

Autism Treatment Network

Improving the quality of medical care for children with ASD



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A National Profile of the Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in the United States, 2005–2006

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Health care experience and family impact

Children with ASD, compared to other children with special health care needs:



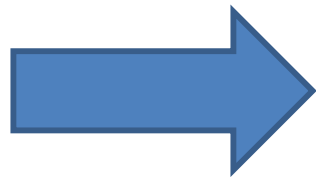
- Are more likely to have unmet needs for health care and family support services
- Have difficulty receiving coordinated care and appropriate referrals
- Families have more financial problems and large out-of-pocket expenses
- Parents more likely to reduce or stop work to care for child

Key Issues

- Individuals with ASD face many *barriers* in accessing adequate health care
- Many physicians have not received *training* in the assessment and treatment of health issues associated with ASD
- Tremendous variability in the *documentation* of health concerns of individuals with ASD
- Currently, there is no agreed upon standard of care of *clinical guidelines* for medical treatment of ASD

Treatment of medical conditions associated with ASD¹

- Sleep problems - 52-73%
- Seizures and epilepsy - 5-49%
- GI problems - 8-59%
- Food sensitivity - 30-90%
- Anxiety - 43-84%
- Depression - 2-30%



Significant impact on quality of life for Individuals with ASD and their families

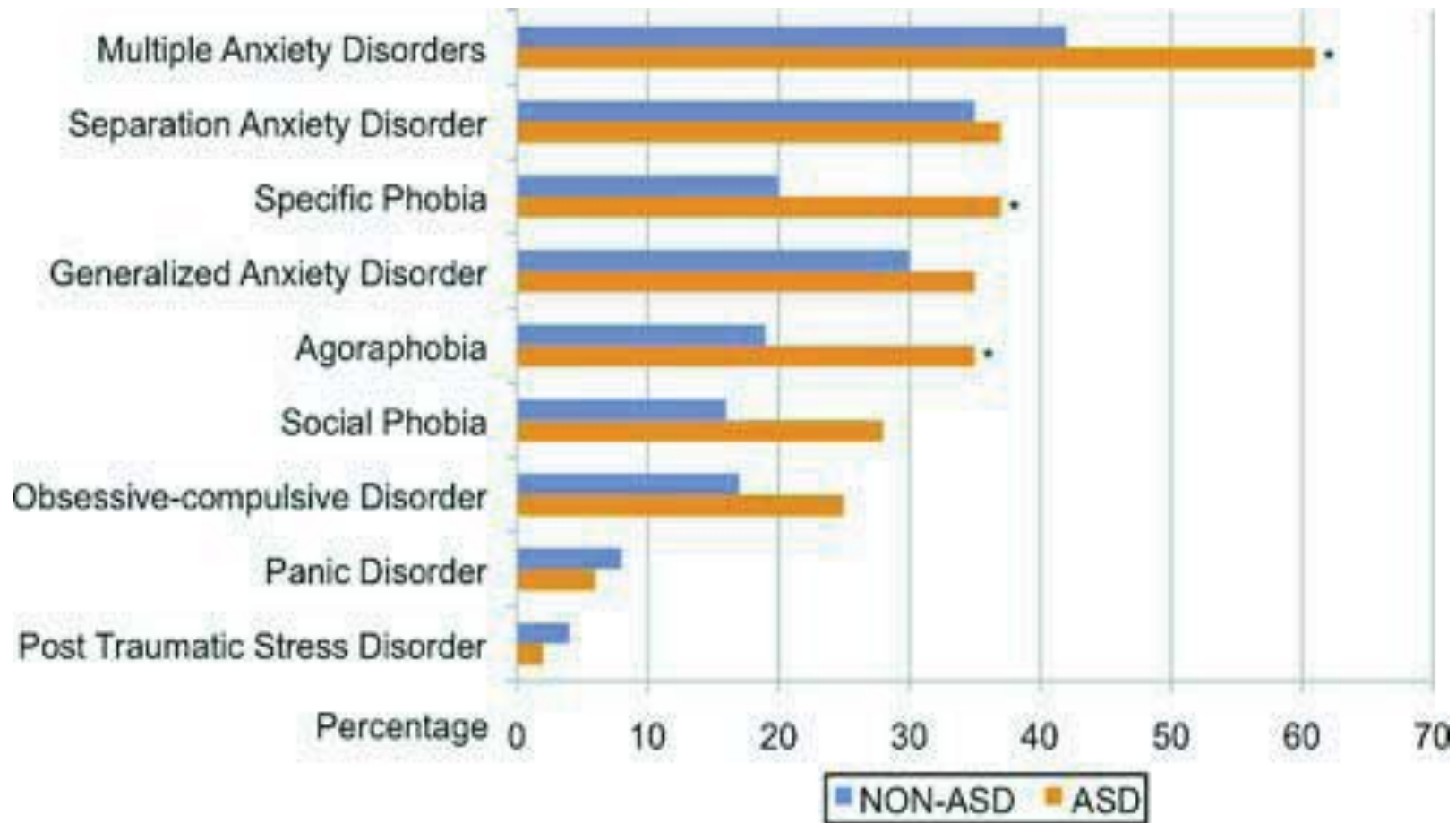
Many times go unrecognized and untreated

