Evidence-based practice is not enough

Steps to scaling up intervention programs for population-level impact

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ASD Roadmap

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My background

- As a father
- As a clinician
- As a teacher
- As a researcher
- As a program leader

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Beyond effectiveness: Scaling up intervention

Research ➡ Better Lives!

- Thrilling stories of research and scholarship
  - From observation to experimentation to products to better lives
  - John Snow, The Broad Street Pump, and the discovery of cholera's origins

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Beyond effectiveness: Scaling up intervention

ASD Research ➡ Better Lives?

- An emerging story in ASD: Many practices that appear to be quite effective are not widely implemented
- PA Autism Census (2009)

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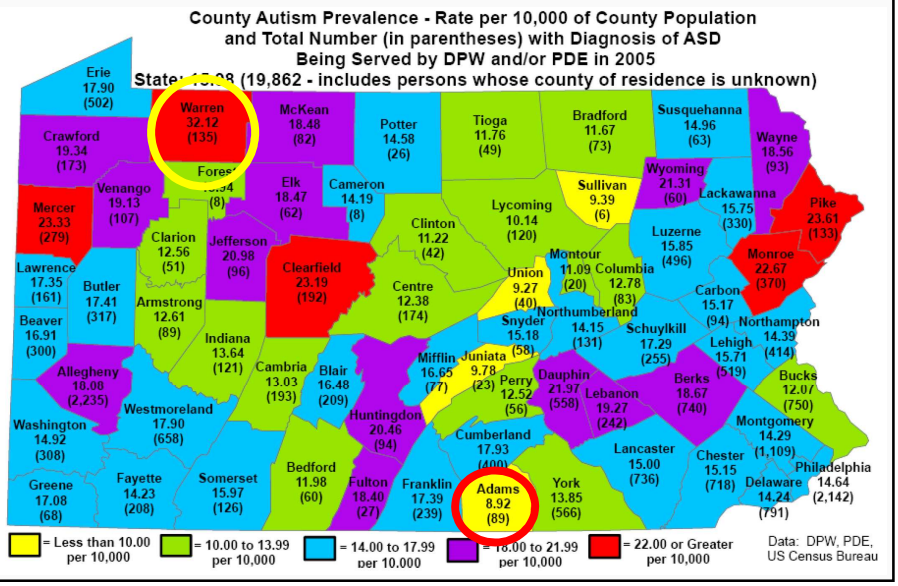
Beyond effectiveness: Scaling up intervention

ASD Research ➡ Better Lives?



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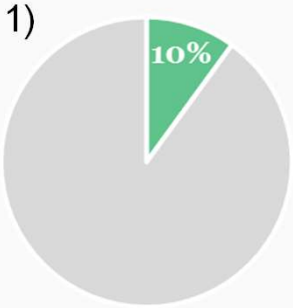
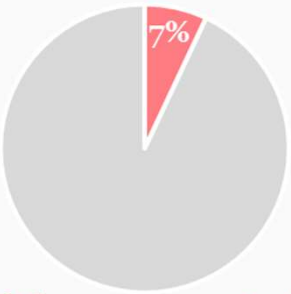
Beyond effectiveness: Scaling up intervention

ASD Research ➡ Better Lives?

How many Pennsylvanian adults were admitted to a hospital in the past year because of a behavioral or psychiatric crisis? (PA Family Needs Assessment, 2011)



10% of those reporting themselves (average of 2 times)



7% of those reported by caregivers (average of 2 times)

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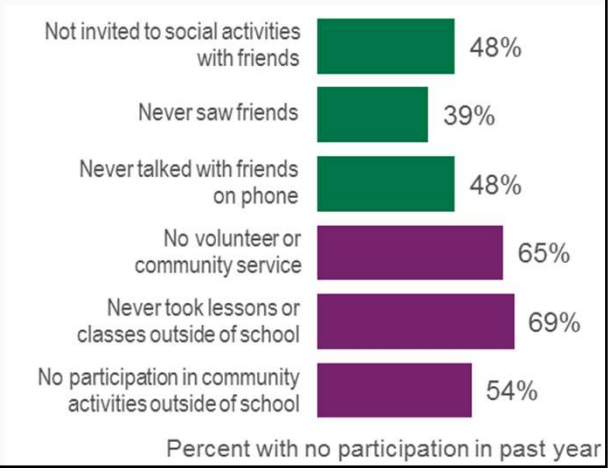
ASD Research ➡ Better Lives?

- 24% of young adults with autism never saw or talked with friends, nor were they invited to social activities in the past year (2015 National Autism Indicators Report)



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Beyond effectiveness: Scaling up intervention

ASD Research ➡ Better Lives?

- What kind of research and scholarship do we need to implement what we have learned to benefit more people?

