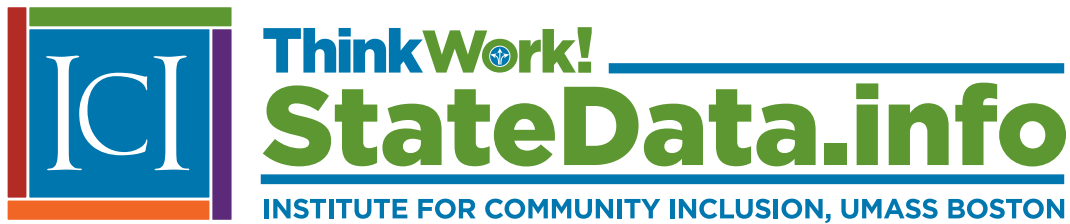


StateData: The National Report on Employment Services and Outcomes Through 2018

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Published 2021



The StateData employment report is a product of ThinkWork! at the Institute for Community Inclusion, University of Massachusetts Boston, supported in part by the Administration on Disabilities, Administration for Community Living, US Department of Health and Human Services, under cooperative agreement #90DNPA0002. The opinions contained in this report are those of the grantee and do not necessarily reflect those of the funders.



ACKNOWLEDGEMENTS

The authors would like to express sincere thanks to our collaborators at the National Association of State Directors of Developmental Disabilities Services, including Mary Sowers, Rie Kennedy-Lizotte, Jeanine Zlockie, Barbara Brent, Teja Stokes, and Mary Lou Bourne. Additionally, the authors acknowledge the contributions of ICI's entire StateData team, including Cindy Thomas, Suzanne Freeze, and Allison Cohen Hall, as well as Jeff Coburn, Paul Foos, David Temelini, and Katie Ashwill Allen, who assisted in the editing, layout, and production of this report.

Special thanks are directed toward the state administrators and key survey contacts in each state who consistently respond to the ICI's Intellectual and Developmental Disabilities Agency National Survey of Employment and Day Services. Their expertise, insights, and assistance have helped to make this report possible.

The authors wish to thank the Administration on Disabilities, and in particular Dana Fink, our Project Officer, and Julie Hocker, Commissioner on Disabilities for ongoing support of this project and its activities.

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SUGGESTED CITATION

Winsor, J., Timmons, J., Butterworth, J., Migliore, A., Domin, D., Zalewska, A., & Shepard, J. (2021). StateData: The national report on employment services and outcomes through 2018. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

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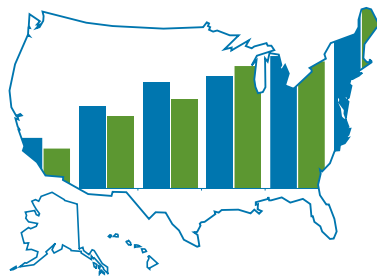
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EXECUTIVE SUMMARY

Recent policy initiatives including Medicaid Home and Community-Based Services (HCBS) guidance, the Workforce Innovation and Opportunity Act of 2014 (WIOA), and settlement agreements between states and the U.S. Department of Justice clarify federal intent and pave the way for supporting opportunities for people with disabilities to have meaningful jobs in their communities. Newer initiatives include the proposed Transformation to Competitive Employment Act and state legislation targeted at eliminating subminimum wage. With an increasing emphasis on integrated employment and adoption of Employment First policy at the state level, the nation is poised for transformation that could put Americans with disabilities on a path out of poverty and toward self-sufficiency.

However, there remains a significant gap in employment rates between people with and without disabilities. The 2018 American Community Survey estimates that 37% of working-age adults with disabilities are employed, compared with 76% of people without disabilities (Winsor et al., 2020). When people with disabilities are employed, they are more likely to work part time (28%) compared to people without disabilities (15%) (Bureau of Labor Statistics, 2020).

For people with intellectual and developmental disabilities (IDD), the disparity in employment participation is even greater. Data from the National Core Indicators project suggest that in 2017–2018, only 18% of working-age adults supported by state IDD agencies were employed in a paid job in the community (National Core Indicators, 2019).

A survey of 190 U.S. community rehabilitation providers reported that only 17.5% of 33,874 adults with IDD served in FY2014–2015 worked for pay in individual jobs with either time-limited or ongoing supports (Domin & Butterworth, 2016). Those who are employed typically work limited hours with low wages (National Core Indicators, 2019). At the same time, participation in facility-based and non-work services has grown, suggesting that employment services remain an add-on rather than a systemic change (Winsor et al., 2019; Nord et al., 2016; Mank, 2003; Domin & Butterworth, 2012).

For over 30 years, the Institute for Community Inclusion (ICI) has been home to Access to Integrated Employment, a national data-collection project on day and employment outcomes funded by the Administration on Intellectual and Developmental Disabilities. Since 1988, this project has described the nature of day and employment services for individuals with IDD, and has contributed to a comprehensive understanding of the factors that influence employment outcomes at the individual, service-provider, and state-policy level.

This report is divided into two sections:

- » **A comprehensive overview that describes national trends in employment for people with IDD.**
- » **An appendix with individual state profiles and a national profile.**

Data from four sources is included: the ICI's IDD Agency National Survey of Day and Employment Services (from FY1988, 1990, 1993, 1996, 1999, 2001, 2004, and 2007 through 2018); the Social Security Administration (Supplemental Security Income Annual Statistical Report); state vocational rehabilitation (VR) programs (RSA-911); and the U.S. Census Bureau (the American Community Survey).

Data continue to highlight the economic disparities between people with and without IDD. State investment in supports continues to emphasize facility-based and non-work services, rather than integrated employment services. In the VR system, earnings of adults with disabilities are substantially lower compared to those in the general population, and weekly earnings of individuals served by VR have declined slightly over time. Overall, the findings suggest that across data sources, people with intellectual disabilities experience greater levels of unemployment, underemployment, low wages, and poverty compared to those without disabilities.

In the IDD system, national estimates suggest that there has been only modest growth in the number of individuals in integrated employment services since 1988. The estimated percentage of individuals participating in integrated employment services was 21.1% in FY2018, while investment in non-work services continues to expand. FY2018 data do suggest steady year-over-year growth in the number of people in integrated employment services over the last five years.

In the VR system, the rehabilitation rate, defined as the percent of people who entered employment out of those who completed an individual plan for employment (IPE), was 46% in program year 2018 for people with intellectual disabilities. For 2019, 27% of all VR closures with an intellectual disability exited with a job within one year of when they applied for services. This is down from a peak of 33% of closures in 2016 and 2017. Overall the number of people with an intellectual disability who exited VR services with a job has decreased over the past five years.

The American Community Survey (ACS), an initiative of the U.S. Census, provides a population perspective on employment, including people who do not have a connection with funded services. ACS data continue to show that people with disabilities are much less likely to work than their counterparts without disabilities, and illustrate the relationship between disability and poverty. People with a cognitive disability who are receiving Supplemental Security Income (SSI) have the lowest employment rate of all disability subgroups examined, and are the most likely to live in a household that is below the poverty line.

Data from the Social Security Administration show that work incentive programs for SSI recipients with disabilities remain underused. SSI recipients with ID work more than their counterparts with other types of disabilities, but participate in work incentive programs less frequently. Older SSI recipients work less frequently than their younger counterparts, but use work incentive 1619(b) at higher rates.

Although data on employment participation for people with an IDD for FY2018 suggest progress, overall data demonstrate the continuing need to strengthen policies, practices, and initiatives that prioritize employment. The shift toward Employment First policies and actions to implement federal policy from the Centers for Medicare and Medicaid Services, WIOA, and the Department of Justice can make an important contribution to raising expectations, improving outcomes, and increasing self-sufficiency for individuals with IDD in every state. Proposed legislation at the federal level including the Transformation to Competitive Employment Act and recommendations to eliminate subminimum wage employment build on existing policy and address the need to expanded capacity to provide high quality employment supports.

INTRODUCTION

DISPARITIES IN EMPLOYMENT

There are significant employment disparities between people with and without disabilities. The 2018 American Community Survey (ACS) indicates that the employment rate for working-age adults without disabilities (75.5%) is more than twice the rate for working-age adults with disabilities (36.9%) (Winsor et al., 2020). When people with disabilities are employed, they are more likely to work part time (28%) compared to people without disabilities (15%) (Bureau of Labor Statistics, 2020). In addition to being under-represented in the workforce, research indicates that individuals with disabilities have less job security, receive less company-sponsored training, and have lower rates of participation in decision-making when compared to workers without disabilities (Mitra & Kruse, 2016; Schur et al., 2009).

For people with intellectual and developmental disabilities (IDD), these disparities are far greater. Data from the National Core Indicators (NCI) Project suggest that in 2017–2018, only 18% of working-age adults supported by state IDD agencies were employed in a paid job in the community (National Core Indicators, 2018).

For individuals with IDD who do obtain employment, data consistently show that the majority work part-time in entry-level positions, have low income, and have limited access to employee benefits. People in individual supported jobs included in NCI data worked an average of 14 hours per week, and earned \$140 per week (National Core Indicators, 2019).

It is also important to note the disparities that exist within the IDD population. For instance, Black individuals with IDD experience disparities in workforce participation compared to their White counterparts with respect to annual earnings and the percent who work in integrated jobs, and are less likely to have a successful outcome when they receive vocational rehabilitation services (Shepard et al., 2020). The authors also found that women with cognitive disabilities, despite being employed at similar rates and working similar hours, earn 28.4% less than men with cognitive disabilities.

Despite these low rates of labor force participation and limited outcomes when employed, individuals with IDD clearly express a desire to fully participate in the typical labor force (Barrows et al., 2016; Self-Advocates Becoming Empowered et al., 2018). Research documents the desire of individuals with IDD to be employed in the community (Migliore et al., 2007; Timmons et al., 2011; Nonnemacher & Bambara, 2011; Walker, 2011). However, data from the NCI suggest that there is a gap between individual's interest in employment and the supports they receive. The NCI found that while 45% of people who are not working want a job in the community, only 29% of those who wanted a job had this goal documented in their service plan (National Core Indicators, 2019).

Although individual desires for employment have not been met, there is some evidence of progress in the delivery of employment services. In FY 2018, Connecticut, Massachusetts, New Hampshire, Oklahoma, Oregon, Rhode Island, Vermont, and Washington reported that at least 40% of individuals with IDD receiving day and employment services were receiving integrated employment services (employment supports that are intended to directly result in paid integrated employment, and services to maintain integrated employment). Surveys of CRPs conducted by the Institute for Community Inclusion (ICI) in 2002–2003, 2010–2011, and 2014–2015 suggest there has been a shift in the employment services CRPs deliver to individuals with IDD from facility-based to integrated settings. In the 2002–2003 survey, 18% of individuals received employment services in integrated settings, compared to 28% in the 2010–2011 survey and 38% in the 2014–2015 survey (Domin & Butterworth, 2016). There are several caveats, however:

- » These figures include participation in group supported employment such as enclaves and mobile groups within integrated settings.
- » These CRPs support more individuals with IDD in facility-based non-work services than in employment services in community settings.
- » This trend is not corroborated in data on services delivered by state IDD agencies, in which the percentage of individuals receiving integrated employment services has only increased slightly from 19% to 21.5% between 2010 and 2018.

