AUTISM SPEAKS®

ATN

Autism Treatment Network

CARE MODEL MANUAL

A TECHNICAL MANUAL FOR PHYSICIANS
AND MEDICAL FACILITIES TREATING PATIENTS
WITH AUTISM SPECTRUM DISORDERS

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*The ATN developed this manual to easily share the
ATN best practices. Its purpose is to improve
medical care for individuals with autism.*

CHAPTER 1
Overview, Values and Principles of the Autism Treatment Network (ATN)

Introduction

Autism, also known as autism spectrum disorder (ASD), is a complex, multi-system disorder associated with profound effects on behavior, daily function and physical health. As such, the diagnostic evaluations for ASD should be made as expediently as possible, and children and adolescents who have ASD deserve comprehensive, multi-disciplinary care by providers knowledgeable in ASD. The Autism Treatment Network (ATN) was established to address these needs, by providing a model for such care, and to continually refine that model as new data and treatment methods become available.

The ATN is a collaboration of Autism Speaks and 12 North American academic medical centers that specialize in multi-disciplinary medical care for children with autism. The ATN works to develop evidence-based protocols and standards of care for the challenging medical conditions that are often co-morbid with autism. The ATN shares best practices with physicians and medical facilities worldwide to improve outcomes for all individuals with autism.

The ATN developed this manual to easily share the ATN best practices. Its purpose is to improve medical care for individuals with autism. The manual can be used as a comprehensive technical tool to develop an autism center or selected chapters can be referenced to address specific areas for improvement. Most chapters in the manual will have a page of takeaway messages for primary care providers to support them in treating their patients with ASD.

The 12 ATN sites in the United States and Canada include physicians, researchers and clinical thought leaders who share a common commitment to:

- Improve autism healthcare outcomes through high quality, data-driven, evidence-based medical care.
- Support community clinicians through information-sharing tools, best practice and research studies.
- Advance understanding and application of new knowledge at the front lines of clinical practice.
- Engage in and support research relevant to clinical practice of the most complex medical conditions related to autism.

The network supports family-centered care, multi-disciplinary team-based care, family education, dissemination and training for professionals, and outreach opportunities. In addition, the network maintains an open access, anonymized registry to support research on physical health in ASD.

The ATN sites continuously strive to improve patient and family experience and patient outcomes by implementing and refining each domain of the ATN Care Model. To achieve this, the Network uses quality improvement methodology to affect systems change to reduce variability and standardize care. It is the goal of the ATN network to build a sustainable system for care delivery, evidence development and research to achieve optimal health and quality of life for all individuals with ASD.

ATN Vision and Mission

VISION:
Optimal health and quality of life for individuals with ASD

MISSION:
Create a sustainable system for care delivery, evidence development, and research

RESEARCH	QUALITY	BROADENING THE REACH	LEADERSHIP
Advance the evidence-base and research on medical issues in order to provide better care for children with ASD	Improve the quality of medical care for children and adolescents with ASD	Increase the availability of a comprehensive, coordinated, longitudinal care model for all children	Continue as the leading clinical network on medical issues related to ASD

ATN Care Model: Whole Care for the Whole Family

The ATN Care Model, based on the chronic care model1 represents a comprehensive, coordinated, multidisciplinary care approach for children with ASD. It promotes a high standard of coordinated care for the whole child and family. An ATN center is essentially a nexus of autism care -- a place that provides the highest level of direct care and clinical expertise and also serves as a resource to local families, community physicians, behavioral practitioners and educational advocates -- a cornerstone of the family's care community.

Members of the ATN have committed to work continuously toward building the full ATN Care Model.

The following principles of the ATN Care Model guide the ongoing enhancement of its clinical program and can help to build and optimize clinical programs for ASD wherever they are found:

Self-Management Support to help families define child-specific treatment goals and to develop a whole-child care plan in collaboration with the family.

- How do you work collaboratively with families to provide a comprehensive care plan?
- Who does or should take the lead? Who takes the role in discussing treatment options with the family?
- How are families educated about available treatments?

Shared-Decision Making that involves parents in decision making concerning their child's treatment and ongoing care.

- How does your center involve parents in the decision-making process around treatment and on-going care?

Delivery System Design to track ongoing patient progress and ensure regular follow-ups, along with clearly defined goals and health outcomes.

- Do you have mechanisms in place to monitor patient progress?
- Do you have a plan for follow up with each patient?
- Are goals and health outcomes clearly defined in treatment plans?
- Does your Center have a plan to maintain contact to build an on-going relationship with the patient and families?

Multidisciplinary Team Care uses the expertise of the full range of professionals necessary for the care of the child.

- How easily can patients access specialist and other ancillary services that they need?
- Are there challenges that your patients face in attempting to access these additional services? Is there a plan to assist families in overcoming these challenges?

Coordination of Care for seamless access to specialized therapies, behavioral interventions, community and educational interventions and other related resources.

- Is there a system of communication for relevant care givers?
- Do clinicians have adequate access to information that they need to care for the patient?

Decision Support processes to allow for monitoring of patient progress through planned follow-up and clearly defined clinical goals and health outcomes.

- Are guidelines being used (when available) in the treatment of patients with ASD?
- Are you sharing this information with families?

Autism Treatment Network Care Model
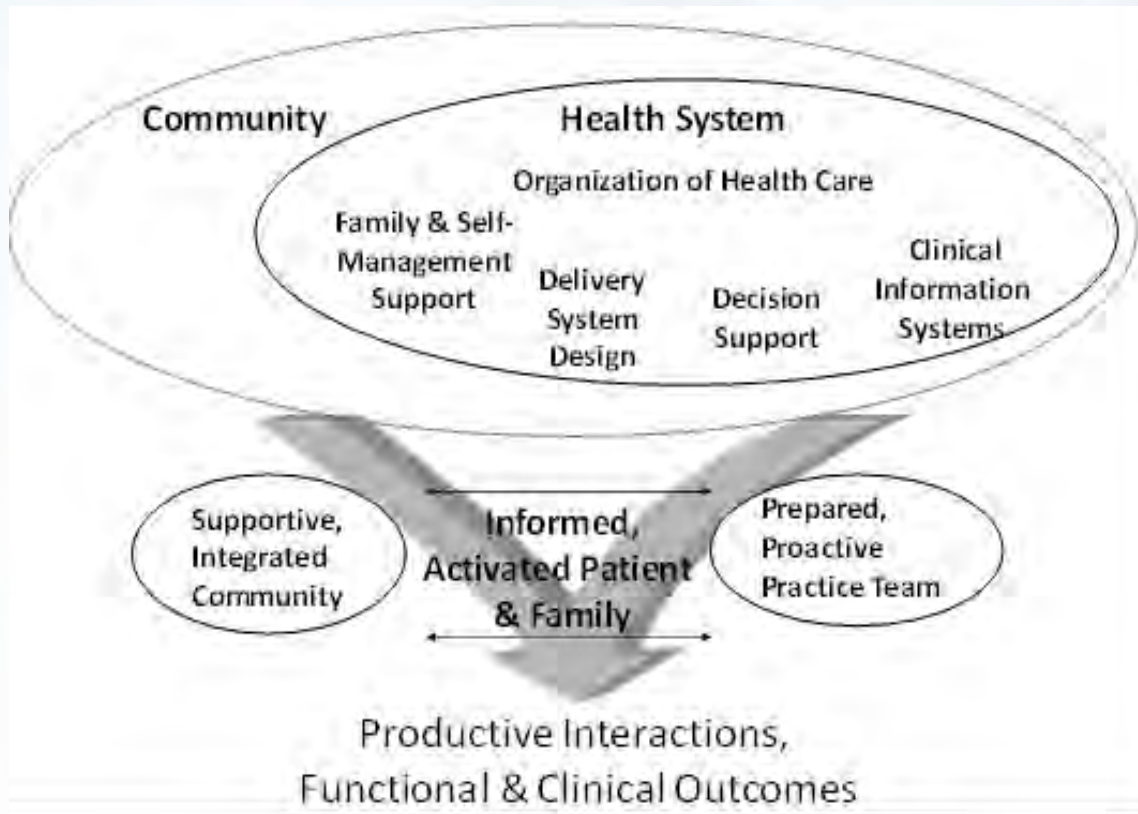
Adapted from the Chronic Care model. For more information, see
www.improvingchroniccare.org

The ATN Care model is based on the chronic care model1 and involves multiple aspects of the health care system. Autism-focused medical clinical programs have many of the components within their scope of care (see Health System circle in diagram), but also rely on the larger community and an activated, informed patient and family to achieve desired outcomes. This manual addresses the components that are part of this autism-focused health system as well as involvement of the family and greater community in meeting the needs of this population.

Reference
Epping-Jordan JE, Pruitt SD, Bengoa R, Wagner EH. Improving the quality of health care for chronic conditions. Qual Saf Health Care. 2004 Aug;13(4):299-305.

The diagnosis of ASD can be a complex process, due in part to the wide variation in symptom presentation.

CHAPTER 2
Diagnosis

Introduction

Most families are referred for an autism diagnostic assessment by their primary medical care providers or schools, when there are concerns about possible symptoms of autism spectrum disorder (ASD). Obtaining a thorough and proper diagnosis is important for a number of reasons. First, the clinician needs to "rule out" other possible causes for symptoms of ASD. For example, a young child might have a significant language delay or other developmental delay that might better explain the appearance of social/communication deficits. An older child might have another mental health disorder (e.g., ADHD, Social Anxiety Disorder) that could better account for the reported concerns. Second, the earlier an ASD diagnosis is made, the sooner services can be initiated and the better the long-term prognosis. In fact, early and accurate diagnoses are essential for optimizing outcomes for children with ASD. Formal diagnoses affect eligibility for services, facilitate timely and appropriate interventions, and provide information about prognosis and future planning. An ASD diagnosis can also enhance self-understanding for individuals with ASD and their families.

Overview of Diagnostic Process

A comprehensive diagnostic evaluation includes assessment of both developmental history and current functioning across several domains. The diagnosis of ASD can be a complex process, due in part to the wide variation in symptom presentation. Individuals with ASD differ in terms of number, type, and severity of core symptoms.

Symptoms also present differently in the same individual over time, emphasizing the need for a developmental perspective. There is also overlap between symptoms of ASD and symptoms of other disorders across the lifespan as noted earlier, requiring careful consideration of other conditions that have similar symptoms.

Assessments should be tailored to the needs of the individual child and family.

In general, comprehensive ASD assessments require a multidisciplinary team of professionals. The lead diagnostic clinician should determine the composition of the diagnostic team, and the team should work together to choose the most appropriate combination of diagnostic tools. For example, a child with limited language skills might require the use of a different set of assessment tools than a child with age-appropriate skills in this area. Also, given that symptoms may present differently depending on the environmental and social context, information should be collected from multiple sources and across different environments (home, school, child care setting). Generally, the assessment process includes gathering information from caregivers and others (through the use of interview and/or rating scales), direct observation of the child, and an assessment of the child's functioning across developmental domains. The use of standardized diagnostic tools is also a key component of comprehensive diagnostic assessments. Most importantly, clinical judgment of team members with specific training and experience in ASD should inform the interpretation of both formal and informal assessment components.

The Diagnostic Team

Members of the diagnostic team should have specific training and experience in the diagnosis of autism spectrum disorder (ASD) as well as a thorough understanding of typical and atypical development across the lifespan. Diagnostic teams typically include a physician such as a developmental behavioral pediatrician, child/adolescent psychiatrist or neurologist; a psychologist; and often a speech-language pathologist. Depending on the needs of the child and his/her symptoms, additional members of the diagnostic team may also include, occupational therapists, audiologists or other medical specialists or healthcare providers. Finally, each assessment should be developed and implemented within the context of family-centered care. As such, families should be key partners throughout the diagnostic process.

Vignette:

Thompson Center for Autism and Neurodevelopmental Disorders at the University of Missouri:

The University of Missouri Thompson Center provides one-day comprehensive diagnostic evaluations for ASD using the Autism Speaks Autism Treatment Network (ATN) assessment battery as a guide. Although a number of different clinics are available depending on the child's age, referral question and complexity, the Autism Diagnostic Entry Clinic (ADEC) is the primary entry point for the majority of children seen for ASD evaluations at the center. Prior to their clinic visit, families complete a packet of questionnaires (including ATN custom forms) assessing background information, medical history and current concerns. Parents also complete standardized measures of their child's prior and current symptoms, including the Social Communication Questionnaire (an autism screening tool), the Child Behavior Checklist (a measure of emotional and behavioral functioning) and the Aberrant Behavior Checklist (a measure of challenging behavior).

A teacher-completed Teacher Report Form (a measure of behavioral and emotional functioning) is also collected for children who attend school. Adaptive behavior is assessed using the Vineland Adaptive Behavior Scales, Survey Interview form or the Adaptive Behavior Assessment System – 2nd Edition (ABAS-2) prior to the clinic visit.

On the day of the evaluation, children are seen by both a psychologist and physician with expertise in autism. The physician completes a full medical evaluation that includes a review of prenatal, birth, medical and neurological history and a complete physical exam including neurologic and dysmorphology evaluation. The psychologist completes a comprehensive psychological evaluation, including both clinical interviews and standardized assessments. The clinical interview focuses on developmental history, current concerns and functioning, and ASD symptoms. All evaluations include the Autism Diagnostic Observation Schedule – 2nd Edition (ADOS-2) and comprehensive cognitive and/or developmental testing. Additional measures may also be administered to assess language and communication, fine motor skills and neuropsychological functioning, depending on the presenting problem and differential diagnostic considerations.

At the end of the evaluation, the psychologist meets with the family to provide feedback regarding the results of the evaluation. This includes an explanation of the child's diagnosis, recommendations for next steps and a discussion of how to access resources. The center also connects families with Family Resource Specialists, who help ensure that the family is able to follow through on recommendations and referrals and helps connect the family with additional resources in their community. If the child receives an ASD diagnosis, medical recommendations include regular follow-up through the Autism Medical Clinic as well as ATN recommended labs (DNA for fragile X, chromosomal microarray, and lead level). Finally, the family receives a detailed report describing the results of the evaluation, including test scores, within two to three weeks of their appointment.

Diagnostic Battery: Essential Components

This section describes the essential components of a comprehensive ASD evaluation. Although standardized tools are not always necessary, their use increases diagnostic accuracy. Examples of standardized measures are in the list below, though this list is not exhaustive. Measures that comprise the ATN diagnostic battery are indicated with a double asterisk (**).

History

A thorough history of the child's development and current functioning across key domains is essential. This should include birth history, family history specifically including learning and intellectual disabilities, genetic conditions, substance abuse and mental health conditions, comprehensive medical history of child and family, developmental milestones, educational history, and mental health history.

Assessment Techniques
Review of Records – medical, treatment, school
Results of Prior Evaluations or Screenings
Parent Interviews

Parent Report of ASD Symptoms
Thorough information should be gathered regarding core ASD symptom domains: 1) deficits in social communication and interaction and 2) restricted, repetitive patterns of behavior, interests and activities. This should include a formal or standardized parent interview focused on ASD diagnostic criteria and may include the use of additional rating scales that specifically assess ASD symptoms.

Assessment Techniques	Example Standardized Tools
Parent Interview	*Autism Diagnostic Interview – Revised (ADI-R)*
	Childhood Autism Rating - 2nd Edition (CARS-2)
Parent-Report Rating Scales	*Autism Behavior Checklist*
	Gilliam Autism Rating Scale – 3rd Edition (GARS-3)
	Pervasive Development Disorders Screening Test – 2nd Edition (PDDST-II)
	Social Communication Questionnaire (SCQ)
	Social Responsiveness Scale – 2nd Edition (SRS-2)

Direct Observation of ASD Symptoms
Direct clinical observation of the child's behavior and interactions is essential. Ideally, the child should be observed in both structured and unstructured situations, and the clinician should have opportunities to observe both social interactions and the child's use of objects, materials and/or toys.

Assessment Techniques	Example Standardized Tools
Behavioral Observation of Child	*Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2)**

Cognitive-Functioning
DSM-5 criteria for ASD specify that observed symptoms must not be better explained by intellectual disability or global developmental delay. Thus, it is necessary to determine the child's overall level of cognitive functioning to determine whether social communication functioning is at or below expectations based on the child's developmental level. The most-appropriate test of intelligence depends upon the child's age and overall language level. For children with minimal verbal abilities, nonverbal tests such as the Leiter International Performance Scale, 3rd Edition may be most appropriate.

Assessment Techniques	Example Standardized Tools
Tests of Cognitive Ability	Differential Ability Scales – 2nd Edition (DAS-II)**
	Leiter International Performance Scale, 3rd Edition (Leiter-3)**
	Mullen Scales of Early Learning**
	Stanford-Binet Intelligence Scales – 5th Edition**
	Wechsler Scales (WISC-V, WPPSI-IV, WAIS-IV, WASI-II)**

Communication

Communication impairment is a core feature of ASD, and DSM-5 criteria now require specification regarding the presence or absence of language impairment. As such, a comprehensive evaluation of expressive and receptive language skills is helpful whenever possible.

Tests of Receptive & Expressive Language Skills	Clinical Evaluation of Language Fundamentals – 5th Edition (CELF-5)**
	*Preschool Language Scale – 5th Edition (PLS-5)** *
	*Oral and Written Language Scales** *

Current Adaptive and Behavioral Functioning

The child's current adaptive, behavioral and emotional functioning are important considerations, particularly as they relate to differential diagnosis and treatment planning. Whenever possible, collect information from both parents and other sources (e.g., teachers).

Assessment Techniques	Example Standardized Tools
Parent Interview	
Parent-Report Adaptive Behavior Scales	*Adaptive Behavior Assessment System-2nd Edition (ABAS-2)*
	Scales of Independent Behavior – Revised (SIB-R)
	Vineland Adaptive Behavior Scales – 2nd Edition, Survey Interview *
Parent-Report Behavior Rating Scales	*Behavior Assessment System for Children, 3rd Edition (BASC-3)*
	*Child Behavior Checklist (CBCL)** *
	*Aberrant Behavior Checklist** *

Medical Evaluation

While ASD is defined by behavioral criteria, it arises from underlying medical conditions, many of which have not been identified. In addition, the patient's medical conditions may be important considerations in developing the ongoing treatment plan. For these reasons, ASD assessment should include a thorough medical evaluation.
 The medical evaluation should include:

Comprehensive Medical History

This should inquire about medical conditions or exposures known to have an increased association with ASD. Factors to address:

- Pregnancy (prenatal conditions) – febrile illnesses, exposure to prescribed medications, substances of abuse, history of prior miscarriages
- Labor and delivery – prematurity, vaginal birth versus cesarean section
- Neonatal period – illnesses, hospitalizations, medications, and other complications
- First year of life – problems with feeding, soothing, comforting, sleeping, GI or other medical concerns

Family Medical History

Do any family members have a history of mental health disorders, intellectual disabilities, learning disabilities, communication disorders or genetic disorders?

