

The Autism Treatment Network
And
The Autism Intervention Research -
Physical Health Network

LEND Webinar
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Goals for this Presentation

- Describe the current recommendations for evaluating children with suspected ASD
- Outline the Structural and Functional Organization of the Autism Treatment Network
- Discuss Core ATN Activities
- Provide an Overview of AIR-P Activities
- Outline Future Directions for ATN and AIR-P with LEND





Hope you didn't miss this

CLINICAL REPORT

Identification and Evaluation of Children With Autism Spectrum Disorders



Chris Plauché Johnson, MD, MEd, Scott M. Myers, MD, and the Council on Children With Disabilities

Pediatrics. 2007 Nov;120(5):1183-215

A more thorough analysis:

NEUROLOGY

Practice parameter: Screening and diagnosis of autism: Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society

P. A. Filipek, P. J. Accardo, S. Ashwal, G. T. Baranek, E. H. Cook, Jr., G. Dawson, B. Gordon, J. S. Gravel, C. P. Johnson, R. J. Kallen, S. E. Levy, N. J. Minshew, S. Ozonoff, B. M. Prizant, I. Rapin, S. J. Rogers, W. L. Stone, S. W. Teplin, R. F. Tuchman and F. R. Volkmar
Neurology 2000;55:468-479

- Over 4,000 articles reviewed
- Strength of evidence ranked using defined criteria
- Recommendations then stratified as Standard (good evidence), Guideline (some evidence), or Practice Option (little or no evidence but some consider this to be appropriate)
- Only 2 of 13 Recommendations rated Standard, remainder rated as Guidelines



However,

- There continues to be significant variation in how these practice parameters are carried out, and whether there is research examining those parts considered Practice Options, or if there is research examining additional items that might advance our understanding and management of children with ASD.
- These parameters are mostly consensus based, and not evidence based because *there is very little evidence*





The Autism Treatment Network (ATN): Improving Medical Care

MISSION

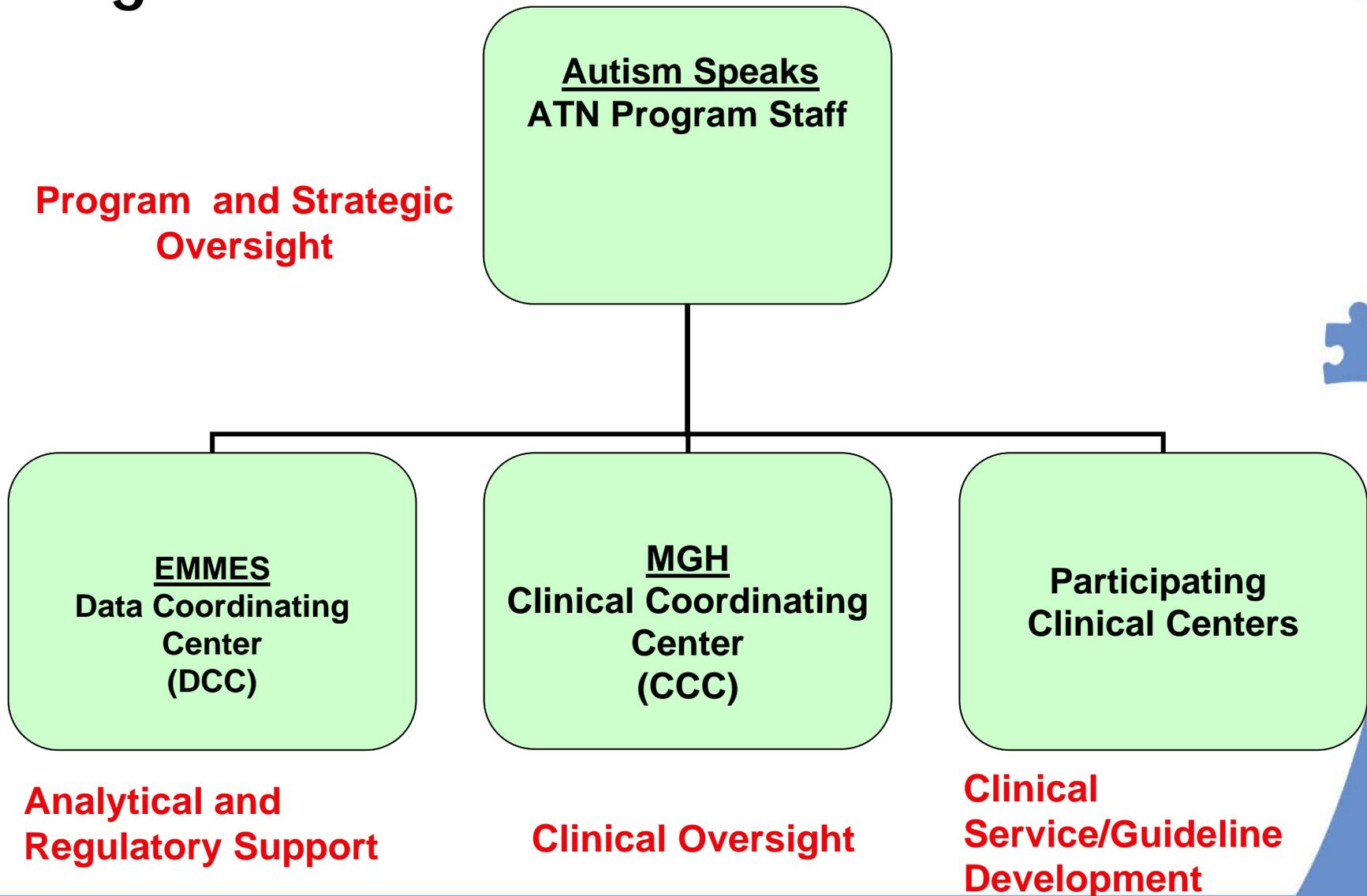
- Create a dynamic network of hospitals and physicians dedicated to **improving medical care and the overall physical health** of children with autism.