¹ Integrated employment services include both (a) job development services (including discovery and career planning as part of a job development process) that are intended to directly result in paid integrated employment and (b) services to maintain paid integrated employment (including job training, job coaching (both individual and group), ongoing supports, and services for self-employment).

EMPLOYMENT SERVICES AND SUPPORTS

Employment supports are provided within a context of state and federal disability policy, workforce development policy, income maintenance policy, and healthcare policy. These include supports related to transportation, housing, income, and childcare. Core supports are funded by state IDD and vocational rehabilitation (VR) agencies, as well as local education agencies.

STATE IDD AGENCIES.

State IDD agencies are the primary source of long-term funding and service coordination for adults with IDD. They provide, fund, and monitor a wide range of day and employment services, including employment supports, facility-based options (prevocational services often based in sheltered-workshops and non-work day habilitation programs), community integration services, and self-directed options.

Funding for state IDD agency day and employment services comes from two main sources: 1) Medicaid, and 2) state general revenue funds. The state and federal government jointly fund Medicaid services. Most long-term day and employment supports are administered by state IDD agencies and delivered by community-based providers under contract.

STATE VOCATIONAL REHABILITATION AGENCIES.

In Program Year 2018 (the year ending 6/30/2019), state VR agencies closed 462,108 case records and a total of 45,108 people with an intellectual disability exited the VR program (Winsor et al., 2020), representing 12% of all closures. In general, the number of case closures for people with intellectual disabilities has declined since 2010, when it was 49,697. The corresponding figure for people with other disabilities was 374,479 in 2019, down from 387,410 in 2018 and 511,441 in 2010.

VR policy and services are authorized by the Rehabilitation Act as amended in the Workforce Innovation and Opportunity Act (WIOA) of 2014. Once the WIOA requirements took effect, each state's public VR system was expected to have formal cooperative agreements with the state agency responsible for administering the state Medicaid plan, and with state IDD agencies, with respect to the delivery of VR services, including extended services. This is an emerging requirement for state VR agencies, although policy under the Medicaid Home and Community-Based Services program requires that individuals access VR for employment support prior to receiving Medicaid waiver funding.

Secondary data analysis of the RSA-911 dataset found that it often takes a long time for job seekers with intellectual disabilities to go through the steps from application for VR services to determination of eligibility, completion of an Individualized Plan for Employment (IPE), and closure into integrated employment (Migliore et al., 2016). In 2019, a large proportion of individuals with ID who exited VR without employment were reported as either the individuals' refusal of services or failure to cooperate (27%); VR counselors' inability to locate or contact the individual (23%); and other reasons, including disability too significant, death, job seeker's relocation, no disability-related need for services, or other non-specified reasons (Winsor, *et.al.*, 2020). Interviews by Eckstein et al. (2017) with VR applicants found that one of the most common barriers to employment cited by applicants was health issues, particularly related to unpredictability of symptoms, pain, and lack of physical energy and adequate time.

WIOA also expanded the role of VR in the transition of students with disabilities from school to competitive integrated employment. The act requires states to spend 15% of public VR funds on pre-employment transition services for students served by the Individuals with Disabilities Education Act or Section 504 of the Rehabilitation Act. WIOA now requires VR offices to collaborate with local schools and workforce development systems to facilitate the transition of students with disabilities from school to competitive integrated employment. Section 511 of the Rehabilitation Act establishes guidelines that must be addressed before an individual can enter subminimum wage employment, and requires annual career counseling for individuals working at subminimum wage.

²Individuals with a primary or secondary impairment code of intellectual disability in the RSA 911.

³RSA program year 2017 data are based on a 9 month data collection time period, October 1, 2016 through June 30, 2017. Prior to 2017 RSA reported data for October 1st through September 30th. The program year for RSA data beginning in 2018 is July 1st through June 30th.

COMMUNITY REHABILITATION PROVIDERS (CRPS).

CRPs and their staff are the primary source of day and employment supports for people with IDD. The ICI estimates that between 5,000 and 6,000 CRPs nationwide offer vocational services to individuals with disabilities (Haines et al., 2013). Most (over 80%) of those served in employment and day services are people with IDD, with the majority supported in facility-based and non-work services (Domin & Butterworth, 2016).

Over two thirds of CRPs provide both work and non-work services (Domin & Butterworth, 2013). Under federal policy, including WIOA and the HCBS Settings Rule, and state Employment First initiatives, CRPs are under increasing pressure to shift from providing facility-based work and non-work services to a focus on competitive integrated employment and community life engagement. ICI's Rehabilitation Research and Training Center (RRTC) on Advancing Employment for People with IDD worked with a Delphi panel to identify ten elements critical to the transformation to competitive integrated employment, ranked in order of importance (Timmons & Lyons, 2016). The three most important elements include the establishment of clear and consistent goals; the development of an agency culture that values inclusion; and maintaining an active, person-centered job placement process focused on moving individuals one person at a time into integrated employment (Lyons et al., 2018). Interviews with providers who have completed a transformation indicated the need for key actions, including committing to the change, translating the commitment into a plan, strategic implementation, and engaging stakeholders in the transformation process (Lulinski et al., 2017).

Sulewski et al. (2019) expanded upon the RRTC findings to focus on provider-level changes that are needed not only to reduce sheltered employment, but to expand community life engagement services. Combining findings across projects to support organizational transformation in both employment and day services offers guidance for providers of day and employment services in their efforts to support competitive integrated employment and meaningful community life engagement for individuals with intellectual and developmental disabilities.

AMERICAN JOB CENTERS.

Established and supported under the Workforce Investment Act and its reauthorizations, American Job Centers (formerly called One-Stop Career Centers) provide an underused resource for individuals with IDD and other disabilities. In Program Year 2018, 58,788 individuals with disabilities were identified as exiting services provided under the Workforce Innovation and Opportunity Act (WIOA) Adult, Dislocated Worker, and Youth Programs and 167,532 were identified as exiting the Wagner-Peyser Program through these centers (U.S. Department of Labor, Employment & Training Administration, 2020). Individuals with disabilities represent about 9% of WIOA exiters who identified their disability status and 5% of Wagner-Peyser participants who identified their disability status. The PY2019 RSA-911 dataset indicates that 209 individuals with ID who closed out of state VR services in 2019 (0.5% of all VR closures with ID) were identified as referrals from American Job Centers.

A number of provisions in WIOA emphasize and increase the requirements for the general workforce development system and American Job Centers to meet the needs of job seekers with disabilities. WIOA explicitly requires that state and local workforce development board members include community organizations that provide or support competitive integrated employment for individuals with disabilities. Since 2010, the U.S. Department of Labor (DOL) has awarded grants totaling approximately \$139 million to 55 projects in 30 states to improve education, training, and employment outcomes of youth and adults with disabilities. This Disability Employment Initiative is jointly funded with the DOL's Office of Disability Employment Policy (ODEP) and administered by the Employment and Training Administration (U.S. Department of Labor, 2018).

Efforts at exploring the impact of the Disability Employment Initiative in Massachusetts revealed a series of successes around the provision of benefits counseling, improved case management, collaborative endeavors with disability-specific state agencies, the establishment of Disability Resource Coordinators in each center, and the use of the Social Security Ticket to Work program (Domin et al., 2017; Landim et al., 2017; Narby et al., 2017; Hoff, 2017).

MEDICAID.

Medicaid is both a primary provider of healthcare for individuals with IDD, and the largest federal source of funds for day and employment services. Medicaid day and employment services are primarily funded under one of several Home and Community-Based Services (HCBS) waiver authorities that allow states to provide supports flexibly in community settings. The HCBS authorities are the largest federal funding source for ongoing day and employment services. Each state designates an agency that administers its state plan. States have a great deal of flexibility in designing their HCBS systems within broad federal requirements.

While historically there has been no clear preference for integrated employment in Medicaid-funded services, in 2011 the Centers for Medicare and Medicaid Services (CMS) issued a policy bulletin that provides guidance for the development of employment-related service definitions in 1915(c) waivers. This guidance was incorporated into the 1915(c) Technical Guide in 2015 and established individual integrated employment as a priority goal (CMS, 2011).

Over the past decade, CMS has expanded its focus on employment. The Medicaid Buy-In Program gives states the option of maintaining Medicaid coverage for workers with disabilities whose earnings would otherwise make them ineligible for coverage. The 2014 Final Rule, CMS 2249-F and CMS 2296-F, or Community-Based Settings Rule, creates the expectation that Medicaid-funded services will support competitive integrated employment and other community life engagement activities, and that states will shift supports away from service settings that isolate or segregate people with disabilities from the general population (CMS, 2014).

Friedman and Rizzolo (2017) examined Medicaid HCBS spending on supported employment for 2014 and found wide variability across available supported employment services, payment rates, and total and average per person spending. Over the long term, the 2014 Final Rule has the potential to lead to major changes in how Medicaid HCBS funds are used for integrated employment services.

Lastly, other elements of Medicaid policy, including increasing access to health care, have the potential to strengthen employment outcomes. Hall et al. (2018) examined states that have implemented the Affordable Care Act Medicaid Expansion option. Studying data from 2013–2017, the authors observed an upward trend in employment for individuals with disabilities in Medicaid expansion states.

SOCIAL SECURITY.

The Social Security Administration (SSA) supports employment participation through several programs, including work incentives targeted at individuals who receive Supplemental Security Income or Social Security Disability Income, the Ticket to Work program, and the Work Incentive Planning and Assistance program. SSA work incentives, such as the Plan for Achieving Self-Support, Impairment-Related Work Expenses, and the Student Earned Income Exclusion, support employment by allowing individuals to exclude money, resources, and certain expenses from total earned income. The SSA also administers the Ticket to Work program, which lets beneficiaries receive employment support and other support services from a participating employment network or state VR agency. An Employment Network is an entity that enters into agreement with the SSA to provide or coordinate the employment supports such as career counseling, job placement, and ongoing support at no cost to beneficiaries. Assigning a Ticket to an Employment Network allows the entity to receive payments based on the job seeker's success in obtaining and maintaining a job. A Ticket may be used along with other employment support services funded with state, Medicaid, or VR resources.

Finally, the Work Incentives Planning and Assistance Program enables beneficiaries to receive free benefits counseling to help them make informed choices about work. SSA contracts with local community-based organizations that provide in-depth counseling about working, earning more money, and how working may affect your benefits. Despite the SSA's initiatives, work incentives and the Ticket to Work program remain underused (Winsor et al., 2019), and workforce participation among beneficiaries remains extremely low (Domin & Timmons, 2017).

PUBLIC PRE-K-12 EDUCATION.

The Individuals with Disabilities Education Act (IDEA) requires that students with disabilities are educated in the least restrictive environment consistent with their needs. IDEA also requires schools to include employment-related transition services in the individual education plans (IEPs) of all students who have reached the age of 16. It defines transition services as having a coordinated focus on improving students' academic and functional achievement.

IDEA facilitates movement from school to post-school activities, including postsecondary education and integrated employment. Services include instruction, community experiences, and the development of employment and other post-school goals. Transition services and placements must adhere to least restrictive environment requirements. Section 511 of WIOA prohibits schools from contracting with programs to serve students when the programs pay employees less than minimum wage. School IEP teams, charged with preparing for transition, can include representation from VR and IDD agencies.

POSTSECONDARY EDUCATION.