Thorough physical examination with attention to:

- Neurologic exam – head circumference, reflexes, muscle tone, coordination, motor skills and milestones
- Dysmorphology exam – abnormalities of skull, eyes, ears, nose, mouth, extremities
- Skin exam – presence of hypo- or hyperpigmented lesions suggestive of disorders such as tuberous sclerosis, neurofibromatosis, PTEN syndromes
- Genetic evaluation. Current recommendations are for chromosomal microarray as part of diagnostic process. Genetic disorders with increased prevalence of ASD include fragile X syndrome, Down syndrome and genodermatoses. Many less-common genetic abnormalities have been identified in individuals with ASD. Genetic testing is important for its potential use in managing the patient but also for providing guidance to the family regarding risks of ASD occurrence in subsequent pregnancies.
- Other laboratory studies. There are no other laboratory tests universally recommended for ASD evaluations. Tests such as MRI or EEG should be performed according to clinical indications. e.g., MRI when microcephaly is present; EEG when symptoms suggest seizures.
- There are no specific medications indicated for treatment of ASD, but there are medications approved for treatment of problem symptoms associated with ASD. Consideration of these medications will require a thorough medical evaluation as described above.

Providing Feedback and Recommendations

Following the assessment, the evaluation team should meet with the family to review the evaluation results, explain the diagnosis and make specific recommendations. The *ATN/AIR-P Guide to Providing Feedback to Families Affected by Autism* provides thorough instructional support for providing feedback to families. It also provides general guidance for consideration. (Follow the title hyperlink to download the guide free of charge.)

This can be a particularly stressful time for caregivers, so ample time should be set aside to meet with the family. Some clinics schedule a separate feedback visit. This provides the evaluation team with more time to consider the information collected during assessment and obtain additional information if needed (e.g., a copy of a prior report, a conference call with a referral source). In addition, the family and child may be exhausted following the assessment. As such, it may not be the most propitious time to talk with the family about the diagnosis and its implications.

Even if a child does not meet criteria for a diagnosis of ASD, the evaluation team will likely need to provide feedback on alternative diagnoses (e.g., intellectual disability, ADHD) and assist the family in addressing those needs. For children diagnosed with ASD, the family will need to understand how the diagnosis was determined, the individual child's strengths and weaknesses, as well as immediate and long-term issues that need to be address.

Typically, these general areas should be covered during a feedback session:

Intervention needs: There should be discussion of intervention, from intensive early intervention programming for young children to individual therapy (behavioral, speech, occupational) and social skills groups for older children and adolescents. Referral for medical follow up or medication management should also be considered.

Education: There should be a review of education placement options with the family, including the possibility of an IEP.

Community: There should be discussion of community-based activities, from play dates and playgroups for young children to joining scouts, youth groups and volunteering for older children and adolescents.

Family: Additional support for the family should be considered, including local parent support groups.

Support Services: Community support services can include contact with local family support groups (e.g., local chapter of Autism Speaks or Autism Society of America) as well as connecting families with case management

services or educational advocates. Within the clinic, families may receive assistance from a family navigator, care manager, social worker, etc.

Insurance: Some states have insurance options for children on the autism spectrum. As appropriate, the family should receive guidance on which may now be available to them.

Other: As appropriate, families should receive additional resources such as the *Autism Speaks 100-Day Kit*, online support sites, etc. In addition, consider appropriate referrals to other medical subspecialists such as gastroenterologists, neurologists, sleep specialists, etc.

To access ATN/AIR-P Tool Kits for family concerns click here.

CHAPTER 3
Ongoing Care for Children with Autism Spectrum Disorder

Introduction
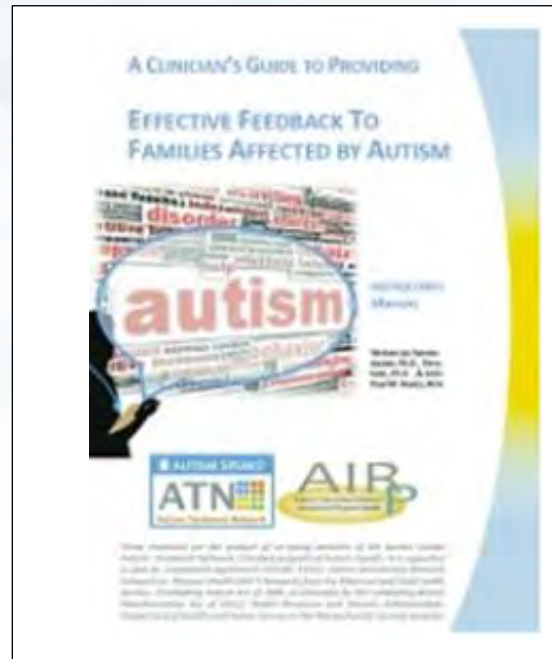
Autism Spectrum Disorder (ASD) is a chronic condition that, similar to other chronic conditions, benefit from access to informed, ongoing follow-up care that is designed to address medical, behavioral and other issues unique to autism. It is imperative that children with ASD have access to informed follow-up care, either with a knowledgeable primary care provider, or with a medical specialist in ASD, such as a Developmental Pediatrician, Child Neurologist, or Child Psychiatrist. Like other children with chronic conditions, children with ASD require "chronic management". Through informed follow-up care, children with ASD and their families access critical information on medical and behavioral treatment and interventions that address issues such as sleep, toilet training, or behavior, and receive developmental and progress monitoring. In addition to ASD specific follow-up care, children with ASD should "have access to the same basic health care treatments as children without disabilities and benefit from the same health-promotion and disease-prevention activities, including immunizations".

Follow-up care is important because parents of children with ASD often need a venue to seek answers for the ongoing questions they may face about their child's ASD, which can be particularly helpful as symptoms may change with age and/or through developmental stages. While information for parents abounds on the internet, having a continuous care approach through ongoing medical follow-up serves as an anchor of credible advice for the family and is critical across the life span. Regular medical follow-up is even more critical for children receiving psychotropic medications as these require monitoring for side effects as well as for potential benefits. Also, parents of children with ASD may seek utilization of CAM (complementary and alternative medicine) at higher rates, and families of children with ASD need reliable information on autism interventions including CAM, thus another reason for ongoing follow-up care with a specialist. However, optimal frequency of follow-up care has not been researched. Within the AS ATN, many children with ASD are seen minimally on an annual basis, with more frequent follow up for younger/newly diagnosed children, as well as for children on any regular medication. Generally, children receiving psychotropic medication should be seen at least semi-annually and ideally quarterly. For children with more stable/uncomplicated ASD, specialized follow-up may be less frequent and/or may be primarily managed by a primary care provider.

Specific health care areas, commonly addressed in neuro-typical children by their primary care provider, warrant extra attention and consideration for children with ASD, in either the PCP or specialist setting. For instance, children with ASD and their families may require additional input and assistance in areas such as toilet training, sleep hygiene, and feeding issues. Families will benefit from regular access to health care providers who can direct families to appropriate community resources, and assist with navigating school systems. Anticipatory guidance, including topics that are unique to children with ASD, such as seizure risk and

monitoring, managing challenging behavior, and issues related to puberty and transition, is an important component of ongoing care for children with ASD.

In this section of the manual, specific topics pertinent to the ongoing care of children with ASD are reviewed. For either primary care providers who provide continuous care to children with ASD, or specialty ASD centers providing follow-up care, the topics cover a number of areas that should be monitored in all children with ASD.

Follow up policies may vary from center to center. For example, at Children's Hospital of Philadelphia (CHOP), we have different follow up policies and procedures depending on the child's treatment plan. Children who are receiving treatment with a psychotropic medication for a behavioral symptom may be asked to follow up as often as every 4-6 weeks to monitor for positive and negative medication effects. Children on stable doses of medication are expected to follow up at least every 6 months. For children who use the ATN Center as a consultation on developmental, educational, or other medical services, follow up may occur every 1-2 years, as a way of monitoring progress, discussing new evidence for treatments, and anticipating upcoming transitions (new classrooms or schools, puberty, etc.). Finally, a select number of follow up appointments are offered on an urgent basis, to help families who are dealing with a short-term crisis related to their child's ASD diagnosis.

At Cincinnati Children's Hospital Medical Center, all children diagnosed with an Autism Spectrum Disorder are given the opportunity to be followed for monitoring of progress, development, behavior, and related medical issues. Newly diagnosed children with ASD are recommended to return in 4 to 6 months for a follow-up visit, while older children may be seen on an annual basis for monitoring. Children receiving medication to address behavior are seen more frequently, as indicated by their treatment. Children who live a further distance from CCHMC may choose to be followed by a primary care provider or specialist to whom they live closer.

Subspecialist involvement in ongoing care may depend on the institution's clinic structure and practice. At Children's Hospital of Philadelphia (CHOP), subspecialists are rarely interacting directly with patients in the ATN Center clinic but offer their own follow up appointments based on the location preference of the family and the most appropriate time for re-evaluation depending on the child's condition. Use of the electronic medical record (EMR) has also allowed for ongoing communication between lead autism specialists (LAS) at the ATN Center and subspecialists at other locations within the CHOP network. When children return to the ATN Center for routine follow up care, their provider is able to view upcoming subspecialty appointments as well as past consultation results within one system, and a secure online health portal system allows families to connect with all clinical services who provide care for their child as well.

At CCHMC, a variety of subspecialists are co-located in the ATN clinic, and see patients alongside ASD specialists/Developmental Behavioral Pediatricians. Gastroenterologists, Pediatric Neurologists, and Child Psychiatrists dedicated to the treatment of children with ASD and other developmental disabilities receive referrals from ASD specialists/Developmental Behavioral Pediatricians, and Pediatric Nurse Practitioners specializing in ASD and other Developmental Disabilities, and patients are seen in the same clinical space for these services. This co-location allows for real time collaboration on patients, as well as shared support staff (i.e. nursing and medical assistants) who work with families through their visits. Some specialists who are not co-located (i.e. sleep specialists) are easily communicated with through the Electronic Medical Record. Regular treatment meetings allow all specialists, medical and otherwise, to meet and discuss more challenging cases.

References:

Myers SM, Johnson CP. Management of children with autism spectrum disorders. Pediatrics. Nov 2007;120(5):1162-1182.

Levy SE, Hyman SL. Complementary and alternative medicine treatments for children with autism spectrum disorders. Child and adolescent psychiatric clinics of North America. Jan 2015;24(1):117-143.

Gastrointestinal Disorders and ASD

Introduction

Gastrointestinal (GI) problems can be challenging to screen, diagnose and treat in ASD. Individuals with autism spectrum disorder (ASD) have a greater risk of general GI symptoms compared to typically developing individuals and may be more prone to specific conditions such as abdominal pain, constipation and diarrhea. Unfortunately many individuals with ASD also have a concurrent GI problem that may go unrecognized, as their maladaptive behaviors are often interpreted by clinicians to be related to their underlying ASD rather than an organic etiology.

Importance

Many individuals with ASD have difficulty communicating and might have difficulty expressing abdominal complaints or providing the necessary details to better inform family or the clinical provider. Instead, GI problems in individuals with ASD may be represented as changes in behavior that include physical, verbal or nonspecific variations impacting sleep or compliance with day-to-day routines. Because of common behavioral differences such as selective food patterns, mouthing of non-edible objects and others, the individual with ASD may be more at risk for GI related issues. The astute clinician who recognizes such changes as possibly representing an organic etiology is then better equipped to provide appropriate screening, evaluation and treatment. Such an approach can improve the quality of life for the patient and family. The prevalence of GI conditions warrant consistent screening and monitoring. Screening for GI conditions at each visit is essential to evaluation of children with ASD. Screening questions including:

- Are there concerns for constipation or diarrhea?
- Does your child strain or have pain with stooling
- Does your child have stooling accidents?
- How often does your child have a stool?
- Does your child have abdominal bloating?
- Does your child suffer from low back pain?

If the child screens positive for constipation, a constipation care plan should be outlined for the patient which includes next steps for treatment and plan for follow-up. The ATN/AIR-P constipation tool kit provides resources that may be a helpful resource. Guide for Managing Constipation in Children

Evidence

Whether GI issues in the population are directly related to the pathophysiology of ASD or are a co-morbid condition of ASD remains unclear. What is clear is that current research and clinical experience continue to indicate GI conditions in ASD as substantially impacting both the individual and their family. A recent large, rigorous, meta-analysis studying GI symptoms in ASD indicates the risk of GI problems among children with ASD is three times that of typically developing peers for GI concerns, constipation and diarrhea. A two-fold increased risk of abdominal pain was also found among children with ASD compared to typically developing children.[1] These findings reinforce expert consensus[2] that parents and clinical providers should be aware that GI symptoms are common in ASD, and that they may be masked by maladaptive behaviors. More importantly, if suspicion is raised for a GI problem, the individual should be screened, evaluated and provided treatment (if necessary). While there is research underway examining why GI conditions are increased and whether they are different in ASD, guidelines for management currently exist and are as effective for individuals with ASD as for typically developing individuals.

How To Use This Guide

The health care provider is encouraged to consider behavior changes as a possible presentation of a GI condition. Significant symptoms may warrant consideration for diagnostic testing and treatment. It is hoped that clinicians can use this information to better understand that individuals with ASD who present to their offices with changes in behavior may have an underlying issue associated with abdominal distress:

The ATN/AIR-P algorithm is a useful guide for evaluating GI conditions in individuals with ASD and the ATN/AIR-P Constipation Tool Kit provides useful resources to help the family manage constipation.

To access the ATN/AIR-P Constipation Tool kit:
[Guide for Managing Constipation in Children](#)
To access the ATN/AIR-P constipation medical guideline:
http://pediatrics.aappublications.org/content/130/Supplement_2

Examples of Changes in Behavior that might signify an underlying GI condition2

Verbal

- Frequent throat clearing, swallowing
- Screaming
- Sobbing for no reason
- Sighing, whining, moaning, groaning
- Delayed echolalia in referencing abdominal pain
- Direct verbalization of pain

Physical

- Facial grimace, tics, wincing
- Gritting teeth
- Constant eating or drinking
- Mouthing behaviors
- Applying pressure to the abdomen by leaning against or over objects, pressing hands into the abdomen or rubbing the abdomen Repetitive tapping especially over the mouth/throat Unusual posturing such as jaw thrust, neck torsion, arching of the back, odd arm positioning or sensitivity to being touched in the abdominal area
- Agitation demonstrated by repetitive pacing or jumping
- Self-injurious behaviors that include biting, hitting, slapping of the face or head banging
- Aggressive behavior
- Decrease or increase in usual activity level or behavior

Routines

- Sleep disturbance such as new onset of night time awakening or difficulty lying down to fall asleep
- New noncompliance with demands

Treatments

Examples of Symptoms that may signify a GI condition and possible evaluation/treatments in individuals with ASD2

SYMPTOMS	POSSIBLE GI CONDITION(S)	POSSIBLE EVALUATION/TREATMENTS
Sleep Disturbance	Gerd	Diagnostic trial of a proton pump inhibitor for two weeks
Self-Injury, Aggression, Tantrums, Oppositional behavior	Constipation, GERD, Gastritis, Intestinal inflammation	Radiograph of the abdomen; Diagnostic trial of proton pump inhibitor for GERD, PEG 3350 for constipation; consider GI consultation.Ph probe, EGD, colonoscopy
Chronic Diarrhea (>3 loose stools daily for > 2 weeks)	Malabsorption, Maldigestion	Stool for occult blood, enteric pathogens, ova/parasites; PEG 3350 if overflow incontinence from constipation suspected; Lactose breath test for lactose intolerance; consider GI consultation
Straining/Hard stools/infrequent stools (<2 stools per week)	Constipation	Abdominal radiograph; Diagnostic trial of PEG 3350
Abdominal Discomfort	Constipation, GERD, Intestinal inflammation, Malabsorption, Maldigestion	Diagnostic trial of proton pump inhibitor for GERD; PEG 3350 for constipation; Abdominal radiograph; Lactose Breath Test for lactose intolerance or lactose restriction; consider GI consultation
Flatulence/Bloating	Constipation, Lactose intolerance, enteric infection,	Abdominal radiography; trial of PEG 3350; Lactose restriction/Lactose breath test/EGD to measure lactase specific activity.

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Vignette #1

Brandon is a 13 yo male with ASD who presented to clinic with parental concerns regarding behavior change over the last three months. Per parent report, Brandon school started junior high school three months ago. Parents believed the change to a new school may have accounted for his moodiness and obstinate behavior. At his new school, his aide helps him navigate from class to class and his aide is the same person from the previous year. His aide doesn't have a good explanation for the change in his behavior and also thought it was the new environment. Conducting a comprehensive review of systems it was learned that Brandon was having hard, painful stools occurring 2-3 times per week over the past three months. On further review of his toileting habits, it was learned that last year, Brandon was able to use a bathroom (with a door lock) near the classroom but this year he had to use a shared bathroom. When questioned about the bathroom at his new school, Brandon was able to state that the bathroom did not have doors on the toilet stalls. It was then learned that Brandon refused to use the bathroom at school like he used to and instead would wait until he arrived home. Diagnosis: constipation related to stool withholding. Intervention: discussed the possibility of implementing a toileting schedule at home and an alternative restroom that Brandon could use that had toilet stall doors for privacy. Parents re-convened his IEP team to discuss the bathroom situation and the school did provide an alternate bathroom for Brandon's use. They also implemented a toileting schedule to get Brandon back on track. After implementing the plan, Brandon's obstinate behavior resolved and he began enjoying his new school.

Vignette #2:

Grace is an 8 yo female with ASD who is new to your practice presents to clinic for her routine, annual follow-up. She has challenges with disruptive behavior since she was very young and has always been on the lean side (BMI 10th%) according to her parents. Grace receives behavioral therapy, speech and language therapy and occupational therapy to address sensory sensitivities. Her parents have concerns about Grace's weight as they think she is not gaining weight. On this visit, you notice her BMI is below the 5th% for age and gender. She has always been a selective eater and it was thought that her selective diet and small portions accounted for her "leanness". On review of systems, you learn that she has disruptive behaviors at home and school that consists of episodes of jumping up and down and screeching. This may last from 5-30 minutes and might occur 3-4 times per day. When asked about temporal relationships, parents report that these episodes can occur any time and occur without any "triggering" event. During the exam, you notice that she is thin and mostly cooperative during the exam. No focal findings are found. You ask if parents have a video of these tantrum-like events and they share a short video that shows Grace jumping up and down and screeching after a meal. Because the video shows Grace to be in pain, you consider gastroesophageal reflux disease as a possibility and refer her to a pediatric gastroenterologist. After both an upper GI series and endoscopy, the gastroenterologist diagnoses GERD and implements treatment. Grace follows up with you 3 months later and her BMI is now at the 30th% and her tantrum behaviors have almost completely resolved.

Summary:

- Individuals with ASD and their families may have difficulty communicating common symptoms associated with GI problems. Also, individuals with ASD may not demonstrate pain in typical ways and may not effectively communicate their level of pain because of high pain tolerance.
- GI conditions in individuals with ASD are common and may present as changes in behavior or routine.
- Individuals with ASD should receive diagnostic evaluation and medical treatments for GI disorders when necessary.
- Individuals with GI conditions and ASD respond to treatment similar to typically developing individuals with GI conditions.

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Introduction:

Individuals with autism spectrum disorder (ASD) have a greater risk of general GI symptoms and may go unrecognized as their maladaptive behaviors are often interpreted by clinicians to be related to the ASD rather than an organic etiology.

