



ASD Policies in New Jersey and in Other States

Peter Doehring, Ph.D.
ASD
Roadmaps

Annual Conference

Disclosures

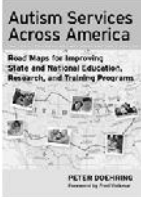
- I might receive book and other royalties related to this topic
- As a consultant, I might benefit from the interest generated by this topic
- I have no other conflicts of interest

My Objectives Today

- My goal is for you to become able to
 - List common statewide policies and programs related to ASD services, training, and research
 - Describe some advantages and disadvantages of new statewide policies and programs perhaps relevant to New Jersey

BACKGROUND
 Autism Services Across America

- Goal: Draw clear roadmaps translating aspirations in research & policy into improved outcomes for everyone
- Advocates & leaders
 - May not build on programs developed elsewhere
 - May lack time & experience to develop long-term plans
- This book provides
 - Background to support comprehensive planning
 - Examples of innovative state/federal programs



BACKGROUND
 Project: Directory of State Programs

- Collaboration of ASD Roadmaps & Easter Seals
- Focus: state-level programs for service, training, research, policy, and advocacy
- Goal: To create
 - Searchable database of programs with links to reports, legislation, and outcomes
 - State-by-state entries for publication in the Encyclopedia of Autism Spectrum Disorders.
 - To date, we have assembled information about a subset of states with recently active statewide committees or taskforces

BACKGROUND
 Other Sources

- State by State summaries of existing policy and services
 - Easter Seals Autism State Profiles
 - (<http://www.easterseals.com/explore-resources/living-with-autism/state-autism-profiles.html>)
 - Center for Medicaid and Medicaid Services State of the States Report (2014)
 - <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf>)

BACKGROUND
How policy influences outcomes

- Science impacts outcomes only through improved policy, training, & services
 - Training & service rely on specific programs
 - Consider training & service for caregivers too!
 - Training & services can shape policy & research

→ Strong Influence ⇨ Moderate Influence

BACKGROUND
How state policy is disseminated

- Not all important policy is set by the state
 - Some important policy is set by local agencies (new staff, new programs, discretionary funding)
 - Other policy may be set at the federal level
- The role of the state in direct services and training is more indirect
 - Most training is delivered regionally or locally
 - Few services are delivered statewide; most are delivered locally

GENERAL POLICY AND PLANNING
ASD Task Forces

- Time limited committees that generate action plan
 - ✓ Mandated via state legislation
 - ✓ Not all report back to the state legislature
- Some focused on one domain (education) OR
 - ✓ Are cross/multi-agency
- State agencies may dominate OR can include
 - ✓ Multiple Parents / Parent Groups AND Self-advocates
 - ✓ Service providers
- Reports are usually broad in scope, may gather some background information, but even better if they
 - ✓ Offer specific strategies and action steps
 - ✓ Include baseline data and measurable goals

GENERAL POLICY AND PLANNING
Standing ASD committees

- Committees that direct state strategy: More heft if
 - ✓ They are mandated via state legislation
 - ✓ They report back to the state legislature
- Some are focused on one domain (education) OR
 - ✓ Are cross/multi-agency
- What can they do?
 - ✓ Share information and document concerns
 - ✓✓ Actively manage projects
 - ✓✓ Develop policy/legislation
 - ✓✓ Specifically follow-up task force recommendations
- Same recommendations as above re involvement of parents, self-advocates, and service providers
 - ✓ Sub-committees with specific mandates

FUNDING
Support for Agencies and Services

- Many direct services rely on state \$\$ to a significant if not major degree
 - May also be affected by rules/regulations (reimbursement rates for specific services)
- Indirect/support services provided by state agencies depend even more on state \$\$
 - Outreach / information
 - Training
 - Level of oversight
 - Capacity to develop new programs

FUNDING
Health Insurance

- Many states have passed private insurance legislation
 - ✓ Look carefully at regulations about what kinds of businesses and policies are exempt
 - ✓ Follow-up to ensure that families can access benefits they are entitled to
- Help shape impact of Affordable Care Act
 - ✓ Act on caps on essential health services (inc. behavioral health) prohibited by ACA