Can contribute to behavioral challenges and impair ability to fully benefit from educational interventions

¹ Levy, Mandell, and Schultz (2009) *Lancet*

Psychiatric Co-Morbidities

Joshi et al (2010) reported that 95% of youth in a psychiatrically referred sample with ASD (N=217) had 3 or more comorbid psychiatric disorders and 74% had 5 or more



Statistical Significance: * $p \leq 0.001$





The Vision

- Create the nation's first network of hospitals and clinicians dedicated to *improving medical care* for children and adolescents with autism
- Develop a *common protocol* for multidisciplinary assessment of children with autism
- Create a *patient registry* to characterize families and track outcomes
- Develop and disseminate *evidence-based treatment guidelines* for physicians and clinicians nationwide
- Create a platform for conducting clinical research, including *comparative effectiveness research*





Goals of the ATN

- **Quality:** Improve the quality of lives of children and adolescents with ASD now through improved medical care
- **Access:** Increase the availability of a comprehensive, coordinated, longitudinal care model for all children with ASD
- **Research:** Advance the evidence-base and research on medical issues in order to provide better care for children with ASD
- **Leadership:** Become the leading clinical and research network on medical issues related to ASD



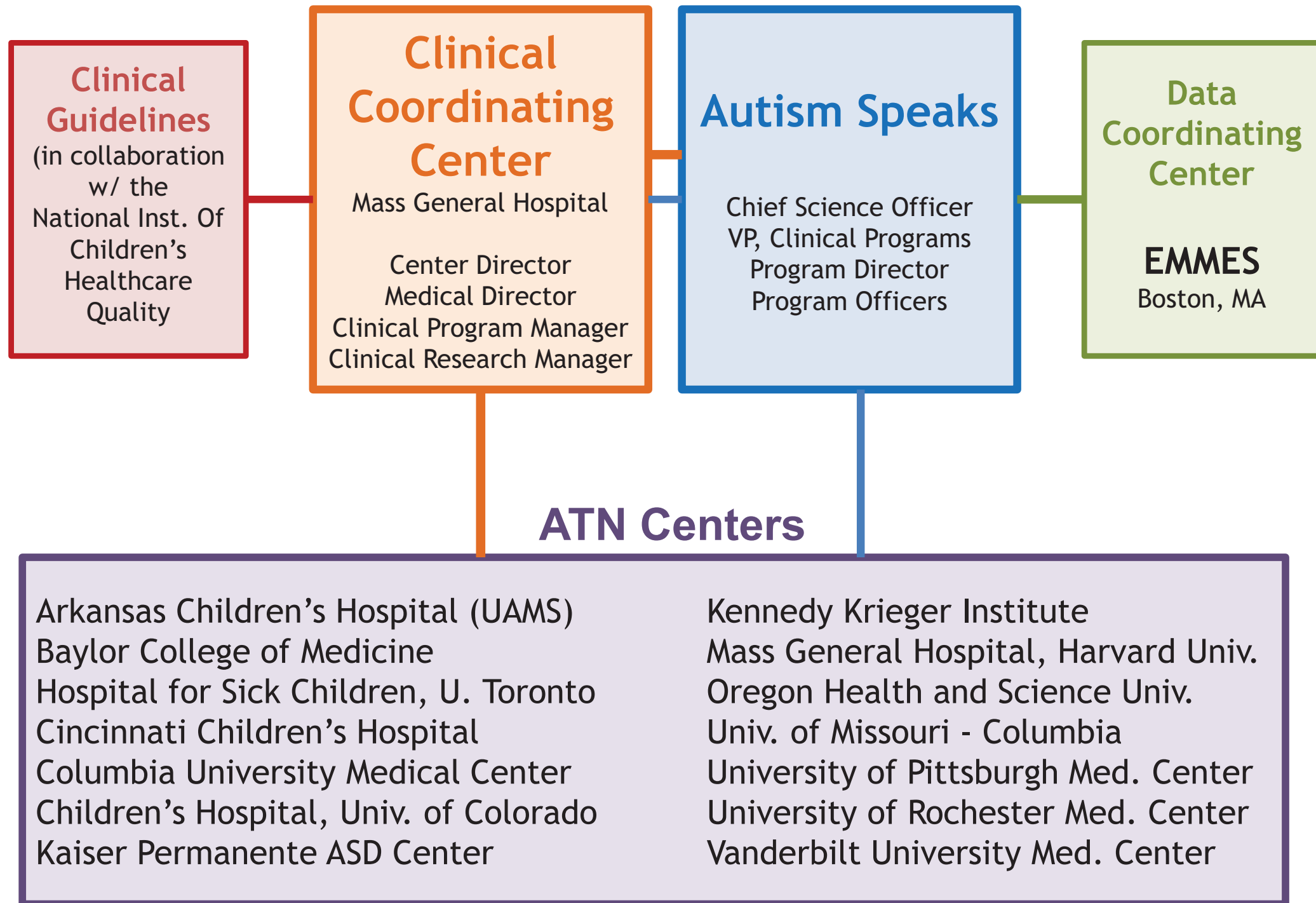
Current ATN Structure and Support

- 14 academic health centers across the US and Canada providing comprehensive medical care with research expertise
 - **126** Physicians/clinicians across **6** subspecialty groups