Importance:

The astute clinician who recognizes behavior changes as possibly representing an organic etiology is better equipped to provide appropriate screening, evaluation and treatment. Individuals with ASD may develop GI issues throughout the life course and consistent surveillance and screening may improve overall care. The ATN algorithm for GI difficulties and the ATN Constipation Tool Kit are two resources that may be helpful Link tool kit and Algorithm

Examples of Changes in Behavior that might signify an underlying GI condition2

Verbal

- Frequent throat clearing, swallowing
- Screaming
- Sobbing for no reason
- Sighing, whining, moaning, groaning
- Delayed echolalia in referencing abdominal pain
- Direct verbalization of pain

Physical

- Facial grimace, tics, wincing
- Gritting teeth
- Constant eating or drinking
- Mouthing behaviors
- Applying pressure to the abdomen by leaning against or over objects, pressing hands into the abdomen or rubbing the abdomen
- Repetitive tapping especially over the mouth/throat
- Unusual posturing such as jaw thrust, neck torsion, arching of the back, odd arm positioning or sensitivity to being touched in the abdominal area
- Agitation demonstrated by repetitive pacing or jumping
- Self-injurious behaviors that include biting, hitting, slapping of the face or head banging
- Aggressive behavior

Routines

- Sleep disturbance such as new onset of night time awakening or difficulty lying down to fall asleep
- New noncompliance with demands

Examples of Symptoms that may signify a GI condition and possible evaluation / treatments in individuals with ASD

PT SPECIFIC COMMUNICATION	• Suffient letters/reports • Clear delineation of roles/responsibilities
CONSULTATION	• Direct phone numbers, emails, call centers • Easily accessed referral process
EDUCATION	• Grand Rounds, presentations to local medical meetings • ATN/AIR-P Tool Kits, other electronic and print materials
NETWORKING	• Open houses, leadership receptions, medical society meetings • Newsletters
PRACTICE RELATED TRAININGS	• Customized presentations to local practices • Topics such as developmental screening, autism friendly
LEARNING COLLABORATIVES	• ADEP, Concerned about Development, Building Mental Wellness (www.ohioapp.org) are some examples • ECHO (thompsoncenter.missouri.edu/training/echo-autism/)
HEALTHCARE SYSTEM INITIATIVES	• Education for ED staff • Trainings for lab techs re blood draws
COMMUNITY EVENTS	• Information re local fund raisers, sensory friendly movies, special needs camps, etc

Sleep

Introduction

Sleep difficulties are very common in individuals with autism spectrum disorder (ASD). Common problems include insomnia, night wakings and early morning awakenings. Furthermore, poor sleep can exacerbate daytime irritability and behavior problems that often occur in individuals with ASD. Addressing and ameliorating sleep problems often leads to improvement in the quality of life for these individuals and their caregivers.

Importance

Given the high prevalence of sleep problems in autism (50 to 80 percent), clinicians should have a high index of suspicion. Sleep is a restorative phase for the human body. It allows our bodies and brains to heal, process events from the day and restore energy for the day to come. Lack of sleep leads to daytime sleepiness, irritability and difficulty focusing. Many patients with ASD present with behavioral abnormalities directly related to poor sleep. They may be more hyperactive, impulsive, aggressive, have more repetitive behaviors and be less tolerant of changes in their environment. Therefore, it is worthwhile to screen for sleep problems at each visit.

Screening questions may include:

- What time is your child's bedtime?
- What time does he/she actually fall asleep?
- Does your child sleep through the night or wake often?
- Does your child snore, have noisy breathing or have pauses in breathing?
- Does your child experience sleepwalking, seizures or other notable events at night?
- What time does your child wake in the morning?
- How difficult or easy is it for your child to get up in the morning?
- Is your child sleepy during the day?

The clinician should consider the possibility of a sleep disorder if a patient has a history of excessive daytime sleepiness, hyperactivity, inattentiveness, difficulty falling asleep, trouble getting out of bed in the morning, snoring, night wakings, screaming or crying in the middle of the night, sudden behavior changes or abnormal movements (walking, moving legs).

Evidence

Research shows that children with ASD are at increased risk of sleep problems, compared to typically developing children. Parents of children with ASD frequently report (via questionnaires) difficulties with their children falling and staying asleep. These parent reports have been substantiated, for the most part, by polysomnography (overnight sleep studies) and actigraphy (activity meters that measure rest and activity to estimate sleep/wake patterns). Studies have also shown that sleep problems are associated with increased challenging behaviors, including aggression and hyperactivity, and with parenting stress. Research also shows that behavioral sleep education can improve sleep, daytime behavior and parents' sense of competence.

How To Use This Guide

Screening for sleep problems should be done at every visit for patients with autism. The ATN insomnia algorithm encompasses screening, treatment and follow-up and may be a helpful resource. To access the algorithm: http://pediatrics.aappublications.org/content/130/Supplement_2.toc).

Following this algorithm, after screening for sleep concerns, clinicians identify and treat any medical co-occurring conditions that may affect sleep. Medical problems that can cause sleep disturbances include mood disorders, thyroid dysfunction, gastrointestinal reflux disease, constipation, allergies, seizures and excessive caffeine intake. If an underlying medical condition is identified, treating it often resolves the associated sleep issues. The algorithm also directs clinicians to offer families behavioral techniques to promote sleep Sleep Strategies for Teens with ASD. In the case of children who do not respond to behavioral techniques or families who are not willing or able to use these techniques, treatment with medications or referral to a sleep specialist is advised.

Treatments

When medical etiology is suspected, treat the underlying pathology (e.g., proton pump inhibitor for reflux)

- Suspected sleep disordered breathing: Perform polysomnography (overnight sleep study) or referral to a sleep specialist.
- Behavioral sleep onset insomnia: Discuss proper sleep habits (e.g., limit caffeine and screen time before bed, consistent bedtime, relaxing bedtime routine, effective interactions with parents that promote sleep).
- Insomnia refractory to behavioral interventions: Consider pharmacologic treatments such as immediate- or extended-release melatonin, alpha-2-

agonists (clonidine, guanfacine), antiepileptic drugs (gabapentin) or antidepressants (trazadone). It is important to consider a medication's side effects, minimize doses and select agents that treat the co-occurring condition while avoiding polypharmacy. Melatonin and Sleep Problems: A Guide for Parents

Summary

Sleep problems are very common in individuals with ASD and should be screened for at every visit.

- Insomnia is the most prevalent sleep disorder encountered in ASD and can lead to daytime behavioral difficulties, including inattention, hyperactivity, impulsivity, aggression and repetitive behaviors.
- Always consider medical etiologies for individuals with problems sleeping. This includes mood disorders, thyroid dysfunction, gastrointestinal reflux disease, constipation, allergies, seizures and excessive caffeine intake.
- Behavioral sleep interventions should be the first line of intervention, followed by pharmacological treatments.

Vignette #1

Alex is a 6-year-old boy with ASD whose parents state he "can't shut his brain down." He goes to bed at 8 pm after watching video games for an hour after dinner. He enjoys a tall glass of iced tea with dinner. He gets limited exercise during the day. He takes hours to fall asleep (usually close to midnight) and frequently leaves his room to ask his parents for water or a hug. After several visits to their room, Alex's parents often let him come to their bed to sleep because they are so exhausted. He does not snore in his sleep and once asleep, he stays asleep until he needs to be woken up for school at 7 am. At school, his teacher describes him as hyperactive. He has good receptive language skills and responds well to rewards.

Diagnosis: Sleep-onset insomnia, largely due to behavioral causes (e.g., caffeine at dinner, stimulating activities close to bedtime, lack of a calming bedtime routine, parent interactions that promote his coming to their room, likely a too early bedtime).

Intervention: Eliminate caffeine. Walks with family or other exercise in the afternoon to promote sleep. Turn off videos and other screens one hour before bedtime. Implement a bedtime routine with a visual schedule and calming activities. Delay bedtime to 9 pm. Give Alex a "bedtime pass" that he can surrender to his parents when he goes to their room or choose to keep and trade in for a reward in the morning.

Outcome: After implementing the plan, Alex began falling asleep within 20 minutes, sleeping though the night in his own bed, with improved behavior at school.

Vignette #2

Susie is an 8-year-old girl with ASD who falls asleep easily at 9 pm. However, she wakes frequently during the night, from around 10:30 pm to 1 am. When she wakes, she often screams or gets out of bed and wanders the house. Her parents cannot console her, and they describe her as "half-awake, half-asleep." In the morning, she doesn't remember screaming or wandering. She is sleepy during the day at school and described as inattentive in class. Her parents also report loud snoring. They have not seen any seizure activity (e.g., stiffening, shaking, stereotyped movements). Both of her parents were sleepwalkers as children and her dad uses a CPAP machine for sleep apnea. Susie has enlarged tonsils. She underwent an overnight sleep study with a full head EEG that captured an event of screaming from deep sleep as well as frequent episodes of sleep apnea. An otolaryngologist found enlarged adenoids as well as tonsils.

Diagnosis: Parasomnias (sleep terrors, sleep walking) triggered by obstructive sleep apnea
Intervention: Adenotonsillectomy
Outcome: Susie's repeat sleep study showed resolution of sleep apnea. She now sleeps through the night without episodes of screaming or wandering, stays awake during the day and focuses much better at school.

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Introduction

Sleep disturbances are very common in individuals with ASD and warrant screening at every patient encounter.

Importance

Suboptimal sleep leads to daytime irritability, inattention, hyperactivity and maladaptive behaviors. When sleep is optimized, behavioral difficulties often improve along with the patient's quality of life. Improving a child's sleep can also significantly reduce caregiver's stress levels.

Screening questions to ask parents:

- What time is your child's bedtime?
- What time does he/she actually fall asleep?
- Does your child sleep through the night or wake often?
- Does your child snore, have noisy breathing or have pauses in breathing?
- Does your child sleepwalk or have evidence of seizures or other unusual behaviors at night?
- What time does your child wake in the morning?
- How difficult or easy is it for your child to get up in the morning?
- Is your child sleepy during the day?

Be sure to screen for common medical conditions that can affect sleep, such as gastroesophageal reflux, eczema or dental pain.

Treatments:

Treat underlying medical conditions and psychiatric comorbidities.

Use behavioral sleep education.

If behavioral interventions inadequate, consider medications or referral to sleep specialist. Melatonin is a generally safe first-line medication for sleep. Alpha-2 -agonists (clonidine, guanfacine), gabapentin and trazadone are other options. Depending on the comfort level of the clinician, consider consultation with a sleep specialist. Always consider a medication's side effect profile, minimize doses, select agents that treat a co-occurring condition and avoid polypharmacy.

Resources:

The ATN insomnia algorithm and the ATN sleep tool kits (for children, teens and quick tips) are readily available tools for patients with autism and sleep difficulties. Resources for Sleep Issues: **Melatonin and Sleep Problems: A Guide for Parents, Sleep Quick Tips for Parents - Visual Supports Insomnia Algorithm (http://pediatrics.aappublications.org/content/130/Supplement_2.toc)**

Neurology/Seizures

Introduction

Seizures are commonly seen in people with ASD. The recognition and treatment of these problems can help to improve the outcome and quality of life of patients with ASD. Untreated, a seizure disorder can cause impairment in learning and development as well as possible brain injury.

Importance

Individuals with ASD may have unusual behaviors which may simply be interpreted as "typical autistic behaviors" when in reality the behaviors may be an expression of an underlying seizure disorder. It is very important for families and clinicians to recognize when a behavior might be a seizure or when there is a concern for seizures or epilepsy.

Epilepsy, when a person has two or more unprovoked seizures. The seizures typically start either in early childhood or as a teenager. We have learned that there is no one type of epilepsy associated with autism but we do know that certain individuals are more likely than others to develop seizures

Many children will present suddenly with a first seizure as a generalized tonic clonic seizure, but sometimes the seizure is quite subtle and may mimic some behavior or repetitive motor movement such as staring or a complex tic like movement. It can sometimes be difficult for the physician and parent to determine if a behavior is a seizure. Often families will film the concerning spells or behaviors and this might help the physician determine if the spell is a seizure. Seizures and epilepsy can also present with change in sleep patterns or a developmental regression. Important questions for the family or clinician include:

- Has there been a regression in the child's development, or has the child lost some skills or language?
- Does the child have staring spells?
- Does the child fall to the ground suddenly?
- Does the child have new onset incontinence?

Evaluation of a seizure:

If there is evidence of a seizure, typically the child will be referred for evaluation by a neurologist and an EEG, electroencephalogram, will be performed. The EEG can be difficult to obtain in a patient with ASD who has anxiety, sensory dysfunction or difficulties understanding directions. Information about obtaining and EEG for parents and clinicians can be obtained at ATN/AIR-P Tool Kit.org.

There are a few different types of EEG's that your physician might request. The sleep deprived EEG is typically a one hour EEG where the child is asked to sleep less than normal, for example six hours instead of 9 hours. The ambulatory study allows the patient to wear an EEG for the day or longer and even go home wearing the EEG apparatus. There is also an EEG study done overnight in the hospital with a simultaneous video recording. Sometimes the physician will also get an MRI scan of the head. However since the child needs to remain still during the MRI scan, the scan can only be done with sedation. Since most children with autism have a normal head MRI, the MRI is not always done.

Evidence

20-30% of children with autism develop seizures. It remains unclear whether seizures are directly related to the pathophysiology of ASD. However we do know that there are some conditions which cause autism and a high risk of seizures. Individuals with an intellectual disability, a specific genetic syndrome such as tuberous sclerosis or Angelman Syndrome and females are more likely to develop seizures. It is well known that uncontrolled seizures can cause developmental regression, so treatment of seizures albeit subtle seizures is important. What is still not yet know is whether it is important to treat an abnormal EEG in a child with autism. There are research studies investigating this question.

How To Use This Guide

The health care provider is encouraged to consider behavior changes and developmental regression as a possible presentation of seizures. We hope that

providers can use this information to better understand and treat those individuals with ASD who present to their offices with changes in behavior or seizures.

Treatment of seizures

Seizures are treated with anticonvulsant medications, the same ones that are used for typical children and adults with epilepsy. If the EEG is abnormal your physician may choose to start a medication. However, the use of anticonvulsant medications is a bit controversial when a child has an abnormal EEG and no seizures. Some physicians will prescribe treatment for an abnormal EEG or for a child who is having a behavioral regression, but we don't yet have research based conclusions about when to treat a child with an abnormal EEG.

Vignette

At the age of five, Joseph's mother noted that he had stopped using the twenty words he typically used. He was still very busy, but did occasionally stare off as if he was daydreaming. He was otherwise in good health and sleeping well. Because of the language changes, he was referred to a neurologist who recommended an EEG. Seizures were found on the EEG and he was started on valproic acid medication. Within two weeks, he had regained his language. Eight years later, after a growth spurt, he became incontinent of urine. He was otherwise well. His urine testing was normal and no source of infection was found, however as a part of his evaluation it was noted that he had gained a lot of weight and his seizure medications had become sub-therapeutic or low. After increasing the medications, Joseph regained continence. This vignette shows the importance both of observing a child's behavior and development and looking for a medical issue which could interfere with development. While a verbal adult might complain of poor concentration a child with ASD might not have the ability to express.

Summary

- Epilepsy is common in children with autism. Seizures should prompt an EEG and a neurological evaluation. The decision to treat the seizures will be based on the examination, story of the seizures and the EEG.

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Diet and Nutrition in Autism Spectrum Disorder

Introduction

Like other children in America, children with ASD are at risk for consuming too many calories with too little nutritional value (Hyman, 2012; Graf-Myles 2013). They are at risk for obesity and consumption of too little fiber, calcium, vitamin D, choline, potassium, and polyunsaturated fatty acids (Hyman, 2012; Berry 2015). Some children with ASD are at additional risk for low iron stores (Reynolds, 2012). Severe food selectivity in children with ASD has been associated with nutritional deficiency disorders like scurvy (vitamin C), rickets (vitamin D) and xerophthalmia (vitamin A).

Severe food selectivity may be among the first behavioral symptoms families are concerned about. Food selectivity is often noted by 15 month of age, typically before children are diagnosed with ASD (Emond). Food selectivity may be more common among children with ASD because of sensory differences, obsessions, perseveration, anxiety (food neophobia) and learned behavior (Johnson, 2014). Children with ASD are 5 times more likely to have feeding problems (Sharp) than other children.

Importance

WHY is diet and nutrition important to be concerned about?

Families report significant stress around feeding behaviors that persist through adolescence. Selective diets interfere with peer interaction at school and limit participation in social settings. There are clear health implications of poor dietary variety, including bone health (low calcium and vitamin D intake) and risk for iron-deficiency sequelae (restless leg syndrome, attention). Adults with ASD are at greater risk for obesity and its associated health problems (Croen). The effect of an energy-dense diet is further compromised by side effects of medication and limited opportunity for exercise. It is possible that some GI symptoms such as constipation might be aggravated by low fiber intake.

In addition to decreased intake of some nutrients, there is the possibility that some children with ASD consume too much of specific nutrients because of their repetitive or restricted diets. This excess consumption might be a problem because of repetitive intake of fortified foods (Stewart, 2015).

Evidence

What is the evidence related to diet and nutrition in ASD?

Selective eating and behavioral challenges around mealtime are common among children and youth with ASD. Prevalence ranges from 25 to 70 percent depending on age, ascertainment and definition. Several studies have examined the nutritional adequacy of diets consumed by children and youth with ASD with somewhat varying results depending on measurement method (Sharp). All studies – those with typical controls and those that compare children with ASD to national normative data – found that, as a group, children with ASD did not eat enough calcium, vitamin D or fiber. Use of the gluten-free and casein-free diets by the family in an effort to treat symptoms of ASD did not affect the overall nutritional status of the child when calcium and vitamin D were supplemented (Stewart, 2015). However, examination of the dietary supplements used for children with ASD found that, even when supplemented, many were still not getting adequate amounts of calcium and vitamin D. Many children given multivitamins were being supplemented with the nutrients they already were getting in sufficient amounts. Despite low variety and limited intake of fruits and vegetables, food fortification often resulted in adequate intake of most nutrients.

While there are many theories related to metabolic differences leading to unique nutritional needs in children with ASD, no physiologic studies have confirmed the need for a diet that differs from the recommendations of the Dietary Reference Intake.

How To Use This Guide

How do clinicians improve diet and nutrition in practice?

Guidance for children with ASD should include review of dietary intake and mealtime feeding behaviors per the Bright Futures recommendations from the American Academy of Pediatrics https://brightfutures.aap.org/Bright%20Futures%20

Documents/BFNutrition3rdEdPocketGuide.pdf) regarding counseling on family mealtime expectations, provision of a varied diet and parent education around nutritional needs for their children from infancy through adolescence.

A history of feeding behavior can inform basic counseling around setting up calm, undistracted meals and snacks during the day, where the adult sits down and eats the same food as the child.

Counsel parents to provide age- and size-appropriate portions with a combination of foods that the child and family typically eats to set the expectation that *one* meal will be served. Children should not be offered snacks or milk if they refuse meals.

Refer mealtime behavioral challenges for behavioral intervention as soon as they are identified as causing family stress and whenever there is concern about nutritional compromise. A behavioral psychologist, speech pathologist or occupational therapist with expertise in feeding disorders will have the greatest success helping families manage mealtime behaviors before they become severe.

