



# **Progress and Opportunities in Ohio's Developmental Disabilities System**

**By: Rose Frech,**  
Guest Author

**May 8, 2023**

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## Key Highlights:

- Progress has been made in key areas to improve services for people with developmental disabilities across the state, including gains in Medicaid HCBS Waiver access, and a significantly smaller waiting list.
- In other areas, including aims to increase access to community employment at competitive wages, results have been more mixed. More individuals are engaged in community employment, but concerns persist regarding sheltered work and sub-minimum wage.
- The SFY 2024-2025 budget provides an opportunity to address the most critical issue facing the system—a severe DSP workforce shortage that has limited access to essential services and support.

## Introduction

Across Ohio, a significant number of people live with a disability or care for someone with a disability. While estimates vary, the most recent data from the American Community Survey suggests that approximately fourteen percent - or over 1.6 million Ohioans - have some type of disability.<sup>1</sup> Definitions of disability vary, are often broad, and encompass a wide range of conditions. As criteria and classification systems differ, determining the number of people with a *developmental* disability can be a challenge. However, studies indicate it's somewhere between one and two percent of all Ohio residents.<sup>2</sup> Nationally, about 17 percent of children have one or more developmental disability, or a developmental delay.<sup>3</sup> Trends indicate this number has increased over time, likely due to improved screening and awareness, resulting in the potential for more people seeking services as adults.<sup>4 5</sup>

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<sup>1</sup> U.S. Census Bureau. "American Community Survey," Types of Disabilities 2021 1-year estimates.

<https://data.census.gov/table?q=disabilities+in+ohio+2021&tid=ACSE2021.K201803>.

<sup>2</sup> Mehdizadeh, S. Kunkel, S. (2014). Projections of Ohio's Population with Intellectual and/or Developmental Disabilities by County, 2010-2030. Scripps Gerontology Center, Miami University, Oxford, OH.

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

<sup>3</sup> Centers for Disease Control and Prevention. "CDC's Work on Developmental Disabilities | CDC," May 16, 2022.

<https://www.cdc.gov/ncbddd/developmentaldisabilities/about.html#:~:text=Recent%20estimates%20in%20the%20United,one%20or%20more%20developmental%20disabilities.&text=Developmental%20disabilities%20are%20a%20group,%2C%20language%2C%20or%20behavior%20areas>

<sup>4</sup> CDC. 2019. "Increase in Developmental Disabilities among Children in the United States." Centers for Disease Control and Prevention. September 26, 2019.

<https://www.cdc.gov/ncbddd/developmentaldisabilities/features/increase-in-developmental-disabilities.html>

<sup>5</sup> Zablotsky, Benjamin, Lindsey I Black, Matthew J Maenner, Laura A Schieve, Melissa L Danielson, Rebecca H Bitsko, Stephen J Blumberg, Michael D Kogan, and Coleen A Boyle. 2019. "Prevalence and Trends of Developmental Disabilities among Children in the United States: 2009-2017." *Pediatrics* 144 (4): e20190811.

<https://doi.org/10.1542/peds.2019-0811>.

The developmental disabilities system in Ohio, charged with overseeing services for this growing population, is complex, comprised of a combination of federal, state, and local resources. While the Ohio Department of Developmental Disabilities (DODD) provides oversight to the statewide system, County Boards of Developmental Disabilities are typically the front door to services. As Ohio is a home-rule state, service delivery can differ from county-to-county. Overall, the system serves over 98,000 people.<sup>6</sup>

As people with developmental disabilities and advocates persist in their efforts to create true community integration, the system continues to evolve and shift in response. There is an ongoing advocacy effort regarding the need to enhance access to community-based services and promote inclusion throughout all facets of life. While there has been progress, challenges remain and additional work is needed to ensure individuals and families receive the support they need to thrive in the setting of their choice.

Multiple initiatives and efforts are underway across the state to address these issues, with the potential for additional transformation and system improvement. This brief will highlight several key issues currently impacting people with developmental disabilities and their caregivers in Ohio, as well as opportunities for additional reform.

