

Evidence-Based Policy Initiative

Gathering evidence on policy and practice issues of importance in developmental disabilities services

Project Overview and Description

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Workshop Purpose: Review Evidence Based Policy Initiative

- Describe the joint NASDDDS/AUCD initiative
 - Introduce key activities and products
 - Provide examples of collaborative activities
 - Recruit individuals and organizations to co-author/review EBPB
-
- Answer your questions

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Evidence-Based Policy

Begins with:

Evidence: 1. “The data on which a conclusion or judgment may be made < glacial evidence of climatic change>”

Webster’s New College Dictionary



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Policymakers radically diminish the potential of reforms if they allow themselves to be walked into accepting impoverished definitions of credible evidence.

Lisbeth Schorr
Education Week, August 25, 2009



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Evidence in Context

It must be remembered that there is nothing more difficult to plan, more doubtful of success, nor more dangerous to manage than a new system. For the initiator has the enmity of all who would profit by the preservation of the old institution and merely lukewarm defenders in those who gain by the new ones.

Niccolò Machiavelli

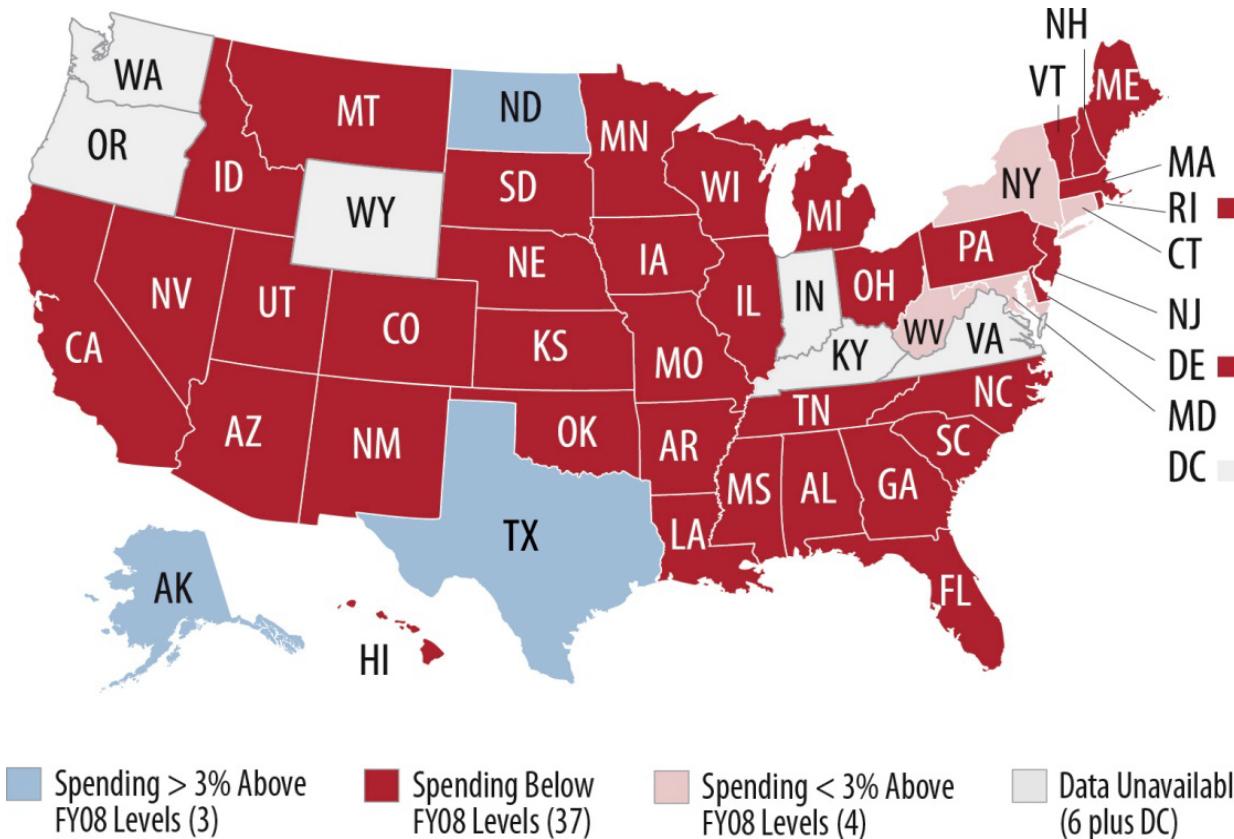


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States Are Under Pressure: FY 2011-12 State Spending is Below Pre-Recession Levels