Clinicians need to become familiar with the nutritional needs of children and youth. Having normal or elevated weight may indicate consumption of adequate or excessive calories *without* adequate nutrition. Eliciting a dietary history can help assess which children need additional laboratory measurement of vitamin D or iron stores. Ask families about frequency and portion size of dairy products and/or fortified dairy substitutes, fruits, vegetables and protein containing foods such as fish, meat, poultry and beans. If the family or clinician is concerned about the nutritional effect of limited or repetitive diets, consultation with a pediatric dietitian is recommended.

Summary

Many children with ASD eat a limited number of foods because of obsession, anxiety and/or sensory differences.

- Most children with ASD consume adequate diets, but like other children in the U.S. have generally low intake of fiber, calcium, choline, vitamin D and polyunsaturated fatty acids.

- Some children with ASD consume such limited and repetitive diets that they ARE at risk for deficiency disorders like rickets, scurvy and xerophthalmia.
- Clinicians should get a dietary history on all children with ASD in the context of well-child care and provide anticipatory guidance around feeding challenges.

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Diet and Nutrition in Autism Spectrum Disorder Chapter Summary

Children and youth with ASD are at increased risk for significant feeding problems including excessive selectivity. This behavior is not limited to early childhood and can extend to adulthood.

Food selectivity may be related to perseverative behaviors, obsessions, anxiety about new foods (food neophobia) and the possibility of abnormal sensory appreciation of taste, smell or oral texture.

Like other children, children with ASD are at risk for food related health risks such as:

- Obesity
- Poor bone health related to calcium and vitamin D deficiency
- GI symptoms related to low fiber intake
- Long term health risks from decreased intake of nutrients such as choline, polyunsaturated fatty acids
-

Severe selectivity may lead to diseases caused by nutrient deficits like scurvy (vitamin C), rickets (vitamin D) or xerophtlamia (vitamin A).

Children on diets restricted in dairy products need fortified products or supplements to meet their nutritional needs. (However, many children who are not on restricted diets do not consume enough calcium or vitamin D either.)

Most children do not need the vitamins and minerals provided by a multivitamin.

When deficits are present, it is important to give enough to meet, but not exceed, the child's nutritional requirements. (What we reported is that even when vitamin D and calcium supplements were given, the majority of children who received them remained deficient!)

Foods in the U.S. are often fortified with nutrients, so a diet with limited variability may be nutritionally adequate. Consultation with a registered pediatric dietitian can help the clinician and family determine what, if any, nutrients require supplementation.

Anticipatory guidance around mealtime behavior should be part of well-child care for children and youth with ASD and may include:

- Calm, routine mealtimes
- Provision of nutritious foods with sufficient variety
- Avoidance of access to snacks/milk if a child does not eat the meal provided
- ATN/AIR-P Guide to Exploring Feeding Behavior in Autism, Bright Futures (American Academy of Pediatrics) for advice on mealtime behaviors and nutrition

Referral to a behavioral therapist or speech or occupational therapist with expertise in feeding before the problem becomes severe
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Psychopharmacology

Introduction

Behavioral therapies, especially early intensive behavioral interventions, continue to be the mainstay of treatment of ASD. These therapies have the most evidence supporting their effectiveness. However, the problem symptoms and behaviors commonly seen in ASD are not always amenable to behavioral therapies alone. Some symptoms, such as anxiety or inattention or hyperactivity, require additional treatment with pharmacologic agents. There are recommended practice pathways for management of inattentiveness and hyperactive-impulsive behavior, anxiety and irritability in ASD1,2,3. In addition to these recommended practices, it is important that medications used to treat these symptoms be monitored appropriately. A recent study showed that very few patients on antipsychotic medications are receiving appropriate monitoring for diabetes, for example4. ATN sites have worked to increase adherence to guidelines for monitoring these medicines.

Importance

The use of psychotropic medications in the management of problem symptoms and behaviors in individuals with ASD has grown significantly in recent years. There are treatments that can provide clear benefit, but this may come at a cost in terms of side effects. The decision to add medication to the overall management plan should receive serious consideration. The ATN/AIR-P has a tool kit to help families work with their physicians in determining if medication is appropriate (Medication Decision Aid). It also has a tool kit to help families give medicine appropriately (Autism and Medication: Safe and Careful Use). These can be downloaded from the Autism Speaks website here.

Evidence

The medications discussed here will be limited to those for which there is evidence in the medical literature of their effectiveness. In some cases these medications are approved by the FDA for specific indications. In many cases these medicines are approved for these symptoms in individuals with other conditions, such as ADHD, and there is evidence of their efficacy when used for these symptoms in people with ASD.

How To Use This Guide

Healthcare providers are encouraged to conduct a thorough evaluation of the problem symptoms or behaviors and rule out underlying medical problems or behavioral responses to changes in the patient's home, school or work environment. Approaching the clinical problem in this manner helps reduce unnecessary use of these medications.

Treatment

In all cases, the goals of treatment should be clearly documented and tracked as part of ongoing care. There are recommended measures for tracking inattentive and hyperactive behavior[4]. The Vanderbilt scales[5] (Add Vanderbilt Scales link) are useful as they are in the public domain and scores are responsive to treatment, permitting an objective measure of improvement. The anxiety and depression portions of the Vanderbilt have had less use in this manner but could also be used[6,7]. The symptom constellation known as irritability consists of mood lability, severe temper tantrums and aggressive behavior to self and others. It has been best characterized by the irritability subscale of the Aberrant Behavior Checklist,[8] which also shows response to treatment, and so, can be used to help monitor symptoms.

At this time, there are no pharmacologic treatments for the core features of ASD. Instead, medical treatment is targeted toward problem behaviors and symptoms. Medication choices for these vary, and mostly follow the medication choices for these symptoms in typically developing individuals.

Medications which have proven efficacy for target behaviors include:

- Stimulants (methyphenidate, amphetamine) for hyperactivity and attention
- Non-stimulants (atomoxetine, clonidine, guanfacine) for hyperactivity
- Melatonin, clonidine for insomnia
- Antipsychotics (haloperidol, risperidone, aripiprazole) for repetitive behaviors, irritability, aggression
-

BEHAVIOR/SYMPTOM	MAY REPRESENT	OPTIONS	MEDICATION/DOSING
Impulsivity *Over-reactivity* *Aggression* *Agitation* *Irritability*	Hyperactivity	First - Stimulants Second - Apha 2 agonists Third - Atypical antipyschoitc	MPH, AMP - start at 50% of lowest dose Guanfacine 0.5mg bedtime Clonidine 0.5mg bedtime Risperidone 0.25mg bedtime Aripiprazole 2.5 - 5mg/day
Poor attention *Daydreams* *Distracted* *Not completing tasks*	Inattention	First - SNRI Second - Stimulants	Atomoxetine, MPH, AMP - start at 50% of lowest dose
Irritability *Aggression* *Agitation* *Mood dysregulation* *Rigidity* *Obsessive rituals* *Transitional issues*	Irritability	Atypical antipsychotics	Resperidone 0.25mg bedtime Aripiprazole 2.5mg - 5mg/day
Trouble falling asleep	Sleep onset insomnia	First - Melatonin Second - Clonidine	Melatonin 1mg qhs; titrate up to 3qhs Clonidine 0.5mg bedtime, may titrate to 2mg

Monitoring

Stimulant medications used to treat inattentive / hyperactive symptoms have common side effects of decreased appetite and disrupted sleep. Both of these can be especially problematic in patients with ASD as there is already an increased incidence of these problems. There are no routine laboratory studies recommended in monitoring this class of medications. The stimulants, norepinephrine reuptake inhibitors such as atomoxetine, and anti-adrenergic medications such as clonidine and guanfacine all have cardiac effects. Recommended monitoring includes vital signs (height, weight, BMI calculation, heart rate, blood pressure) which capture the effects of these medicines on growth and cardiac function. Anxiety and depression medications, or selective serotonin reuptake inhibitors (SSRI), also can have effects on appetite and weight and should be monitored. This monitoring is recommended at every visit.

The antipsychotic medications used to treat irritability have significant potential adverse effects. These include sedation, increased appetite and associated weight gain, and increase in triglycerides levels. They also have neuroendocrine effects, increasing the risk of developing type II diabetes and elevating prolactin. The prolactin increase may be manifest as gynecomastia and even galactorrhea. Perhaps most concerning is the potential for neuromotor effects including twitching and abnormal involuntary movements. Tardive dyskinesia is a potentially irreversible neuromotor adverse effect which usually presents with oral-facial grimacing and tongue movements. This can also progress to writhing head and neck movements. Some patients with ASD may also develop tics, which can be difficult to differentiate from dyskinesia movements. Because of the risk and potential severity of this complication, it is recommended that a neurologic assessment for abnormal involuntary movements be done at each medication monitoring and medical follow- up visit, and that these visits be done quarterly (add ATN med monitoring tool kit link). There are evidence-based guidelines for monitoring the metabolic-

endocrine side effects which should also be followed.

ATN sites have established a "bundle" of measures ((height, weight, BMI calculation, heart rate, blood pressure, blood glucose, lipids) to be done at these visits, and audit medical charts to assure adherence to the guidelines. While the CAMESA guidelines have medication-specific recommendations for performing each of these components of the bundle, we have found that conducting the full bundle on every patient for every antipsychotic medication promotes more thorough adherence to the guideline's intent of monitoring. Because of the literature documenting poor adherence to monitoring, and because some patients have their medications managed by a physician outside of the ATN center, we also work to assure monitoring is done through communication with the community managing clinician or even conducting this bundle at our site as part of collaborative care.

Summary

Behavioral (non-drug) intervention for problematic autism symptoms and behaviors continue to be the preferred treatment strategy. When medication is considered, the principal symptoms should be identified as clearly as possible to help guide choice of appropriate medications. Once initiated, medications require ongoing management and adjustment to reach target goals and close monitoring to assure safe use and minimize adverse effects.

Psychopharmacology PCP Chapter Summary

Introduction

Patients with ASD frequently have problem symptoms and behaviors that are not adequately managed with non-medical treatments. When medication is prescribed, careful attention to the target symptoms and choice of the medication is important.

Medication monitoring is crucial when children are on psychotropic medications.

MEDICATION	WHAT TO MONITOR?	HOW OFTEN?
Stimulants	Height, weight, BMI calculation, heart rate, blood pressure	Every vist
SNRI	Height, weight, BMI calculation, heart rate, blood pressure	Every vist
Alpha-Agonist	Height, weight, BMI calculation, heart rate, blood pressure	Every vist
Atypical antipsychotics	BMI, abnormal involuntary movements	Every vist
	Fasting glucose, lipid profile, prolactin	Baseline 6 months annually

Importance

Clinicians should be acquainted with common problem symptoms and target behaviors and be able to make informed decisions regarding choice of medication for these issues.

BEHAVIOR/SYMPTOM	MAY REPRESENT	OPTIONS	MEDICATION/DOSING
Impulsivity *Over-reactivity* *Aggression* *Agitation* *Irritability*	Hyperactivity	First - Stimulants Second - Apha 2 agonists Third - Atypical antipyschoitc	MPH, AMP - start at 50% of lowest dose Guanfacine 0.5mg bedtime Clonidine 0.5mg bedtime Risperidone 0.25mg bedtime Aripiprazole 2.5 - 5mg/day
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Puberty

Introduction

It is important to be proactive with parents of children with autism, to help prepare them for the changes that will take place through puberty and adolescence. For instance, the physical and emotional changes of puberty may seem out of sync with their child's social and academic development.

As clinicians, we need to work with families to help them communicate effectively with their children about the changes of puberty. Parents need the skills and confidence to talk about puberty and sexuality with their children in order to confidently teach important life skills, including appropriate public and private behaviors, natural body changes and healthy social and romantic relationships.

In this chapter we define:

- Puberty as the physical changes in the body that make a person able to sexually reproduce
- Adolescence as the period of emotional and social transition between childhood and adulthood

This difference is important to keep in mind, as people with ASD often experience delayed development of social and emotional skills. They may not achieve the transition of adolescence until their late teens or early twenties. However, they will most likely undergo the physical changes of puberty within the typical time frame, which can be as early as 10 or 11 years of age.

Simply put, many teens with ASD experience the sensations of a physically mature body without the social, emotional or psychological maturity to understand these sensations.

Importance

Preparation and anticipatory guidance will help improve the knowledge of providers who care for children with autism and other behavioral health concerns. This includes the following issues:

- Hormones surges
- New emotions and feelings
- Different responses to others
- Body changes
- Same time course as children without autism
- Start preparing family

Evidence

While individuals with ASD often progress in ways that are different from other children, their bodies generally develop at a similar rate as their peers. However, children with ASD may have nontypical responses to what is happening to their bodies and may need additional guidance when navigating this time of transition.

Research has also shown that many children and teens with autism have unmet medical needs and do not have the same degree of access to standard preventative care as typically developing children. It is crucial that children and teens with autism have equal access to adolescent preventative care. In keeping with the Autism Treatment Network's "whole care for the whole family" framework, this chapter in the manual provides guidance to clinicians as it relates to puberty and adolescence.

How To Use This Guide

- Discuss puberty with parents early (before the onset of puberty)
- Discuss the need to prepare the child with autism for the upcoming changes
- Recommend the same preventative measures to people with autism as without autism
- Refer family to the Autism Speaks/ATN AIR-P Puberty and Adolescent Resource tool kit for tips and resources on issues such as menstruation, internet safety and private touch

Puberty tool kit:
https://www.autismspeaks.org/family-services/tool-kits

Healthy Bodies for Boys/Girls:
http://vkc.mc.vanderbilt.edu/healthybodies/

Treatments

Provide guidance around

- Safety
- Self-care
- Physical changes
- Sexuality
- Use the team – psychology, psychiatry, therapy, etc.

Importance of visual supports

Consider using scripting for adolescents who need guidance on how to communicate their needs. Families need resources to use with these children during this time. Key concepts around safe touch and boundaries are crucial. In addition, research shows that helping families and pre-teens develop skills around self-care has a significant benefit on adult outcomes. Important considerations include dental hygiene, showering/bathing, toileting and skin care. Scripting information about physical changes, hygiene and boundaries can be a valuable strategy to help individuals with autism navigate puberty and adolescence. Referral to additional professionals may be helpful and necessary.

Start by using picture resources and/or visual supports that would be appropriate for the child based on their age, learning needs and abilities.

Below is also an example a script to prompt conversation, to be customized to the child's maturity and verbal skills.

> For the less verbal child with ASD, adjust language and information to the level of the child and add visual supports. Start saying something like …" the rule is that your body will change and I want to show you how. Everyone's body changes as we become a grown up. Your body is going to change like this (using pictures). You will start to look more like a grown up body like me (or another person)."

Use these visual aides as individual cards to reinforce public and private behavior.

Public/Private Behaviors – Story

Private Parts

Public places are where other people can see me. Private means away from other people, like in my bedroom or bathroom with the door closed. Everyone has private parts of their body. I can tell what parts of my body are private because I cover them with my underwear. I don't touch my private parts in public where other people can see me. I don't ever put my hands inside my pants in public. I can help myself remember not to touch by putting my hands by my side, crossing my arms, or folding my hands. Sometimes I need to touch my private parts, like when I itch or my underwear is uncomfortable. I can ask to go to the bathroom. When I am alone in my bedroom or bathroom, I can touch my private parts.
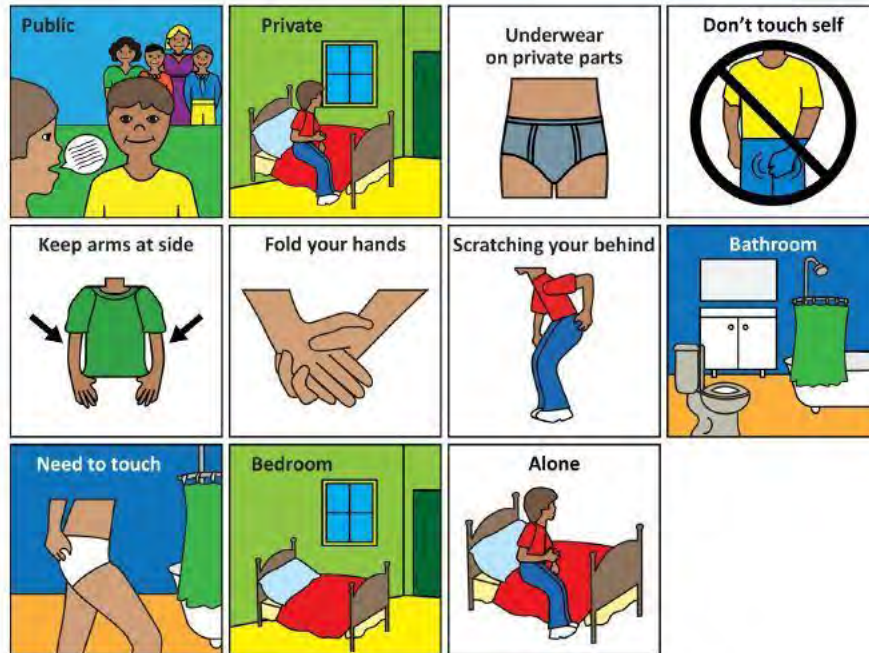
Summary

When addressing puberty in adolescents with autism spectrum disorder, parents and professionals should collaborate and start early, using concrete examples and visual aids to prepare for upcoming emotional and physical changes. Important concepts for parents include understanding the difference between adolescence and puberty and the appropriate ways to communicate with children depending on verbal and functional development. Best practice suggests that puberty conversations should start early and happen regularly. Most ATN sites advocate address puberty with children and families around age 9 to 10. The goal of this proactive discussion is to allow time for thoughtful consideration and planning. This ongoing conversation underscores the need for a longitudinal relationship with a trusted medical provider who understands the unique needs of each person with autism across the life course. In addition, it is important to consider referring for additional professional supports when necessary. This may include occupational therapy, counseling and/or behavioral therapy. With adequate preparation and communication, we can help ease and promote the successful transition through puberty for those with autism and their families – enabling them to enter young adulthood with confidence.

Vignettes

At 13, our son has started puberty and does not have the verbal skills or the awareness of social boundaries. It became evident when we were in church and something was bothering him. When I asked, he said "the carrot nose" was bugging him and pointed to his pants. (Carrot nose was how he described his erection in terms he could relate to.) Although he didn't have any knowledge or direction in masturbation, he knows what feels good and has figured it out. We've been using redirection or distraction when necessary and simple instruction about how the activity he's engaging in is okay in private (his bedroom) but not in other areas of the house or community (church, school, shopping centers, etc.). So far, he has accepted this well and we haven't had a real problem - but, then again, we're just beginning!

Charlene P., Parent Partner, Edmonton, AB Canada

In my opinion, my daughter really turned into a different person around nine years old. She's high functioning and speaks very well, but she would completely stop talking and do things like spit, scratch and bite during times when she was frustrated, nervous or anxious.

I became determined to make life better for my family and me. I strongly requested to learn non-violent safety strategies from my Regional Center for her increased aggression, property destruction and elopement. I also worked with an outpatient program to get Therapeutic Behavioral Services in the home. I spoke to our psychiatrist about adding medication that could help and held an IEP meeting to request an assessment from an occupational therapist, family counseling, social skills activities and elopement observation.