## Summary of Key Issues

### *Historic Gains in Waiver Availability*

In Ohio, important gains have been made in some key areas over the past decade, including increased access to Medicaid Waivers. Medicaid Home and Community Based Service (HCBS) Waivers allow people with disabilities to receive services in their homes and communities, rather than in Intermediate Care Facilities (ICFs) or other institutional settings. HCBS Waivers are the state's most important tool to provide people with independence, choice, and dignity. The state has continued to increase investments in waiver services over the past several budget cycles, resulting in increases in enrollment.<sup>7</sup> According to DODD, "Since 2013, enrollment in SELF waivers has increased by 690%. In the same time span, enrollment on Individual Options and Level One Waivers have increased by 33% and 17% respectively." Currently, over 51,000 people in Ohio are served by these three DODD waivers.

Relatedly, working in concert with stakeholders and advocates, DODD has made crucial strides in addressing the issue of waiting lists for Medicaid Waivers—a massive issue that has plagued the state for years. Due to these long waiting lists and inconsistencies in waiting list management, many individuals were unable to access essential community-based services. Additionally, because counties addressed eligibility for waiting lists differently, the state lacked a clear picture of the unmet needs that existed.<sup>8</sup> New state rules, made effective in 2018, required local Boards to utilize a standardized assessment to determine level of need when individuals applied for

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<sup>6</sup> "People Served by DODD." 2019. Ohio.gov. 2019. [https://dodd.ohio.gov/about-us/dodd\\_data/quickstats/quickstats\\_people\\_served](https://dodd.ohio.gov/about-us/dodd_data/quickstats/quickstats_people_served).

<sup>7</sup> "People Served by DODD," n.d. [https://dodd.ohio.gov/about-us/DODD\\_Data/QuickStats/QuickStats\\_People\\_Served](https://dodd.ohio.gov/about-us/DODD_Data/QuickStats/QuickStats_People_Served)

<sup>8</sup> Frech, Rose. "Ohio at a Crossroads: Three Years Later, an Update on the State's Developmental Disabilities System." The Center for Community Solutions. July 2018. <https://www.communitysolutions.com/research/ohio-crossroads-three-years-later-update-states-developmental-disabilities-system/>

waivers, with a greater emphasis on ensuring services are provided to those with current unmet and immediate needs first.<sup>9</sup>

As a result, waiver waiting lists have decreased drastically. In 2014, over 45,000 people were on Ohio's waiting list.<sup>10</sup> As of February 2023, this had dropped to approximately 1,300 individuals, a decline of over 97 percent. According to data provided by the Cuyahoga County Board of Developmental Disabilities, there are currently zero people on its waiver waiting list, down from 1,600 in 2018, prior to the policy change.

### ***Efforts to Improve Access to Community Employment Have been Mixed***

In other areas, efforts at reform have been mixed. In Ohio, like most other states, policy has gradually been shifting to align with a philosophy that people with disabilities should have the right, and opportunity, to work for competitive wages in community settings. Overall, more individuals across the state have opportunities to express choice and explore opportunities for community employment. Employment First, the state's initiative designed to support the transition from an overreliance on non-integrated settings (like sheltered workshops) into competitive integrated employment, recently celebrated ten years since its inception. The combination of this effort, along with changes to federal Medicaid rules which discouraged sheltered work settings, has led to a decline across the state in facility-based work programs.

According to the most recent data publicly available through the Employment First Outcome Tracking System (OTS), for Reporting Period 2021,<sup>11</sup>:

- Twenty percent of people (5,553) receiving services were engaged in competitive employment, a 21 percent increase from the prior year. This is an important indicator as many individuals with developmental disabilities are capable of, and interested in, competitive integrated employment. Survey research shows that as many as 40 percent of individuals with developmental disabilities in Ohio who are not engaged in paid community work would like to be. Other studies have shown that "people with intellectual disabilities generally experience higher rates of job satisfaction in integrated employment environments (e.g., competitive employment) than they do in sheltered employment settings."<sup>12</sup> Contrary to commonly held beliefs, people with developmental disabilities can work in a range of industries in a variety of roles,