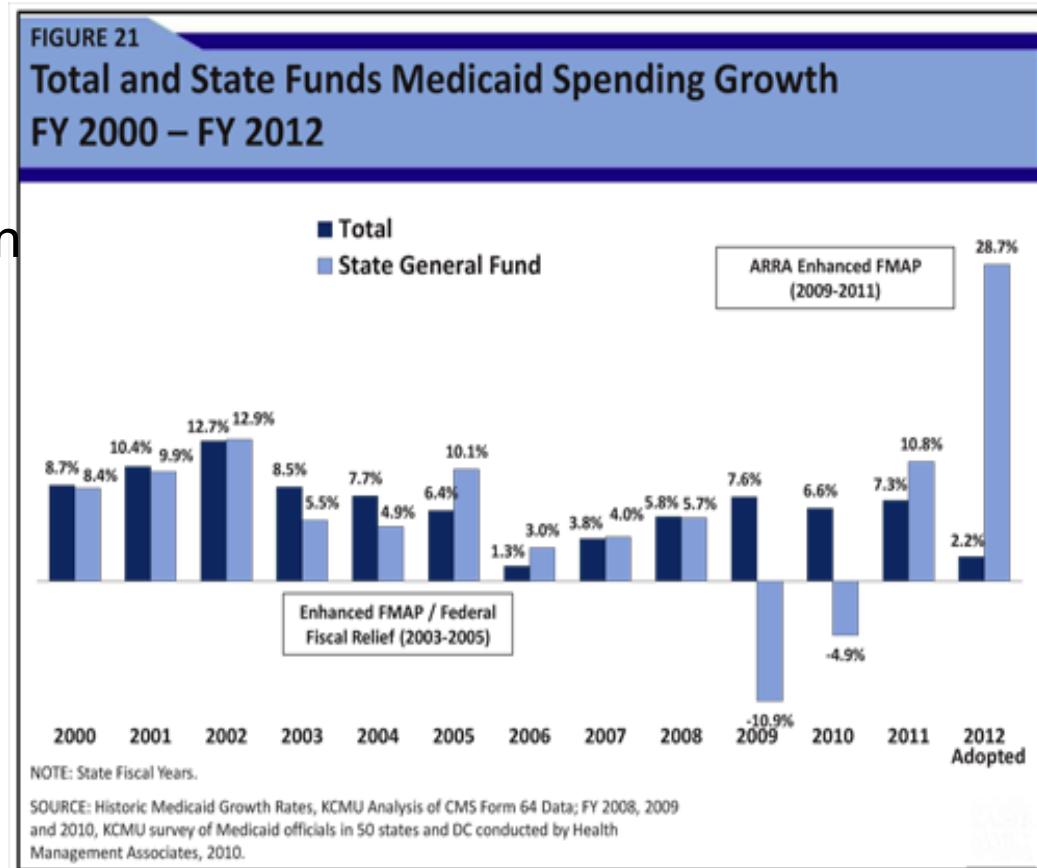


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Service Demand Continues to be Significant

- State Medicaid spending is projected to grow by an average of 29% in FY 2011-12
- The biggest increase in the history
- Picking up from loss of Federal stimulus dollars



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NASDDDS: “Evidence-Based Policy”

Evidence-Based Policy is the responsible application of best available evidence to the design and management of programs, services and supports for persons with developmental disabilities in a manner consistent with achieving greater independence, productivity, inclusion and exercise of free will for individuals and cost-effectiveness in public expenditures.

Adopted NASDDDS Research Committee, 2009



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The Evidence-Based Policy Commitment

We recognize that:

Individual policymakers do not control all aspects of policymaking, and that competing interests may impede application of the best evidence.

But we believe that:

Individual policymakers have a responsibility to acquire, understand and interject best evidence into policy deliberations.

Because we know that:

Failure to use the best available evidence in policymaking reduces the likelihood of benefit and increases the likelihood of detriment in services provided to people with disabilities



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Why this NASDDDS/AUCD Collaboration?

- Need to work together to identify and document research evidence in support of progressive policy and practice
- Competition for resources
- Expectations for efficiency/cost effectiveness
- Demand for data-based decisions
- Attention to the sustainability of systems
- EBP Initiative is a “natural” point of collaboration between public agencies and universities
- Desire for accessible information by all stakeholders



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Increased Focus on Sustainability in DD Systems

- What can we (and future generations) afford?
- What can we justify based on:
 - Relative costs of various options?
 - Resources spent in comparison with others in need?
 - Outcomes achieved for resources spent?
- What should we justify based on the need to:
 - Support the most integrated settings,
 - Employment and community participation



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Major Parts of Evidence-Based Policy Initiative

- **Identifying and Synthesizing Existing Evidence**
 - Too little research is accessible to policymakers
 - Need brief authoritative summaries
 - Need credible partners with research credentials
 - AUCD/NASDDDS synergy
- **Gathering and Analyzing Original Data**
 - Policymakers need data that responds to current issues
 - Need reliable and accessible data
 - Need data for comparison of programs/funding
 - Need data for complex questions (low incidence disabilities, controlling for related factors)
 - AUCD/NASDDD partnership's focus NCI