Although historically individuals with IDD have not had opportunities to access postsecondary education, this has changed in recent years. The Higher Education Opportunity Act of 2008 contained several provisions to increase the access of individuals with IDD to higher education. In 2010, Congress authorized creation of new model demonstration programs, and awarded grants to 27 higher education institutions to fund Transition and Postsecondary Education Programs for Students with Intellectual Disabilities, and this initiative was extended in FY2016 and again in FY2021.

Additionally, opportunities to pursue postsecondary education continue to expand for students with IDD. In 2019, a national directory of postsecondary programs enrolling students with ID reflected 266 programs in 49 states. An estimated 6,200 students with ID are enrolled in these colleges and universities and the numbers are growing every year (Think College, 2019). Emerging studies consistently show that postsecondary education improves employment outcomes for individuals with IDD (Sannicandro, 2016).

RECENT POLICY DEVELOPMENT

Recent legislation and regulation governing Medicaid HCBS, WIOA, and settlement agreements between states and the U.S. Department of Justice are clarifying federal intent and paving the way to supporting opportunities for people with disabilities to have meaningful jobs in their communities.

HCBS guidance in 2011 and in the 2015 1915(c) Technical Guide make it clear that individual competitive integrated employment is the preferred outcome of employment-related supports, including prevocational and group supported employment services. The guide defines the outcome of individual supported employment services as “paid employment at or above the minimum wage in an integrated setting in the general workforce, in a job that meets personal and career goals” (CMS, 2011; 2015, p.152). HCBS rules governing community settings were issued in 2014, and support “full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS” (CMS, 2014, p. 249).

WIOA defines competitive integrated employment as full-time or part-time work at minimum wage or higher, with wages and benefits similar to those without disabilities performing the same work, and fully integrated with co-workers without disabilities. Additionally it establishes competitive integrated employment as the optimal outcome of vocational rehabilitation services. The legislation dramatically expands the role of state VR services in supporting transition-age youth by establishing requirements for pre-employment transition services, and emphasizes interagency collaboration through mandatory agreements between state VR systems, state Medicaid systems, and state IDD agencies.

Finally, WIOA places new restrictions on the use of subminimum wage under Section 511. As of July 2016, this section requires a series of steps that an individual under the age of 24 must undergo before being placed in a job paying less than minimum wage. These individuals must first be provided pre-employment transition services, be determined ineligible for VR or have an unsuccessful VR closure, and receive career counseling and referrals to assist with achieving competitive integrated employment. In addition, any individual working in subminimum wage employment must receive career counseling, information and referral services, and information on self-advocacy, self-determination, and peer mentoring every six months for the first year after starting a job that pays less than minimum wage, and then on an annual basis.

In recent years the Department of Justice has initiated legal actions in states related to access to integrated employment. Settlement agreements with Rhode Island in 2014 and Oregon in 2015 extended enforcement of the Americans with Disabilities Act (ADA) and the Olmstead decision to mandate access to integrated community employment supports. Both settlements require that states take action to ensure that employment is offered as a priority outcome, and to improve both participation in integrated employment and the quality of employment outcomes.

THE RISE OF EMPLOYMENT FIRST POLICIES.

In addition to federal policy under CMS, WIOA, and the Department of Justice, Employment First has become a national initiative, with policies in 38 states (Hoff, 2019). These policy commitments take the form of executive orders, state agency policy statements, or legislation making community employment the first outcome considered for people with disabilities who receive state services. Regardless of whether an Employment First initiative is a formal effort, a

grassroots effort, or a combination of the two, states use it as an opportunity to present their definition, goals, and values around employment (Bose & Winsor, 2018).

Employment First represents a commitment by states and state IDD agencies to the proposition that all individuals with IDD (a) are capable of performing work in typical integrated employment settings; (b) should receive, as a matter of state policy, employment-related services and supports as a priority over other facility-based and non work day services; and (c) should be paid at minimum or prevailing wage rates (Kiernan et al., 2011; Rogan & Rinne, 2011).

Employment First policies are recognized nationally as a path toward greater community employment for people with IDD. They anchor a service delivery system, focusing funding, resource allocation, training, supports, and the provision of residential services on the overall objective of employment. This makes it easier for individuals receiving publicly financed supports to enter the workforce and become contributing members of society (Moseley, 2009).

RECENT FEDERAL INVESTMENTS

There has been a recent increase in federal investment in supporting employment outcomes. In September 2016, the Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities, established by WIOA, submitted its final report to the Secretary of Labor on ways to increase participation in competitive integrated employment for individuals with IDD and other people with significant disabilities. This report provides recommendations for building on federal policy and administrative structures to increase the competitive integrated employment of individuals with IDD. The authors emphasize increased interagency collaboration and focus on the federal level, to build capacity for systems and services that encourage and support competitive integrated employment for individuals with IDD (Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities, 2016).

The Administration on Intellectual and Developmental Disabilities (AIDD) issued three rounds of multi-year system change grants (2011–2016, 2012–2017, 2016–2021) to support 14 states in cross-system collaboration to increase employment outcomes for youth and young adults with IDD. AIDD also issued grants to establish community of practice opportunities for states engaged in Employment First efforts. The U.S. Department of Labor’s Office of Disability Employment Policy has supported the development of Employment First policy and strategy with initiatives that include the Employment First State Leadership Mentoring Program, Advancing State Policy Integration for Recovery and Employment (ASPIRE), and Visionary Opportunities to Increase Competitive Integrated Employment (VOICE).

In 2013, the SSA launched a competitive grant program, Promoting Readiness of Minors in Supplemental Security Income (PROMISE). That year, over \$211 million was awarded to five individual states and to a consortium of six states (U.S. Dept. of Education, 2013). PROMISE is designed to improve the education and career outcomes of low-income children with disabilities, ages 14–16, who receive Supplemental Security Income through the SSA. A recent evaluation of PROMISE found that multi-agency partnerships served as the foundation for positive change and new opportunities for youth and families, but that full systems change was an ongoing process (Johnson et al., 2020)

Many supports cultivate the participation of families, whose expectations and ability to navigate systems, beginning in early childhood, can be key to attaining competitive integrated employment outcomes for individuals in adulthood (Kramer, Bose, & Shepard, 2017). A five-year grant (2012–2017) from AIDD funded the National Association of State Directors of Developmental Disabilities Services to work with partners (the University of Missouri Kansas City Institute on Human Development and the Human Services Research Institute) to help states develop systems of support for families throughout the life span (Supporting Families, 2018).

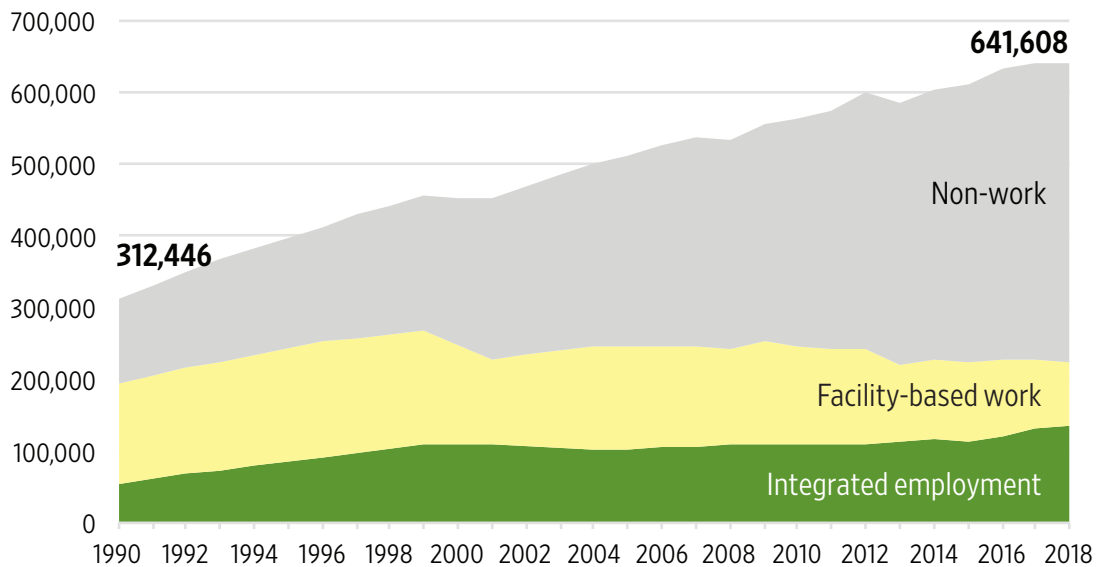
CHALLENGES TO SYSTEMS CHANGE

Despite state and federal initiatives, policy change, and emerging leadership, widespread integrated employment for people with IDD has not occurred. Nationally, an estimated 21.1% of individuals receiving day supports from state IDD agencies participated in integrated employment services during FY2018 (see Figure 1.) This number declined between

2001 and 2012 after reaching a peak of almost 25% in FY2001, and has only recently shown signs of modest growth. Overall growth in integrated employment slowed following the end of the RSA-supported Employment Systems Change grants in the mid-1990s.

At the service delivery level, best practices evolved, including person-centered career planning, customized employment, job creation, and self-employment, but adoption of these practices is limited (Migliore et al., 2018). Continuing challenges for systems change include inconsistent policy, variable allocation of CRP resources, problematic funding mechanisms, and insufficient professional development for staff. Transition-age youth and young adults continue to face challenges in preparing for and acquiring competitive employment in integrated settings.

Figure 1. Number Served by IDD Agencies



STATE AND FEDERAL POLICY DO NOT CONSISTENTLY PRIORITIZE EMPLOYMENT.

While more individuals with IDD are in integrated employment, the number participating in facility-based and non-work services has grown more rapidly. Despite investments in education, income supports, and healthcare for Americans with disabilities, few of these resources encourage or reward integrated community employment (Niemiec et al., 2009).

Expansion of community-based non-work (CBNW) services has competed with integrated employment (Sulewski, 2010). Forty-one of 47 state IDD agencies providing data reported supporting individuals in CBNW services in FY2018. Respondents to the ICI’s 2014–2015 National CRP Survey reported a significantly more modest but still meaningful role for CBNW services, indicating that 12.6% of individuals with IDD participated in CBNW (Domin & Butterworth, 2016). This difference reflects both the ability of CRPs to more accurately report on individual service settings when compared to state IDD agencies, and challenges state agencies face in separating community-based and facility-based services.

Data suggest that CBNW services are loosely defined with respect to requirements, activities, populations served, and goals (Lyons & Hall, 2015). There is increasing interest in supporting community life engagement in response to the CMS Settings Rule, and emerging concern about supporting non-work time for individuals who are working a limited number of hours (Sulewski & Timmons, 2015; Timmons & Sulewski, 2016). New research is working to define community life engagement and the outcomes and characteristics of services that support individuals to be full participants in their community. These efforts seek to understand how supports for community life engagement can, in turn, support employment outcomes (Sulewski et al., 2017).

CRPS HAVE NOT REALLOCATED RESOURCES TO COMMUNITY EMPLOYMENT.

For many providers, the organizational change process is a challenge. Beyond societal barriers such as low expectations for individuals with IDD to work and the belief that people must be “job ready” before receiving integrated employment services, there are issues surrounding funding responsibilities, transportation, confusing definitions of employment models, and lack of training on understanding the business world (Rosenthal et al., 2012).