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<sup>9</sup>"Ohio Department of Developmental Disabilities Comprehensive Guidance Ohio's Waiting List for HCBS Waivers and Assessment for Immediate Need and Current Need." Ohio Department of Developmental Disabilities, January 2019. [https://dodd.ohio.gov/wps/wcm/connect/gov/5a386f6c-2840-4601-9a65-2b34f5375303/Waiting+List+Assessment+Comprehensive+Guidance.pdf?MOD=AJPERES&CONVERT\\_TO=url&CACHEID=ROOTWORKSPACE.Z18\\_M1HGGIK0NOJO00QO9DDDDM3000-5a386f6c-2840-4601-9a65-2b34f5375303-n1Ef80-](https://dodd.ohio.gov/wps/wcm/connect/gov/5a386f6c-2840-4601-9a65-2b34f5375303/Waiting+List+Assessment+Comprehensive+Guidance.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=ROOTWORKSPACE.Z18_M1HGGIK0NOJO00QO9DDDDM3000-5a386f6c-2840-4601-9a65-2b34f5375303-n1Ef80-).

<sup>10</sup> Frech, Rose, Jon Honeck, Kate Warren, and The Center for Community Solutions. "Ohio at a Crossroads: The Developmental Disabilities System," March 2015. [https://www.communitysolutions.com/wp-content/uploads/2018/04/MajorReport\\_DD-System\\_032015\\_Frech\\_Honeck\\_Warren.pdf](https://www.communitysolutions.com/wp-content/uploads/2018/04/MajorReport_DD-System_032015_Frech_Honeck_Warren.pdf).

<sup>11</sup> The Ohio Department of Developmental Disabilities, Employment First. "Outcome Tracking System," 2021. [https://ohioemploymentfirst.org/up\\_doc/OTS\\_Employment\\_Data.pdf](https://ohioemploymentfirst.org/up_doc/OTS_Employment_Data.pdf).

<sup>12</sup> Voermans, Moniek A C et al. "The value of competitive employment: In-depth accounts of people with intellectual disabilities." *Journal of applied research in intellectual disabilities: JARID* vol. 34,1 (2021): 239-249. doi:10.1111/jar.12802

depending on their specific skills and interests, and the supports and accommodations available.

- Wages also increased from the previous two years, with an average hourly wage of \$13, up from \$10 in 2019.
- Significantly fewer people were participating in facility-based work (3,440 fewer) between 2019 and 2021.
- Data was only submitted for 72 percent of individuals through the outcome portal; therefore, the data is incomplete in reflecting all outcomes across the state.
- Other datasets demonstrate that the greatest number of individuals continue to participate in non-work, unpaid activities, either in the community or facility-based settings (such as adult day support programs).

Overall, the decrease in facility-based “sheltered” work over the past decade has been meaningful, while increased access to competitive employment has been less noteworthy. However, the impact of COVID-19 on community employment, as well as group and facility-based work and non-work services, cannot be overstated, and muddies the ability to analyze the impact of prior related policy changes. This issue will be explored in a future installment.

The gains in wages for those in competitive employment are a crucial step forward, however, is offset by historically high inflation. Issues continue to persist related to subminimum wage for individuals engaged in facility-based work. There are approximately 4,800 individuals engaged in facility-based “sheltered work” across the state. According to OTS data from 2021, the average wage for individuals in Ohio engaged in facility-based work was \$6/hour, with an average of 11 hours worked per week. Ohio law allows employers in some settings to pay less than minimum wage to people with disabilities, however, the U.S. Department of Labor must grant permission. Currently, over 30 providers are listed on the DOL website as 14(c) certificate holders, which authorize employers to pay subminimum wage, and several others are listed as pending. Proponents state that the protection allows employers to offer more opportunities to more people, while creating a pathway to competitive work at competitive wages. Opponents believe the allowance invalidates the work of people with disabilities and exploits their labor. Meanwhile, some states have passed legislation prohibiting employers from paying less than minimum wage.<sup>13</sup> Ohio legislators have introduced similar legislation, but it has yet to gain any real momentum.<sup>14</sup>

It is worth noting that efforts to address stereotypes and fight stigma regarding the employment of people with disabilities is also necessary, in addition to policy reform. Employers often lack education regarding the benefits of hiring people with developmental disabilities, which can result in bias in hiring. Ongoing advocacy is essential in this area.

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<sup>13</sup>Association of People Supporting Employment First. “State Legislative Watch - Association of People Supporting Employment First.” March 30, 2023. <https://apse.org/state-legislation/>.