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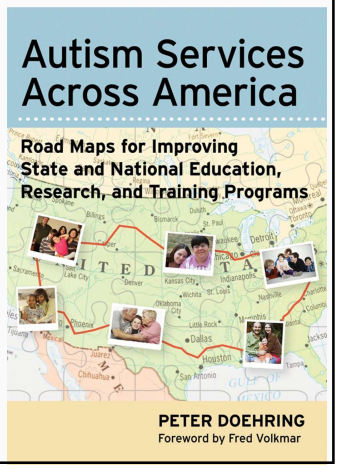
Beyond effectiveness: Scaling up intervention

A Roadmap for Implementation

- Outcomes only change through better services and supports
- Impact of research on services & outcomes is mediated by
  - Training
  - Policy
  - Advocacy



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Beyond effectiveness: Scaling up intervention

A Roadmap for Implementation

Research → Improved Outcomes

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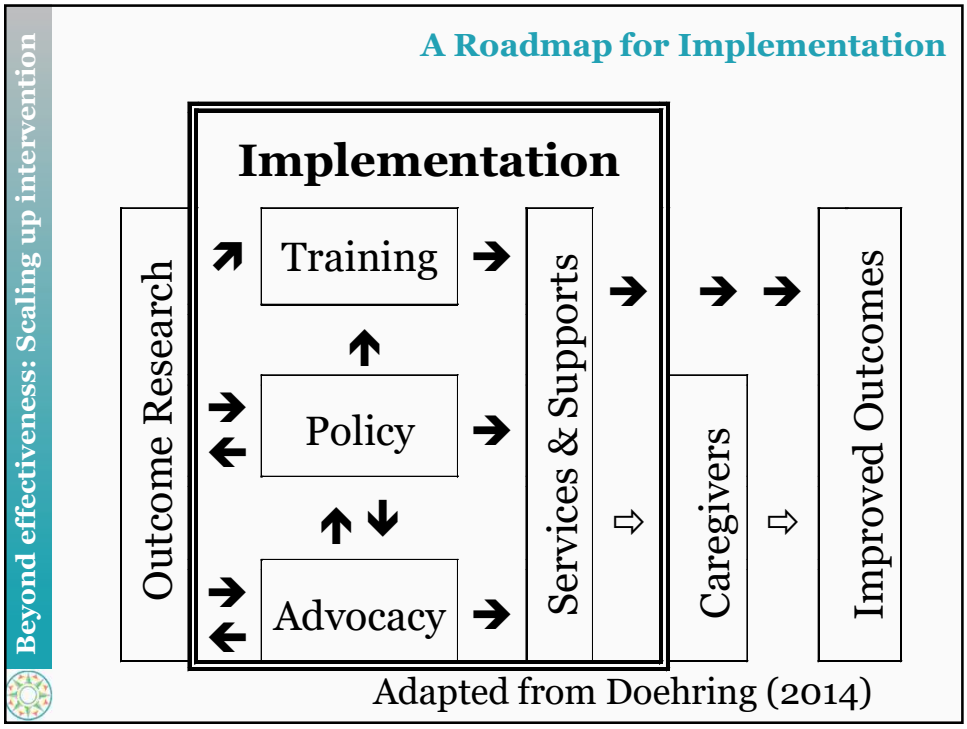
Beyond effectiveness: Scaling up intervention
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Outcome Research
Training
Policy
Advocacy
Services & Supports
Caregivers
Improved Outcomes
Adapted from Doehring (2014)

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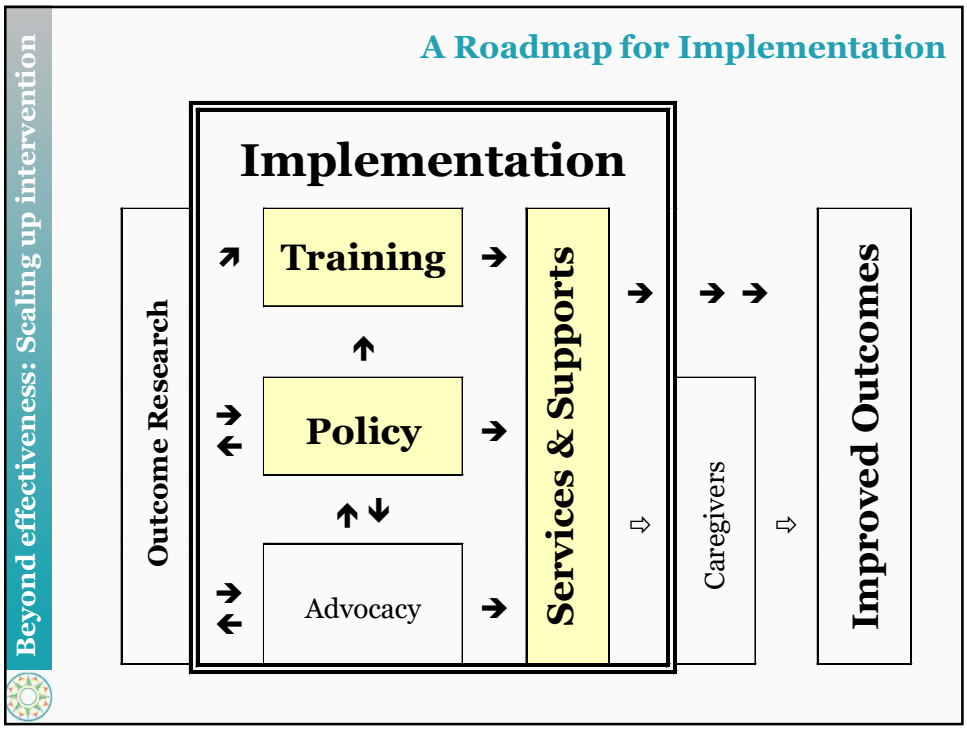
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Beyond effectiveness: Scaling up intervention

