

A Medical Home for Children with Developmental Disabilities including ASD

Components

1. *Quality Improvement team* which includes one or more parents
2. *Identification*
 - Developmental Surveillance at all well child visits (special attention to siblings)
 - Regular developmental and behavioral screening as per AAP recommendations (link to LTSAE materials)
 - Flagging of charts of children with ASD and DD/ID
3. *Pre-visit planning* (OCCYSHN will provide representative forms and resources)
 - Tips for a successful visit
 - 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 (Bright Futures)
4. *Care Coordinator*
5. *Regular well child visits* including at least an *annual chronic condition management visit*
6. *Care Plan* (will also function as an ER plan and can be modified as transition plan) and *Next Steps Plan* (visit to visit working care plan including child/family goals)
7. *Tracking lab tests, procedures and referrals*
8. *Care Partnership Supports*
 - Advocacy
 - Disorder specific Information, materials and resources for families:
 - a. Information for families of children with new diagnosis of ASD or DD/ID; e.g., Getting Started, First 100 Days Toolkit, Helpful Community Resources
 - b. Other handouts for families; e.g., handouts on Nutrition, Picky Eaters with ASD, Complementary and Alternative Medicine
 - c. Links to additional information on specific topics; e.g., Autism Speaks/ATN documents on understanding behavior, medication decision toolkit, dental toolkit, blood drawing toolkit, using visual schedules/supports
 - d. Links to resources on how to use and construct visual schedules, First/Then pictures and Help/Break cards
 - e. Transition resources including Life Skills Checklist and other materials at www.gottransition.org
 - Self-management supports for children and families
 - a. Goal setting
 - b. How to monitor for treatment effectiveness and side effects
 - c. Data monitoring log, e.g., Sleep Diary, Seizure monitoring log
9. *Regular input of parents and families*, for example, by their participation on the practice's Advisory Group or Quality Improvement team, or by survey of families in your practice
10. *Information, materials, resources for providers*
 - Forms for pre-visit planning, care plans/next steps plan

Helpful community resources

National advocacy groups and organizations

Resources on how to construct visual schedule/social story for the office, use of First/Then pictures and Help/Break cards, creation of sensory kit for the office (from Hands in Autism's Tips for medical providers)

Data monitoring log (see above)

Transition resources

Other useful resources for further information including training materials and curricula, e.g., AADMD modules, CDC Autism Case Training, ASD video glossary (Autism Speaks)

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 including use of the M-CHAT R/F or similar ASD screen

Step 4: "Flag" charts of children with ASD and DD/ID to assist with scheduling/pre-visit planning, notify the family of the office care coordinator for their child

Step 5: Collect hand-outs, materials and resource lists for families of children with a new diagnosis of ASD or DD/ID

Step 6: Regularly seek the input of parents and families, e.g., by inclusion of parents on the practice's Advisory Group or Quality Improvement team, or by survey of the families in your practice.

Step 7: Implement a pre-visit planning program for the office including a social story and visual schedule about an office visit, the pre-visit planning form, and child and family strengths and needs assessment

Step 8: Conduct regular well child visits including at least an annual chronic condition management visit

Step 9: Regularly use and update shared care plans for children with ASD and DD/ID, use a Next Steps plan as needed for interval visits (shared among PCP, specialists and family)

Step 10: Make referrals, advocate for services and provide families information, materials and links to services and resources as needed

Step 11: Initiate (or maintain) a tracking mechanism to assure families receive recommended services

Step 12: Plan for the transition of the adolescent and family to adult services, use the Life Skills Checklist and other materials at www.gottransition.org

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