<sup>14</sup>“Disability Rights Ohio - #AdvocacyMatters: Real Wages for Real Work,” September, 2022. <https://www.disabilityrightsohio.org/news/advocacymatters-real-wages-for-real-work>.

### ***The Workforce Crisis***

There are multiple areas where additional system improvements are still necessary. The most urgent concern among stakeholders and advocates is the well-documented crisis facing the Direct Support Professional (DSP) workforce. A DSP is an individual who works with people with disabilities to promote their independence, support daily activities, assist with personal care, and help to address other various needs. The workforce crisis has had resounding impacts on the system and diminished some of the gains made in access to key waiver services, as individuals have struggled to access the care they need. Data summarized by DODD Director Kim Hauck in her Department's state budget request makes clear the severity of the situation.

"The federal poverty line for a family of four is \$13.34, while the average starting wage for a DSP providing essential support for Ohioans with developmental disabilities is just \$12.10 an hour. It is estimated that 18% of the Ohio direct care workforce falls below the federal poverty line. Additional workforce statistics are just as sobering, with an estimated 44% of Ohio direct care workers receiving public assistance, 25% receiving food and nutrition assistance, and 32% on Medicaid."

"It is estimated that by 2028, the anticipated demand for new direct care workers in Ohio will grow by 24%. Considering expected growth and projected separations due to workforce demographics, the total number of anticipated direct care job openings in Ohio is over 150,000." According to a survey conducted by the Ohio Provider Resource Association (OPRA), providers in Ohio have had to turn away referrals and even discontinue services for existing clients due to a lack of staff.<sup>15</sup>

It is important to note that Medicaid rates, established by the state legislature, drive wages for DSPs. These rates are not typically adjusted for inflation. Furthermore, federal law requires that Medicaid payments be accepted as payment in full, which means providers cannot supplement wages with funds from other sources. Therefore, changes to rates are the primary mechanism to provide more competitive wages to the workforce and drive more people into the field.

### ***Disparities within the system***

Finally, other lingering systemic issues embedded within Ohio's system remain. This includes ongoing inconsistencies from county-to-county, resulting in disparate access to services across the state. Variable access to local levy dollars is an important factor. According to financial rankings tracked by DODD, counties vary widely on the percentage of people served, availability of local funding to support waivers, provider capacity and numerous other factors.<sup>16</sup> Where you live is still an important predictor of what services are available.

Nationally, health disparities exist among racial and ethnic minorities with disabilities; one study explored this issue and found that "racial and ethnic minorities with IDD have a compounded risk of underutilization of general care services," noting that racial minorities with developmental

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<sup>15</sup> Testimony to Finance Subcommittee on Health and Human Services, March 14, 2023

<sup>16</sup> Ohio Department of Developmental Disabilities, "County Board Financial Ranking," <https://dodd.ohio.gov/county-boards/business-management/cb-workbook>

disabilities are “doubly stigmatized” within the healthcare system.<sup>17</sup> Other studies have indicated disparities in access to care and health outcomes.<sup>18</sup> Racial equity efforts occurring statewide and nationally must consider the needs of, and the disparities that exist, among people of color with disabilities.

## Opportunities for System Improvement

Each of these areas requires attention by policymakers and opportunities exist to continue modernizing and improving the system. This includes opportunities within the State Budget and the Medicaid Waiver Redesign Initiative.

### ***SY 2024-2025 State Budget***

As of May 2023, Ohio is mid-way through the biennial state operating budget process. Given the workforce crisis facing the DD system, advocates are looking to the state budget as an essential tool to improve this issue and have been highly engaged throughout the process. In January, the Governor released his Executive Budget where he paid significant attention to DD issues.

Of greatest note, the Governor’s budget included a Medicaid HCBS Waiver rate increase specifically designed to result in wage increases for DSP staff. This included a proposed increase for residential HCBS of 16.5 percent, resulting in \$16/hour **average** wage, and a proposed rate increase for other HCBS services of ten percent. The budget also proposed ICF rate increases. The Governor’s budget also included the creation of a new Department of Children and Youth that would combine the services and resources of several departments into one. The intention behind the new Department is to promote greater collaboration and resource sharing, while demonstrating the state’s commitment to supporting children. This would have implications for early identification and intervention services, which are now housed within the DODD, but would move to the new department. The proposed budget includes continued support for youth with complex needs, through the state’s Multi-Disciplinary Comprehensive Assessment Team, which can provide youth access to a team of experts for assessment and recommendations on intervention strategies, and the Keeping Families Together initiative, which provides supports to families with children who have complex needs, designed to keep the child in the home (including respite care, incentives, and recreational opportunities).