GOALS

1. Provide access to comprehensive, multi-disciplinary medical care to families in their communities
2. Build a leadership and manpower base of medical and behavioral experts to provide more families the highest quality medical care
3. Develop evidence-based practice and treatment guidelines to improve medical care for families and to leverage insurance reimbursement for autism treatments



The Network: Institutional Organization





The Network Overview

Autism Speaks Program Core

- Provide overall strategic and managerial oversight of the program
 - Set the strategic vision
 - Ensure successful progress towards key milestones
 - Ensure the alignment of project-specific objectives with overall program objectives
 - Provide funding and resources; manage overall budget
 - Develop community, training, publicity and dissemination programs



The Network: Coordinating Centers

Clinical Coordinating Center (CCC):
Mass General Hospital for Children



- Provide clinical leadership
 - Lead the clinical sites in the development of evidence-based standards of care
 - Spearhead the on-going development of the patient registry and its analysis
 - Provide support and scientific leadership for the application and implementation of ATN-based research studies
 - Provide oversight of clinical activities





Data Coordinating Center: EMMES Corporation

- Provide statistical/analytical support
- Maintain patient registry database
- Provide oversight of data quality and integrity
- Maintain and track regulatory documents and advise on regulatory issues
- Advise on protocol development for core battery
- Provide support for ATN-based research project development and implementation





The Network: Treatment Sites

Led by Site Director (PI) and a Co-PI

1. Provide clinical care to families and collect a standard battery of assessments as part of standard of care
2. Committee Participation
 1. Subspecialists participate in designated committees: GI, Sleep, Neurology-Genetics-Metabolics, Behavioral Scientists, Lead Autism Specialists (Pediatricians/Psychiatrists)
 2. Site Director or representatives participates in Clinical Operations Committee
3. Enroll patients in the Patient Registry



