- Brief, Longer and Longest Handouts on ASD
 - First 100 Days Tool Kit
 - Getting Started
- Books
 - Ingersoll and Dvortsck, *Teaching Social Communication to Children with Autism*
- Online resources, for example.....
 - www.oregonautism.org , www.autismspeaks.org
 - Spanish language resources (e.g., Autism Speaks, U of Washington, Indiana Resource Center)
- Useful Community Resources
 - CaCoon (public health care coordination)
 - Developmental Disability Services
 - Social Security Administration
 - ASD and Developmental Disability specific treatment resources

Links to additional information on specific topics

For example:

- Information on Complementary and Alternative Medicine (CAM)
- Autism Speaks/ATN materials, www.autismspeaks.org
 - Guide to Providing Feedback to Families
 - Challenging Behaviors, Introduction to Behavioral Health Treatments
 - Medical issues (sleep, constipation)
 - Autism and Medication tool kit, Medication Decision Aide
 - Dental toolkit
 - Toileting
 - Visual Supports
- Safety - Big Red Safety Box (National Autism Association)
 - <http://nationalautismassociation.org/resources/awaare-wandering/>
- Construction of social stories/visual schedules
- Sexuality – Terri Couwenhoven, *Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality*

Getting Started in Your Office

- Step 1: Form your office quality improvement team and meet regularly
- Step 2: Identify an office care coordinator
- Step 3: Regularly screen the development and behavior of all children in the practice as per AAP guidelines
- Step 4: Identify and “flag” charts of children with ASD and DD/ID to assist with scheduling/pre-visit planning
- Step 5: Collect hand-outs, materials and resource lists
- Step 6: Implement a pre-visit planning program for the office

OCCSYHN Supports for the ASD/DD Medical Home

- OPS Start Autism 101 module
- Packet of materials (hard copies of most resources)
- As needed TA/consultation
- Site visits
- Webinars
- Online discussion group
- <http://www.ohsu.edu/xd/outreach/occyshn/>

Parents as Team Members

- Improves the planning process
- Helps you carry out your mission
- Increases your knowledge and skills
- Helps you do a better job
- Brings fresh perspective to problems
- Provides an ally to advocate for better services for children and families
- Increases your empathy and understanding for families
- Brings about better consumer satisfaction

Powerful Partnerships, NICHQ

*Better: A Surgeon's Notes on
Performance, Atul Gawande*

Better is possible. It does not take genius.
It takes diligence. It takes ingenuity. And
above all, it takes a willingness to try.