While Governor DeWine did not propose an increase in funding for Employment First, the proposed budget would allow the state, for the first time in twenty years, to draw down its full federal match for vocational rehabilitation services to support moving more individuals into community employment.

Other relevant items include a proposed requirement that counties appoint an individual who is eligible for services to local Developmental Disability Boards—while some counties have long

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<sup>17</sup> Scott HM, Haverkamp SM. Race and health disparities in adults with intellectual and developmental disabilities living in the United States. *Intellect Dev Disabil*. 2014 Dec;52(6):409-18. doi: 10.1352/1934-9556-52.6.409. PMID: 25409129.

<sup>18</sup> Mitra, Monika, Linda M. Long-Bellil, Ian Moura, Angel Miles, and H. Stephen Kaye. “Advancing Health Equity And Reducing Health Disparities For People With Disabilities In The United States.” *Health Affairs* 41, no. 10 (October 1, 2022): 1379–86. <https://doi.org/10.1377/hlthaff.2022.00499>.



made this practice, others have not. Additional proposed changes relate to investments in technology support and the availability of universal changing tables in public places and businesses.

Throughout February and March, the Health and Human Services Subcommittee held hearings on the budget and had multiple opportunities to hear from advocates, caregivers, providers, and consumers within the DD system. Testimony continued into April as the budget returned to the Full Finance Committee. While the general response to many of the items introduced by the Governor have been positive, advocates have largely focused their efforts on the need for higher rate hikes than those proposed to allow for greater increases in wages, that allow DD providers to compete in the current labor market and adequately compensate DSPs for the critical and challenging work they perform.

A call for pay parity, or the need to ensure that DSP wages are similar across the system, has also been raised by advocates, with concerns that the differential rates proposed could result in people leaving jobs where rates are lower (like adult day) for more lucrative DSP opportunities. Specifically, advocacy efforts have coalesced around the need for a HCBS rate increase that would result in an average \$20 per hour wage for DSPs.

Highlights of testimony include:

—**Bill Adams, Board Member, Scioto County Board of Developmental Disabilities, and recipient of DSP services,** “Our DSPs are not only paid supports, but they have become friends and sometimes more like family. The lack of a living wage promotes rapid turnover and when we don't have the opportunity to build these foundations with our staff, we lose our independence and quality of life.”

—**Former DSP, Joshua Peterson, on the need to leave a job he loved in order to meet his financial needs:** “I am often asked if I would consider returning to this field, which is one I still believe is very important. However, the financial reality of my life and the lives of many DSPs who leave this field ultimately has the final say. I would be able to return—and gladly do so—for a living wage that started at \$20.00 an hour, in addition to seeing foundational resources given to the provider agencies that would allow them to create a workforce infrastructure that ensures consistent and reliable healthcare coverage and opportunities for advancement commensurate with wages.”

—**Connie Boros, Achievement Centers for Children:** “Not being able to add team members has limited ACC’s ability to accept new clients.... Despite performing their job at the highest level and despite our families and ACC holding them in high regard, the inadequate waiver rates do not allow us to pay employees at a rate that reflects their value.”

—**Gary Tonks, The Arc of Ohio:** “It is not uncommon for me to receive a call in the morning that goes like this: “Gary, no one showed up. I can’t get out of bed and I have to pee. I don’t want to wet myself. Please help.” If the call was within Franklin County, I would absolutely try to help myself, but these calls are often from over an hour away.



There are no support staff available.”

In mid-April, the House Finance Committee released its version of the budget. While many provisions remained untouched, there were several key changes. It was clear that members took seriously the concerns raised regarding wages; the substitute bill includes additional funding to support an average DSP wage of \$17/hour beginning in January 2024, increasing to \$18 in SFY 2025. Another new provision would permit probate courts to consider “supported decision-making” as a less restrictive alternative to guardianship for adults with developmental disabilities, in some instances. This seeks to address the concerns of some advocates that guardianship arrangements can be overly restrictive and limit self-determination. The House budget also proposes reductions in funding for the aforementioned multi-system youth initiatives, in the amount of \$2 million per year, as well as reductions to DODD’s Technology First initiative.

