

# 2021 Online KT Conference: Research Results for Policy Outcomes

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Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**

at American Institutes for Research ■

# TRANSLATING RESEARCH INTO DISABILITY POLICY— INSIGHTS OF A FORMER CONGRESSIONAL STAFFER

Presented by

Bobby Silverstein, JD

Principal, POWERS PYLES SUTTER & VERVILLE, PC

[Bobby.Silverstein@powerslaw.com](mailto:Bobby.Silverstein@powerslaw.com)

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# BACKGROUND

- Former staff director and chief counsel, U.S. Senate Subcommittee on Disability Policy, Committee on Health, Education, Labor, and Pensions (1986–1997)
- Currently principal in the law firm of Powers, Pyles, Sutter & Verville, PC (lobbyist, researcher and policy counsel with a focus on advancing disability policy)
- 45 years experience translating research into disability policy

# FOCUS OF PRESENTATION

- Explore how disability-related research informs the policymaking and policy implementation process
- Provide tips on how researchers can present their research in a form that maximizes its use by policymakers (and particularly their staff)

# WHAT IS PUBLIC POLICY?

- Public policy includes the formation of solutions to problems of general concern to the public.
- Policy:
  - Specifies rights and standards and proscribes inappropriate behavior (e.g., discrimination) and appropriate behavior (e.g., affirmative action)
  - Provides financial assistance to entities (often state and local government and nonprofits) offering services and supports
  - Provides assistance to individuals in the form of benefits (e.g., cash assistance)

# WHAT IS DISABILITY POLICY?

- Disability policy is specifically targeted at addressing the needs and strengths of individuals with disabilities and their families. Examples include the Individuals with Disabilities Education Act (IDEA), Title I of the Rehabilitation Act, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs.
- Disability policy also includes generic law that address the interests of individuals with disabilities as well as nondisabled individuals. Examples include the Affordable Care Act (ACA), Medicaid (Home and Community-Based Services), and Workforce Innovation and Opportunity Act (WIOA).

# ROLE OF RESEARCH IN ADVANCING DISABILITY POLICY

**Research helps explain to policymakers why change is necessary and the nature and scope of change**

- Document the nature and severity of the problem (understand historical and policy context)
- Identify policy options (prohibitions, prescriptions, funding and resources)
- Justify policy options (cost/benefit analysis)
- Develop and advance implementation methodologies and strategies
- Measure compliance (goals, benchmarks, standards, and guidelines)

# ROLE OF NIDILRR IN ADVANCING DISABILITY POLICY

- The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) plays a unique and critical role in advancing disability policy.
- NIDILRR invests in applied and action-research designed to explore new and innovative strategies, interventions, and technologies to better achieve the goals of disability policy articulated in the ADA—equality of opportunity, full participation, independent living, and economic self-sufficiency.



# EXAMPLES OF NIDILRR-SUPPORTED RESEARCH ADVANCING DISABILITY POLICY

- NIDILRR-supported research led to the development by the World Wide Web Consortium (W3C) of international standards for accessibility and usability of information and communication technology (Web Content Accessibility Guidelines, WCAG 1.0, 2.0 and 2.1). These guidelines are now incorporated by reference in the regulations implementing Section 508 of the Rehabilitation Act (ICT accessibility by federal agencies).
- A standard by the Federal Communication Commission (FCC) to allow phone companies to support real-time text was developed with NIDILRR funding.
- The Technology-Related Assistance for Individuals with Disabilities Act (P.L. 100-407) was based, in large part, on the research performed by NIDILRR grantees.

# EXAMPLES OF NIDILRR-SUPPORTED RESEARCH ADVANCING DISABILITY POLICY

- Research carried out by a NIDILRR grantee on personal assistance services (PAS) was used to justify the inclusion of PAS as a mandatory form of affirmative action under regulations implementing Section 501 of the Rehabilitation Act (affirmative action by federal agencies).
- Research and development of advanced technologies supported by NIDILRR is being used to expand and improve reasonable accommodations provided to employees with disabilities under Title I of the ADA (nondiscrimination in employment).

# RESEARCH ADVANCING COVID-19 POLICY FROM A DISABILITY PERSPECTIVE

- Since the beginning of the COVID-19 pandemic, the [Disability and Rehabilitation Research Coalition](#) (DRRC) has used research to advocate for enhanced collection of disability status information in all health care-related data collections.
- Disability populations have often been undercounted throughout the health care system, especially when new efforts (such as tracking around COVID-19 testing, infections, morbidities, and mortality) are launched, which exacerbates existing health disparities and makes it more difficult to develop solutions.

# COVID-19 RESEARCH (CONTINUED)

This advocacy has resulted in significant advances over the past few years, such as:

- Inclusion of disability status on the CDC's COVID-19 [case reporting form](#);
- [Interim recommendations](#) from the COVID-19 Health Equity Task Force recognizing the gaps in disability and other demographic data and incentivizing improved data- and community-driven approaches to better prepare for future pandemics;

# COVID-19 RESEARCH (CONTINUED)

- An [Executive Order](#) from President Biden on Advancing Racial Equity and Support for Underserved Communities, which formally recognizes people with disabilities as an underserved community and forms the Federal Equitable Data Working Group to address deficiencies in federal data, including lack of disaggregation by disability status and other demographic factors; and
- Report language in the House-passed Fiscal Year 2022 Health and Human Services appropriations bill that:
  - [Directs the CDC](#) to ensure disability data is included as a core demographic component across surveys and surveillance systems administered by the National Center for Health Statistics; and
  - [Directs the Interagency Committee on Disability Research](#) to work with the Federal Equitable Data Working Group to coordinate the collection of disability-specific data.