BEYOND EFFECTIVENESS

- So far, we have focused on outcome research that tests the effectiveness of practices

Effective Practices Lead to Important Outcomes

Delivered by Programs that are
Replicable, Sustainable, AND Accessible,

To become Scalable, to meet the needs of the entire population of people with ASD

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BEYOND EFFECTIVENESS

Effective+Important

↓

Replicable+Sustainable+Accessible

↓

Scalable

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Beyond effectiveness: Scaling up intervention

BEYOND EFFECTIVENESS

Practices ready for launch

- Practices ready to move beyond effectiveness
  - ASD screening and diagnoses
  - Individualized positive behavior support:
- How do we know these are ready?
  - Many of the procedures and tools have been developed and tested
  - Many examples of effective implementation at individual sites across the country

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Beyond effectiveness: Scaling up intervention

EFFECTIVE PRACTICES

Evidence-Based Practice Guidelines

- Systematic reviews of high quality outcome research to identify specific methods that have a clear impact
  - Agree on definition of high quality research
  - Disagree on comprehensive programs
- See also guidelines for timely identification published by different organizations
- Practice guidelines: A new training tool?
- But are useless without data-based decision making at the individual and program level

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EFFECTIVE PRACTICES

Populations and Targets

- Early mistakes: Overgeneralization
  - Whole disciplines (like ABA) are not EBP
- Research must clarify which populations the practice applies to ?
  - All ages?
  - All skill levels? Any prerequisite skills?
- What targets is the practice applicable to?
- Practitioners need clear guidelines re how to generalize beyond the populations and practices originally studied

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Beyond effectiveness: Scaling up intervention

IMPORTANT OUTCOMES

Leading to BIG outcomes

- How important are the outcomes targeted?
- Problem: Many peoples with ASD struggle to achieve BIG outcomes, like fulfilling work, independence, satisfying relationships, health and well-being
  - And we lack research to demonstrate which practices help to achieve big outcomes?
  - Accurate identification, timely & effective behavior support are absolutely critical
- Demonstrating big impact fuels advocacy

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REPLICABLE PRACTICE

Fidelity of practice and program

- So far, treatment fidelity for specific practices been desired but not required for high quality research
  - Well-designed tools will naturally facilitate training and dissemination
  - Need to demonstrate capacity to train trainers
- Challenges
  - Behavior support must be very individualized
  - We need a reliable diagnostic protocol for community practitioners

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SUSTAINABLE PRACTICE

Treatment intensity

- What is the "dose" needed to achieve the desired effect? Research questions include
  - How long each day? Over how many days?
  - What kind of staffing do you need? Delivered individually or in a group?
  - Training/supervision time/resources needed?
- Amount and type of staffing will drive cost

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ACCESSIBLE PROGRAMS
Delivered to diverse communities

- Must integrate the practice into existing programs of services to ensure access
  - School? Home? Community
- Must include programs for traditionally underserved groups
  - Address any barriers related to race/ethnicity, education, income, and so on
- Scholarship to describe how this is done

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SCALABLE PROGRAMS
Experts and Leaders

- Expert practitioners who can
  - Work with parents and different professionals
  - Develop into coaches and trainers
  - Assimilate new research findings
  - Get a head start with post-graduate training
- Leaders
  - Coordinate policy/program development
  - Few relevant training programs
- How do you build the training infrastructure to create experts and leaders?

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SCALABLE PROGRAMS

Networks

- No one person or center will do it all
- Mobilize for system change with the help of
  - Advocacy organizations
  - Agency and government leaders
- Implement system change with better collaboration across agencies
  - In health, education, community services
  - At local, state, (and sometimes federal) level
  - That conduct research, provide training, deliver community services, and set policy

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Beyond effectiveness: Scaling up intervention

RESEARCH & SCHOLARSHP NEEDED

More Implementation Research

Basic Research

↓

Outcome Research

↓

Implementation Research

Adapted from Doehring (2013)

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Beyond effectiveness: Scaling up intervention

RESEARCH & SCHOLARSHP NEEDED

More Implementation Research

Basic Research

Outcome Research

Research on implementation

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Beyond effectiveness: Scaling up intervention

RESEARCH & SCHOLARSHP NEEDED

Basic ⟷ Implementation Research

Basic Research

Outcome Research

Implementation Research

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