While the House-passed sub-bill no doubt represents progress in the mind of advocates, the proposed funding is still short of the \$20/hour average wage that many believe is needed. Stakeholders will continue to have opportunities to describe their challenges as the budget moves to the Senate, and wages will likely remain front and center.

### ***Ongoing reforms in Medicaid Waivers***

Meanwhile, as the debate regarding rates continues and despite recent reforms and increased investments, DODD recognized the need for broader changes to address issues within the waiver system, including growing complexity, duplication, and inconsistencies. In July of 2022, the Department announced a Waiver Redesign Initiative. The redesign is intended to address the need for “redesign, modernization, and simplification of current processes related to assessments, funding, rate setting, data collection, and establishing individual budgets for Medicaid Home and Community-Based Services Waivers administered by DODD.”<sup>19</sup>

More specifically the stated goals of the Initiative are to:

- Create a simpler and more streamlined funding system built on fair and logical payment systems;
- Continue to be good stewards of limited public resources by incorporating sustainable structures;
- Provide quality outcomes by establishing processes that are flexible enough to meet the diverse needs and preferences of people receiving services;
- Be responsive to choices made by the people served, in alignment with community supports; and
- Develop a system-wide vision and long-range strategic plan by listening to those we support, funding partners, and stakeholders.”

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<sup>19</sup> “Vendor Selected: DODD Waiver Redesign Initiative,”. <https://dodd.ohio.gov/communication/news/news-vendor-selected-dodd-waiver-redesign-initiative>

As a first step, DODD released a Request for Proposals, seeking an entity to provide oversight to the redesign initiative. In January 2023, the department selected Deloitte Consulting LLP as the vendor. Deloitte, one of the largest consultancy firms in the country with a global reach and an Ohio office located in Columbus, has been involved in state Medicaid projects across the country, including prior and current work within Ohio's Medicaid system.

The Redesign Initiative is in its preliminary stages. Most recently, DODD has begun outreach to stakeholders regarding opportunities for engagement and feedback, and will be conducting surveys, focus groups and interviews.

## Conclusion

This represents only a sampling of potential reforms that will have significant implications for the DD system, and more importantly, the people it serves. While the new state budget will likely result in reforms, a multitude of other proposed policy changes at the federal level could also result in major changes.

For example, in addition to the aforementioned state-led efforts, legislation has been introduced at the federal level to phase out subminimum wages for people with disabilities. In February 2023, Representative Robert Scott of Virginia introduced the bipartisan Transformation to Competitive Integrated Employment Act that would end the practice of issuing new 14(c) certificates and support employers to transition to supporting competitive community employment for people with disabilities. This legislation faces an uphill battle to clear Congress and requires significant advocacy efforts if it is to pass.

Also, and of great importance, any potential for deep cuts to federal Medicaid spending proposed by some Congressional members would have a profound impact on services, as Medicaid is the primary funder of services for people with disabilities.

This is a system where the hard work of advocates has been seen and felt for decades, resulting in substantial changes to policy and cultural norms. Ongoing advocacy will be necessary given the range of pressures and opportunities that currently exist.

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This research represents a partnership between Achievement Centers and Children, the George Gund Foundation, and the Center for Community Solutions. Achievement Centers for Children in their recently adopted strategic plan identified being an advocacy leader on behalf of persons with disabilities as one of their strategic priorities. This research on state funding and policy related to persons with developmental disabilities is one of the first outcomes of the Achievement Centers for Children's new strategic focus. Community Solutions is grateful for the opportunity to reexamine a topic which hasn't been reviewed since 2015.

For additional information about Achievement Centers for Children please contact Connie Boros, Vice President, Public Policy, Advocacy, and Engagement at [connie.boros@achievementctrs.org](mailto:connie.boros@achievementctrs.org) or 216-292-9700 ext. 250 or visit [www.achievementcenter.org](http://www.achievementcenter.org)



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