 - **2,174** Children enrolled in the patient registry
 - **3,000** children – projected enrollment by 12/31/2010
- Program Funding:
 - Autism Speaks: **\$3M/yr** for administration, clinical infrastructure, clinical care coordination, and patient registry
 - DHHS/HRSA/Maternal and Child Health: **\$4M/yr** for guideline development and protocol-driven research (Autism Intervention Research Network for Physical Health)*



*CAA due to sunset in 2011

ATN Organizational Structure







ATN Clinical Activities

- Providing **care to > 5000 children** with ASD
- Collaborating with HRSA-funded Leadership Education in Neurodevelopmental Disabilities (LEND) Programs to **provide education and training** to physicians throughout US and Canada
- Developed and piloting **three evidence-based guidelines** (Sleep Disturbance, GI, Neurological/EEG) to improve quality of care



ATN Patient Registry: Demographics



Number of Patients Enrolled:

2,174

Gender Ratio (M:F):

5:1

Ethnicity:

80% White, 20% Minority

Mean age of enrollment:

6.2 ± 3.6 years

Diagnosis (ADOS, DSM-IV)

67% - Autism

24% - PDD.NOS

9 % Asperger syndrome





ATN Research Activities:

Autism Intervention Research Network for Physical Health

- \$12 million grant over three years (*PI: Jim Perrin, MD, Director of the ATN Clinical Coordinating Center at the Mass General Hospital for Children*)
- Part of four initiatives developed by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) under the Combating Autism Act
- The goals of the AIR-P support guideline development, protocol-driven research, and education and training





