



# Roadmaps for Leaders of ASD Programs

Integrating Training, Research, and  
Policy in a Coordinated Network for  
Behavior Support



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**ASD Roadmaps**



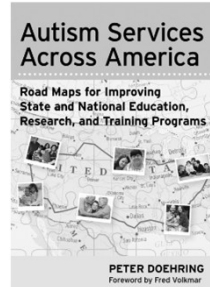
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## Disclosures

- 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

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## My Objectives Today

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- To illustrate how different gaps in services and support contribute to crises
- A simple case study helps make us accountable for the real costs
- Focus on behavioral crisis because
  - We have evidence-based practices and many of the resources already in place
  - A small proportion of such cases take up a lot of education and health resources
  - Many crises can be prevented with basic techniques implemented consistently across settings

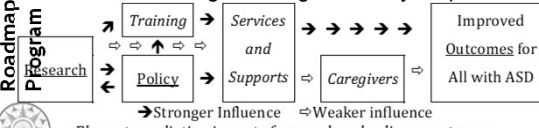
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## A COORDINATED NETWORK

### Elements of your mission

- Efforts to promote broad system change
  - Involve all of these elements: Who is your partner for elements not key to your mission
  - Must be translated into concrete services, often through training: What is your plan



→ Stronger Influence ⇌ Weaker influence

*Elements mediating impact of research and policy on outcomes*  
Adapted from Doehring (in press)


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## A COORDINATED NETWORK

### Levels, Domains, and Sectors

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- Domain: Community, Education, Health
- Sector: Public and Private
- Level: Local/City, Regional/County, State, and National
  - Not all elements are available at all levels
- What is your plan to partner with agencies at different domains and levels?

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## A COORDINATED NETWORK

### Levels, Domains, and Sectors

**LEVEL**

	Local	Regional	State	National
<b>SERVICES</b>				
<b>TRAINING</b>				
<b>RESEARCH</b>				
<b>POLICY</b>				

**CONTRIBUTION**

	None	Little	Moderate	Strong	Very Strong
<b>SERVICES</b>					
<b>TRAINING</b>					
<b>RESEARCH</b>					
<b>POLICY</b>					

Doehring (2013)

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**JOE'S STORY**  
 About Joe and his family

- Joe: 17 years old
  - ASD, Profound ID, Seizure Disorder
  - Aggression (AGG): Hitting, punching, kicking
- Joe's family
  - Mother (Jill) is a single parent
  - Some extended family (her mother)
  - Works as a nurse in a local hospital

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**JOE'S STORY**  
 How do we tell Joe's story?

- **Problem:** This the problem Joe faces

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**Solution:** It may include different elements, levels, & domains, & result in better services  
 —It is marked in dark bold text in diagram

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**JOE'S STORY: EDUCATION**  
 No standards for FBAs and BSPs

- **Problem:** School does FBA but plan focuses on immediate antecedents & consequences
  - Misses communication deficits & sleep problems

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**Solution:** State DOE sets new standards for plans, contracts with UCEDD to provide related training and support to districts

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**JOE'S STORY: EDUCATION**  
 Inconsistent, ineffective 1:1 support

- Parade of 1:1 contractors postpones crises by blocking AGG, or removing Joe from class

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**Solution:** District hires its own 1:1's, using private agency to design training program

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**JOE'S STORY: EDUCATION**  
 Teacher does not prioritize EBP

- Teacher focusses on implementing a sensory diet she learned about in a graduate ASD course at state college

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**Solution:** State college revises syllabi to prioritize EBP derived from objective review of outcome research conducted & summarized by NPDC

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**JOE'S STORY: COMMUNITY**  
 School/Community BSP not coordinated

- BCBA targets AGG in community, initiates FCT, but progress is slow

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**Solution:** Agency & School change policy, require collaboration on home & school BSPs, increasing progress in FCT

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**JOE'S STORY: COMMUNITY**  
 Support terminated prematurely

- Insurance ends service: Remaining AGG & related deficits deemed to reflect "baseline"

Education	Training Change in state regulations	Policy	FBA training Hire own 1:1s Training in EBP Coordinate BSP Define baseline
Community	Services Home support continues	Local	BHRS Provider National
Health	State	State	Agency

- State Insurance Agency changes regulations redefine behavioral baseline

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**JOE'S STORY: HEALTH**  
 Physician cannot improve sleep

- Jill gets little help from Joe's physician for chronic sleep problems that contribute to AGG

