

Projects of National Significance: Tracking Data Trends

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What are Projects of National Significance?

With the passage of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), came the introduction of many programs and services that benefit the I/DD community. The legislation established three different Longitudinal Projects of National Significance (PNS):

- The State of the States in Developmental Disabilities
- StateData: The National Report on Employment Services and Outcomes
- The National Residential Information System Project

The overall goal of these projects “support innovation, provision of practical information, data collection with respect to people with developmental disabilities, and training and technical assistance.”¹

These programs have been collecting data for almost four decades, and are a very helpful resource for academics, policy makers, and advocates that want to collect information on population of, and services for, the I/DD communities. All these projects are funded by the Administration for Community Living (ACL). This guide will briefly introduce each project of significance and explain how each may be utilized.

The State of the States in Intellectual and Developmental Disabilities

State of the States in Intellectual and Developmental Disabilities tracks spending and funding for services for the disability community. This includes institutional care and home and community-based services. They are based out of the University of Kansas. Though established in 82' their records date back to 1977. The project collects quantitative data about supports and services, including “community services and supports, public and private institutions, fiscal expenditures in states, and demand for services and supports.”²



State of the States
In Intellectual and Developmental Disabilities

The website hosts profiles on each state, the District of Columbia, and the territories as well. The primary data sources are the states themselves, with the state Medicaid offices and other authorized agencies, with secondary sources coming from the US Census for validation. The data is collected and reported every two years. The spending data shows “actual expenditures” to be as accurate as possible. The state agencies approve the data before being published.³

The data shows the impact over time of federal, state, and local government fiscal policy and shows trends in service delivery for community living, public and private residential institutions, family supports, supported employment, supported living, technology solutions, and Medicaid waivers.⁴ You can utilize this resource to see how much the state is funding long-term services and support and how many people are using these services.



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StateData: The National Report on Employment Services and Outcomes

Established in 1988, the StateData.info project researches the factors that influence employment at individual, service provider, and state level. Based out University of Massachusetts, Boston, this program also assesses employment and economic status of individuals with disabilities, and effectiveness of state agencies and vocational rehab agencies in promoting “full inclusion of individuals with developmental disabilities through employment and other community activities”.⁵



StateData.info promotes the ideas of Employment First and systems change by supporting outcome-based management and planning. Data is sourced mainly from I/DD Agencies, Vocational Rehabilitation, and supplemented by Social Security Administration, U.S. Census, and other datasets. StateData.info has two chart generation tools, where users can combine the data sets and get customized information related to employment for people with disabilities.⁶

The tools are State Snapshots and Build a Chart. The “State Snapshots” tool can be used to investigate trends in state performance of IDD work and participation, comparing states versus the national figures.⁷ The “Build a Chart” tool allows users to compare multiple states’ data, narrowing down the data by disability, number of people employed, mean annual earnings, and more.⁸ StateData.info resources are versatile and can be used to show the employment rate amongst individuals with disabilities and can compare them in many ways.

National Residential Information Systems Project

Since 1977, the National Residential Information Systems Project, known also as RISP, tracks the living situations of individuals with disabilities. RISP conducts its’ work out of University of Minnesota’s Research and Training Center on Residential Services and Community Living Institute on Community Integration. The statistics they gather relate to public residential facilities and the status therein, and characteristics of people living in those settings, while also reporting on trends around residential and community living supports.⁹



RISP’s website hosts a wide array of customizable data visualizations, divided into topics such as Living Arrangements, People Served by IDD Agencies, Medicaid, and more.¹⁰ RISP also provides assistance to individuals, government agencies, and others on residential and community supports for people with IDD, and publishes annually and monthly updates on the status and trends in residential and community living supports.¹¹

RISP also creates reports and projects tracking residential facility surveys, deinstitutionalization, and staff stability. The most recent data is from 2019. ¹² This resource is helpful for people wanting to know where people are living and what settings are available for individuals with disabilities.

Conclusion

These Longitudinal PNS provide a wealth of information about the landscape of the I/DD population and are a valuable resource. This is only a small look into the knowledge bank available. By introducing you to these resources, my hope is that you will expand your toolbox for creating more thoughtful products and show the wider scope of how policies affect the disability community, on local, state, and federal levels.

Citations:

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Images:

State of the States Logo www.stateofthestates.ku.edu

StateData.info Logo www.thinkwork.org/statedata

RISP Logo www.risp.umn.edu

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