Although we're not completely through puberty yet, my daughter is now becoming such a pleasure and joy to be around once again. She makes more grown-up jokes and even talks about her future, which gives me hope that she'll be okay. Above all, I believe that she is a budding advocate for herself and for others with ASD, now that she is starting to be able to express her feelings more... and she's only 11!

Kameena B.D., Parent Partner, Burbank, CA

References

Puberty tool kit: https://www.autismspeaks.org/family-services/tool-kits

Healthy Bodies for Boys/Girls: http://vkc.mc.vanderbilt.edu/healthybodies/

While individuals with ASD often progress in ways that are different from other children, their bodies generally develop at a similar rate as their peers. Children with ASD may have nontypical responses to what is happening to their bodies and may need additional guidance when navigating this time of transition. Simply put, many teens with ASD may experience the sensations of a physically mature body without the social, emotional or psychological maturity to understand these sensations. As primary care providers, we need to help parents and individuals with autism navigate the changes through puberty and adolescence. The more proactive the preparation and communication, the more likely a successful transitions through puberty.

Key definitions

Puberty refers to physical changes in the body that make a person able to sexually reproduce.

Adolescence is the period of emotional and social transition between childhood and adulthood.

Important Steps

- Discuss puberty with parents early.
- Discuss the need to prepare the child with autism for the upcoming changes
- Recommend the same preventative measures to people with autism, as without autism
- Refer family to the *Autism Speaks/ATN AIR-P Puberty and Adolescent Resource Tool Kit* for tips and resources on issues such as menstruation, internet safety and private touch

Puberty tool kit: *https://www.autismspeaks.org/family-services/tool-kits*

Healthy Bodies for Boys/Girls: http://vkc.mc.vanderbilt.edu/healthybodies/

Key Concepts

- Provide guidance around
- Safety
- Self-care
- Physical changes
- Sexuality
- Use the team – psychology, psychiatry, therapy, etc.

It is imperative that families have resources to use with these children during this time. Key concepts around safe touch and boundaries are crucial. Research has shown that helping families and pre-teens develop skills around self-care can improve adult outcomes. Important considerations include dental hygiene, showering/bathing, toileting and skin care. Scripting information about physical changes, hygiene and boundaries can also be a valuable strategy to help individuals with autism navigate puberty and adolescence. Referral to additional specialists may be helpful and necessary. In particular, occupational therapists, psychologists, behavioral therapists and others can offer additional strategies for developing adaptive skills around the changes associated with puberty.

Importance of visual supports

As appropriate, consider using scripting for adolescents who need guidance on how to communicate their needs. Start by using picture resources and/or visual supports that are appropriate for the child's age, learning needs and abilities.

References: Puberty tool kit: https://www.autismspeaks.org/family-services/tool-kits
Healthy Bodies for Boys/Girls: http://vkc.mc.vanderbilt.edu/healthybodies/

Anxiety and ASD

Introduction

Anxiety disorders and symptoms are among the most common co-occurring conditions in individuals with autism spectrum disorder (ASD), affecting between 39 percent and 84 percent of the ASD population.[1-3] Children with ASD are at higher risk for anxiety than typically developing children or those with other developmental problems.[4] Despite the prevalence and impact of anxiety, it often goes unrecognized and untreated among children with ASD due to assessment and treatment challenges.

Importance

Anxiety is an important consideration for clinicians because it can have a significant impact on a child's overall well-being and day-to-day functioning. In children with ASD, anxiety is associated with increased stereotyped behaviors,[5] aggression and irritability[6] and depression.[7] Anxiety and avoidance of anxiety-provoking situations can make it more difficult for children to engage in daily activities, can reduce opportunities for learning and can interfere with intervention success. Accurate identification and timely treatment of anxiety symptoms can improve quality of life for children with ASD and may have positive effects on other areas of functioning. Thus, assessing for anxiety should be a regular part of ongoing clinical care for children with ASD.[8]

Evidence

A recent meta-analysis estimated that 39 percent of children with ASD meet criteria for at least one anxiety disorder,[3] with specific phobia, obsessive-compulsive disorder, generalized anxiety disorder and social anxiety disorder being the most common.[3,9] Several studies have found that anxiety appears to increase with age in children with ASD, with older children and adolescents experiencing more significant symptoms.[10-12] Despite the prevalence and importance of the problem, assessing and treating anxiety in children with ASD can be difficult. Thus, clinicians are encouraged to follow evidence-based approaches to management of anxiety in this population.

The recently published guide "Assessment and Treatment of Anxiety in Youth with Autism Spectrum Disorders," developed by the Autism Speaks Autism Treatment Network/Autism Intervention Research on Physical Health (ATN/AIR-P) Anxiety Workgroup outlines an evidence-based approach for both assessment and treatment of anxiety.[8] [http://pediatrics.aappublications.org/content/137/Supplement_2]

The following suggestions are based on these guidelines as well as additional available empirical evidence compiled through recent systematic reviews and meta-analyses.

Assessment

Screening and assessment of anxiety in children with ASD requires careful attention to choice of assessment technique and to potentially different presentation of symptoms in this population. Many children with ASD have limited verbal abilities and may not be able to describe their own symptoms. Additionally, there are no current tools designed specifically for assessing anxiety in children with ASD. These are important considerations because the characteristics of ASD often overlap with symptoms of anxiety, making differential diagnosis more difficult. For example, sensory hyper-reactivity and anxiety share many features, including distress and avoidance of specific stimuli. Ritualized behaviors and the need for sameness commonly seen in ASD can also be features of anxiety disorders. Due to this complexity, the current best-practice recommendation is to use multiple modalities and multiple informants when assessing for anxiety in children with ASD.[2,8,13]

Specifically, assessment should include the following:

- **Child self-report** via clinical interview when possible. Helpful modifications might include:
  - Clarification and explanation of emotional terms
  - Forced choice response options
    - Visual response options or visual analog scales
  - Checklists
- Parent- and caregiver-report via clinical interview.
- Anxiety assessment instruments that provide standardized scores or clinical cut-offs. Tools that have shown good properties in the ASD population include the following[14,15]:
  - Screen for Child Anxiety Related Emotional Disorders (SCARED)
  - Spence Children's Anxiety Scale (SCAS)
  - Revised Child Anxiety and Depression Scale (RCADS)
  - Child and Adolescent Symptom Inventory – 4th Edition (CASI-4R)
  - Pediatric Anxiety Rating Scale (PARS)
- **Behavioral observation and/or examination** focused on physiological or behavioral signs of anxiety, such as:

  - Avoidance or distress in response to certain stimuli or situations
  - Freezing behavior or trembling
  - Clinging behavior
  - Fearful facial expressions or body language
  - Increased repetitive behavior or vocalizations in response to certain stimuli
  - Elevated heart rate or blood pressure

Careful assessment of other contributing factors is likewise important for accurate identification of anxiety. Psychosocial stressors or other environmental changes should be considered. Clinicians should also rule-out other potential medical or psychiatric conditions that may cause, mimic or exacerbate symptoms of anxiety in children with ASD. These might include medication effects, symptoms of ADHD, sleep problems, seizures and gastrointestinal problems, among others.

Treatment

Management of anxiety in children with ASD should begin with a discussion with the child and family regarding the nature and impact of symptoms, available treatment options and family resources and preferences. Families should be partners in decision-making throughout the treatment-planning process. Coordination of care across all care providers is essential.

Based on current available evidence, cognitive behavioral therapy (CBT) has the most empirical support for treatment of anxiety in children and adolescents with ASD.[8,16-20] Cognitive behavioral therapy focuses on psychoeducation about anxiety symptoms and behaviors, building skills to recognize and change anxious thoughts, building coping and relaxation skills, reducing avoidance and building mastery through gradual exposure to feared situations. For children with ASD, modifications to standard CBT may include greater use of visual supports and strategies, more opportunities for practice and greater parent involvement in therapy.

Although there is ample evidence to support the use of pharmacological treatment of anxiety in typically developing children,[21] there has been very little research on the use of medications to treat anxiety in children with ASD.[16] In spite of limited rigorous evidence, experts may recommend a trial of medication to address significant anxiety symptoms that are not responding to other interventions. Medication trials should be introduced cautiously with low initial doses and slow titration. Selective Serotonin Reuptake Inhibitors (SSRIs) have the most supportive evidence in the typically developing population, and are often prescribed for children with ASD.[22] Existing data do suggest, however, that children with ASD may be especially vulnerable to negative side effects from SSRIs, particularly behavioral activation.[16,20]

In many cases, medications may also help manage symptoms commonly associated with anxiety, such as insomnia, irritability/agitation and/or behavioral dysregulation. Clinicians who lack experience prescribing psychotropic medications for children are encouraged to partner with a developmental or mental health specialist for guidance during either initiation or dose titration. [http://pediatrics.aappublications.org/content/137/Supplement_2]

How to use this guide

The healthcare provider is encouraged to consider anxiety symptoms when evaluating an individual with ASD for challenging behaviors and to explore all potential non-pharmacologic treatments for anxiety as early as possible. In cases where psychotropic medications are required, clinicians are encouraged to seek guidance from a mental health or developmental professional and take a "low and slow" approach to dosing. It is hoped that clinicians can use these approaches to manage mild to moderate anxiety symptoms in their patients within the primary care setting and to identify need for further expertise in individuals with more severe symptoms.

Vignette #1

Billy is a 9-year-old boy with ASD who is experiencing increasing difficulties both at home and at school. Parent and teacher report on standardized rating scales indicate significant anxiety symptoms across settings. During the clinical interview, his mother reports that Billy has a number of specific fears that have changed over time and seem to be increasingly interfering with his day-to-day life. For example, she reports that he has always been wary of dogs, but that this fear has worsened recently to the point that he "freaks out" if he sees a dog or even if a dog appears in a commercial on TV. He has recently begun refusing to visit his maternal grandparents because their neighbors have a dog, and he no longer wants to play at the neighborhood playground due to his fear that dogs might be at the park. His mother also noted that he has been increasingly distraught during family meal times and refuses to eat in restaurants or with others. At school, he has "meltdowns" in the cafeteria. As a result, his teachers now allow him to eat alone in the classroom, and his family allows him to eat at the kitchen counter rather than at the table with the family.

Behavioral observations conducted during the clinical visit indicate physiological and behavioral symptoms of anxiety when discussing anxiety-provoking situations. Parent report of his symptoms are also consistent, indicating heightened repetitive behavior, crying and avoidance behavior in the presence of feared situations. Although Billy is able to participate in a clinical interview, he has trouble describing his own thoughts and feelings and has trouble with open-ended questions. When provided with a checklist, he is able to check the situations that bother him and is able to check the symptoms he experiences. He is also able to describe the intensity of his anxiety in different situations using a visual "fear thermometer." The results of the parent-report, self-report and behavioral observations indicate that Billy meets criteria for a diagnosis of Specific Phobia, Animal type, as well as clinically significant contamination fears that are leading to avoidance of eating with or near other people. Billy is referred for cognitive behavioral therapy (CBT) to address these symptoms.

Billy's therapist focuses first on psychoeducational strategies to help Billy recognize and understand his anxiety symptoms. The therapist then begins to work with Billy on specific skills to address his symptoms, including relaxation strategies and positive self-talk. Finally, Billy and his therapist develop a plan for overcoming his fear through behavioral practice. By gradual step-by-step exposure to increasingly difficulty steps, Billy increases confidence and mastery while decreasing his anxiety. Billy's parents help by providing prompts, praise and reinforcement for frequent practice along the way. After 12 weeks of CBT, Billy's anxiety symptoms have improved significantly. His parents and teachers help him maintain these gains by encouraging coping skills and "brave" behavior both at home and at school.

Maggie is a 12-year-old girl with ASD and ADHD symptoms who presents to the clinic with worsening history of crying and picking at her skin during the school day. Parents report that symptoms began approximately 2 months into the school year and have persisted and possibly worsened in recent weeks. Maggie transitioned from elementary school to middle school this academic year, and though she is typically an excellent student, her homework time seems to be associated with increased agitation and skin picking at home. She has been working with the school counselor, discussing stress management strategies, but she continues to become easily upset at school when faced with an assignment or project. Parents also report more difficulty getting her to join extracurricular activities in their community center, previously a great source of enjoyment for Maggie. She has also begun to have more difficulty falling to sleep at night, reporting that she is "thinking about lots of stuff." Parent-, teacher-, and self-report rating scales highlight anxiety and emotional dysregulation symptoms.

Diagnosis: Generalized anxiety with possible social anxiety symptoms. Interventions: Maggie would benefit from working individually with a cognitive behavioral therapist to develop strategies for managing her anxiety around schoolwork and social events. A low dose of melatonin may help her with sleep onset difficulties while she is establishing with a therapist. If symptoms begin to interfere with learning or community function, a low dose of SSRI might be considered.

Summary/Key Points

- Individuals with ASD are at increased risk of having at least one anxiety disorder, and anxiety symptoms may present differently in children with ASD than they do in typically developing children.
- Assessment for anxiety in children with ASD should use multiple modalities and informants and should rule out other possible medical, psychiatric and psychosocial contributing factors.
- Cognitive behavioral therapy (CBT) is currently the most evidence-based treatment available for anxiety in children with ASD and may be modified to the needs of individuals with ASD by including visual supports and parent training.
- When needed, pharmacologic treatment for anxiety in children with ASD should incorporate low initial doses and slow dose titration with extra attention to potential adverse medication effects. Clinicians are encouraged to seek guidance from a mental health or developmental specialist during the dose titration process.

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Introduction

Children with ASD are at very high risk for significant symptoms of anxiety. Anxiety disorders are one of the most common co-occurring conditions in children and adolescents with ASD; however, these symptoms often go unrecognized or inadequately treated. Thus, assessing for anxiety should be a regular part of ongoing clinical care for children with ASD.

Importance

Anxiety is an important consideration for clinicians because it can have a significant impact on a child's overall well-being and day-to-day functioning. For example, anxiety can lead to increased repetitive or stereotyped behaviors, aggression, irritability, depression and social difficulties, and reduced engagement in activities. Accurate identification and timely treatment of anxiety symptoms can improve quality of life for children with ASD and may have positive effects on other areas of functioning.

The following suggestions for assessment and treatment of anxiety in children with ASD are based on currently available empirical evidence, systematic reviews, meta-analyses and clinical guidelines [http://pediatrics.aappublications.org/content/137/Supplement_2]

Assessment of anxiety

Multiple modalities and informants should be used when assessing for anxiety, including:

- **Child self-report** via clinical interview when possible. Helpful modifications include
  - Explanation of emotional terms and forced choice response options
  - Visual response options, visual analog scales or checklists
- **Parent- and caregiver**-report via clinical interview.
- **Anxiety assessment** instruments that provide standardized scores or clinical cut-offs.
- Behavioral observation and/or examination focused on signs of anxiety, such as:
  - Avoidance or distress in response to certain stimuli or situations
  - Freezing behavior, trembling and/or clinging behavior
  - Fearful facial expressions and/or body language
  - Increased repetitive behavior and/or vocalizations in response to certain stimuli
  - Elevated heart rate and/or blood pressure
-

Treatment of anxiety

Management of anxiety in children with ASD should begin with a discussion with the child and family regarding the nature and impact of symptoms, available treatment options, and family resources and preferences. Primary care providers are encouraged to explore all potential non-pharmacologic treatments for anxiety as early as possible. Cognitive behavioral therapy (CBT) currently has the most empirical support for treatment of anxiety in children and adolescents with ASD. When psychotropic medications are required, clinicians are encouraged to incorporate low initial doses and slow dose titration with extra attention to potential adverse medication effects. Primary care providers are also encouraged to seek guidance from a mental health or developmental specialists during the dose titration process.

Attention Deficit-Hyperactivity Disorder and ASD

Introduction

Children and adolescents with ASD often have comorbid problems with symptoms of inattention, impulsivity and overactivity. Such problems can adversely impact both academic success and the ability to attend to social cues. In addition, overactivity and impulsivity can be highly disruptive to the classroom environment, leading to the placement in more restrictive settings for some children in the spectrum (1). Until recently, ADHD symptoms were thought to be so commonly seen in ASD that ADHD could not be diagnosed (APA 2000). However, while a significant number of children with ASD have deficits in attention, impulsivity and overactivity, this is not always that case (2,3). Therefore, the practitioner/clinician should conduct a diagnostic evaluation for individuals with ASD who present with relevant concerns and consider providing appropriate treatment.

Importance

Many individuals with ASD have deficits in attention span, impulsivity and overactivity. Therefore, it is important for the practitioner/clinician to be able to determine when symptoms meet criteria for a diagnosis of ADHD and require further treatment. Recent surveys suggest that around one-third of children with ASD meet criteria for a comorbid diagnosis of ADHD (2,3), a rate that is significantly higher than among neurotypical children. As with neurotypical children, information obtained from both the home and school (typically using standardized questionnaires) will be an important step to determining if a child has ADHD. There are no ADHD assessment tools that have been specifically normed with the ASD population (although some have been normed with individuals with developmental disabilities). As when assessing neurotypical children, attention to possible medical causes or other contributing factors (e.g., sleep problems, seizure disorder, GI concerns) need to be taken into account and addressed. Symptoms that appear suddenly, without any prior history of concerns, may be due more to problems in the child's immediate environment (e.g., a poor child-teacher match, parents' marital discord) than to ADHD.

The prevalence of ADHD among children with ASD warrant careful screening, treatment and monitoring. Some common screening tools include["1] :

- Vanderbilt Scale
- Conners Scale
- SNAP 5 Checklist
- Aberrant Behavior Scale (standardized for individuals with developmental disabilities)

If screening scales from both home and school are consistent with ADHD, the ATN/AIRP medical guidelines for ADHD (http://pediatrics.aappublications.org/content/130/Supplement_2) provides resources that may be a helpful. For families considering medication as a possible option, the ATN-Medication Tool Kit also is an excellent resource for families to review prior to talking with their child's practitioner about treatment options. Autism and Medication: Safe and Careful Use

Evidence

With the adoption of DSM-5 (APA 2014) in 2014, clinicians have been able to diagnose ADHD as a comorbid disorder in children with ASD. The current research indicates that ADHD is substantially impacting functioning at home, school and in the community among a large portion of children with ASD. Surveys conducted over the past 10 years have consistently documented a high rate of ADHD symptoms in the ASD population (2,3). In addition, surveys of prescribing patterns for children with ASD suggest that ADHD continues to be the most frequently treated behavioral disorder (4). This suggests that practitioners should early on screen for ADHD symptoms in their patients with ASD, starting in the preschool years. As will be summarized below, there is a wealth of research on the safety and efficacy of both pharmacologic and psychosocial treatments for inattention, impulsivity and overactivity in the ASD population.

How To Use This Guide

The health care provider is encouraged to consider ADHD in children with ASD who have overactivity, inattention or impulse control difficulties. It is hoped that clinicians can use this information to

better understand such difficulties in individuals with ASD who present to their offices, and initiate meaningful treatments.

Treatment

A detailed pathway to treatment of ADHD in children with ASD was published in 2012 by the ATN group (5).

