Surveying statewide programs for services, training, & policy
Lessons for leaders

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Our Objectives Today

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- Our goal is for you to become able to
  - List common statewide policies and programs related to ASD services, training, and research
  - Describe some opportunities or barriers these might present to advocates, front-line professionals, or program leaders

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BACKGROUND
Directory of State Programs

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- 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
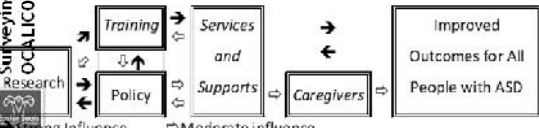

BACKGROUND
Other Sources

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- 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)
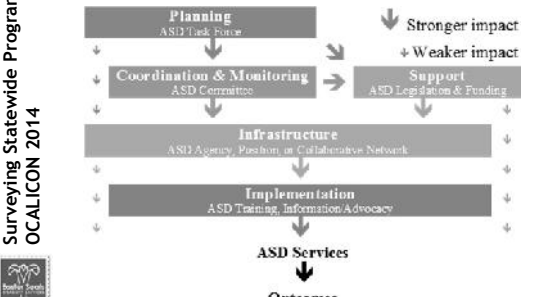

BACKGROUND
How policy influences outcomes

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- 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

ROLE OF THE STATE
Path to sustainable impact

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STATEWIDE PLANNING
ASD Task Force

- Time limited committees that generate action plan
  - ✓Some focused on one domain (education) OR Are cross/multi-agency
- Planning may lead directly to improved infrastructure/support BUT may work better with ongoing coordination via a Committee

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STATEWIDE PLANNING
ASD Task Force: Key Elements

- Evidence of 48 task forces in 36 (72%) of states
  - AL; **AR; AZ; CA**; CO; CT; DE; FL; GA; HI; **IL;** IN; KS; KY; MD: ME; MN; MO; MS; MT; NC; **ND;** NE; NH; NJ; NV; NY; OH; OK; OR; PA; RI; **TN;** TX; WA; WI
    - Those with an active task force are in bold
- Key element: Mandate by legislature
  - 31 (65%) of task forces; 29 (82%) of states
    - **ALL BUT** MO; MT; NE; NY; OK; PA; WI

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STATEWIDE PLANNING
ASD Task Force: Key Elements

- Transparency: Described on website maintained by host agency
  - 17 (35%) task forces; 14 (39%) states
    - AL; AR; AZ; CA; CO; FL; IN; KY; MD; MN; ND; NY; RI; WA
  - Good: a) List of participants; b) mandate (including legislation)' 4 task forces (9%); 4 (11%) of states
    - CA; KY; MD; WA)
  - Better: c) Meeting agenda/minutes; d) final report: 4 task forces (9%); 4 (11%) of states
    - IN; KY; MD; ND
  - 1 task force met a-d above criteria: MD

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STATEWIDE PLANNING
ASD Task Force: Key Elements

- Participation beyond state agencies: Less than 50% voting members
- Voice for advocates: Participants include
  - Good: Parents OR Self-Advocates OR Representatives from Advocacy groups
  - Better: Parents AND Self-Advocates AND Representatives from Advocacy groups
  - Best: These constituted at least 1/3 voting members

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STATEWIDE PLANNING
ASD Task Force: Key Elements

- Data based: Needs assessments OR actual data on services utilized
- Anticipates implementation
  - Good: A committee or agency is designated to report back regarding overall progress
  - Better: PLUS recommendations are supplemented by specific strategies or action steps
  - Best: PLUS Recommendations are assigned to specific agencies

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STATEWIDE COORDINATION
Standing ASD committees

- Committees that direct state strategy: More heft if
  - ✓ They are mandated via state legislation
  - ✓They report back to the state legislature
- Committee can build on the work of a task force or lead directly to improved infrastructure/support
  - BUT is not well placed to directly implement programs of services, training, or research

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STATEWIDE COORDINATION
Standing ASD committees

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- We found 28 committees in 25 (50%) of states, with 23 (96%) of these states having a committee that is active (in bold text):
  - **AK; AL; CO; CT; DE; IA; IN; KS; KY; MA;** MD; **MO; MS; NE; NH; NJ; NV; OH; OR; RI; TX; VA;** VT**; WA; WI**
- ✓Sub-committees with specific mandates

Key elements described for Task Forces apply to Committees: how are they different?

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STATEWIDE COORDINATION
ASD Committees: Key Elements

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- Committee is mandated
  - 21 of 28 committees had a mandate (75%), in 21 (88%) of the 24 states with a committee
    - **All but** OH; RI; WA; WI
  - Good: Recommended by task force: 9 (32%) committees, in 9 (38%) states
    - CO; CT; DE; IN; KY; MS; NE; NH; NV
  - Better: Mandated by legislature: 17 (61%) committees, in 16 (67%) states
    - **All but** DE; IN; NE; NV; OH; RI; WA; WI
  - 5 committees mandated using both means
    - CO; CT; KY; MS; NH;

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STATEWIDE COORDINATION
ASD Committees: Key Elements

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- Transparency: Activities are available on a website maintained by the agency
  - Websites for 21 of 28 (75%) committees, or in 20 (80%) of 24 states with a committee
    - **All but** AK; DE; KS; MS; NV
  - Good: a) Mandate or legislation described 11 committees (39%) in 11 (44%) states
    - AL; CO; IA; IN; MA; NH; NJ; OH; OR; TX; VA