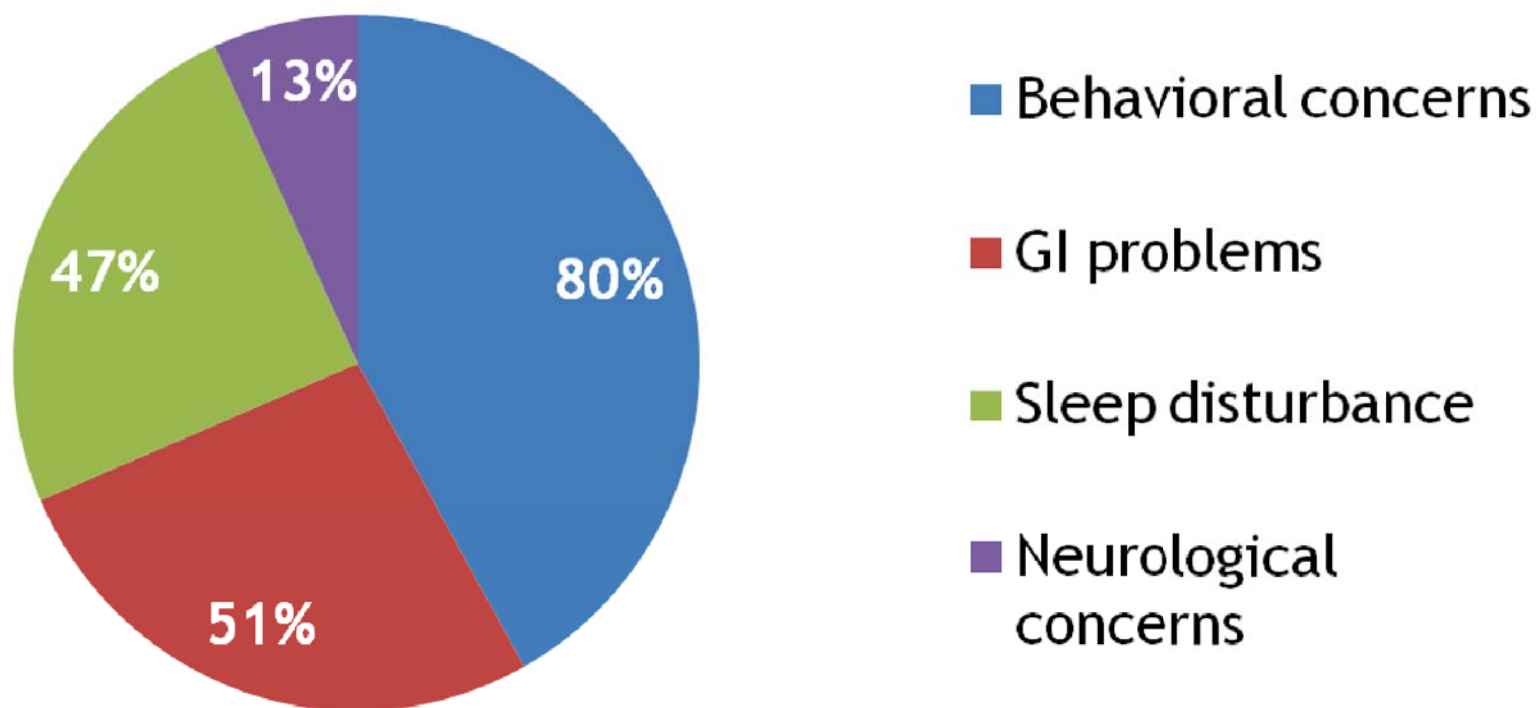
2008-2009 Research Activities

- Six AIR-P Research Projects funded by HRSA
 - Assessment of nutritional deficiencies
 - RCT of intervention to improve sleep
 - Assessment of bone density
 - Creatine deficiency in ASD
 - Iron deficiencies in children with ASD
 - Relationship between sleep disturbance and behavior
- ATN researchers received additional grants through NIH ARRA, Autism Speaks, and MCHB R40
- In conjunction with American Academy of Pediatrics, held summit to develop a research agenda for GI disorders in ASD



What are the most common presenting problems?

