

Evidence-Based Policy Brief

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

An overview of the NASDDDS/AUCD evidence-based policy initiative

In 2010 the National Association of State Director of Developmental Disabilities Services (NASDDDS) and the Association of university centers on Disability (AUCD) entered into a partnership to develop products and activities that would promote evidence-based policymaking. NASDDDS defines evidence based policy as “the responsible application of the best available evidence in the design, administration and reform of programs, services and supports for persons with intellectual and developmental disabilities consistent with achieving the outcomes desired by the Nation and the individual states” (NASDDDS Research Committee, 2009). By engaging the Association of University Centers on Disability and its network of researchers and scholars NASDDDS is seeking to establish a stronger foundation of knowledge to fulfill commitments in federal laws and court cases and parallel statements within the states to achieve National goals for people with intellectual and developmental disabilities , including —

- Increasing self-determination and personal control in decisions affecting people with disabilities and their families

- Providing opportunities to people with disabilities to live and participate in their own communities
- Improving quality of life for individuals and families as they define it for themselves
- Supporting families as the most important and permanent unit of development, protection, and lifelong assistance to persons with disabilities
- Investing in each individual’s developmental potential and capacity to contribute in age-related roles as productive, respected community members
- Assuring access to sufficient, high-quality health and social supports to protect each person’s health, safety, rights, and well-being

(See for sources: Developmental Disabilities Assistance and Bill of Rights Act; Americans with Disabilities Act (ADA) and the Supreme Court’s affirmation in *Olmstead*; Individuals with Disabilities Education Act (IDEA), The Rehabilitation Act of 1973 as amended; and UN Convention of the Rights of Persons with Disabilities)

Evidence-based policy

The concept of evidence-based policy

The concept of “evidence-based policy” as conceived by NASDDDS derives from the widely endorsed focus on “evidence-based practice” in clinical health services. Evidence-based policy recognizes that just as clinical practitioners, policymakers also share professional responsibility for the acquisition and application of the best available knowledge in their professional roles. Specifically, it acknowledges the responsibility of policymakers for the conscientious and efficacious use of evidence to design, manage and reform systems of support for persons with intellectual and developmental disabilities that predictably yield outcomes of benefit. At the same time, NASDDDS and AUCD as proponents of evidence-based policymaking recognize that the individual policymaker does not control all aspects of policymaking and that completing interests may impede the judicious application of knowledge and best practice. But they are certain that policymakers who do not use of knowledge of the predictable effects of their decisions as the primary in-

The *Evidenced-Based Policy Brief* series is a product of commitment of the National Association of State Directors of Developmental Disability Services and the Association of University Centers on Disability to assure that the design and management programs, services, and supports for persons with developmental disabilities is guided by the best available research evidence. *Evidenced-Based Policy Brief* selects topics of importance to the quality, accessibility, and affordability of services for individuals with developmental disabilities, their families, and provides a critical analysis of the best research evidence on those topics.

Issues of *Evidence-Based Policy Brief* can be found at <http://evidence-basedpolicy.org>

NASDDDS
National Association of State
Directors of Developmental
Disability Services

 **AUCD**
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH. EDUCATION. SERVICE

strument of policymaking and administration are less likely to benefit and more likely to harm the well-being of those persons for whom they have accepted responsibility. To the end of NASDDDS has made a commitment to be a significant source of assistance to state directors of developmental disability services and other public officials in meeting that responsibility.

Distinction between evidenced-based policy and evidenced-based practice

In recent years there has been substantial emphasis on evidence-based practices in health services. The foundation of evidence-based practices is generally well-designed, random assignment clinical trials. Such trials are effective and desirable, but are rarely possible within disability services in which people are assured the right to choose their own “treatment”. In fact adherence to clinical standards in disability service raises the substantial danger articulated by Lisbeth Schorr —

“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)

Evidence-based policy derives its definition of evidence less from the realm of clinical research and more from the realm of the everyday world, specifically as articulated in the first definition appearing in the standard Webster’s dictionary —

Evidence: 1. “The data on which a conclusion or judgment may be made < glacial evidence of climatic change>” (Webster’s New College Dictionary)

Challenges of “evidence in policy arenas”

There are significant challenges in using evidence in policymaking. Many of these challenges derive from the fact that social research seldom produces unequivocal results; other challenges derive from the fact that much of the available social research does directly congruent with policy-manipulable variables. In topics in which there are multiple studies there are likely to be seemingly contradictory finding within individual studies. This derives from the variation among individuals, social settings and/or the ways in which interventions or policies are implemented. In policy research it is often necessary to accept preponderance of good evidence through comprehensive reviews of all the available evidence. In the absence of comprehensive authoritative reviews, policymakers are often confronted with “cherry-picked” research in which advocates of different perspectives pick carefully within the available research those studies which best make the case for their desired policy. In addition to promoting the development of comprehensive objective reviews of literature on key policy topics in developmental disabilities, this initiative is also focused on substantially expanding access and use of outcome based research and evaluation to increase knowledge about the outcomes of policies and policy options within the various states and the nation as a whole. In pursuing the best available research and evaluation as the foundation for evidence-based policy there is recognition that while one might wish for availability of studies of the highest clinical rigor, the absence of the ability to random assign people to specific “treatment/non-treatment” has not impeded some of the most important policy decisions in the Unit-

ed states (e.g, seat belt laws, speed limits, protection from second hand smoke) all of which depended on a preponderance of non-clinical data.

Activities of the NASDDDS and AUCD partnership in evidenced-based policy

Among the activities being jointly pursued by the NASDDDS and AUCD networks are —

- Identifying the topics of highest importance and/or recurring attention in policy discussions within the states or Nation on which a comprehensive and objective review of high quality research and evaluation is needed;
- Developing policy relevant summaries of research and evaluation findings related to topics of highest importance and/or recurring attention to policies affecting persons with developmental disabilities;
- Create a jointly supported website for the posting of research/evaluation summaries, related research documents and other publications and presentations to search the purpose of educating public officials, advocates and others with key roles in the policy process;
- Maximizing the use and benefits of National Core Indicators or other outcomes assessment data sets data sets within the states with a specific goals of promoting policy relevant research questions, analyses and products;
- Developing capacities through UCEDD to UCEDD technical assistance in states with National Core Indicators or other outcome-related data sets in which experience and personnel of the state UCEDD is relatively inexperienced and unfamiliar with policy research and outcome evaluation;
- Serving as a training opportunity to increase the expertise of graduate students and state staff in policy research and evaluation, and in the development of policy relevant research questions and analyses;
- Undertake other activities with promise of increasing the effective gathering and use of the best available information to develop, evaluate and improve policies of importance to individuals with developmental disabilities and the commitments of the Nation and states to them.