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STATEWIDE COORDINATION
ASD Committees: Key Elements

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- Better: b) Participants are listed - In 14 committees (50%) in 14 (67%) states
  - AL; CT; IA; IN; MA; NH; NJ; OH; OR; RI; TX; VA; VT; WI;
- Best: c) Annual/biennial reports or d) Meeting agenda/minutes are available - In 8 committees (29%) in 8 (33%) states
  - AL; IO; MA; NH; NJ; OR; TX; VT
- 7 committees met all criteria (a-d above)
  - AL; IO; MA; NH; NJ; OR; TX

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STATEWIDE COORDINATION
ASD Committees: Key Elements

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- Monitors implementation
  - Better: A committee or agency is designated to report back regarding overall progress
  - Best: Reports document progress towards specific recommendations

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STATEWIDE SUPPORT
Funding: Agencies & Services

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- 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

STATEWIDE SUPPORT
Funding: Health Insurance

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- 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
- Shape impact of Affordable Care Act
  - ✓ Act on caps on $ (though not hours) on essential health services (inc. behavioral health) prohibited by ACA

STATEWIDE SUPPORT
Funding: Waivers

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- 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

STATEWIDE SUPPORT
Other legislation

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

STATEWIDE SUPPORT
Other legislation

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- Agency Mandates: Specific regulations may interfere with needed services
  - Align medical diagnosis and educational classification
  - Allow behavioral health services to provide "habilitation"
  - Promote active collaboration between school and home
- Other specific guidance and oversight
  - ✓ Seclusion and restraint

STATEWIDE INFRASTRUCTURE
ASD State Agencies

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- Specific Bureaus, offices, or divisions housed within in state govt to address ASD issues
  - Complete office/division, full staff complement
  - 14 State Agencies in 12 different states
    - AK; CT; DE; MA; MO; NJ; NV; PA; RI; SC; TX; UT; WI;
- ASD designated positions
  - Isolated position identified as specifically focusing on ASD
  - Three states: CO; NJ; TN

STATEWIDE INFRASTRUCTURE
ASD Collaborative Networks

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- A non-state agency which receives designated state funding to offer service, training, or information/advocacy on a statewide basis
  - 25 Collaborative Networks in 22 different states
    - AK; CT; FL; IA; ID; IL; IN; KY; LA; MD; MI; MT; NC; NE; NY; OH; OK; OR; SC; VA; WV

STATEWIDE IMPLEMENTATION
ASD Information/Advocacy

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- Service is offered through a physical or virtual (e.g., web-based) resource center
  - Focused here on agencies or networks that offer more than generic links to information or resources available elsewhere
  - This service can be provided by a state agency or collaborative network
- All but 1 of 39 networks have a website
  - 29 (74%) of the 39 websites in 22 states offer one element from A-D below
    - AK; CT; FL; IA; ID; IL; IN; KY; MA; MD; MI; MO; MT; NC; NE; NJ; NV; NY; OH; OK; OR; PA; RI; SC; TX; UT; WV;

STATEWIDE IMPLEMENTATION
ASD Information/Advocacy

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- Disseminate information
  - A) Statewide events / activities: 13 (33%)
  - B) State policies, committees, reports: 15 (38%)
  - C) Breaking news about research and policy at the national level: 11 (28%)
- D) Connect families w/ resources: 19 (49%)
  - Several have online searchable resource guides
- Most complete resource centers (at least 3 of A-D above): CT, IL, IN, OH, MO, OK, PA, TX, WV

STATEWIDE IMPLEMENTATION
ASD Training Programs

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- Develop/disseminate training activities or programs intended for statewide impact
  - More than occasional invited speakers or workshops
  - Training program can be provided by a state agency or collaborative network
- 25 (74%) of 39 programs in 21 states offer at least one element from A-I below
  - AK; CT; FL; IA; ID; IL; IN; KY; LA; MI; MO; NE; NY; OH; OK; PA; RI; SC; TX; VA; WV;

STATEWIDE IMPLEMENTATION
ASD Training Programs

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- A) General workshops in basic awareness for a broad audience: 19
- B) Statewide Conference: 12
- C) More specific, discipline/topic-specific workshops (Screening/diagnosis, etc.): 9
- D) Series of workshop: 6 (PBS, paraprofessionals, etc)
- E) ASD Course: 7

STATEWIDE IMPLEMENTATION
ASD Training Programs

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- F) Mentoring/Coaching: 5
- G) Model sites: 3
- H) Develop or endorse practice guidelines: 3
- I) Train-the-trainer programs: 2
- 12 agencies in 11 states offered 3 to 7 of the above
  - AK, DE, IN, KY, MI, MO, NE, OH, PA, SC, TX

STATEWIDE IMPLEMENTATION
Services

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- 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
- Specialized Services for those with especially challenging behaviors:
  - Specialized residential programs
  - Intensive case management and coordination

OTHER STATEWIDE PROGRAMS

Registries

- Intended to get a "count" of number of people with ASD
  – Q's: How is this better that 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

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OTHER STATEWIDE PROGRAMS

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
- A handful of states set aside funds for targeted research
  – Always related to services (Evaluate a pilot intervention program)

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