Education	Training On a sleep protocol	Research	FBA training Hire own 1:1s Training in EBP Coordinate BSP Define baseline Sleep protocol
Community	Services Improved Sleep	Local	MD in private practice Advocacy group
Health	State	State	Chapter of AAP

- Advocacy group sponsors research collaborative to generate a toolkit; State AAP chapter sponsors training, which MD uses with Joe

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**JOE'S STORY: HEALTH**  
 Multiple medications for behavior

- Weight ↑, activity ↓ from multiple medications  
 Neurologist juggles to control seizures and behavior

Education	Training School Team	Policy	FBA training Hire own 1:1s Training in EBP Coordinate BSP Define baseline Sleep protocol MD ↔ beh. data
Community	Services Data inform med. changes	Local	MD & School
Health	State	National	Academy Guidelines

- AAN guidelines underscore benefits of behavior support; MD uses data from school to inform decisions to ↑, ↓, or change meds

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**JOE'S STORY: BEHAVIORAL CRISIS**  
 No clear policy regarding restraint

- AGG increases until Joe breaks his nose when 1:1 fails to properly restrain him

Education	Training In addressing intense behavior	Policy	FBA training Hire own 1:1s Training in EBP Coordinate BSP Define baseline Sleep protocol MD ↔ beh. Data Review restraint
Community	Services Manage intense episodes	Local	School
Health	State	National	DOE, independent experts

- Independent expert review implemented by state  
 DOE sanctions case-by-case use of restraint with appropriate safeguards and training

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**JOE'S STORY: BEHAVIORAL CRISIS**  
 No accommodations in ER

- 12 hour wait in ER while nurses struggled to manage Joe, until he was formally admitted

Education	Training Accommodation for ASD	Policy	FBA training Hire own 1:1s Training in EBP Coordinate BSP Define baseline Sleep protocol MD ↔ beh. Data Review restraint ER Protocol
Community	Services Manage behavior in ER	Local	Hospitals
Health	State	National	Disseminated via LEND

- State agency funds hospital to develop ER protocol for people like Joe, then disseminated through LENDs as community project

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**JOE'S STORY: BEHAVIORAL CRISIS**  
 No specialized programs

- No specialized in-patient / residential program
- State discourages out-of-state treatment

Education	Training Staff training & internships	Policy	FBA training Hire own 1:1s Training in EBP Coordinate BSP Define baseline Sleep protocol MD ↔ beh. Data Review restraint ER Protocol Spec. Program
Community	Services Resid./in-patient program	Local	
Health	State	National	Group offers standards

- Cross-agency collaboration to fund and develop new inpatient / residential program: Colleges provide training & interns; Joins new national consortium

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**JOE'S STORY: BEHAVIORAL CRISIS**  
 Suspended from school

- Joe stays home, suspended from school.
- Jill can't effectively advocate: she never learned how, is about to lose her job, and is exhausted & overwhelmed thinking about Joe's future

Training Research/Policy  
 Education Local  
 Community Health State National

FBA training  
 Hire own 1:1s  
 Training in EBP  
 Coordinate BSP  
 Define baseline  
 Sleep protocol  
 MD uses beh. Data  
 Review restraint  
 ER Protocol  
 Spec. Program

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**JOE'S STORY**  
 Other distal factors

- Other gaps in family support
  - No after school care because Joe is too old
  - Jill uses all her vacation/sick leave for many appointments or when Joe is out of school
  - No summer camp because of Joe's behaviors
  - Impact: Jill cannot advocate for system change, advance her career, or ever get a break!
- Don't under-estimate cumulative impact of a factors leading to poor quality of life
- All of the necessary system changes will require advocacy coordinated at all levels

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**TO TAKE AWAY**  
 The Role of UCEDDS

- UCEDDs can play an key role in each of these
  - Training
  - Research
  - Policy
  - What about services???
- System changes will require advocacy coordinated at all levels

FBA training  
 School hires own 1:1s  
 Training in EBP  
 Coordinate BSP  
 Define baseline  
 Sleep protocol  
 MD uses behavior data  
 Review use of restraint  
 ER Protocol  
 Specialized Programs

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**TO TAKE AWAY**  
 Think BIG about System Change

- Document the gaps in services and support contribute to crises
- Collaborate across sectors and domains to leverage resources and expertise
- Coordinate advocacy, training, research & policy at multiple levels to change systems
- Make us accountable for true costs by telling stories of real families
- Once we have the evidence we need, shift resources towards implementation

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