Rogan and Rinne state that “moving to integrated community services necessitates a complete rethinking of mission, vision, values, and practices” (Rogan & Rinne, 2011, p. 250), and Timmons et al. (2019) identified elements that span goals, infrastructure, and employment support practices that are necessary to refocus an organization. At the same time, many organizations face myriad external and internal barriers to change, and often lack the strategic planning needed to complete the process successfully.

Research also suggests continued service and philosophical variation within the provider community, making the creation of a unified vision for service delivery difficult (Office of Disability Employment Policy, 2014). Inge et al. (2009) found that almost 89% of respondents to a national survey of provider administrators believe that facility-based programs are essential for individuals with disabilities who are having difficulty getting or maintaining real work in the labor force, and only 47% had a formal plan to expand integrated employment.

The most cited challenges to successful organizational transformation were related to the transition of organizational finances and resources to integrated employment (Office of Disability Employment Policy, 2014; Rosenthal et al., 2012; West & Patton, 2010). Asking providers to deliver more services that lead to competitive integrated jobs and fewer facility-based work and non-work services requires a substantial change to their business models. For example, facility-based work and non-work services typically have more predictable staffing levels and funding streams when compared with integrated employment.

The transformation away from segregated settings is compounded by a lack of planning, leadership, and communication (Timmons et al., 2019). Resistance can also be met from stakeholders, including family members (Rogan & Rinne, 2011). Research on organizational transformation suggests that successful organizations implement an approach that addresses ten critical elements: 1) clear and consistent goals; 2) a culture that values inclusion; 3) an active and person-centered job placement process; 4) a strong internal and external communications plan; 5) the reallocation and restructuring of resources; 6) ongoing investment in staff professional development; 7) a focus on customer engagement; 8) methods for ensuring employment performance measurement, quality assurance, and program oversight; 9) a holistic approach; and 10) multiple and diverse community partnerships (Timmons et al., 2019; Lyons et al., 2018). Community rehabilitation providers who participated in an intervention based on these ten elements reported that indicators of successful job development support all increased after the intervention, particularly “Engaging with families” and “Person-centered planning.”

Qualitative data from the intervention suggested that staff began viewing facility-based work as a transitional step to integrated employment (Lyons et al., 2020).

FUNDING MECHANISMS VARY ACROSS STATES AND DO NOT ALWAYS REFLECT POLICY PRIORITIES.

Research has shown that state specific fiscal efforts affect the likelihood of employment outcomes for individuals with IDD across the lifespan (Nord et al., 2020). In an environment of increasing fiscal limitations and individualized budgeting, there is a growing need for state employment systems to discuss rate-setting and funding strategies. Analysis of five states’ employment funding structures suggests there is no “best” approach, but there are several key elements for success (Hall et al., 2011). Rate and contracting structures should be selected with a clear intent regarding goals. Unambiguous definitions and service categories should also reflect these priorities. States with policy and funding alignment pay more for desired outcomes (a community job), and less or nothing at all for other outcomes.

Work with State Employment Leadership Network (SELN) member states suggests that changes made to funding rates should be based in the real-world costs of providing high-quality integrated employment services, and should not solely rely on the typical approach of revising funding based upon historical costs. When considering states’ funding methodologies, all state agencies that pay for employment services should be involved in the discussion. Making fragmented changes to one or two service rates is not sufficient to address the underlying funding issues faced by providers and service recipients. Consideration of the entire funding system helps ensure that individuals receive services that support a whole-life, individualized, community-centered approach to employment (Winsor et al., 2017).

BEST PRACTICES IN JOB SUPPORTS ARE NOT CONSISTENTLY IMPLEMENTED.

Research suggests that employment specialists inconsistently use established promising practices, including spending time with individuals in community settings, working with families, and negotiating job responsibilities with an employer (Migliore et al., 2012; Migliore et al., 2010). Front-line staff often report difficulties placing individuals with

IDD in community employment, particularly those who had high support needs (Butterworth et al., 2000; Rogan & Rinne, 2011). Staff also experience confusion about job development responsibilities, do not feel prepared to engage the mainstream business community, and have little training in providing appropriate supports to individuals with IDD in community settings (Migliore et al., 2012; Rosenthal et al., 2012; West & Patton, 2010).

Findings also suggest that job developers have limited opportunities for effective professional development, including both formal and informal chances for learning (Timmons et al., 2018), although employment specialists who receive training with mentorship to support implementation improve the number and quality of the jobs they develop (Butterworth et al., 2012). Because employment consultants do not always implement best practices and have limited opportunity for training, researchers have begun to explicitly articulate and translate the latest practices into clearer, more easily communicated elements. These practices include building trust, getting to know the job seeker, addressing supports planning, finding tasks or jobs, and providing supports after hire, all in the context of identifying the best job match (Butterworth et al., 2017).

While continued research on effective employment strategies for individuals with IDD is vital, the strategies are only as successful as the workforce delivering them. The success of job seekers depends in large part on the knowledge, skills, and abilities of employment specialists (Hewitt & Larson, 2007; Migliore et al., 2012). Employment support professionals experience high turnover, low salaries, and limited opportunities for both formal and informal development (Lyons et al., 2016; Hall et al., 2014). Research has demonstrated that when employment specialists receive appropriate training combined with mentorship and performance feedback, they improve the number and quality of the jobs they develop, suggesting the importance of both formal learning and effective supervision and coaching (Butterworth et al., 2012; Butterworth et al., 2020).

TRANSITION-AGE YOUTH CONTINUE TO FACE CHALLENGES.

Employment is a primary pathway to independence and autonomy, yet research shows continuing disparity between the employment outcomes of youth with and without disabilities. American Community Survey data show that in 2014, the employment rate for young adults without a disability aged 16–21 was 41%, compared to 20% percent for youth with a cognitive disability. For young adults between the ages of 22 and 30, the employment gap widens, with 76% of youth without a disability employed, compared to 41% of youth with a cognitive disability (Butterworth & Migliore, 2015). Moreover, younger adults (18–24) with IDD experience lower employment outcomes as compared to their older counterparts (25–55) (Nord, 2020)

Data from the National Core Indicators Project suggest that in 2014, only 4% of youth supported by state IDD agencies aged 18–21 were employed in individual integrated jobs, and only 9% of those aged 22–30. This population also experiences low wages and hours, averaging 12 hours and \$92/week for 22- to 30-year-olds (Butterworth & Migliore, 2015).

Poor employment outcomes have persisted despite the fact that people with disabilities want to work in the community. Individuals with IDD have clearly expressed both a desire to be full participants in the typical labor force and an expectation that they will be employed after graduation (Barrow et al., 2016; Timmons et al., 2011; Nonnemacher & Bambara, 2011; Walker, 2011). Sixty-five percent of young adults aged 18–22 who are not working receive support from a state IDD agency would like a job in the community (National Core Indicators, 2019). However, Timmons et al. (2011) found that individuals with IDD are often discouraged from community employment during the transition from school to adulthood.

Grigal et al., (2011) found that students with IDD were less likely to have competitive employment goals and outcomes, and more likely to have sheltered employment goals and outcomes, compared to students with other disabilities. NLTS2 data on high school students' transition plans show that 20% of students with intellectual disabilities had primary goals related to sheltered employment, despite the national focus on integrated employment (Shogren & Plotner, 2012).

Poor employment outcomes for youth with IDD are a result of a confluence of issues. For example, interagency collaboration is well established as a predictor of employment outcomes during transition (Haber et al., 2016), yet insufficient linkages between the education, rehabilitation, and adult IDD systems are primary factors in the low employment outcomes of youth with IDD (Certo et al., 2008; Martinez et al., 2010; NCD, 2008; Plotner & Marshall, 2015; Haber et al., 2016). Research has found a need for the clarification of roles between education and rehabilitation professionals and for the documentation and dissemination of guidelines for collaboration across systems (Stevenson & Fowler, 2016; Oertle & Seader, 2015).

Confirming findings from previous research, Carter et al. (2011) found that many students with significant disabilities lack early vocational experiences. Other education system factors include low teacher expectations for employment (Carter et al., 2010), limited professional development related to transition practices (Mazzotti & Plotner, 2016; Winsor et al., 2010), lack of long-term follow-up of graduates following transition to employment (Rusch & Braddock, 2004; Callahan et al., 2014), and limited diffusion of evidence-based transition practices in schools (Mazzotti & Plotner, 2016).

LIMITED FAMILY ENGAGEMENT.

Family engagement is a key component not only in successful transition planning, but in employment in general. However, parents report that they do not receive enough information to support their children in the transition process, that transition programs are a poor fit for student needs, and that they have insufficient information about the interaction of work and benefits (Hetherington et al., 2010; Almutairi, 2016; Winsor et al., 2010). Carter et al. (2011) found that the family factor most predictive of paid work experiences in school was parental expectations, but families frequently experience low expectations and support from school programs (Blustein et al., 2016; Henninger & Taylor, 2014; Almutairi, 2016). Gibson et al. (2018) researched employment-related expectations, preferences, and concerns of family members of adults with IDD. Families prioritized paid integrated employment over sheltered options, and valued their family members' opportunities for personal satisfaction and social interaction more highly than fiscal benefits of employment.

A recent comprehensive literature review related to family engagement confirmed the importance of family engagement to employment outcomes: Family members' modeling of roles and expectations shapes positive experiences of employment for people with IDD, and builds a proactive vision, while engaging with family members leads to employment-focused decisions. When family members have advanced knowledge about the service system and develop partnerships with service professionals, individual outcomes are stronger (Kramer et al., 2017).

Family members also shared that they were frustrated by the service system's low expectations for their family member and the lack of clear guidance on how to support their family member's employment goal (Kramer et al., 2020). Another barrier they identified was a lack of alignment and continuity across various service agencies with which they interact. The system's capacity was perceived as inadequate to meet individuals' and families' needs, both in terms of availability of employment supports and the qualifications of personnel (Kramer et al., 2020).

Effective strategies for engaging families are emerging in the literature. Results from a recent intervention suggests that when family members of youth with IDD engaged online with peers, and had online access to both content and experts in employment and transition planning, they increased their expectations for future integrated employment, as well as increased the number of small steps they took towards the future goal of obtaining integrated employment (Shepard et al., 2020)

INADEQUATE ACCESS TO TECHNOLOGY.