As mentioned, undiagnosed medical and mental health problems need to be first identified, and optimally treated. Discrepancies in symptoms across settings, typically suggest that educational and/or behavioral interventions may need to be optimized. Some children have fewer ADHD symptoms in a structured environment in school, whereas others have more difficulties with increasing demands. When ADHD symptoms occur only in school, parents should ask for a behavior support plan to be incorporated into the Individualized Educational Program. Successful behavioral strategies may include functional behavioral assessment, alternative teaching styles, and accommodations for learning disorders, provision of related services (e.g., speech and language therapy). Psychoeducational and/or neuropsychological testing are sometimes useful to evaluate the child's cognitive strengths/weaknesses, which, in turn, may help design an appropriate individualized educational plan. ADHD symptoms that occur only at home usually require behavioral or family-oriented interventions.

Sometimes optimization of medical, mental health and educational/behavioral interventions are not adequate to address ADHD symptoms. In these cases, a medication trial may be warranted. The following medications show evidence for treatment of ADHD symptoms in children with ASD.

		EVIDENCE OF EFFICACY	CAUTIONS	CONTRAINDICATIONS	SIDE EFFECTS
Stimulants	Methylphenidate Amphetamine salts	Most effective for both attention and hyperactivity. Over-all response rate is around 50X%. [6, 7]	<5 years, IQ<50, severe tics psychosis, unstable mood disorder, low weight, anorexia	Personal or family history of childhood heart disease, without cardiology clearance	Anorexia, insomnia, agitation, effects on growth
Alpha agonists	Clonidine Guanfacine [8,9]	Effective for hyper-activity, inattention and impulsive behaviors. Over-all response rate around 50%.		Personal or family history of childhood heart disease, without cardiology clearance	Drowsiness, fatigue and decreased appetite [9]
NRIs	Atomoxetine [10]	Effective for both attention and hyperactivity (check this). Overall response rate around 50%. [10]	Age<6 years, history of activation or bipolar disorder		Fatigue (but no insomnia), anorexia, gastrointestinal symptoms, and central nervous system-related AEs
Atypical antipsychotics [11, 12]	Sleep onset insomnia	First - Melatonin Second - Clonidine	Melatonin 1mg qhs; titrate up to 3qhs Clonidine 0.5mg bedtime, may titrate to 2mg		
		Research also shows significant decrease in ADHD symptoms as well.	Obesity, personal or family history of diabetes, dyslipidemia.		Tardive dyskinesia

*modified from Fig 2, Mahajan et al 2012

Summary

ADHD is a common co-occurring condition affecting about one third of children and youth with ASD. Symptoms of hyperactivity, inattention and impulsivity deserve careful examination to 1. Rule out medical and mental health comorbidity that may better account of such symptoms; 2. Develop appropriate behavioral / family / school interventions to accommodate such symptoms; and 3. In some cases consider medication use to improve school performance, safety, and quality of life.

Vignette #1

A ten- year old boy with ASD presents with severe hyperactivity and inattention complaints at both school at home. He has "a little motor" and "cannot stop". In addition to ASD, he uses phrase speech to communicate and his full scale IQ is in the average range. At the pediatrician's office, the mother discloses severe constipation and difficulty falling asleep. The pediatrician and family agreed to first develop a plan to address constipation and to work together to improve sleep hygiene. The family completed questionnaires at the office and also took a packet of questionnaires for the teacher. A request was made to release the results of the most recent IQ testing to the pediatrician. The family returned to the pediatrician's office in 3 weeks. Both constipation and sleep difficulties had greatly improved. The pediatrician reviewed the questionnaire data completed at the time of the last visit and both parents and teacher reported significant difficulties in activity levels, inattention and impulsivity. The family completed an updated questionnaire at this visit. Although the symptoms had greatly improved, they still remained in the clinically worrisome range. In addition, the IQ test results released to the pediatrician revealed a significant split between verbal and non-verbal functioning, which may affect the child's performance in school. A conference call was set up with the school to discuss a common plan. The school agreed to complete a psychoeducational assessment to further clarify the learning disability likely present and to modify the IEP accordingly. However, school staff continued to find the boy's hyperactivity to be extremely difficult to manage in the classroom, despite appropriate accommodations. The family and pediatrician discussed the available options. Given no history of childhood heart disease in the family or the child, they decide to initiate a stimulant medication trial. The child returned to the pediatrician's office 4 weeks later reporting significant improvements across the board. Questionnaires sent to school also documented significant reduction in concerning symptoms across domains.

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Intervention –Collaborative Partners

Introduction

ASD is a multifaceted disorder that usually requires involvement of multiple providers. When developing intervention programs for children with autism spectrum disorder (ASD) it is imperative to consider how to gain valuable expertise from professionals from a range of disciplines in order to build a more comprehensive approach.

Importance

There is agreement that a collaborative multidisciplinary approach is considered best practice in both diagnosis and intervention of ASD [1]. However, this is much easier said than done. Most children with ASD are engaged in some version of a multidisciplinary team approach, as in "seen by multiple providers," but few are treated in a true collaborative team approach – particularly for intervention. Sadly, the benefits of the combined expertise of multiple disciplines often fails to be maximized due to difficulty in communication and coordination across team members. Improved patient experience and satisfaction, reducing costs, and providing patient centered care is not attainable without a team approach[2]. There isn't an argument that this type of collaborative care is best practice, however, executing collaborative care remains a challenge in a busy clinical setting with little incentive/time for care coordination. This Chapter will discuss some approaches to improve collaboration between providers across various clinical models.

Collaborative Partners

In a Collaborative team approach, each discipline brings unique knowledge to the team including expertise from their field. A strong ASD intervention team consists of professionals that, first and foremost, are experienced in the treatment of autism then apply specific discipline knowledge to the overall intervention plan. Children with ASD demonstrate a variety of strengths and weakness that are interwoven across domains and impact and/or build on each other, therefore intervention should be designed comprehensively rather than in discrete silos. Effective collaboration requires two constant and key elements (1) construction of collective action that addresses the complexity of client needs and (2) the construction of a team life that integrates the perspectives of each professional where each member experiences respect and trust [3].

One of the common challenges for the lead provider (usually the child's pediatrician or developmental behavioral Pediatrician) and caregiver, is how to effectively and efficiently coordinate multiple team members. All too frequently care is delivered in "silos." A true integrated approach may not be possible, particularly if the providers work in different settings. But at a minimum, thoughtful consideration should be given to how care plans and progress will be communicated across providers so that interventionists can support the goals and objectives of the other, thereby providing more learning opportunities and strengthening the learning across environments.

Team Models

The terms "Multidisciplinary" and "Interdisciplinary" are often used interchangeably, but they do have different meanings. A "multidisciplinary team" has been defined as "activities that involve the efforts of individuals from a number of disciplines. These efforts are disciplinary-orientated and, although they may impinge upon clients or activities dealt with by other disciplines, they approach them primarily through each discipline relating to its own activities.[4]" An Interdisciplinary approach is defined as "a group of individuals with diverse training and backgrounds who work together as an identified unit or system. Team members consistently collaborate to solve patient problems that are too complex to be solved by one discipline or many disciplines in sequence.[4]" For a team approach to be most successful, careful consideration should be given to the coordination of multiple providers in order to maximize the benefit. Although most frequently referred to as a multidisciplinary, the goal should be to move to an interdisciplinary team approach. Multidisciplinary and Interdisciplinary approaches require considerable thought and effort – not only for the development of discipline specific goals- but for the development of effective team interaction and collaboration. Team members need

to effectively transfer discipline specific objects and intervention strategies to other team members including caregivers, in order to promote integration of therapeutic activities. In a collaborative model, the result is greater than the activities of each individual discipline.

A collaborative model may be a challenge for a family of a child in an Applied Behavior Analysis (ABA) program with a single interventionist (particularly a home based model). Careful thought and planning of how the expertise of other specialties (the "what" we need to do/teach) is integrated into the overall program should be considered. The importance of the contribution of other specialists' is too often overlooked and the opportunity for a more comprehensive program is lost. These programs should include a focus to, not only share information across other behavioral interventionists (i.e. in home tutors), but in gathering and implementing recommendations from other multidisciplinary team members.

Tips for improving Communication across team members

There are a variety of methods to improve communication across team members. Most providers conceptually understand the importance of collaboration, however, the challenge is developing a consistent and effective method that 1) fits within the service delivery model and 2) remains a priority for the team. A team communication plan remains an afterthought when developing a patient care plan, and yet it is one of the most important components to therapeutic success.

Low tech methods for increasing communication across team members include the use of patient centered spiral note book or binder for quick notes or updates on goals, instructions/ handouts on how to practice skills for caregivers, or suggestions for carryover for other providers can be very helpful.

- Caregivers bring the notebook/binder to therapy and doctor appointments. Each clinician adds a brief update on goals and suggestions for the collaborating clinicians as well as suggestions for caregivers to do at home.

- Some teams will establish team goals and each provider comments on progress toward that goal for each setting as well as comment on discipline specific goals and objectives.
- Medium/High tech approaches may include; tablets/iPads, apps etc. These are higher tech versions of notebooks to capture notes and memos across providers.
- These devices may be used to relay notes regarding goals and suggestions for carryover.
- These devices may also be used to c
- These video demonstrations can be extremely helpful in sharing information and demonstrating how to implement an intervention across settings or used to check fidelity of an intervention across providers.
- Additionally, there are a number of apps being developed that assist in coordinating care. These apps assist in storing diagnostic info, therapy goals and progress notes. Many apps will provide graphs of progress to share with other team members and with the child's physicians and therapists.

More time intensive methods include regularly scheduled case conferences. These can be held in person (some billing codes allow for billing of this type of meeting-check CPT codes and regulations). Teleconference and or telehealth video conference may also be use. These methods allow for direct conversation, but may be easier to schedule within busy clinical demands and collaborators from different departments or agencies, than an in person meeting.

Considerations when developing an Autism Treatment Program

The one stop shop – Specialized Centers

By far this is the most frequent request from families is the convenience of having all or most providers in one place. If developing an autism treatment center this model is highly recommended. Having providers in a single location is not only convenient for families; it also promotes teaming. Staff may be hired specifically for the center, or a matrix relationship that allows each

discipline to "sit" professionally in their department but be physically located within the specialty center on a full or part time basis depending on need. The matrix relationship- although it takes considerable effort in departmental negotiations- can allow for more flexibility. The goal is to create a ready team with a unified focus that is able to have more frequent interactions. This allows for more rapid building of trust and a system for collaboration. This 'one stop" model gives a sense of belonging and promotes the teaming process.

While having providers in one center, as described above, provides increased opportunities for teaming and communication, effective collaboration still takes planned effort. Electronic medical records (EMRs) assist by allowing multiple providers to read the clinical notes of another. However, face to face teaming such as case conferences is often most effective. Short meetings in which cases are reviewed allow for multiple providers to weigh in and for clinical decisions and changes to take place. Face to face meetings allow the sharing of ideas and opportunities to clarify questions or concerns. These team meetings should focus on the exchange of ideas, discussions, reporting on progress or barriers to achieving goals, and goal setting for the patients. All the team members have equal status and the decisions are made by the team. [5]" There are some billing codes that allow for some minimum billing for team conferencing within a medical center (check ICD codes for requirements).

Single Institution

A similar but less unified model, is to have providers within the same institution but not housed within the same clinical unit. For example: a hospital setting where the providers are each physically housed within their discipline specific departments. In this model intervention is provided by clinicians located within different departments within a single institution. The lead provider will need to take a more active role in assuring communication such as arranging case conferencing – which may be more challenging since each provider will be working within a different department with different set of standing meetings, appointments, and billing requirements. However, providers within the same intuition can usually access a shared EMR, this can allow for sharing of ideas through written communication. If face to face meeting proves to challenging, consider the use of teleconferencing, or telehealth technology make these meetings more feasible. Also keeping discussions to 15 minutes for targeted discussions may be helpful in increasing participation.

Collaborators across multiple settings

This is by far the most common scenario. Even when there is a comprehensive autism center, the child frequently receives one or more services from providers outside that center. This is nearly always the case for school age children attending school. It is important for the medical and school based teams to communicate effectively. It may not be possible to hold full team meetings for teams of this type due to real financial/time limitations. However, as state previously, technology may provide opportunities for improved teaming and thereby create more opportunities for at least brief communications. In these scenarios consider the use of apps, written note. For full team meetings consider the use of technology such as teleconferencing or videoconferencing. Again, keeping these brief and targeted may be helping in finding coordinated times to discuss patent goals and progress.

It is essential not to underestimate the importance of collaborating with intervention team members. A communication plan should be added to all care plans for children with ASD. The time and effort put in to developing effective teaming will pay off for the patient with ASD and their caregivers while providing an important network for the providers on the team.

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CHAPTER 4
Primary Care Provider (PCP) Engagement

Children with Autism Spectrum Disorder (ASD) often have limited access to comprehensive medical care in their communities (1). Primary Care Providers (PCPs) report significantly lower self-perceived competency and a greater need for education about children with ASD (2). Autism Treatment Network (ATN) Centers recognize the key element of coordinating care across settings and the need to build and reinforce connections with PCPs to improve access to community –based medical care for individuals with ASD.

Engagement with PCPs can and should occur on multiple levels. The specifics of engagement will vary depending on the needs of the particular community. Regardless of location, PCPs need:

- Increased access to information
- Specialty consultation
- Training and networking opportunities

Collaborative relationships with autism specialists and PCPs can lead to success in providing ongoing care for children with autism within their community medical settings.

PCP engagement can be thought of falling into various themes, shown, along with examples, in the graphic below. None of these are mutually exclusive nor are the examples exhaustive. Some autism centers may find certain activities unnecessary or impractical at the present time.

Patient specific communication is a necessity, but the other themes represent a flexible framework for engaging PCPs.

Some activities (i.e., learning collaboratives) require coordinated efforts with outside organizations and additional resources. System initiatives, such as training lab technicians in best practices for blood

draws in children with autism, may entail institutional support for work flow modifications and staff release time for training. Community events may not seem relevant to PCPs, but represent an important way to give PCPs information that they can provide to families, or even volunteer at or attend themselves. This broader community engagement helps strengthen primary care medical homes for children with autism.

PCPs also benefit from having autism specific anticipatory guidance material, either in print or electronic format. Community specific customized material from your local Autism Center would undoubtedly be much appreciated! Some general topics and sources of information are listed in Table 1. This list is intended to be illustrative, not exhaustive, and does not imply endorsement/recommendation of the particular organization or content.

PCP Engagement

PT SPECIFIC COMMUNICATION	• Suffient letters/reports • Clear delineation of roles/responsibilities
CONSULTATION	• Direct phone numbers, emails, call centers • Easily accessed referral process
EDUCATION	• Grand Rounds, presentations to local medical meetings • ATN/AIR-P Tool Kits, other electronic and print materials
NETWORKING	• Open houses, leadership receptions, medical society meetings • Newsletters
PRACTICE RELATED TRAININGS	• Customized presentations to local practices • Topics such as developmental screening, autism friendly
LEARNING COLLABORATIVES	• ADEP, Concerned about Development, Building Mental Wellness (www.ohioapp.org) are some examples • ECHO (thompsoncenter.missouri.edu/training/echo-autism/)
HEALTHCARE SYSTEM INITIATIVES	• Education for ED staff • Trainings for lab techs re blood draws
COMMUNITY EVENTS	• Information re local fund raisers, sensory friendly movies, special needs camps, etc

Table 1:

TOPIC	RESOURCE
Sleep, toilet training, hair-cuts, blood draws, feeding, new diagnosis, IEPs, transition, etc.	ATN/AIR-P Tool Kits **autismspeaks.org** Tool Kit for Primary Care Providers **http://www.iddTool Kit.org/**
Basic info, policy statements	American Academy of Pediatrics **aap.org** American Academy of Developmental Medicine and Dentistry **Aadmd.org**
Assessment, evidence based practices	Ohio Coalition for Autism **ocali.org** Centers for Disease Control **cdc.gov/ncbddd/autism/index.html** ATN/AIR-P Medical Guidelines **pediatrics.aappublications.org/content/130/Supplement_2**
Family issues and support	**autismspeaks.org**; **autism-society.org**

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Thompson Center Diagnostic and Follow-up Requirements

DIAGNOSIS	FOLLOW-UP
• ADOS • Cognitive assessment • Adaptive behavior assessment • Teacher report (if applicable) • Past medical records requested • IEP requested • Medical exam and dysmorthophology screen • Medical comorbidity screen • Developmental history • Family history • DSM 5 criteria • MO ACE diagnostic documentation requirements • Treatment plan/next steps	• Minimum recommended annual follow-up • Recommended medical work-up – CMA, DNA Fragile X, lead plus additional based on clinical findings • All patients screened at each visit with comprehensive review of systems and documented medical record • All patients screened positive have family centered care plan for treatment of medical comorbidities intitiated and documented in medical record • Transition planning starts at age 12 and continues through successful healthcare transition • Follow recommended atypical antipsychotic monitoring guideline (BMI, vital signs, glucose and involuntary movements) and documented in the medical record • Coummunication across settings with primary care providers and family

Strong family engagement can lead to better service and improved health outcomes.

CHAPTER 5
Developing A Family Advisory Committee (FAC)

Introduction
Family engagement is a well-known and popular practice with many organizations that prioritize families as equal partners. Modeling the values and principles of family-centered care (FCC), the ATN encourages creating family engagement opportunities that build a system that integrates family feedback to improve clinical and continuing care practices. While family engagement can take several forms, the ATN promotes building local Family Advisory Committees (FAC) as an effective method for family engagement in the context of FCC.

Importance
An organized and integrated FAC can provide a critical feedback loop that enables organizations to enhance service and improve quality through a family-centered model of care that embraces family engagement. Simply put, FCC is the meaningful partnership that exists between families and professionals[1]. It is about engaging patients and their families in meaningful ways to improve services, to make service delivery more responsive to the needs of families and ultimately to save resources. Strong family engagement can lead to better service delivery and improved health outcomes.

How To Use This Guide
When your practice is ready to consistently embrace family engagement by developing a FAC, consider the recommendations and resources listed in this chapter. The information is not exhaustive, it pulls from various sources to provide concrete steps your practice can use to develop a strong FAC.

Are You Ready to Create a Family Advisory Committee?
The National Institute for Children's Health Quality (NICHQ) is a leader in the fight to improve children's health. In the early stages of the ATN, NICHQ provided many ATN centers crucial support in developing their local FACs. Once your practice is ready to begin the process of assessing readiness for creating meaningful family engagement through a FAC, NICHQ's Creating a Patient and Family Advisory Council: A Tool Kit for Pediatric Practices will provide a step-by-step guidance on how to effectively engage family perspectives.

See more at:

NICHQ's Tool Kit

http://www.nichq.org/sitecore/content/medical-home/medical-home/resources/pfac-Tool Kit

Need to learn more about Family-Centered Care?

There are several sources of information on FCC. Your practice can look to The 2001 National Survey of Children with Special Health Care Needs, sponsored by the Maternal and Child Health Bureau of the Health Resources and Services. MCHB describes FCC as "an approach to the planning, delivery and evaluation of health care whose cornerstone is active participation between families and professionals. Family-centered care recognizes that families are the ultimate decision makers for their children, with children gradually taking on more and more of this decision-making themselves2."

The Institute for Patient- and Family-Centered Care is a non-profit organization that provides leadership to advance the understanding and practice of patient- and family-centered care. The IPFCC has an excellent library of tools and resources on patient

and family-centered care as well as suggestions on how to build FACs.