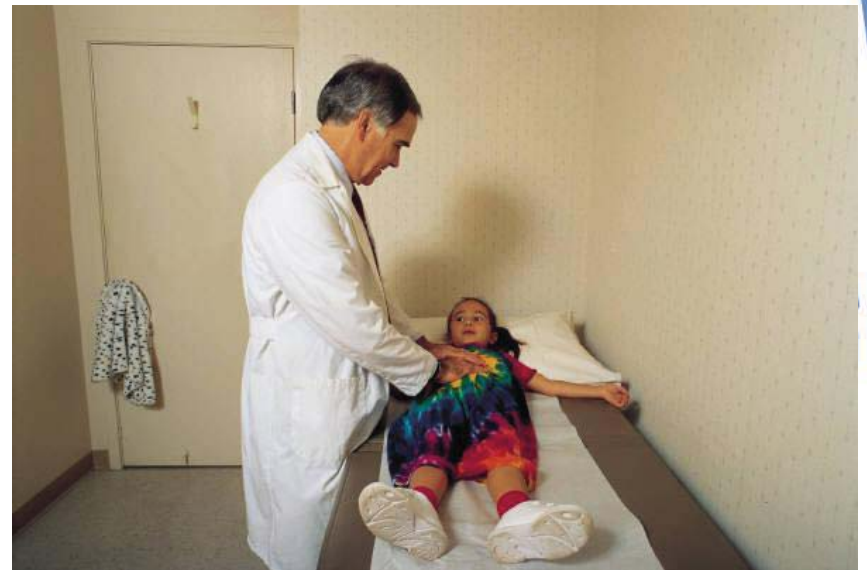
Presenting problems N = 2,174



Behavioral concerns: Language, Attention, Social behavior, Hyperactivity

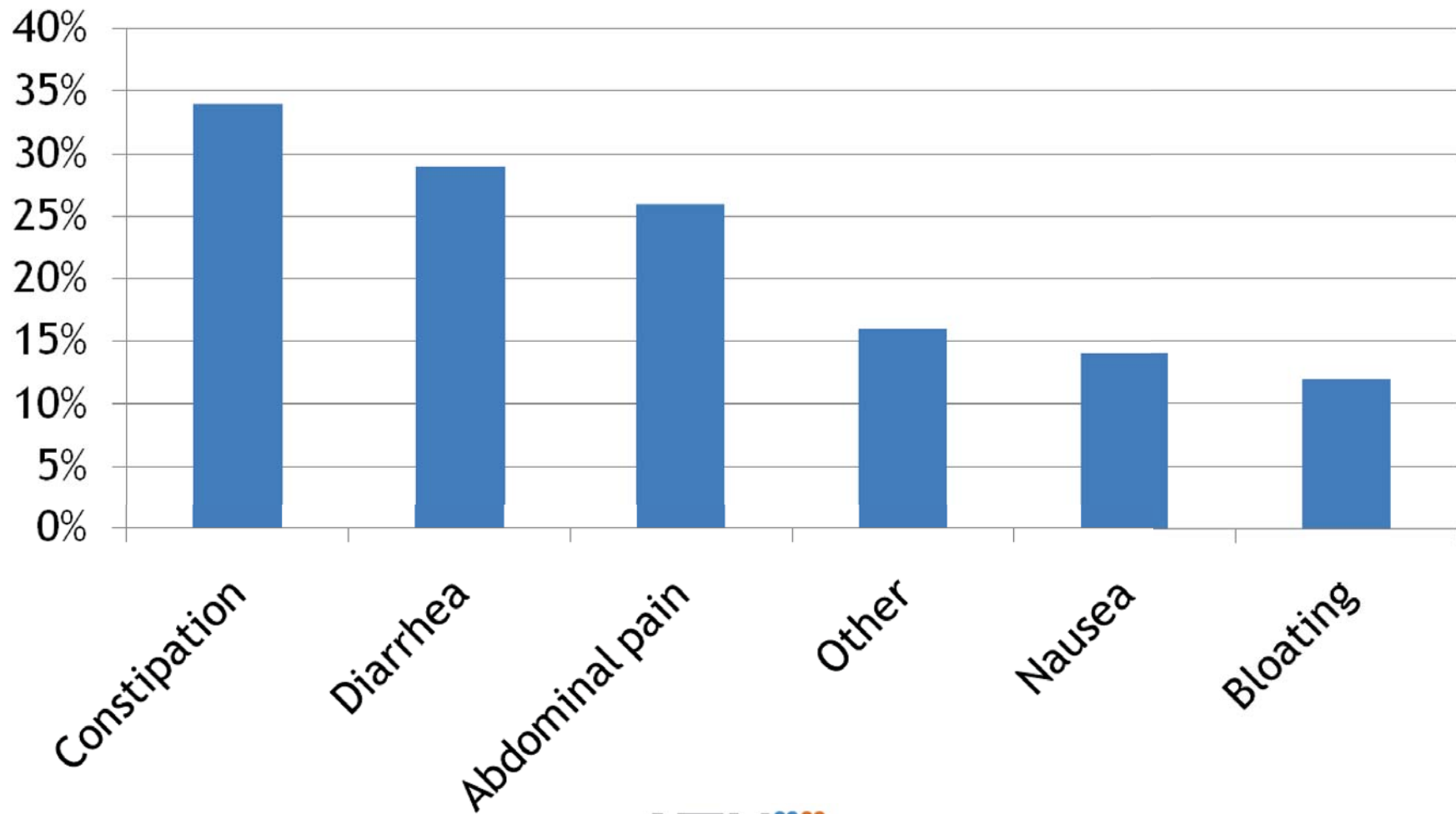
Gastrointestinal symptoms (N = 1,884)