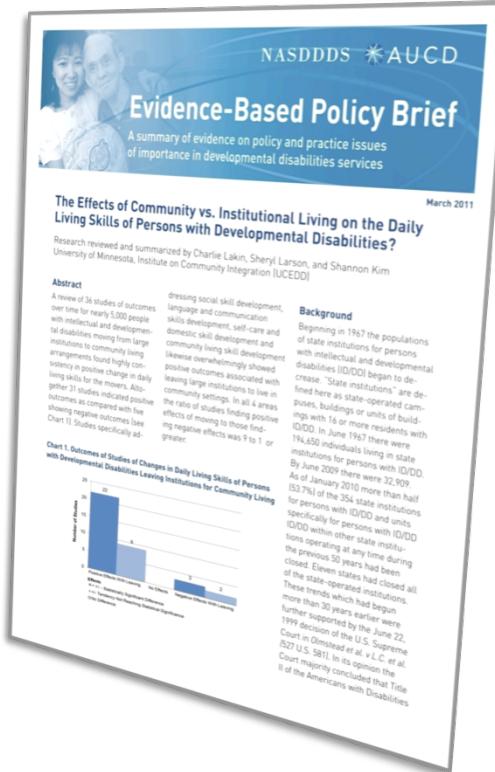
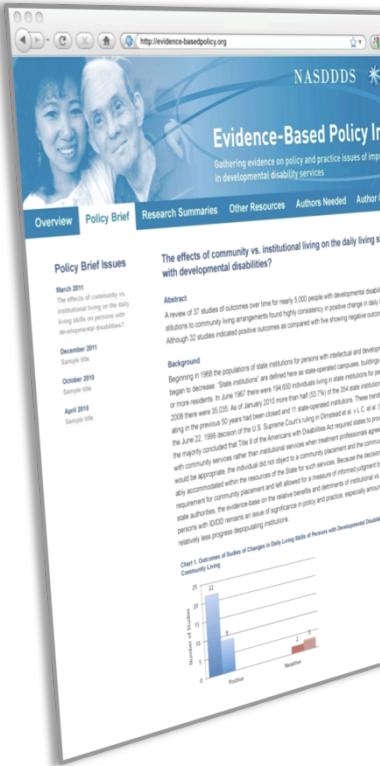
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Preparing the Briefs

- Project Description
- Policy Briefs
- Resources
- Author guidelines



- ## Addresses
- State and Federal policy needs
 - Key Topics of interest

Disseminating the Information

Challenges of Using Evidence in Policy

- Social research seldom produces unequivocal results; must accept preponderance of good evidence
 - Conflicting interests “cherry pick” research
 - Need comprehensive summaries
 - Need authoritative interpretations
- Clinical trials with random assignment is difficult in real life; but good evidence can still guide decisions:
 - Seat belts
 - Second-hand smoke
 - Speed limits



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States Need Data Consistent with Promised Outcomes and Available Resources

- Increasing self-determination and personal control in decisions and their families
- Providing opportunities for people to live, work and participate in their own communities
- Improving quality of life for individuals and families as they define it
- Supporting families as the most important and permanent unit of development, protection, and lifelong assistance
- Investing in each individual's developmental potential and capacity to contribute
- Assuring access to sufficient, high-quality health and social supports to protect each person's health, safety, rights, and well-being



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NASDDDS Members' Evidence-Based Policy Needs

- Comparative developmental outcomes associated with moving to community settings from large facilities/institutions.
- Trends, characteristics, costs and outcomes of adults with ID/DD or autism living in the family home.
- Comparative effectiveness of specific employment strategies for people with ID/DD
- Trends, costs and outcomes of host family and companion models of support for adults with ID/DD.
- Trends, characteristics, outcomes and challenges experienced by individuals and families directing their own services.
- Individual, program and policy factors are associated with the number of people with ID/DD in integrated employment.
- Effects of general or specific models of staff training on outcomes for service recipients; lower staff turnover, higher morale, lower costs, etc.



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Implementing Evidence Based Policy

Requires..

- More than well crafted research designs
- More than an analysis of relevant topics and issues
- More than an expectation that people will read and act on data and materials



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Implementing Evidence Based Policy

Requires

- Move beyond traditional methods of disseminating research findings and publicizing policy initiatives
- Adopt collaborative strategies to transfer knowledge specific to the topic under consideration
- Open, dynamic dialog between researchers, policymakers and key stakeholders
- The direct participation of policymakers and knowledgeable people who care about the issue throughout the research, data analysis and dissemination process*



* Tyden & Nordfors 2000

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Smart Policy: Using the Full Range of Tools

- Developing an evidence base alone is not enough to move public developmental disabilities policy forward.
- Follow the example of international diplomacy and Secretary of State Hillary Clinton's concept of accomplishing socially legitimate policy and diplomatic goals through the application of "smart power" - ***using the full range of tools at our disposal*** to reach strategic outcomes.

We need to adopt a similar approach and pragmatism.

- Policymakers and researchers must work together on multiple fronts with providers, families, people with disabilities, legislators and others to transfer the knowledge and strategically use the evidence to advance sound public policy.
- At a practical level, this means that state policymakers must use the ***full range of tools at their disposal*** to drive the evidence to policy:
 - explain the implications of the data, place it in perspective,
 - describe evidence in a way that is relevant to the everyday lives of people with and without disabilities.

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For More Information

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