See more at:

The 2001 National Survey of Children with Special Health Care Needs:
http://mchb.hrsa.gov/chscn/index.htm

The Institute for Patient- and Family-Centered Care's tools and resources:
http://www.ipfcc.org/tools/downloads-tools.html

Let's Get Started

It all begins with prioritizing your commitment to engage individuals with autism and their families. Next steps include communicating this commitment to your families, staff and community. By communicating that you value family engagement, you will be able to identify both the natural-born leaders and those who need a little nudging to join you in this mission.

Developing a FAC is no easy task. It will take resources, creativity and collaborative relationships. Be ready to have deep conversations with your leadership staff around financial resources, space and logistics, and staffing support. Be ready to think creatively and strategically to identify individuals at your practice and in your community who will make the commitment to share their perspective and lead others on behalf of families and individuals with autism. To build trusting and collaborative relationships, transparency is key. Get creative and find leadership who are trusted individuals in the community, partnering with them to take action as you carry out your mission. And remember that there are several approaches to building successful FACs. Some are more structured and formal, while others are more freeform and unofficial. Work with your FAC to find the right fit for your center and community.

Ensuring Diversity in all Aspects of the FAC

FAC membership should not be limited to parents or individuals with autism, nor limited to solely your practice. Be open to the participation of grandparents, foster parents, legal guardians and other members of the community. They can bring new and unanticipated insights if invited to the table.

Recruiting a FAC membership that reflects the diversity of your entire practice and community takes effort. Diversity takes many forms, including gender, race, culture/heritage, age (of patients and of family members), language, socio-economic background, disease or disability, family structure and sexual orientation.

Overcoming Barriers in Developing a FAC

The following are possible barriers and challenges you may encounter. It is adapted from one of our favorite online resources4.

Remove as many barriers to participating as possible. Offer child care, food, parking vouchers and even stipends in the form of cash or a gift certificate to a local grocery store as recognition of members' contribution of time.

- Ask families about the accommodations they need to attend.
- Translate the invitation and recruiting materials and make arrangements for interpreters at your meeting.
- Use simple and welcoming language and make sure it is easy to read.
- In recruiting materials, use the term "family" instead of "parents" and allow families to define themselves to widen the range of voices.
- Make a special effort to reach out to both parents. Providing child care, for example, makes it easier for both parents to attend. For some families, both parents may not think to attend — so ask!
- Seek help from others in your practice who have expertise in multi-cultural affairs or who have close community connections.
- If possible, connect with community organizations as well as your individual site resources for recommendations and referrals for families.
- If possible, provide the opportunity for networking with other Family Advisors and/or consider integrating an additional support group for families.
- Create an ongoing recruitment plan, as some families become less active over time.

Continue to refine and improve your FAC

Tips for success for your FAC

Meeting logistics: Carefully consider meeting time, accessible locations, transportation concerns and child care needs. Consider hosting teleconferences in addition to in-person meeting to offer more opportunities for all members to participate.

Prepare meeting materials to enhance family participation: Depending on the Family Advisors' level of experience, pre- and post-meeting support may be needed.

Adopt a meeting structure that facilitates engagement: Create a welcoming space. Have staff welcome each person and let a family advisor facilitate the meeting. Use an agenda and walk attendees through it at the beginning, then stay on task.

Understand the trajectory of family leadership development: Family advisors provide a valuable service to your organization by contributing their perspectives as consumers of your services. As they become involved at the advisory level, their understanding of service delivery grows and their leadership skills will develop further.

Survey your parent leaders: A simple survey of expectations of parent leaders can provide insight into simple yet profound learning.

Create tiers of work to help family advisors participate at their current level: For example, some family advisors might be able to provide input/feedback primarily by email. Other family advisors may be able to attend community events. Still others may want to participate in ATN/AIR-P network-wide activities.

Encourage family advisor leaders to become involved in ATN/AIR-P activities: This can include workgroups, committees, research projects and more.

Integrate family advisors into workshops, classes and other events that involve your site: This can include resource fair booths and other opportunities to represent the family perspective.

Remember: Family advisors work best when treated as full members of the team!

Continue to refine and improve your FAC

Engage your FAC leaders to help you continually evaluate your progress and fidelity to the purpose of the FAC. Monitor progress, share findings and train your FAC membership. Conduct surveys, focus groups or one-on-one interviews and ask the hard questions. Remember, building a FAC is about developing and embracing a trusting, collaborative partnership with your members.

Summary

Family and patient engagement is critical to the successful delivery of services to individuals with autism. Creating opportunities for feedback from the people you serve is the right and ethical commitment to your families and patients. Take time to assess your readiness to engage with families and individuals. Share your commitment to family-centered care and family engagement with everyone. Let natural leaders and hidden gems from your community join your efforts to improve the quality of life for all through the development of a Family Advisory Committee. Keep in mind that this will take time and effort. It takes courage, relationship building and a lot of planning to achieve success. Look to online resources on family engagement and building a FAC. Stay true to your community by building open and trusting relationships and keep diversity at the forefront. Ensuring that diverse perspectives and individuals of different backgrounds are equally engaged and are valued partners will help you reach success in improving service delivery and quality of life for your practice and community.

References

1. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2001. Rockville, Maryland: U.S. Department of Health and Human Services, 2004.

2. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2001. Rockville, Maryland: U.S. Department of Health and Human Services, 2004.

3. Goode, T., & Jones, W. (2006). A guide for advancing family-centered and culturally and linguistically competent care. Washington, DC: National Center for

Cultural Competence, Georgetown University Center for Child and Human Development.

4. Creating a Patient and Family Advisory Council: A Tool Kit for Pediatric Practices - See more at: http://medicalhome.nichq.org/resources/pfac%20Tool Kit#sthash.SGwd6Jwa.dpuf

5. Other online resources:

6. Standards for Patient-Centered Medical Home (PCMH) 2011, National Committee for Quality Assurance (NCQA), PDF, https://www.ncqa.org/Portals/0/Programs/Recognition/PCMH_2011_Overview_5.2.pdf

7. Medical Home Index: The Center for Medical Home Improvement, PDF, http://www.medicalhomeimprovement.org/pdf/CMHI-MHI-Pediatric_Full-Version.pdf

*QI methodology has helped members
of the ATN become more consistent in practices
for caring for children with autism.*

CHAPTER 6
Quality Improvements

Background

Quality Improvement (QI) focuses on changing care delivering to improve quality of care (Lemer, Cheung, & Klaber, 2013). QI methodology can be a helpful strategy to ensure evidence-based and promising practices are consistently used within a practice or across multiple practices. QI methodology has helped members of the ATN become more-consistent in practices for caring for children with autism. To date, we have worked on improving screening for constipation and sleep problems, developing care plans and monitoring side effects for children on atypical anti-psychotic medications. Through this work, we have successfully applied evidence- and consensus-based practice across our network sites.

In 2001, the American Board of Pediatrics adopted the approach to measuring core physician competency through the strategy of Practice-Based Learning and Improvement, approved by the ACGME and ABMS (Miles & Moyer, 2013). Rather than measure individual performance, Maintenance of Certification (MOC) Part 4 (see definition below) focuses on performance at the practice and/or population level. In 2001, the Institute of Medicine (IOM) (Committee on Quality of Health Care in America Institute of Medicine, 2001) defined six domains of quality, including effectiveness, patient centered, timeliness, safety, efficiency and equity. This set the stage for further directions of measurement of quality and quality of care. This chapter provides guidance to practices seeking to use QI methods to improve care for people with ASD and instruction on how to offer Maintenance of Certification credit.

QI Methodology in the ATN

All ATN institutions embrace a culture of continuous improvement in processes and outcomes that affect children with autism. The ATN has chosen to use the Model for Improvement for our QI endeavors.

The Model for Improvement, a framework for doing QI, is centered around three questions:

1) What are we trying to accomplish?

2) How will we know the change is an improvement?

3) What changes can we make that will result in an improvement?

Plan-Do-Study-Act cycles, or PDSAs, test changes in an iterative way to determine whether the change results in an improvement. See Figure 1 for example of PDSA cycles, which are derived from the three questions above.
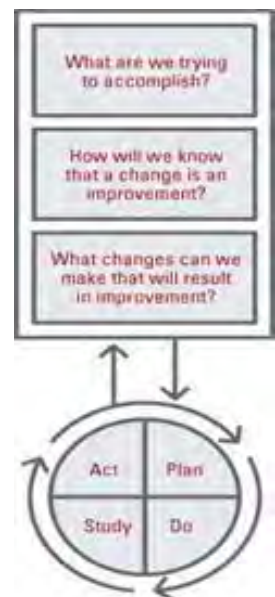

Figure 1: PDSA CYCLE

Plan: Identify a goal or aim and define metrics for success

Do: Implement components of the plan

Study: Examine outcomes or results and how they relate to the goal

Act: Adjust next steps to develop the next plan (Langley et al, 2009).

PDSA worksheets are available on the website of Institute for Healthcare Improvement (http://www.ihi.org/resources/pages/tools/plandostudyactworksheet.aspx).

To start, a practice should identify an improvement team. Suggested members include clinical leadership, senior institutional leadership (project sponsor), a family member or patient representative and a data manager. Members may vary based on the specific areas planned to improve care. It is important to have buy-in from senior leadership who can provide needed resources and support plans for implementation of successful improvements.

The team develops a communication plan to determine how often they will meet. In the beginning, the team meets to identify a general goal and the aim or aims (the **Specific Measureable Achievable Realistic Timely**, or **SMART**, for the work) and to draft measures to monitor progress.

Teams can develop a **key driver diagram** (KDD) to guide the work. The KDD presents the aims and how they may connect with primary drivers and secondary drivers or interventions. (See figure 2.) The KDD is a "living document" that will evolve as the QI project moves forward.

Primary drivers are elements likely to influence aim achievement. Secondary drivers are more specific interventions that will likely affect the primary drivers.

The practice team works together and may bring in other members such as office staff or key stakeholders to identify drivers and interventions. Ideally, these interventions are evidence-based. However, in the case in autism, it's common for interventions to be based on expert consensus, due to limited research-based evidence for some treatments. The team tests interventions frequently and in stepwise fashion using PDSA cycles. Interventions that result in improvements are implemented and/or more widely disseminated through the practice, institution or network.

Figure 2: Key driver diagram template
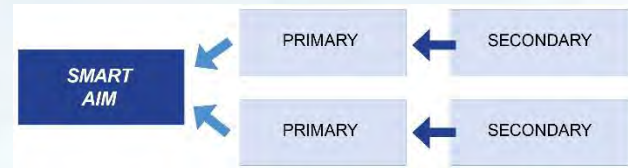
Resources for building a QI Project:
- For more information about the Model for Improvement, go to the following Institute for Healthcare Improvement (IHI) webpagehttp://www.ihi.org/resources/Pages/HowtoImprove/default.aspx
- To access an online key driver diagram template with more detailed information, go to: http://www.cdc.gov/std/foa/aapps/driver-diagram-template.pdf
- IHI also has many on-line quality improvement courses that can be accessed here: http://www.ihi.org/education/ihiopenschool/overview/Pages/default.aspx
- American Academy of Pediatrics has resources to provide support for participation in QI activities, and providers may obtain credit for Part 4 MOC (Maintenance of Certification) activities. https://www.aap.org/en-us/continuing-medical-education/moc/Pages/default.aspx)

ACTIVITY	DESCRIPTION

AAP based resources to support QI activities	**Council on Quality improvement and Patient Safety (_aap.org/ en-us/about-the-aap/Committees-Councils-Sections/coqips/ Pages/default.aspx_)**
	
	• COQIPS is focused on innovations and activities supporting the integration of policy and practice, education, advocacy and implementation around the topic areas of quality improvement and patient safety.
	
	• Training
	  - _NCE full day_
	  - _MOC Part 4 focused on health literacy_
	  - _Other educational activities_
	
	QI projects
	• Quality Improvement Innovation Networks (QuIIN)
	• Chapter Quality Network (CQN)
	• Section/council/program led QI
	• Web-based QI: Education in Quality Improvement for Pediatric Practice (EQIPP)
	
	AAP MOC Portfolio program (_aap.org/en-us/continuing-medical-education/mocportfolio/Pages/home.aspx_)
	Manager, QI and Certification (Jill Healy, MS jhealy@aap.org; ABP Kristi Gilreath, Amy Hodak, moc@abpeds.org)
	
	• Participate in existing AAP MOC Activity or program
	  - _Has had portfolio sponsorship status since 2012 (aap.org/en-us/ continuing-medical-education/mocportfolio/Pages/overview.aspx)_
	  - _listing of AAP QI activities (aap.org/en-us/professional-resources/ quality-improvement/Pages/ActivityList.aspx)_

Maintenance of Certification (MOC) requirements for pediatricians, including 4 parts. _- Parts 2 & 4 total of 100 points every 5 year cycle_	**PART 1:** _Professional standing – maintain a valid, unrestricted medical license_ **PART 2:** _Lifelong learning – assessment of individual knowledge (see ABP website)_ **PART 3:** _Cognitive expertise – secure board certification examination (every 10 years)_ **PART 4:** _Performance in practice – participate in approved QI projects designed to assess and improve quality of patient care_
Options for Part 4 MOC: QI	**Collaborative QI project created by another organization or agency** **Recognition for NCQA PCMH (engagement in their facility's effort in obtaining patient centered medical home recognition from NCQA)** • QI program development: groups or hospital based (apply for ABP certification of MOC)

References:

Committee on Quality of Health Care in America Institute of Medicine. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, D.C.: The National Academies Press.

Langley GL, Nolan KM, Nolan TW, Norman CL, Provost LP. (2009). *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance (2nd Edition)*, 23-25, San Francisco, California, USA: Jossey-Bass Publishers.

Lemer, C., Cheung, C. R., & Klaber, R. E. (2013). An introduction to quality improvement in pediatrics and child health. *Arch Dis Child Educ Pract Ed, 98*(5), 175-180. doi:10.1136/archdischild-2013-304325

Miles, P. V., & Moyer, V. A. (2013). Quality improvement and maintenance of certification. *Acad Pediatr, 13*(6 Suppl), S14-15. doi:10.1016/j.acap.2013.08.001

Abbreviations

- AAP – American Academy of Pediatrics
- KDD – Key Driver Diagram
- MOC – maintenance of certification
- NCQA – National Center for Quality Improvement
- PCM – patient centered medical home
- PDSA – Plan, Do, Study, Act
- QI - Quality Improvement

Vignette

- A 10-person medical staff in developmental and behavioral pediatrics outpatient program cares for patients with various developmental disabilities.
- At a monthly staff meeting, one of the clinicians notes that during the course of care, parents of children with ASD frequently report sleep problems, and the clinicians are not sure how to manage this problem. Upon discussion, the clinicians talk about uncertainty regarding the frequency of this problem and if it merits developing resources to track and address. The group decides that this might be a good question for clinical QI project.
- A member of the group has had experience working on a QI project and has suggestions about the next steps.
    - They check the AAP website's QI portfolio to see if a similar program exists.
        - https://www.aap.org/en-us/continuing-medical-education/mocportfolio/Pages/overview.aspx
        - They click on the last column of the activity list ("status") to see which AAP quality improvement activities are open. They review the list, and none seem appropriate.
    - They contact the hospital of their clinical division, in the department of pediatrics, the QI section to ask about approved projects in the hospital's portfolio. They are directed to a link on the Medical Staff Affairs website labeled "ABP Maintenance of Certification" and then click on CHOP-Approved MOC projects. In the listing, they find "Improving the approach to evaluation, diagnosis and follow-up care in children with autism spectrum disorder." This looks like it might be an appropriate "home" for this project.
        - If there was not an appropriate project, another option would be to look at National Collaboratives and Projects
    - Upon contacting the administrator for the Department of Pediatrics QI portfolio, the DBP explains their question and asks if the sleep issue would be appropriate for inclusion in that project. The administrator agrees and directs the DBP to the appropriate resources to apply for involvement.

- **Application for approval of a QI project**. Each organization or hospital has a different process to follow, but in general projects will need to include the following components:
  - Physician team leader
    - At our hospital, the physician leader is strongly encouraged to completed online training in the IHI Open School (especially QI 102, 1I 103, QI 105)
    - http://www.ihi.org/education/ihiopenschool/Pages/default.aspx
  - Aim statement
  - Outcome and process measures
  - Explanation of relevance of project to physician practice
  - Criteria for active, meaningful physician participation
  - Documentation of relationships of the project to IOM Dimensions of quality
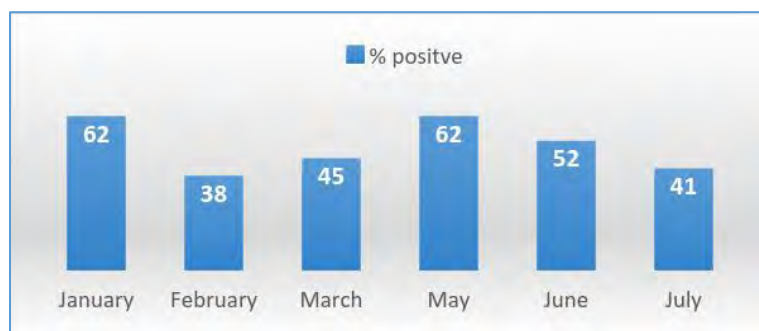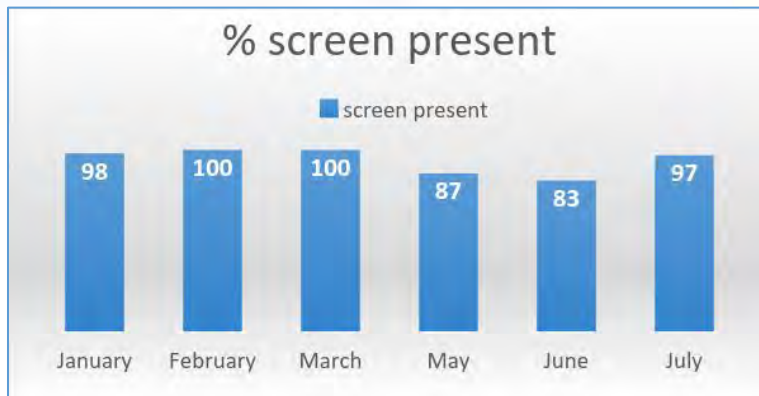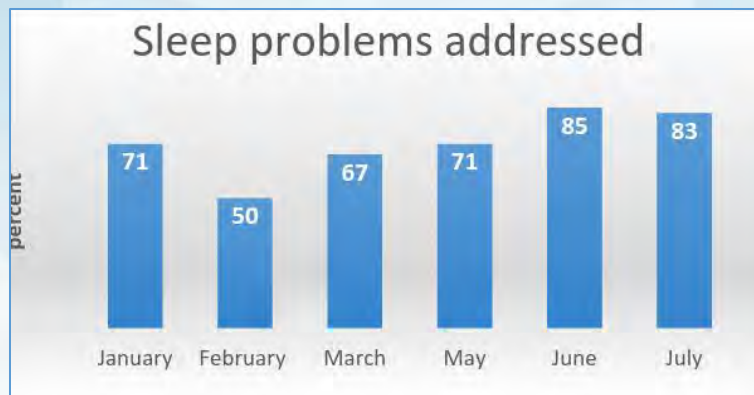
Sample project
- Team leader: Dr. X Jones
- Aim statement
  - What is in need of improvement and why?
    - Children with autism spectrum disorder (ASD), a common neurodevelopmental disorder (affecting over 1 percent of children) have deficits in core symptoms (social-communication and behavior). They frequently have co-occurring/comorbid medical and behavioral disorders or difficulties. Sleep disruption is a common comorbid condition, affecting more than 60 percent of children with ASD, with significant negative impact on health, well-being and behavior. Causes of sleep disruption are physiological or medical disorders (e.g., OSA) and behavioral and/or disordered sleep habits.
    - At present in our DBP clinic, we do not have baseline data demonstrating the magnitude of the problem in our population. Without a description of baseline levels of insomnia, we cannot effectively counsel parents and develop resources to guide treatment.
    - This project will also facilitate a standardized approach to screening for sleep problems.
  - Aims
    - To improve provider detection, diagnosis and treatment of sleep disorders and disruptions through standardized screening.
    - Goal
- By the end of the project all clinicians will screen for sleep disorders and evaluate medical contributors.
- When identified at least 80 percent of providers will indicate treatment and recommendations.
-
- **IOM quality dimensions** (check which apply)
  - ✓ Safety – Patients should not be harmed by the care.
  - ✓ Effectiveness – Care should be based on scientific knowledge.
  - ✓ Patient-centered – Care should be respectful of individual patient preferences.
  - ✓ Timely – Waits and harmful delays in care should be reduced.
  - ✓ Efficient – Care should be given without wasting equipment, supplies, ideas or energy.
  - ✓ Equitable – Care should not vary in quality because of patient characteristics.