- 50% of children reported to have GI symptoms
- Children with GI symptoms more likely to have
 - Sleep disturbances
 - Behavioral problems
 - Lower health-related quality of life
 - Use complementary and alternative therapies



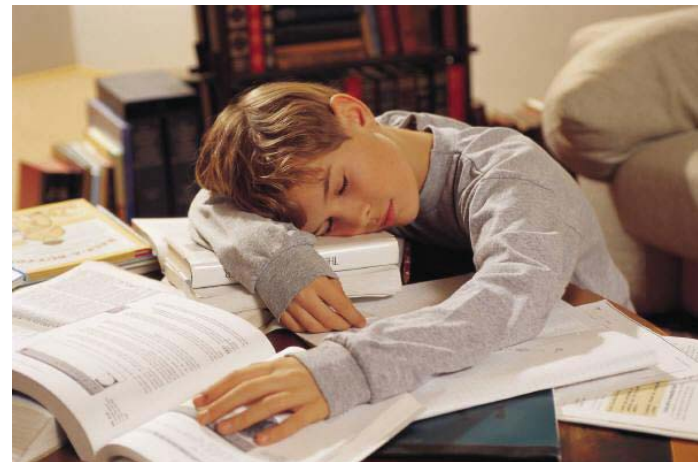
Most Common GI Problems Reported (N=1884)

