

Lindsay Shea MS DrPH¹, Kaitlin H. Miller MPH¹, Paul Turcotte MPH¹, & Michael J. Murray MD²

¹Autism, Services, Education, Resources, and Training Collaborative (ASERT) Eastern Region, A.J. Drexel Autism Institute, Drexel University

²Autism, Services, Education, Resources, and Training Collaborative (ASERT) Central Region, Penn State Hershey

Background

- Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder that has become a pressing issue over the past two decades (figure 1).
- ASD is a lifespan disorder.
- Research has indicated that individuals with ASD will require services and supports throughout adulthood.
- The increase in ASD prevalence is a public health concern.
- The population level effects of ASD include: societal costs, namely to public service sectors and the clinical capacity of providers to support the growing number of individuals with ASD.
- The increase of children, adolescents and adults with ASD diagnoses has been met with substantial investment in research and clinical interventions.
- Government programs and policies have also been developed to meet the needs of individuals with ASD.
- There is a gap that exists between clinical and research endeavors and the translation to state and federal level programs and policies.
- In order to address the ASD public health issue, this gap will need to be addressed.

Figure 2. Process



Figure 3. Number of Autism-Specific Research Articles on Children or Adolescents versus Adults, by year

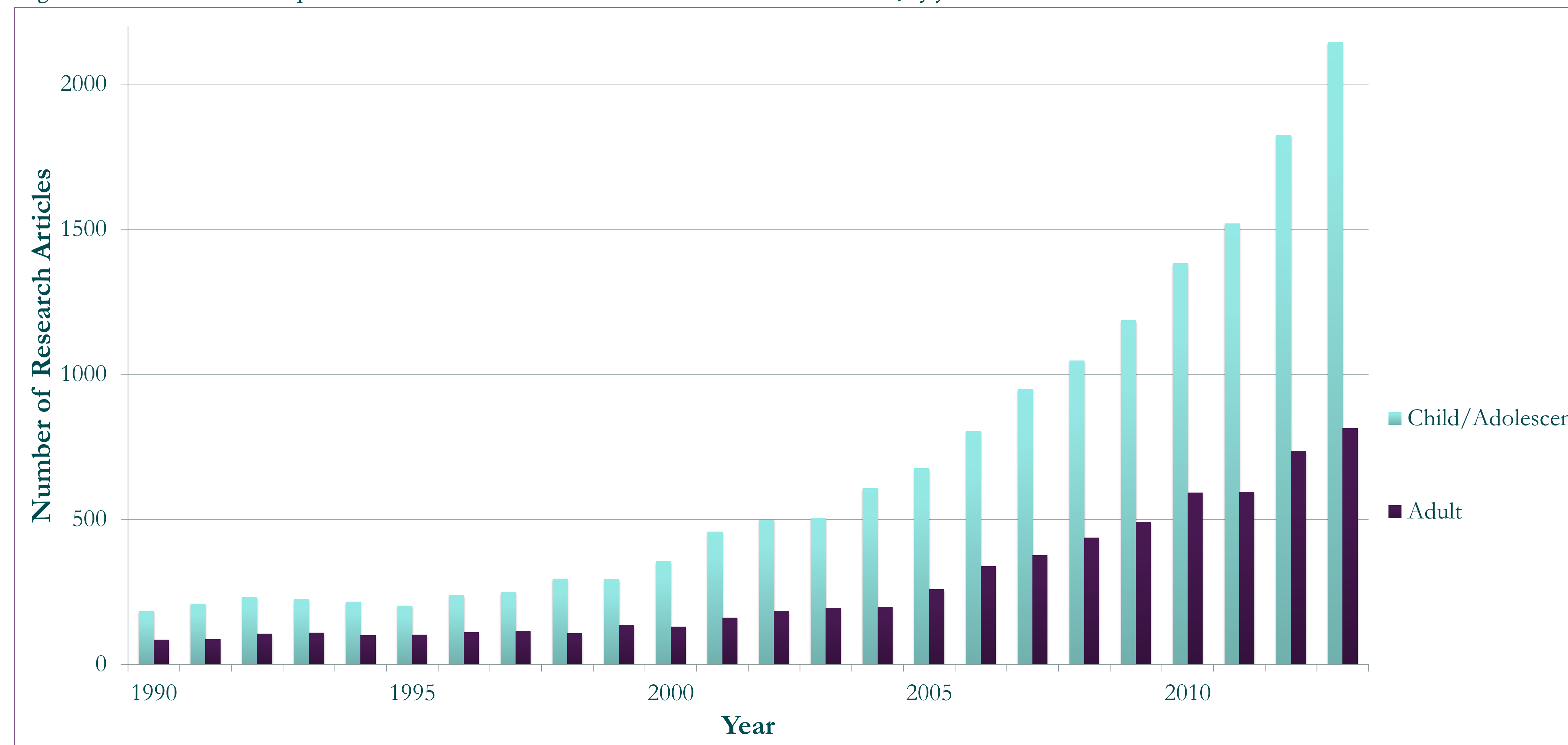
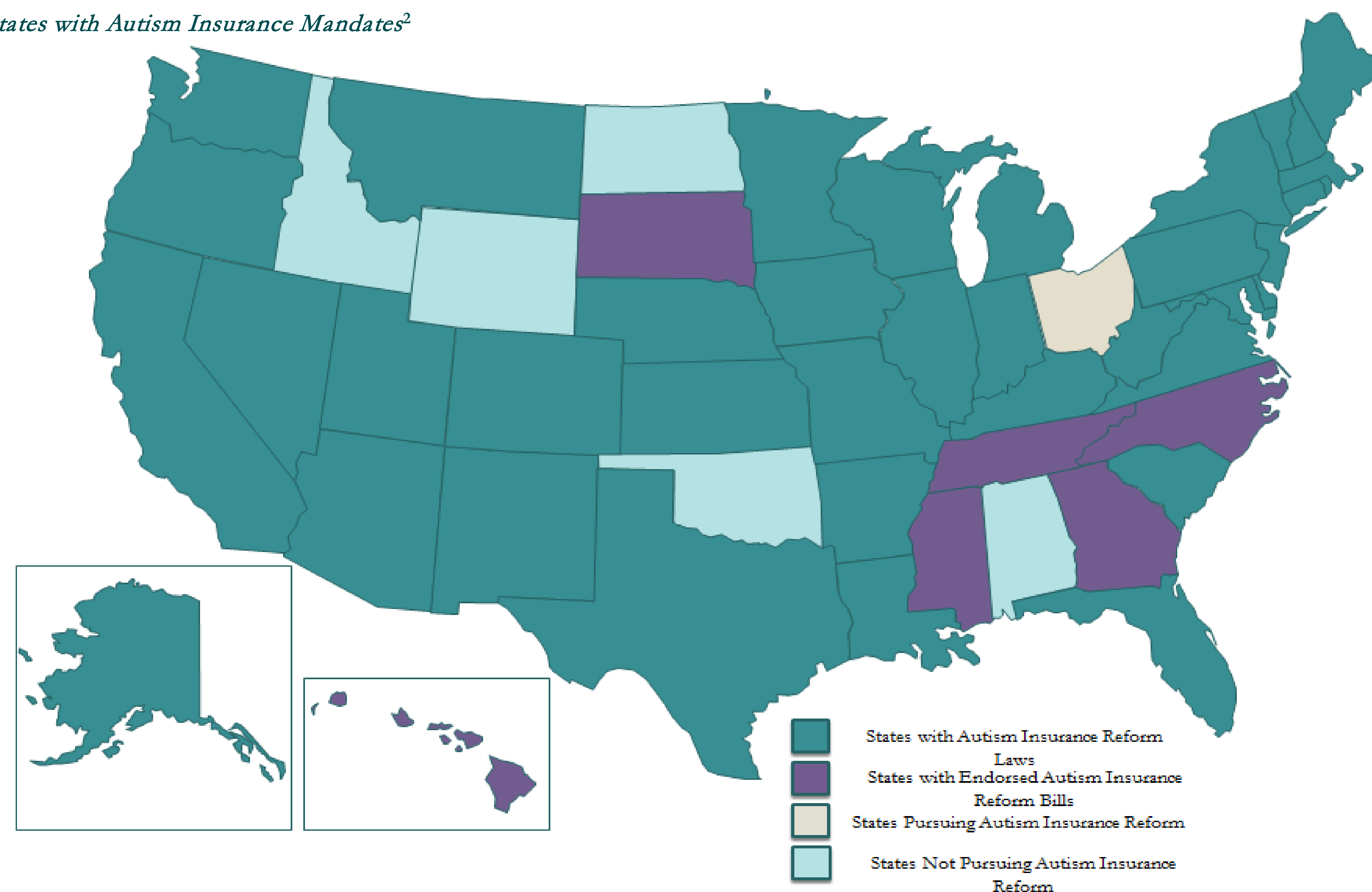