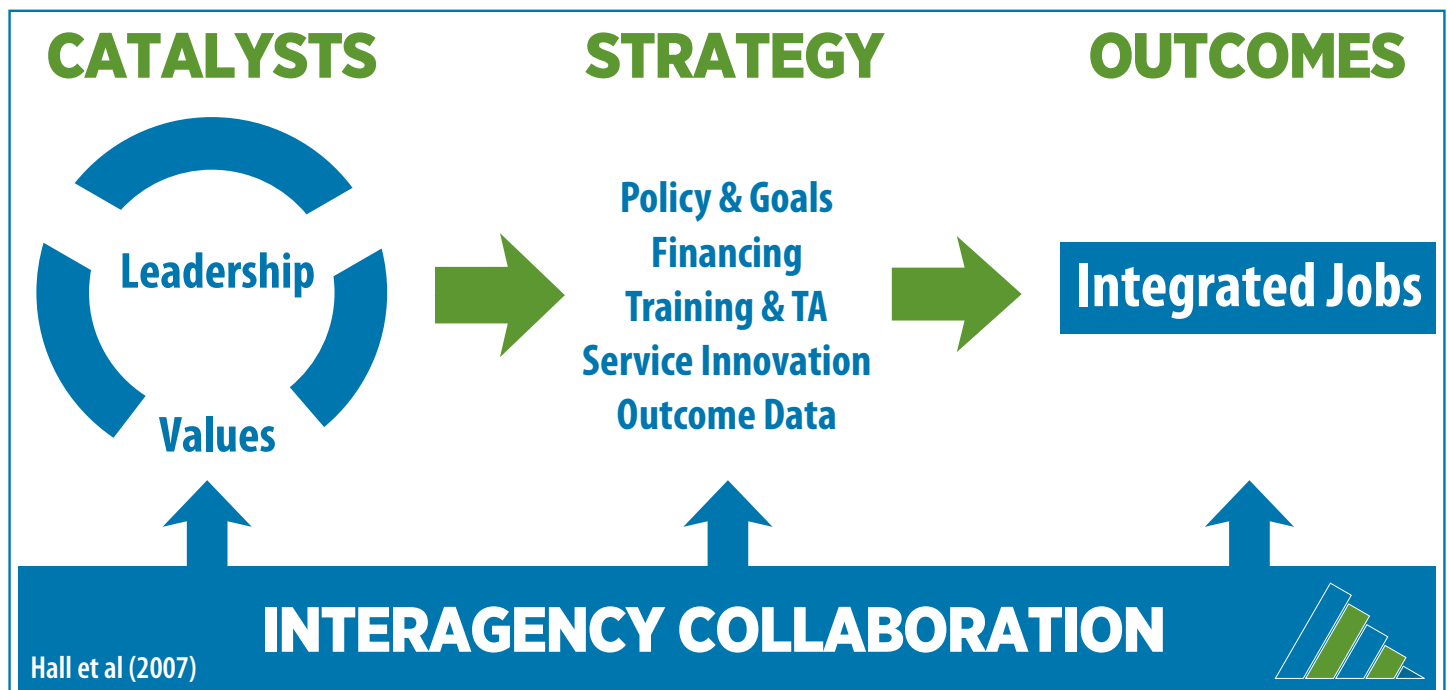
Emerging technology, including smart phone and tablet applications, remote communication, and smart home devices, provide an opportunity for individuals to be more independent at work, self-manage work tasks, engage in continuous learning, and improve safety. Use of these tools is expanding in concert with research on "applied cognitive technology," defined by Wehmeyer and Shogren (2013) as "technology supports that enable people with cognitive disabilities to successfully function in inclusive environments, participate in tasks and activities in inclusive environments, and promote social inclusion, self-determination and quality of life" (p. 92). These supports have the opportunity to reduce the presence of employment support professionals in the workplace, facilitate natural workplace relationships, and promote efficient use of resources. The use of technology at work is promising, but not yet widely implemented due to barriers including state policy and financing, employment provider expertise, knowledgeable employers and HR staff, and digital literacy (Administration for Community Living, 2015; National Council on Disability, 2018).

A FRAMEWORK FOR SYSTEMS CHANGE

Since 2007, the ICI, in partnership with the National Association of State Directors of Developmental Disabilities, has used the High Performing States (HPS) framework (see Figure 2) to guide systems change to expand integrated employment in its work with the State Employment Leadership Network (SELN). Twenty-three states are currently active members of the SELN, a membership roundtable of state IDD agencies that use the model to structure their efforts to expand integrated employment for individuals with IDD (<http://www.selnhub.org/home>).

The HPS model was developed through case studies of three states with strong competitive integrated employment outcomes for individuals with IDD enrolled in adult day and employment services (Hall et al., 2007). The model identifies seven elements that transmit and maintain commitment to the goals of community inclusion and integrated employment. The seven elements are leadership, policy and goals, interagency collaboration, financing, training and technical assistance, service innovation, and outcome data.

Figure 2: High Performing States Model



These high performing states maintained a consistent focus on employment in policy, procedure, and infrastructure within each of the elements, suggesting that meaningful change requires a holistic approach. Outcomes and experience suggest this framework is a helpful guide to systems change. Between 2010 and 2017, the percentage of individuals receiving an integrated employment service increased from 20.6% to 23.7% (a 13% increase) for SELN states, and decreased from 18.5% to 17.5% (a 5% decrease) for non-member states (SELN, 2020).

Research continues to examine the HPS framework. Work with states funded by the Partnerships in Employment project (2011-2016) applied the framework when developing the systems that support access of transition-age youth with IDD to postsecondary education and employment. In addition, ICI's Rehabilitation Research and Training Center on Advancing Employment for Individuals with IDD conducted state-level case studies to investigate the ways in which the elements of the HPS framework operate, not only within state IDD agencies, but also state VR and education agencies. These studies build on the findings of Hall et al. (2007), but also seek to identify the elements that support these state agencies to work collaboratively to support employment for individuals with IDD across the lifespan. An important finding that emerged from this work was that higher performing states had a shared cross-agency investment for employment outcomes, in particular with a common emphasis on youth (Butterworth et al., 2020)

METHODOLOGY

This report provides a comprehensive overview of the national trends in employment for people with intellectual and developmental disabilities (IDD). Appendices show individual state profiles with data from several sources, including:

- » The National Survey of State Intellectual and Developmental Disabilities Agencies' Employment and Day Services
- » The Rehabilitation Services Administration 911
- » The American Community Survey
- » The Social Security Administration

For most data sources, the most recent data are through 2018. The authors use abbreviations for both intellectual disability (ID) and intellectual and developmental disabilities (IDD). We do this because data sources vary in the specific target groups that can be described. Please refer to each section for the disability definition used for that data source.

DATA SOURCES

NATIONAL SURVEY OF STATE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AGENCIES' EMPLOYMENT AND DAY SERVICES.

This survey is administered by the ICI annually. It is part of a longitudinal study commissioned by the Administration on Disabilities to analyze community-based employment and day service trends. Data are available for services received between FY1988 and 2018 for individuals with IDD and closely related conditions. Between 1988 and 2004, the survey was administered on a semi-annual basis; starting in 2007, information has been collected annually. The most recent version of the survey is focused on state IDD agency data for FY2018.

The survey is designed to provide the following information:

- » Trends in the number of people served in integrated employment, facility-based employment, and facility-based and community-based non-work programs
- » Trends in the number of individuals waiting for services
- » Funding sources being used to support day and employment services
- » The allocation of funds across day and employment services

The survey was developed with input and field-testing support from state IDD agency administrators. Core variables include the number of people served (total and by day and employment service categories), number of people on waiting lists, expenditures by service, and total funding by source. All questions focus on community-based day or employment services monitored by the state IDD agency, including services funded by another state agency (such as the Medicaid agency), even if the IDD agency does not provide or directly contract for the service. In 1996, the category of community-based non-work services was added to the survey. The most recent changes to the survey occurred in the FY2016 data collection. States are now asked specific questions about the number of individuals that they serve who are working for pay in jobs in the community, in order to distinguish between services and employment outcomes. Additionally, the definitions of integrated employment services and community-based non-work services have been updated to emphasize the goal of an individualized community outcome. Since FY2001, states have had the opportunity to complete the survey using a secure website. Each state's responses from the previous year are listed on the website for reference and updating if necessary.

The survey was most recently administered in June 2019 to IDD agencies in all 50 states and the District of Columbia. The agency director from each state and the staff members who responded to the previous survey were contacted to ensure consistency in the data reported. Initial contact was made by email, and follow-up was completed via email and telephone.

The survey home page provides general information and instructions for completing the survey. Additionally, instructions and guidance for responding to the survey questions are included within each question. The survey requests data on the total number of individuals served in day and employment services during the fiscal year; however, if a state does not have the capacity to adjust for individuals who enter or exit the system during a fiscal year and can only provide the number served at the end of the fiscal year (or at some other specific point in time), there is a place on the survey to provide this information. States are able to report an individual in multiple service categories, so the total of the percentage served across services may sum to greater than 100%.

Each step of the survey provides an opportunity for states to enter explanatory comments on their data. The final step of the survey offers states the chance to make suggestions for how the survey could be revised in the future. States are also asked to identify the information source used to provide service category data. There is a definitions page that can be referred to from any page of the survey. A summary of the service category definitions can be found in Table 1.

After a state has finalized its response to the survey, ICI staff review the data and follow up with states whose data shows an unexpected increase or decrease in the total number served, number served in a service category, or total funding.

Table 1. IDD National Survey of Employment and Day Services Definitions

Type of Setting/ Service	Work	Non-Work
Community	Integrated employment: Integrated employment services are provided in a community setting and support or lead directly to paid employment of the participant. Specifically, integrated employment includes services that support entering or maintaining competitive employment, individual supported employment, group supported employment, and self-employment supports.	Community-based non-work: Community-based non-work includes all services that are focused on supporting people with disabilities to access community activities in settings where most people do not have disabilities. It does not include paid employment.
Facility	Facility-based work: Facility-based work includes all employment services that occur in a setting where the majority of employees have a disability. These activities occur in settings where continuous job-related supports and supervision are provided to all workers with disabilities. This service category is typically referred to as a sheltered workshop, work activity center, or extended employment program.	Facility-based non-work: Facility-based non-work includes all services that are located in a setting where the majority of participants have a disability. These services do not involve paid employment of the participant.

In a typical year, between 44 and 47 states complete the IDD survey. The authors estimate the national figures for total served in day and employment services and total served in integrated employment by estimating the missing data for states that did not complete the survey. The researchers use linear regression for estimating missing values. To increase stability of the estimates, data are added from the most recent literature available (State of the States in Intellectual and Developmental Disabilities).

REHABILITATION SERVICES ADMINISTRATION 911.

The Rehabilitation Services Administration 911 (RSA-911) is a public access database that captures individual characteristics, services provided, and employment outcomes at the point of closure from VR services. Records are at the individual level, covering roughly 550,000 case closures in recent years. In 2017, RSA changed from reporting for the federal fiscal year to reporting for a program year that runs from July 1 to June 30. The program years 2010-2016 refer to the period from October 1 to September 30. The program year 2017 refers to the period from October 1 to June 30 (9 months only). The program years 2018-2019 refer to the period from July 1 to June 30. Each program year refers to the end date of the reported period. For example, the program year 2019 refers to the period July 1, 2018, to June 30, 2019.

Table 2. RSA Service Definitions

Term	Explanation
Closure	Data in the RSA-911 are collected at the time of closure (conclusion) of VR services. The VR closure categories used in this report include closure with an employment outcome after receiving services (formerly Status 26), closure without an employment outcome after receiving services (formerly Status 28), and closure after eligibility but before an individual plan for employment is developed (formerly status 30)
Successful rehabilitation	Closure with an employment outcome, including integrated employment (including supported employment), self-employment, state-agency-managed business enterprise, homemaker, and unpaid family worker.
Rehabilitation rate	The percentage of individuals receiving services who achieve a successful rehabilitation. Calculated as: closures with an employment outcome / closures with an employment outcome + closures without an employment outcome after receiving services.

For the purposes of this report, a person is considered to have an intellectual disability (ID) if code 25 (mental retardation in the RSA-911 dataset through 2016) was reported as the cause of either a primary or secondary impairment to employment.

AMERICAN COMMUNITY SURVEY.

The American Community Survey (ACS) is a national survey designed and administered by the U.S. Census Bureau to better understand changing communities. The ACS collects information from all 50 states and D.C. on topics such as disability, age, race, income, and other demographic and personal data (www.census.gov).