Types of GI Problems Reported by Parents

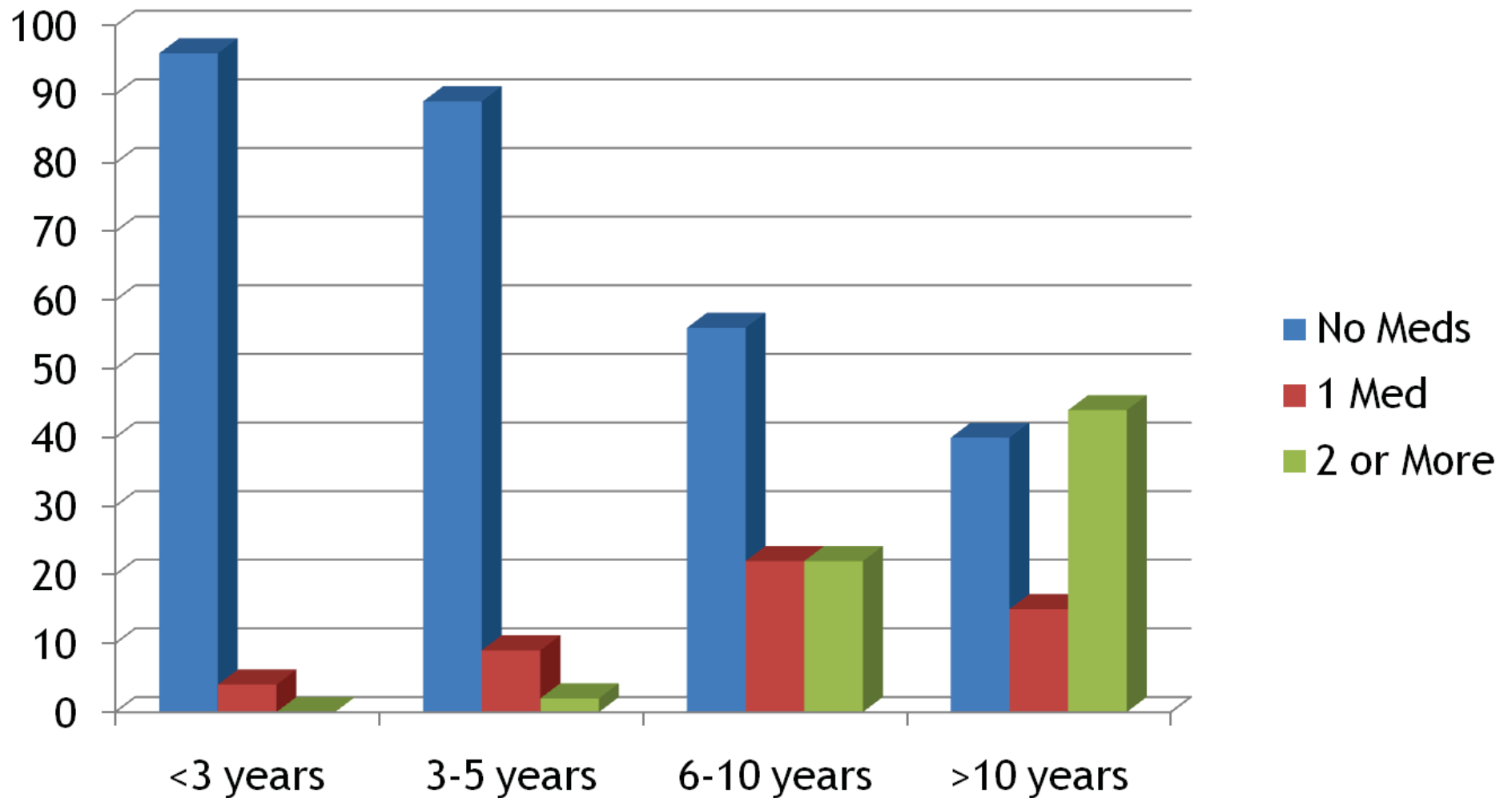


Sleep disturbances (N = 1,653)

- 65% of children reported to have sleep problems.
- 14% of children with sleep problems have seizures.
- Children in the ATN Registry have a higher rate of reported sleep problems compared to published community samples of typically developing children.
- Children with GI problems also have higher rates of parent-reported sleep problems than children without GI problems.
- Sleep problems are associated with increased problem behaviors and poor attention and concentration.