Current ATN Sites

EAST

- Columbia University
- Kennedy Krieger Research Institute, Inc.
- LADDERS/Mass General Hospital for Children
- University of Pittsburgh, School of Medicine and University of Pittsburgh Medical Center (UPMC)
- University of Rochester

MID-WEST

- Cincinnati Children's Hospital Medical Center
- University of Missouri Thompson Center for Autism and Neurodevelopmental Disorders



SOUTH

- Baylor University Medical Center
- University of Arkansas for Medical Sciences (UAMS) and Children's Hospital (ACH)
- Vanderbilt University Medical Center

WEST

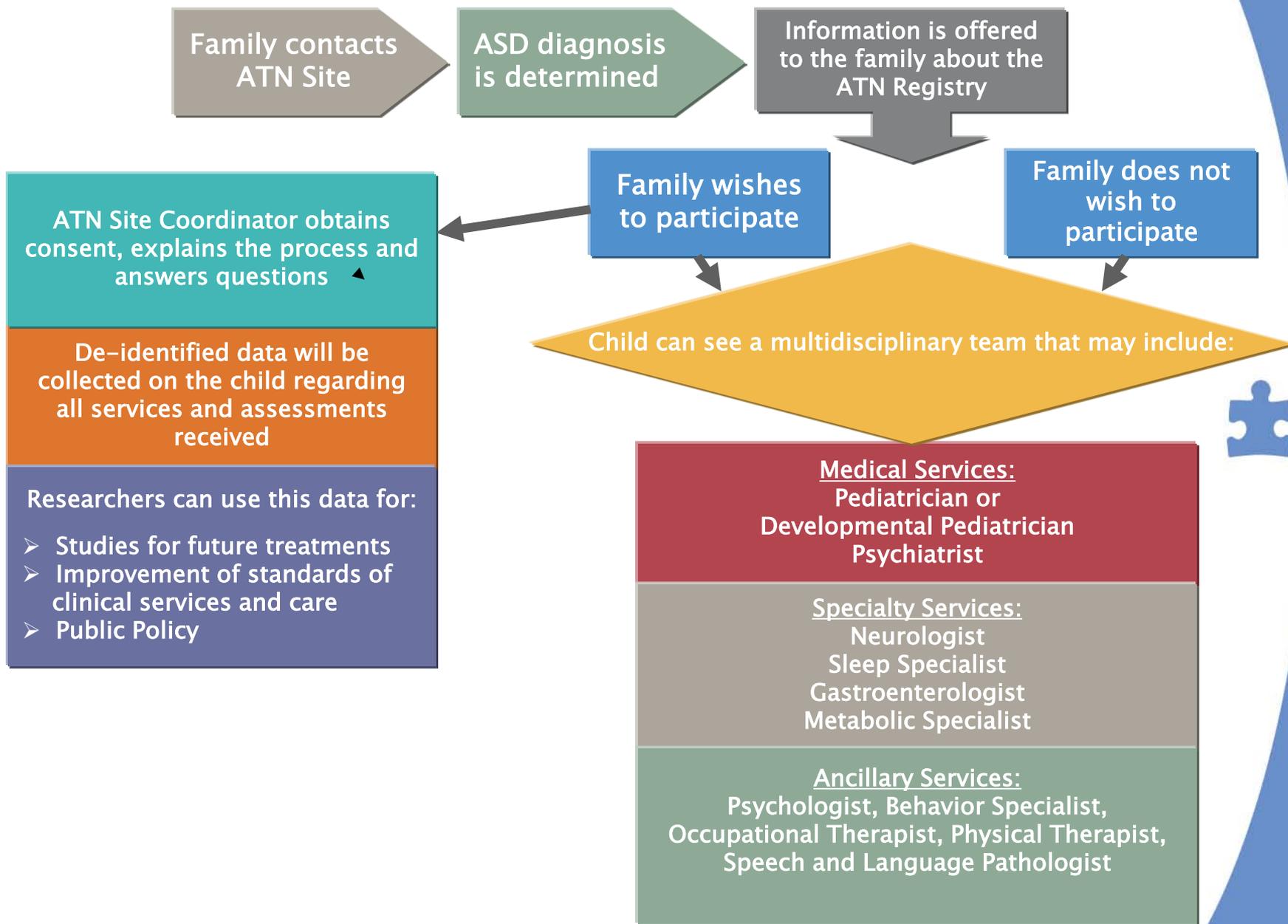
- Kaiser Permanente Medical Care Program Northern California/Kaiser Permanente Division of Research
- Oregon Health & Sciences University
- University of Colorado at Denver and Health Sciences Center