To gather information on people with disabilities, the Census Bureau asks six questions on long-lasting conditions and functional impairments. Any person who indicates having one or more of these conditions or functional impairments is considered as having a disability. The individual items used to collect these data points are outlined in Table 3.

Table 3. ACS Service Definitions

Term	Explanation
Employment rate	The percentage of civilian, non-institutionalized working-age (16–64 years old) individuals who have a job.
Disability categories	<p>The ACS classifies individuals as having a disability based on answering affirmatively to one or more of the following items:</p> <ul style="list-style-type: none"> • Is this person deaf or does he or she have serious difficulty hearing (hearing disability)? • Is this person blind or does he or she have serious difficulty seeing even when wearing glasses (vision disability)? • Does this person have serious difficulty walking or climbing stairs (ambulatory difficulty)? • Does this person have difficulty dressing or bathing (self-care difficulty)? • Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor’s office or shopping (independent-living difficulty)? • Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions (cognitive disability)?

SOCIAL SECURITY ADMINISTRATION (SSA).

These data are from the Supplemental Security Income (SSI) Annual Statistical Report. The SSA reports work-incentive participation and the number of individuals receiving SSI who are working.

Beginning with the 2010 SSI Annual Statistical Report, tables showing data by diagnostic group provide more specific details for mental disorders in these categories: autistic disorders, developmental disorders, childhood and adolescent disorders not elsewhere classified, intellectual disability, mood disorders, organic mental disorders, schizophrenic and other psychotic disorders, and all other mental disorders. Data from previous years use three categories for mental disorders: retardation, schizophrenia, and other.

Table 4. Work Incentive Program Definitions

Program	Definition
Plan for Achieving Self-Support (PASS)	Allows a person with a disability to set aside income or resources to support achieving a specific work goal. Money set aside under a PASS is excluded both as current income and from the SSI resource limits.
Impairment-Related Work Expenses (IRWE)	Allows people to exclude the cost of certain impairment-related services or items needed to earn income when determining the beneficiary’s current earned income for SSI eligibility and benefits.
Section 1619(a)	Allows people with disabilities to continue receiving SSI income even if their earned income is at Substantial Gainful Activity levels, i.e., the amount that would normally make them ineligible for SSI.
Section 1619(b)	Allows individuals to continue receiving Medicaid benefits if their earnings disqualify them from eligibility for SSI cash payments but are not enough to afford medical insurance.

STATE DEMOGRAPHICS.

State demographics are compiled from multiple data sources. State population data is taken from the U.S. Census website (www.census.gov). Unemployment data is taken from the Bureau of Labor Statistics website (www.bls.gov).

National Survey of State Intellectual and Developmental Disabilities Agencies' Employment and Day Services (1988-2018)

The data reported here are the core elements of the Institute for Community Inclusion's National Survey of State Intellectual and Developmental Disabilities Agencies' Employment and Day Services. These data focus on participation in integrated employment, community-based non-work, and facility-based services (both work and non-work). Data are requested from all 50 states and the District of Columbia. Between 2010 and 2018, between 44 and 47 states completed the survey in each year, and in FY2018, 47 states completed the survey.

The researchers calculated national estimates for the total number of people served by state IDD agencies, as well as the total number of people who received integrated employment services. For some states, data reported by service setting represent duplicated counts because individuals were served in multiple settings. For these states, the percentage served across settings may add up to more than 100%. Other services, including services for individuals who are elderly, are not reported.

Analysis of the national survey revealed these key findings:

- » National estimates suggest that, after remaining flat between 1999 and 2009, there has been modest growth in the number of individuals in integrated employment services between 2012 and 2018.
- » The number in integrated employment services grew by 4% between 2017 and 2018.
- » The estimated percentage of individuals participating in integrated employment services was 21.1% in FY2018, an increase from 19.4% in FY2016.
- » Rapid growth in integrated employment occurred between the mid 1980s and late 1990s as supported employment was adopted as a new service. Between 2004 and 2012 growth in the number of individuals receiving integrated employment services stalled, and there was a gradual decline in the percentage of people with IDD in integrated employment. The percentage has hovered around 19% to 21% for the past decade.
- » There is large variation across states in participation in integrated employment.
- » Individuals who receive an integrated employment service include those who are receiving services with an immediate goal of entering employment such as job development and those receiving long-term services to support maintaining employment.
- » There continues to be evidence that individual states are taking steps to reduce facility-based work, and the number and percent of individuals in facility-based work is declining.
- » As community-based non-work services continue to grow, more data is needed about the quality of outcomes and implementation of service delivery practices.
- » Funding for integrated employment services continues to lag.
- » Medicaid Title XIX Waiver dollars have not transitioned to integrated employment services.

Figure 3. Trend Line for Estimated Total Number of People Served by State IDD Agencies and Estimated Number Served in Integrated Employment

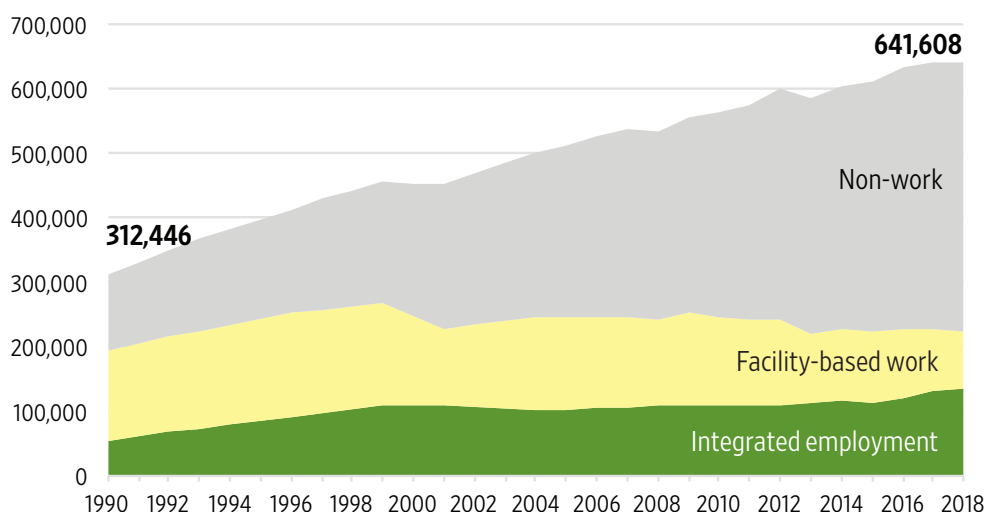


Table 5. Participation in Employment and Day Services in FY2017

State	Total Served	Percent Integrated Employment	Percent Community-Based Non-Work	Percent Facility-Based Work	Percent Facility-Based Non-Work
AK	2,064	22%	99%	n/a	n/a
AL	4,896	17%	3%	8%	86%
AR	n/a	n/a	n/a	n/a	n/a
AZ	12,836	21%	n/a	9%	87%
CA	92,640	12%	80%	7%	0%
CO	16,739	19%	45%	4%	32%
CT	10,830	41%	11%	1%	48%
DC	1,700	26%	24%	22%	42%
DE	2,391	35%	6%	15%	39%
FL	22,694	10%	27%	n/a	n/a
GA	16,671	13%	21%	12%	49%
HI	2,217	3%	77%	0%	64%
IA	15,023	29%	n/a	10%	n/a
ID	n/a	n/a	n/a	n/a	n/a
IL	19,605	9%	n/a	1%	86%
IN	14,257	13%	63%	26%	56%
KS	7,597	12%	64%	35%	53%
KY	9,882	37%	43%	12%	8%
LA	4,722	30%	n/a	12%	n/a
MA	17,479	40%	39%	0%	54%
MD	13,806	29%	10%	11%	66%
ME	5,230	15%	80%	n/a	n/a
MI	14,807	28%	81%	18%	17%
MN	32,134	11%	36%	44%	8%
MO	6,276	15%	44%	0%	67%
MS	4,658	36%	28%	2%	35%
MT	1,917	27%	10%	23%	62%
NC	18,577	17%	55%	12%	35%
ND	n/a	n/a	n/a	n/a	n/a
NE	4,493	19%	63%	22%	72%
NH	3,480	44%	84%	0%	0%
NJ	9,604	10%	n/a	n/a	92%
NM	5,101	27%	87%	0%	16%
NV	2,575	17%	2%	47%	34%
NY	59,398	18%	8%	4%	77%
OH	32,761	30%	0%	51%	52%
OK	3,702	66%	37%	58%	0%
OR	8,043	57%	51%	15%	37%
PA	30,468	18%	68%	25%	39%
RI	3,844	52%	66%	0%	32%
SC	9,862	28%	10%	29%	32%
SD	2,683	20%	32%	51%	31%
TN	6,073	18%	97%	0%	17%
TX	25,964	6%	0%	0%	94%
UT	3,825	24%	76%	0%	n/a
VA	14,312	29%	19%	7%	45%
VT	2,911	45%	77%	0%	0%
WA	9,289	85%	18%	2%	0%
WI	16,691	25%	18%	38%	56%
WV	n/a	n/a	n/a	n/a	n/a
WY	1,971	14%	28%	0%	58%

0% indicates that the state IDD agency reported it did not provide this service during FY2018

n/a = data not available

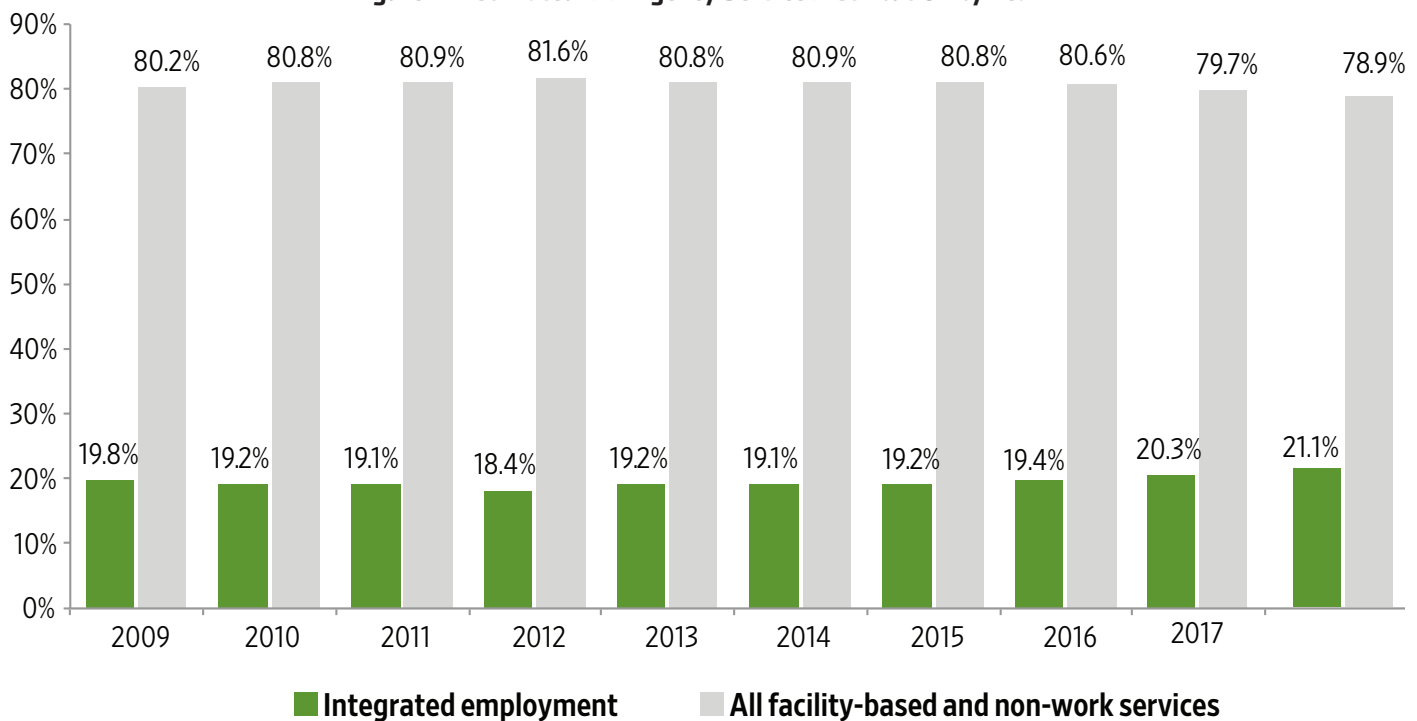
Figure 3 shows that in FY2018, an estimated 641,608 individuals received day or employment supports from state IDD program agencies. This number grew from 455,824 in FY1999. The estimated number of individuals in integrated employment services increased from 108,227 in FY1999 to 135,228 in FY2018.