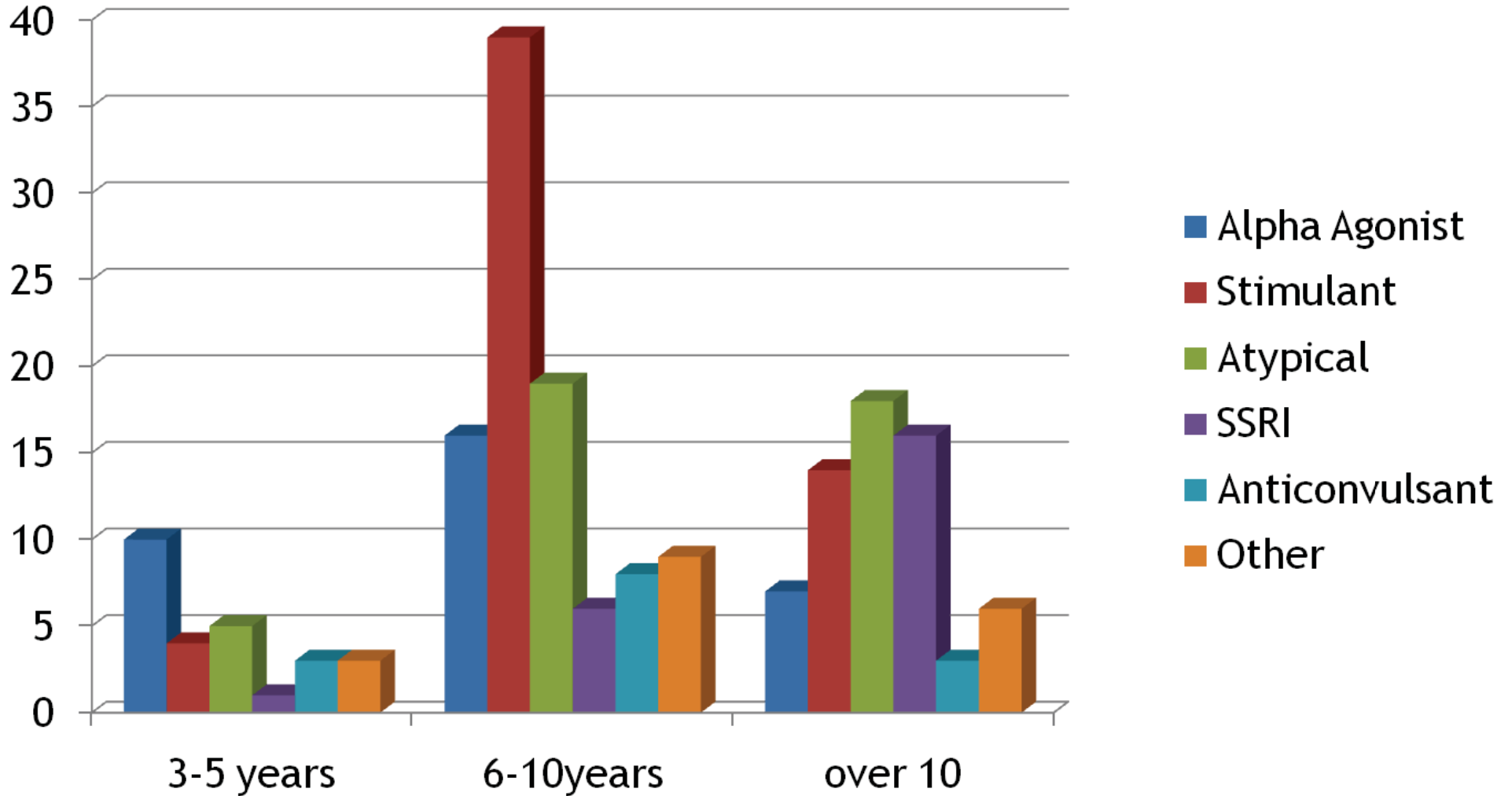


Medical treatments used by children in the ATN registry



Percentage of children on medication

Category of Psychotropic Medication Use by Age Group



Complementary/alternative treatments

	n	%
Vitamins	280	67.1
Probiotics	183	43.9
Essential fatty acids	115	27.6
Other	110	26.5
Digestive enzymes	77	18.5
Vitamin B6 & Magnesium	74	17.8
Chiropractic	49	11.8
Amino acids	48	11.6
Antifungals	36	8.7
Glutathione	23	5.6
Chelation	18	4.3
Acupuncture	9	2.2
Hyperbaric oxygen	8	1.9
Sulfation	5	1.2

22% of children receive complementary/alternative treatments and 18% are on special diets



Model for Growth of the ATN

- **Clinical Care:** Expand the ATN beyond 14 clinical care sites, with emphasis on comprehensive care and on-going quality improvement.
- **Guideline Development:** Continue to partner with professional organizations to develop and disseminate empirically-based clinical practice guidelines.
- **Research:** Expand federal funding for clinical research, including creation of a biomaterial repository, to accelerate personalized medicine approach to ASD treatment.