FUNDING
Waivers

- Access federal funding for specific kinds of direct services and supports IF states
 - Commit to matching levels of funding
 - Comply with necessary regulations
- Many states have waiting lists (some very long) for some waiver services

RESEARCH
Registries

- Intended to get a “count” of number of people with ASD
 - Q’s: How is this better than CDC estimates?
- Implementation varies
 - Sometimes reporting is anonymous: no possibility to verify diagnosis
 - Sometimes reporting is mandated
- Ultimate goal varies from state to state
 - Get a “true” count of the need?
 - Connect families with research or other services
- ✓ Option: Census of those receiving services
 - PA 2009 Census

RESEARCH
Statewide Needs Assessment

- Many states informally gather information regarding satisfaction, gaps, and needs
 - Focus groups, surveys posted on a website
 - But is this representative enough?
 - ✓ Population-based surveys invite everyone identified with a need to participate
- PA Family Needs Assessment
 - Generally representative sample
 - ✓ Breaks down gaps by region, groups, etc., potential for region-by-region goals

RESEARCH
Targeted grants

- A handful of states set aside funds for targeted research
 - Always related to services (except in NJ)
 - ✓ Evaluate a pilot intervention program
 - ✓ Conduct an evaluation of statewide needs

INFORMATION / ADVOCACY
ASD state offices

- Some states have created specific entities in state govt to address ASD issues
 - ✓ Complete office/division, full staff complement
 - Or one or two designated positions
- Scope and mandate varies
 - ✓ A) Coordinate efforts within agency(ies)
 - ✓✓ B) Administer/oversee services and grants
 - ✓ C) Connect people with resources
 - ✓✓ D) Coordinate and/or provide training
 - ✓✓ E) Establish standards for best practice

INFORMATION / ADVOCACY
ASD Resource Centers

- May also contract with another agency to address C-E above
 - ✓ Usually based in a university, and often in a center focused on disabilities
 - ✓ Easier to address gaps between health/education
 - ✓ Coordinate with degree training programs

TRAINING
Training programs

- Can be coordinated by an ASD office or resource center
- The range of activities varies
 - Workshops addressing basic awareness
 - ✓ Training targeting underserved groups
 - ✓ Statewide ASD conference
 - ✓✓ Programs to develop trainers and experts
 - ✓✓ Model sites or specialized ASD practica

TRAINING
Certification and licensure

- Can create, recognize, or mandate specific types of training
 - ✓ Recognize a professional group (i.e. BCBA's)
 - ✓ Endorse a specialized certificate (post-graduate ASD teacher training)
 - ✓ Require that a specific training program be completed for a specific task (i.e., FBAs)

SERVICES
Agency Mandates

- Sometimes specific regulations interfere with needed services
 - ✓ Align medical diagnosis and educational classification
 - ✓ Allow behavioral health services to provide "habilitation"
 - ✓ Promote active collaboration between school and home
- Provide specific guidance and oversight
 - ✓ Seclusion and restraint

SERVICES
Pilot projects

- Limited role for state program in direct service delivery BUT can support
 - ✓ Specific pilot programs to test interventions addressing gaps in services
 - ✓ Model / demonstration sites

SERVICES
Regional Collaboratives

- Some states are too large for a single statewide entity to reach everyone
 - ✓ Support or mandate regional center to provide more specialized services
 - ✓ Create regional training networks

Autism Services Across America
Road Maps for Improving State and National Education, Research, and Training Programs
PETER DOERING
Foreword by Fred Volkmar

Evidence-Based Practices and Treatments for Children with Autism
Foreword by Alan L. Rachtel
Springer

Autism: Pervasive Developmental Disorders
CHRISTOPHER D. BIRD
Translating Research into Effective Social Policy
WILEY

Peter Doering ASD Roadmap

For more information
peter@asdroadmap.org