Between FY2017 and FY2018, there was a slight increase in the number of individuals reported as receiving an integrated employment service by state IDD agencies. However, when comparing the percentage of individuals, the rate has hovered around 19%–21% since 2001, increasing to 21.1% in 2018.

As states implement Employment First policy and revise service definitions to reflect individual integrated employment in the community, there is anecdotal evidence that states are strengthening the definition of integrated employment, and this has led to outcomes previously counted as integrated employment being reclassified to other service types. This suggests that the impact of Employment First policies is stronger than the trend in integrated employment suggests. Overall, though, state investment continues to emphasize facility-based and non-work services, rather than integrated employment services.

Figure 4 shows trends in the percentage of people served in integrated employment and in facility-based and non-work settings between FY2008 and FY2018. In FY2018, an estimated 21.1% of individuals receiving day supports from state IDD agencies received integrated employment services. The estimated percentage of people served in integrated employment services declined from 24.2% in 2001 to 18.4% in 2012, suggesting that the growth seen in employment as a result of the RSA Supported Employment Systems Change Grants between the mid-1980s and mid-1990s did not continue. The current modest growth in the percent in integrated employment services likely reflects the implementation of state-level employment strategy and policy.

Figure 4. Estimated IDD Agency Service Distribution by Year



The percent of individuals served in facility-based and non-work settings has stayed fairly stable since 2008, varying between 78.9% and 81%. Variability in the number of states that report data in these three individual service categories (facility-based work, facility-based non-work, and community-based non-work) limits our ability to pinpoint the specific setting in which growth is occurring. However, analysis using data from states that report data in each of the three service categories suggests that participation in facility-based work has steadily declined, and the percentage of individuals served in non-work settings is increasing.

State-by-state variation masks growth in integrated employment.

There is significant long term variation in individual state level growth in integrated employment. To demonstrate this variation, data from the survey were examined for 37 states that provided the total number of individuals served and the number of individuals in integrated employment services between 2007 and 2018. Between those two points of time, twenty-six states reported an increase in the number of individuals in integrated employment services, with an

average increase of 1,168 individuals (range: 15–3,961). States that reported increasing the number of individuals served in integrated employment by more than 500 individuals between 2007 and 2018 were AL, CA, CO, KY, MA, MN, MO, MS, NC, NH, NY, OH, OR, SC, WA, and WI. These states have engaged in strategic efforts and systematic changes to their service delivery system to make integrated employment the preferred service outcome for adults with IDD in their state. However, the number of individuals reported as receiving integrated employment services declined in 11 states, with an average reduction of 632 (range: 21–2,100).

What do the data tell us about the number of people working?

In FY2009, the survey began asking states about their ability to provide data on the number of individuals working for pay in integrated community jobs, including competitive employment, individual supported employment, group supported employment, and self-employment.

In FY2018, the majority of states (n=33) that responded to the survey reported collecting data on the number of individuals working for pay in the community. Table 6 shows states that identified how many of the individuals who are participating in any employment and day service also work for pay in the community.

Table 6. Individuals Working in the Community in FY2018

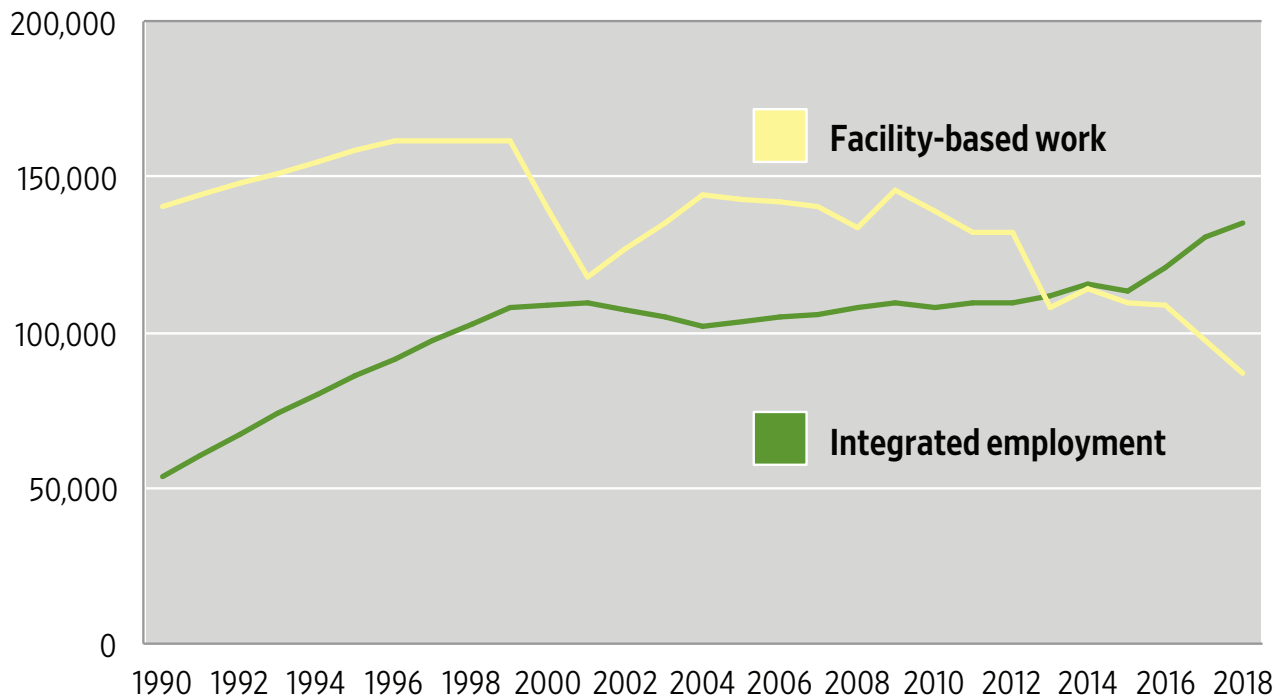
State	Total Receiving Any Employment or Day Service	Total in Integrated Employment Services	Total Receiving Any Employment or Day Service and Working in the Community
AL	4,896	824	824
AZ	12,836	2,371	2,371
CA	92,640	11,388	11,388
CO	16,739	3,207	3,207
CT	10,830	4,416	4,416
DE	2,391	842	709
DC	1,700	434	190
FL	22,694	2,257	1,922
KS	7,597	933	933
KY	9,882	3,693	3,356
MD	13,806	3,937	3,658
MA	17,479	7,073	4,697
MI	14,807	4,207	1,702
MN	32,134	3,687	3,687
MO	6,276	963	727
MT	1,917	511	511
NV	2,575	430	430
NH	3,480	1,534	1,534
NJ	9,604	994	774
NY	59,398	10,972	8,863
OH	32,761	9,833	9,833
OK	3,702	2,444	2,444
OR	8,043	4,613	4,613
PA	30,468	5,365	4,208
RI	3,844	2,001	965
SD	2,683	531	1,635
TN	6,633	1,188	1,188
TX	25,964	1,614	992
UT	3,825	934	833
VT	2,911	1,323	1,323
VA	14,312	4,220	4,220
WA	9,289	7,898	5,521
WI	16,691	4,183	4,183

Thirty-three states reported on the total number of individuals served in any employment and day service who were working for pay in community jobs. In some states, for example South Dakota, the number of individuals working is greater than the number who receive integrated employment services. This is possible because there are individuals with IDD working for pay in the community who are not receiving funded employment supports from their state IDD agency, but who receive other funded day services. Similarly, in other states, the number of individuals in integrated employment services is higher than the number working for pay. These states may be providing job development and other direct supported employment pathway services to individuals who are not yet working. The total number of individuals who worked in paid integrated employment in FY2018 as reported by these 33 states was 97,757. In these states, 19.3% of individuals who received any day and employment service were working in the community in integrated jobs. This is an increase from FY2016, when 18% were working for pay.

States are making significant efforts to reduce facility-based work.

As Table 5 indicates, in FY2018 19 state IDD agencies did not report individuals in facility-based work services. However, this does not mean that those 19 states have eliminated all funding for facility-based work. A state's ability to report on facility-based work is impacted by service structure and state reporting capacity. Many states have facility-based work services embedded within their facility-based non-work services or rely on other state agencies to fund these services. In order to distinguish states that have eliminated facility-based work services, the table contains 0% for those states whose IDD agency did not provide the service in 2018 and n/a for states who indicated not being able to report on this specific service. Participation in facility-based work services has declined steadily since 1999, and reached a benchmark in 2013 when it dropped below participation in integrated employment. Overall, the number of individuals reported as participating in facility-based work settings dropped by an estimated 74,650 individuals between 1999 and 2018 (Figure 5).

Figure 5. Change in Facility-based Work and Integrated Employment over Time



Vermont's IDD agency is nationally recognized for not funding facility-based or group supported employment services, and a review of active 14(c) subminimum wage certificates indicates that there are no active certificates in the state. Other states that have strong IDD agency policies for not funding facility-based work services are Alaska, District of Columbia, Maine, Maryland, Massachusetts, New Hampshire, and Washington. In 2015, New Hampshire passed legislation to end subminimum wage; Maryland passed legislation in 2016 that phased out the use of subminimum wage in 2020; Alaska ended payment of less than minimum wage effective February 2018; the City Council of Seattle eliminated subminimum wage in the city in April 2018 and Washington State is no longer funding facility-based work services as of 2019. Wyoming has also stopped providing facility-based work services through their Medicaid waiver. Additionally, reports from the National Council on Disability (2020) and the U.S. Commission on Civil Rights (2020) have provided clarity on the need to move away from facility-based work on a national scale.

State IDD agencies are making other policy decisions to reduce the number of individuals in facility-based work services. For example, states are placing limitations on the time that an individual may receive facility-based work services. Some are requiring that an individual's service plan describe the specific skills that the person will gain in the sheltered workshop, and how those skills will improve the likelihood that the individual will be employed in the community. As states move toward full compliance with the HCBS settings rule, it is anticipated that as a whole, we will see a significant reduction in facility-based work services in 2023 due to the inherent difficulty of these services becoming compliant with the settings rule.