- What are the measures for the project?
  - Outcome measures (results of carrying out an action)

- Chart review – when review of systems is positive for sleep disruption, there is an appropriate medical investigation for cause of insomnia and a plan for monitoring or treatment present in the note.
  - Process measures (reliability of carrying out an action)
    - Chart review of frequency of documentation of sleep disruption
  - Balancing measures (how will you demonstrate that the change has not resulted in unintended negative consequences)
    - Monitor for visits too long and other important issues not addressed
- Will project meet all of the following ABP requirements for active meaningful participation for physicians?
  - Physicians will provide direct or consultative care to patients as part of the QI project.
  - Physicians will implement the project's interventions (the changes designed to improve care).
  - Physicians will collect, submit and/or review data in keeping with the project's measurement plan.
  - Each physician will collaborate actively by attending at least four project meetings/discussions.

DATA

Sleep problems addressed

Below is an example of the ATN improvement project on medication monitoring.

Team leader(s): Clinical lead at each ATN site

Aim statement

What is in need of improvement and why?

Many children with ASD are prescribed atypical antipsychotic medication but often are not monitored for side effects.

Our aim in this project was for all providers at each ATN site to monitor atypical antipsychotic medication side effects in 95 percent of children with ASD on antipsychotic medication seen at their centers, effective July 1, 2014.

Operational definition of APM Monitoring: blood pressure, BMI, abnormal voluntary movement assessment, glucose screen

IOM quality dimensions (check which apply)
- ✓ Safety – Patients should not be harmed by care.
- ✓ Effectiveness – Care should be based on scientific knowledge.
- ✓ Patient-centered – Care should be respectful of individual patient preferences.
- ✓ Timely – Waits and harmful delays in care should be reduced.
- ✓ Efficient – Care should be given without wasting equipment, supplies, ideas or energy
- ✓ Equitable – Care should not vary in quality because of patient characteristics

- What are the measures for the project?
  - o Number of records reviewed where blood pressure and BMI are documented at last visit/ number records reviewed where child is currently on APM
  - o Number of records reviewed where abnormal voluntary movement assessment is documented at last visit / number records reviewed where child is currently on APM
  - o Number of records reviewed where glucose screen was ordered or discussed within the past year/number records reviewed where child is currently on APM

- **Clarifications on Aim 1 Measures**:
  - o Documentation in the record stating that one or more aspects of monitoring was discussed but not completed counts as documented (and can be entered as a "1" on the data collection tool). For example, BMI is not documented but the record notes that a provider attempted unsuccessfully to measure height and weight..
  - o The Abnormal Voluntary Movement Scale (AIMS) is not required. Providers can use clinical judgment to determine best way to assess this.
  - o Monitor for visits too long and other important issues not addressed

Figure 2 summarizes one site's measures and interventions (highlighted in yellow). Interventions (or PDSAs) for this work included sharing this site's data in comparison to others, education of providers and signs on computer monitors and reminders ("you rock" statements to acknowledge providers who were monitoring).
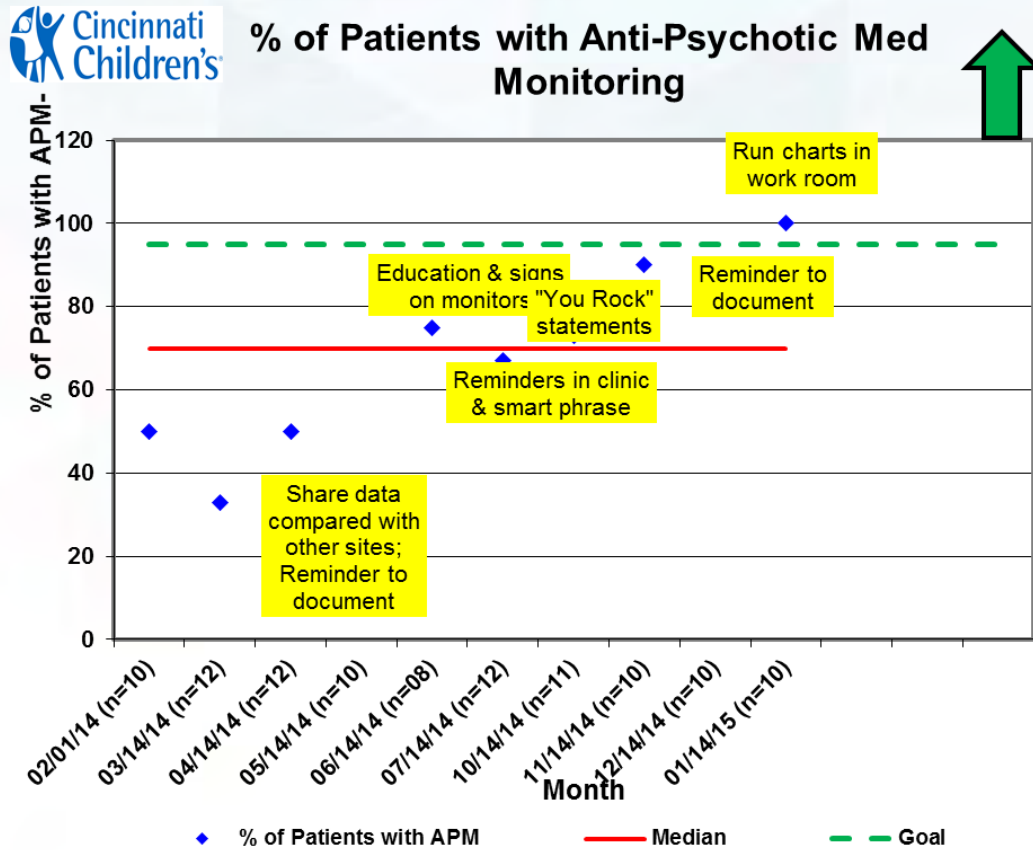
CHAPTER 7
Training, Outreach and Dissemination

Introduction

Autism Treatment Network (ATN) Centers must have well-developed programs and processes that support training, outreach, and dissemination. Part of what makes this network unique is the access to cutting-edge interventions, research, and innovative, best-practice care. The ATN is a beacon of knowledge, poised to lead the way by providing opportunities for training and outreach, in addition to disseminating evidence-based resources to families and professionals and the larger community. As we advocate for increased integration for people with ASD, it is important that the wider community be educated in order to increase their understanding of ASD. With knowledge and understanding comes greater acceptance, involvement, and improved quality of life for all.

Importance

Autism is a complex neurodevelopmental disorder that requires families, and those who work with individuals with autism, to be knowledgeable and have access to helpful resources. Parents of children with ASD are at a higher risk of experiencing stress, anxiety and depression compared to parents of children with other developmental disorders and typically developing children [1,2]. In addition to this, there is a significant lack of adequately trained providers to serve individuals with ASD and often times, they feel ill equipped to care for this population[3]. Expanding knowledge, supports, and resources will enable patients and families to become **informed** and **activated** and professionals to be **prepared** and **proactive**.

Who?

"Whole Care for the Whole Family" The ATN recognizes that individuals are not the only ones affected by autism; the entire family requires support from multiple community providers. Therefore, each center must build capacity, by sharing expert knowledge and resources, to create a supportive, integrative community.

The ATN focuses primarily on building capacity of healthcare providers- specifically physicians, in the care of treatment of persons with ASD. However, we recognize the need for training and support for a wide variety of community providers.

Below is a list of **community providers** you may want to reach:

- Healthcare Personnel (Hospitals, Emergency Room Departments, Doctor's offices, Dentists, Allied Health professionals, Therapy Centers, etc.)
- Educators/Schools
- School Bus Drivers
- Camp Personnel
- Community Centers & Clubs
- Churches/Synagogues/ Mosques/ etc.
- Public Transportation Personnel
- Day Care Providers
- First Responders (i.e., Police, Firefighters, Emergency Medical Technicians, etc.)
- Airport Personnel
- Local Businesses

Part of caring for individuals with ASD is **providing families with education, support, and resources** to help them understand how to best support the

individual they care for. It is important to tailor information to meet a variety of needs, across the entire spectrum of autism.

Groups you may want to reach include:

- Parent Groups
- Foster Families
- Grandparents
- Friends
- Extended Family Members
- Siblings of children with autism

When?

Offering a variety of times and dates for all training and research activities is suggested. It may be helpful to poll when the most convenient time for the majority of your audience is.

What?

Information presented in training and outreach activities or in the resources you disseminate should meet the following guidelines:

- Based upon evidence-based practices
- Patient and Family Centered
- Meet a variety of educational levels
- Culturally sensitive
- Presented in a variety of ways to foster understanding (i.e., written, audio, visual)
- Cover a wide range of topics & learning levels for professionals and families (i.e., beginner, intermediate, advanced)
- Professional Trainings - Offer CMEs or certificates of attendance if appropriate
- Promote awareness and acceptance
- Provide evidence-based tools and strategies that meet the needs of individuals across the spectrum
- Promote self-efficacy and build necessary skills for both families and professionals
- Content should allow families and professionals to build on their current strengths and prior knowledge

Examples of resources for training, outreach opportunities:

ATN/AIR-P Tool Kits, Tool Kit Designed for PCPs

Algorithms (Diagnosis, ATN/AIR-P Sleep Difficulties, ATN/AIR-P Constipation)

 ATN / AIR-P Publications in medical journal *Pediatrics* (2012 Supplement, 2016 Supplement)

Autism Speaks Website and Autism Speaks Canada Website

Connect families with local information, resources and opportunities: Autism Speaks Autism Response Team - 888-AUTISM 2 (288-4762) En Espanol: 888-772-9050, familyservices@autismspeaks.org

For video resources check out ASD Video Glossary

Centers for Disease Control and Prevention (CDC) - Learn the Signs Act Early Resources

Ohio Center for Autism Low Incidence (OCALI)

ECHO Autism

Available services within your community

For additional information, you may contact the Autism Speaks Autism Treatment Network at atn@autismspeaks.org or locate an ATN Center near you by clicking here,

Where?

Several methods can be used to support training and outreach activities. In-person sessions or web-based sessions are both effective ways to educate any target audience. Utilizing both options will allow a center to reach across the community, beyond the front doors.

Examples of successful options for Training and Outreach Activities:

In-person Activities*:

Conferences

Workshops

Lunch & Learns

Symposiums

Parent Support/Education Groups

Web-based Activities

Virtual Trainings (e.g., ECHO Autism)

Online Modules (OCALI, Thompson Center)

Webinars

[*]In-person activities can be done in a variety of settings (hospitals, community centers, community partner organizations); choose settings that are easily accessible to families (e.g., near public transportation).

Paper and electronic versions of all resources are necessary for effective dissemination. It is highly encouraged that you consider developing video versions, when appropriate.

How?

There is no master plan on how to be successful in sharing knowledge and resources, due to the uniqueness of centers and communities. Below are helpful tips to help guide you in building a sustainable, effective program.

- It is crucial that information is based upon evidence-based practices and presented in multiple ways to ensure understanding and application.
- If you do not have a current Patient and Family Advisory Council, it is highly recommended that you establish one, as families are key partners in developing successful programs.
- Collaborate with your local Patient and Family Advisory Council (PFAC) to develop content for trainings, as they have first-hand knowledge about what is needed and where the gaps are in services. Families also have valuable cultural/ethnic connections that will help to expand and diversify the reach of your dissemination of resources, and marketing of events. When creating resources, pare down text and increase bullet points or visuals.
- Consider translation of presentations and resources. This is essential for critical information that addresses the signs and symptoms of ASD, what do families do while on the waitlist for a diagnosis, next steps, after a diagnosis of ASD, and managing comorbidities.
- Create an email list of parents who would like to receive updated information on workshops, new research studies, new

research findings, new programs, camps, resources, etc.

- Work with your Family Navigator to ensure families have the opportunity to sign up for the email list.
- Collaborate with your local university's Leadership Education in Neurodevelopmental and Related Disorders (LEND) or University Centers for Excellence in Developmental Disabilities Education (UCEDD) programs.
- Create relationships with other service organizations within your community; offer to collaborate in training and share resources.
- Engage the Primary Care Providers (PCPs) in your community: Establish strong relationships with the PCPs in your area who care for your patients. Frequent training and other activities are recommended. Additionally, provide them with up-to-date resources and information about your center to give to families.
- Develop partnerships with your local school districts/school boards.
- Providing incentives (i.e., food, drinks, free materials, child care, monetary, etc.) will increase attendance during outreach and training activities.
- Make partnerships with other Healthcare Systems within your state. Collaborate for training and outreach activities and share resources.
- Distribute the appropriate version of the "First 100 Days"/"Manual de los Dias" Autism Speaks Tool Kit or create a document that will outline community services "First Steps After a Diagnosis of ASD" for families.
- *Distribute to local PCP offices for the families they serve.
- Conferences are premier venues to disseminate resources

Vignette

University of Missouri Thompson Center, Columbia, Missouri

Approximately 63% of the patient population at the University of Missouri Thompson Center live in rural communities. To address the barriers of distance and scarcity of resources, the Central Missouri ATN team created "Tool Kit Talk Workshops." They collaborated with Healthcare Systems and/or Universities across the state to host the workshop series and took tool kit information, developed by the ATN/AIR-P, to underserved areas. Workshops addressed some of the common medical comorbidities of children with ASD. The content was put into a PowerPoint format and taught by Thompson Center experts.

The team had great expectations for the workshop series, but they were surprised by the high level of networking opportunities that occurred during the workshops. *"Though our primary target audience was families, we welcomed professionals to attend. We designed workshops to be informal, so that people felt comfortable asking questions or clarification. What we didn't expect was the rich experiences that parents, teachers, and healthcare professionals shared, which enhance the answers we provided to questions asked. It added so much meaning and depth to the conversation. Many connected after sessions to talk more. As a parent of a child with autism, myself, I know first-hand how vital these connections are during the journey of raising a kiddo on the spectrum."* said **Alicia Curran, Director of Tool Kit Talk Workshops in Missouri**.

Holland Bloorview Kids Rehabilitation Hospital, Bloorview Research Institute, Toronto, Canada

There are 10,000 students with special needs, who are transported to and from school each day in the Greater Toronto Area. Many children can spend as much as 2 hours a day on a school bus. This is particularly common for children traveling out of their neighborhoods for special-education classes. Many of these bus drivers receive no training in ASD, and therefore do not understand the behaviors, sensory issues and communication needs that are so common among these children. Many hours are spent dealing with the daily issues that arise on the school bus, and we have long recognized the need for training in this area. In Toronto, we have begun to address this need. Initiated and organized by one of our ATN Family Advisory Council (FAC) co-chairs, the ATN team created a training module for school bus drivers, and delivered the training to 150 drivers at one of the larger school bus companies. The response to this training was overwhelmingly positive: "You have just described every kid on my bus! How did you know?", "Now I understand why he gets so upset when I change the route!", "Now I understand why she is so much calmer when I let her play with the strap of her schoolbag.", "I want all of my parents to fill out the "All About Me on the Bus" form so I can do my best to help their kids!"

Following the success of the training, an ATN@work blog was published ASD and the School Bus. This resulted in increased awareness of this need, as well as requests for more training from school boards and bus companies in the GTA and beyond.

Training, Outreach and Dissemination Chapter Summary

Autism is a complex neurodevelopmental disorder that requires families, and those who work with individuals with autism, to be knowledgeable and have access to helpful resources. Parents of children with ASD are at a higher risk to experience stress, anxiety and depression compared to parents of children with other developmental disorders and typically developing children 1,2. Expanding knowledge, supports, and resources will enable patients and families to become informed and activated and professionals to be prepared and proactive.

 Care for the Whole Family

Individuals with autism are not the only ones affected by autism; the entire family requires support from multiple community providers. Therefore, it is important that primary care providers are aware of the increased needs of families and are equipped to provide resources to support them.

Part of caring for individuals with ASD is providing families with education, support and resources to help them understand how to best support the individual they care for. It is important to tailor information to meet a variety of needs, across the entire spectrum of autism.

 Providing Support, Education and Resources in a Busy Practice

To meet the needs of families, having access to a wide variety of resources is essential. For example, in person or web-based training and outreach activities or having access to both paper and electronic and video versions of resources will be helpful. As a Primary Care Provider (PCP), you are on the front lines with families and they will often look to you or your staff for resources.

Families will often go to the internet for resources and this can be overwhelming. Consider creating a one page "First Steps after an ASD Diagnosis" document, so that families receiving a diagnosis are clear on what they should do next.

 It is important that families understand the information they access. Talking to families about what they are learning and coaching families about the importance of best-practice and evidence based, peer reviewed research is crucial to ensure they are not misguided.

Below are some examples of training, outreach opportunities and easily accessible resources/supports to consider for you, your staff and families.

> *ATN/AIR-P Tool Kits, Tool Kit Designed for PCPs*
> *Algorithms (Diagnosis, ATN/AIR-P Sleep Difficulties, ATN/AIR-P Constipation)*
> *ATN / AIR-P Publications in medical journal Pediatrics (2012 Supplement, 2016 Supplement)*
> *Autism Speaks Website and Autism Speaks Canada Website*
> *Autism Speaks Autism Response Team - 888-AUTISM 2 (288-4762) En Espanol: 888-772-9050,*
>   *familyservices@autismspeaks.org*
> *Centers for Disease Control and Prevention (CDC) - Learn the Signs Act Early Resources*
> *Ohio Center for Autism Low Incidence (OCALI)*
> *ECHO Autism*
> *Autism Navigator (Video and written material-families and professionals) ASD Video Glossary*
> *Available services within your community (includes local Autism Speaks Chapters and Support Groups)*
> *For additional information, you may contact the Autism Speaks Autism Treatment Network at*
>   *atn@autismspeaks.org or locate an ATN Center near you by clicking here.*