# RESEARCH ADVANCING ADA

- Research was essential to documenting the need for and development and passage of the ADA.
- Research documented the historical mistreatment and discrimination faced by people with disabilities.
  - “The severity and pervasiveness of discrimination against people with disabilities is well documented.” [National Council on Disability]
  - “Discrimination persists.” [U.S. Commission on Civil Rights]
  - “Discrimination against individuals with HIV infection is widespread and has serious repercussions for both the individual and the Nation’s efforts to control the epidemic.” [President’s Commission on HIV Epidemic]

# ADA EXAMPLE (CONTINUED)

- Research was essential for justifying key nondiscrimination provisions, including reasonable accommodations (cost), standards for making facilities accessible (Americans with Disabilities Guidelines, ADAG), documenting the modest cost of making new construction accessible when part of the initial design), and requiring the establishment of a nationwide telephone relay service.
- Research was critical to reaching the conclusion that the benefits to society of the ADA outweighed the costs.
- Most recently research was the basis for the guidance issued by the Justice Department and Office for Civil Rights that long COVID may be considered a disability under the ADA.

# RESEARCH ADVANCING EARLY INTERVENTION POLICY FOR INFANTS AND TODDLERS WITH DISABILITIES

- The Education of the Handicapped Act Amendments of 1986 (P.L. 99-457) established the landmark early intervention program for infants and toddlers with disabilities and their families.
- The need for the program, as reflected in the report accompanying the legislation, was based on research supported by the Department of Education and others. The Seventh Annual Report to Congress [regarding the implementation of P.L. 94-142] concluded that: “Studies of the effectiveness of preschool education for the handicapped demonstrated beyond doubt the economic and educational benefits of programs for young handicapped children. In addition, the studies have shown that the earlier intervention is started, the greater is the ultimate dollar savings and the higher is the rate of educational attainment by these handicapped children.”



# EARLY INTERVENTION PROGRAM (CONTINUED)

- The Committee Report also cited to research to indicate that early intervention accomplishes the following:
  - Helps enhance intelligence in some children;
  - Produces substantial gains in development and self-help skills;
  - Helps prevent the development of secondary disabling conditions;
  - Reduces family stress;
  - Reduces the need for special class placement; and
  - Saves substantial costs to society and schools.

# EARLY INTERVENTION PROGRAM (CONTINUED)

- The Committee Report also explains that the language in the legislation was based on and derived from research in child development and early childhood education and from experience of states that had tried early intervention programs.
- The legislation specified nine minimum components of a statewide system consisting of a comprehensive, coordinated, multidisciplinary, interagency, program providing early intervention services for infants and toddlers with disabilities and their families. These nine components were taken directly from the research.

# TIPS FOR PRESENTING RESEARCH TO POLICYMAKERS

## GUIDELINES FOR WRITTEN TESTIMONY

- Include a title of your presentation that grabs the attention of the policymakers and goes to the heart of the issue, consistent with basic American values
- Include information about your background that establishes your credibility
- Frame the issue in personal terms (get to policymakers' hearts before get to their heads)
- Define the issue/problem that needs to be addressed and identify the themes, principles, and approaches for addressing the problem
- Explain how your research addresses the issue/problem

# TIPS FOR PRESENTING RESEARCH TO POLICYMAKERS

## GUIDELINES FOR WRITTEN TESTIMONY [Continued]

- Describe your research findings, conclusions, and recommendations
- Do not use technical jargon—know your audience
- Focus on how research informs the policy making process
- Compare and contrast your research with research conducted by others

# TIPS FOR PRESENTING RESEARCH TO POLICYMAKERS

## GUIDELINES FOR ORAL TESTIMONY

- Follow general guidelines for written testimony
- Stay in role—present testimony from a consistent perspective (researcher, not advocate)
- Message—keep it simple; only make a few points (highlight key findings, conclusions, and recommendations from research)
- NEVER READ TESTIMONY—maintain eye contact with policymakers at all times
- Use examples and real-life anecdotes to personalize policy implications

# SUMMARY

Researchers can (and often do) play a critical role in informing the disability policymaking process, including documenting the problem, identifying policy options, justifying policy options, developing and advancing implementation methodologies and strategies, and measuring compliance.

Researchers can maximize the likelihood that their research will be used by policymakers and their staff by following certain guidelines, including getting to a policymakers' heart before getting to their head, keeping it simple, staying in role, and explaining how your research is relevant to the issues (bills) before the committee.



[www.ktdrr.org](http://www.ktdrr.org)



[ktdrr@air.org](mailto:ktdrr@air.org)



4700 Mueller Blvd, Austin, TX 78723



800.266.1832

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