CANADA

- Hospital for Sick Children (SickKids), Bloorview Kids Rehab, Surrey Place Centre



How does ATN work?





Patient Registry

- Includes children 2-17
- De-identified data collected on clinical assessments required in the ATN battery
- Data collected on subsequent clinical visits including required annual follow up
- Track subspecialty referrals





The Autism Intervention Research-Physical Health Network (AIR-P)

- Funded by Combating Autism Act Initiative (CAAI) through the Health Resources and Services Administration (HRSA)
- Mission is to develop evidence based guidelines regarding diagnosis and management of children with ASD
- Mission is to conduct research regarding autism treatments
- Mission is to conduct community outreach to increase awareness of autism and the need for autism research





The National Initiative for Children's Healthcare Quality (NICHQ)

- NICHQ's mission is to improve children's healthcare by improving the systems responsible for the delivery of children's healthcare.
- NICHQ has extensive experience in developing evidence-based clinical guidelines, and
- Extensive experience in helping organizations implement these clinical guidelines





Current Activities of ATN and AIR-P

Clinical Guidelines are being developed for

- Assessment of diarrhea
- Assessment of constipation
- Assessment of sleep problems
- Assessment of possible food allergy
- Role of routine EEG
- Role of routine MRI
- Role of routine lead screening





Current Activities of ATN and AIR-P

Research protocols include:

- Three projects funded thru Autism Speaks research program
 - GI disorders in children with ASD
 - Improving sleep outcomes for children with ASD
 - Developing quality of life measures for children with ASD and their parents
- Two projects funded through the AIR-P research program
 - Management of sleep problems in ASD using non-pharmacologic methods
 - Review of diet and nutrition in children with ASD





Current Activities of ATN and AIR-P

Review of current enrolled subjects regarding

- Use of medical treatments/therapies
- Numbers of children and adolescents seen
- Numbers receiving comprehensive care, as indicated by....
- Numbers receiving medical attention, including subspecialty use
- Prevalence and type of medical conditions among children with ASD
- Relation of child characteristics with response to treatment
- Provide information about clinical consensus standards





Future Goals for ATN and AIR-P

- Demonstrate a feasible, comprehensive diagnostic approach to children with suspected ASD
- Demonstrate the benefits of a coordinated treatment plan in managing children with ASD
- Conduct additional research on the medical conditions accompanying ASD and best practices in managing these conditions
- Conduct additional research on treatment of ASD



Improving Medical Care: Intervention Research

ATN Goal	How the goal is reached
1. Provide access to comprehensive, multi-disciplinary medical care to families in their communities	<ul style="list-style-type: none">•Core ATN clinical activity
2. Build a leadership and manpower base of medical and behavioral experts to provide more families the highest quality medical care	<ul style="list-style-type: none">•Core ATN subspecialty committees•Program Initiatives: Community Physician Training, Mentoring Program, Medical Fellowship, Minority and Family Outreach▶ HRSA Research Project teams
3. Develop evidence-based practice and treatment guidelines to improve medical care for families and to leverage insurance reimbursement for autism treatments	<ul style="list-style-type: none">•Core ATN subspecialty committees▶ HRSA: NICHQ-Guided Guideline Development and Dissemination•Patient Registry•AS-funded ATN Research Projects: GI, Sleep and Quality of Life▶ HRSA Research Projects: Sleep and Nutrition▶ HRSA Research Initiatives (AIR-P Steering Committee)



- Questions -