Figure 4. States with Autism Insurance Mandates²



Evidence of Impact

- As the prevalence and the public health concern surrounding ASD has grown, the amount of research on ASD has increase as well (figure 3).
- Despite this influx of research efforts, a gap persists in the translation of research findings into federal or state level policies and clinical programs.
- 38 states and Washington D.C. have all signed Autism Insurance Reform Mandates into law (figure 4).
 - Currently, the extent to which the implementation of these laws remains unclear.
- A survey of 292 policymakers found that they are “overwhelmed” by both the amount and presentation of research that they are given.³
- The ASERT Collaborative was established by Bureau of Autism Services, PA Department of Human Services to address unmet needs in the ASD community in Pennsylvania.
- One of the first activities was to conduct a joint statewide autism needs assessment:
 - More than 3,500 individuals and families participated making it the most comprehensive survey to date.⁴
- 55% of parents of adolescents with ASD and 58% of parents of young adults with ASD stated that their children were receiving inadequate social skills training.⁴
- 77% of parents of adolescents with ASD stated that their children were receiving no or inadequate transition planning services.⁴
- These findings led to development of ASERT clinical programs targeting improved social skills training for adolescents and adults with ASD as well as the development of the **Autism Life Care Model (ALCM)** a program which integrates assessment and care coordination to improve service engagement and quality for transition-aged youth.
- Initial findings from these programs are informing policy considerations such as the need to fund peer generalization in social skills interventions for individuals with ASD and the value of person-centered care for transition-aged youth with ASD.

Conclusions & Recommendations

- In distributing research to policymakers, researchers and clinicians should avoid jargon and technical language. Instead, they should opt for short, bulleted, and visual displays for maximal impact.³
- Clinicians and researchers should include the policy implications of their research or intervention modality as a translation mechanism for policymakers.³
- Policymakers should include researchers in the policy development or consultation process.⁵

References

¹Centers for Disease Control and Prevention (2014). Data and statistics. Retrieved from <http://www.cdc.gov/ncbddd/autism/data.html>

²Autism Speaks (2015). State initiatives. Retrieved from <https://www.autismspeaks.org/state-initiatives>

⁴Bureau of Autism Services PDOHS. Pennsylvania Autism Needs Assessment: A Survey of Individuals and Families Living with Autism. 2011.

⁵Recommendations for researchers and policy makers arising from the joint UNCTAD-WTO-ITC workshop on trade policy analysis, Geneva, 11 - 15 September 2006

ASERT is funded by the Bureau of Autism Services, Pennsylvania Department of Human Services

Objectives

- I. Illustrate the evidence base on barriers to research influence clinical practice and policy.
- II. Outline a promising private-public partnership program in Pennsylvania working to address these barriers, the Autism Services, Education, Resources and Training Collaborative(ASERT).
- III. Provide concrete strategies for public health professionals, clinicians and researchers to work together to maximize the cohesive translation across research, clinical practice and policy.

Figure 1. Increase in Autism Prevalence¹