If people aren't working, where are they spending their time?

As illustrated in Figures 4 and 5, participation in facility-based work has steadily declined, however individuals are not transitioning to integrated employment and instead are using non-work services. Added to the survey as a service option in FY1996 in response to state feedback, the number of states that report providing community-based non-work (CBNW) services has grown from 18 in FY1996 to 41 in FY2018. Nationally, reported participation in CBNW has grown steadily for states that report it as a service, from 18.7% in FY1999 to more than 43.6% in FY2018 of all employment and day services. CBNW services accounted for a reported 39.4% of state IDD agency expenditures for FY2018, for states that reported expenditures for this service (n=38).

There is a limited amount of data on the structure, activities, and outcomes of CBNW services, and states have not established clear service expectations or quality assurance strategies (Sulewski & Timmons, 2015; Lyons & Hall, 2015; Timmons & Sulewski, 2016). The rapid growth states report in CBNW services reflects a desire to improve the community presence of individuals with IDD, but the quality of the services being reported and the contribution of this service on a national level to authentic community engagement remain unclear.

While some states report service requirements for how much time CBNW participants spend in the community, it is possible that some states have reclassified services from facility-based to community-based as the emphasis on community participation grows, even though substantial time is still spent in facility-based settings. The trend toward CBNW services also raises concerns about the clarity of the service system's goals for community employment. It is likely that as funds transition to the community, due to the lack of specificity of the goals of CBNW services, non-work services are seen as an alternative to (rather than a complement to or an avenue toward) integrated employment services.

Data reported by community rehabilitation providers (CRPs) in a 2014–2015 national survey suggest that only 13% of individuals with IDD participate in CBNW services (Domin & Butterworth, 2016). While CRP and IDD agency responses are not directly comparable, and may reflect differing approaches to reporting duplication of services, the disparity raises concerns about how integrated CBNW services are in practice and the capacity of IDD agencies to distinguish non-work service experiences.

Research by ICI staff on CRPs has found that some CRPs are developing innovative ways to support individuals to be engaged members of their community as a way to improve integrated employment outcomes. Sulewski et al. (2017) identified four guideposts that define high-quality Community Life Engagement (CLE) supports. These include the individualization of supports for each person, promoting community membership and contribution, building human and social capital to decrease dependence on paid supports, and ensuring that supports are outcome-oriented and regularly monitored.

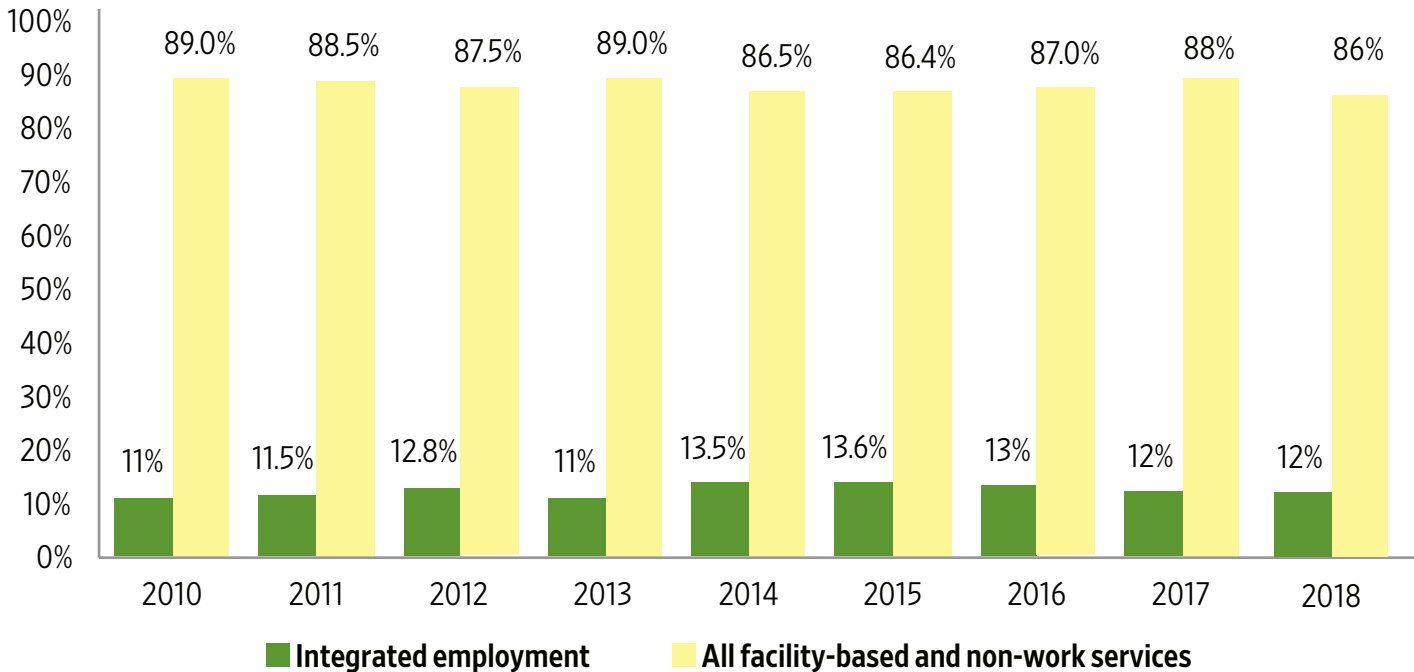
Findings from case studies of providers delivering quality CLE practices suggest that individuals are being supported in a variety of activities including volunteer work; postsecondary, adult, or continuing education; accessing community facilities such as a local library, gym, or recreation center; and participation in retirement or senior activities. Researchers also found that such activities support career exploration for those not yet working or between jobs, supplement employment hours for those who are working part-time, or serve as a retirement option for older adults with IDD (Timmons & Sulewski, 2016). These findings serve as guidance for states and service providers seeking to increase and improve CLE.

As emphasis on CBNW services grows and states implement their home and community-based services transition plans, additional research is needed on how state IDD agencies are translating best practices at the provider level into state policy and quality service monitoring.

Funding for integrated employment services continues to lag.

States vary in their ability to report on funding for employment and day services by service setting. Figure 6 shows trends in funding allocation by service setting for states that reported these monetary figures. Facility-based and non-work settings continue to comprise the largest percentage of expenditures for day and employment services. Collectively, states allocated 86% of day and employment service funding in FY2018 to services that are not integrated employment including community-based non-work, facility-based work, facility-based non-work, and other services (n=44). In contrast, states that reported funding for integrated employment (n=45) allocated 11.6% of the funding for all day and employment services to integrated employment services in FY2018. There has been little fluctuation over time in the percentage of funding allocated toward integrated employment, which peaked in 2001 at 16.6%, but otherwise has ranged between 9.6% and 13.6% in all other years since 1999.

Figure 6. Percentage of All Day and Employment Funding by Year



Medicaid Title XIX Waiver dollars have not transitioned to integrated employment services.

Medicaid Title XIX Waiver funds are the largest sources of funds for day and employment services, representing 81.8% of total reported funds in FY2018 (n=43). Medicaid waivers as a funding resource to support individualized integrated employment have received significant attention in recent years. Based upon recommendations provided by State Employment Leadership Network member states, CMS released an informational bulletin in September 2011, that addressed “Updates to the §1915 (c) Waiver Instructions and Technical Guide regarding employment and employment related services.” The bulletin emphasized the importance of integrated employment and person-centered planning, and distinguished between pre-vocational and supported employment services.

The bulletin also discussed best practices in employment services. It split supported employment into two core service definitions—individual and small group (two to eight people)—and added a new core service definition for career planning (Kennedy-Lizotte & Freeze, 2012). As states address the role of employment in their Medicaid Home and Community-Based Services Waiver under the Community Rule, the guidance will continue to play a significant role in employment systems change.

In September 2015, CMS offered clarification to state Medicaid authorities on the development of reimbursement strategies to create incentives for integrated employment and specifically individual supported employment (Center for Medicare and Medicaid Services, 2015). Specifically, CMS clarified that benefits planning is an allowable service under Medicaid 1915(i) and 1915(c) waiver authorities, and that states can develop pay-for-performance methodologies, including the use of outcome-based payment, tiered outcome payments based upon level of disability, milestone payments in addition to fee-for-service, and payment for hours the individual works.

Additionally, many states are making use of technical assistance available through the State Employment Leadership Network, Administration on Community Living grants, and the Office of Disability Employment Policy to support the redesign of their Medicaid Title XIX Waivers to increase individualized integrated employment outcomes.

States vary in their ability to report Medicaid Title XIX Waiver funds on specific IDD agency services. As the number of states able to report these figures increases, it will be important to examine both the cross-sectional and trend data for this type of funding. For states that have been able to report these figures (n=43), the allocation of these funds has varied based upon year and service category: integrated employment, community-based non-work, facility-based work, and facility-based non-work.

In FY2018, 43 states reported expenditures by day and employment service for the Medicaid Title XIX Waiver. These funds represent both the federal dollars allocated to the state and the state matching dollars. The percentage of waiver funds spent by state IDD agencies on integrated employment services was 10.8%, closely mirroring the percentage of all day and employment dollars spent on this service. Title XIX expenditures reported for facility-based non-work services declined slightly from 2017, but still made up the greatest percentage of Title XIX dollars spent (44%). Title XIX expenditures reported for community-based non-work services remained steady and made up 41% of Title XIX dollars spent, representing a continued investment in all non-work services.

Winsor et al., (2017) suggest several reasons why, despite the increased emphasis on individual integrated employment as a priority in the development and administration of Medicaid Title XIX Waivers, dollars from this source continue to be overwhelmingly spent on non-work services. These reasons include:

- » overly complicated funding systems that are not easily understood by provider agencies, case management staff, resource allocation staff, and individuals and their families;
- » the inability to bill for non-direct services needed for successful job development;
- » the failure to capture the real-world cost of providing individual integrated employment services and an over-reliance on the historical cost;
- » the failure to include the cost of individual integrated employment when developing individual service budget allocations;
- » the expectation that transportation of the individual to a job in the community will be paid for out of the integrated employment rate; and
- » the failure to identify transportation as a separate service that has a distinct payment rate from the payment for an employment or day service.

REHABILITATION SERVICES ADMINISTRATION 911 (2010–2019)

This section describes the employment outcomes of adults with an intellectual disability (ID)¹ who exited from the vocational rehabilitation (VR) program during program years 2010 through 2019, in the 50 states and the District of Columbia (DC). For context, we compare the findings with the corresponding outcomes of people with other disabilities. These data are from the Rehabilitation Services Administration 911 (RSA-911) database.

Analysis of the data describing people with intellectual disabilities who exited the VR program between 2010 and 2019 found:

- » The number of people who exited the VR program decreased by 9%.
- » The percentage of people who received services increased.
- » The rehabilitation rate ranged from 46% in 2019 (the lowest level) to 56% in 2014 and 2015.
- » Wages remained largely unchanged after adjusting for inflation.
- » Weekly work hours decreased.
- » Time from application to exit with employment increased between 2018 and 2019 reversing a five year trend.
- » The majority of people with ID are male, white, and transition-age young adults.
- » Outcomes varied considerably across states.

The number of people with intellectual disabilities who exited the VR decreased by 9%.

As Table 7 shows, in 2019, a total of 45,108 people with intellectual disabilities exited the VR program. This figure is slightly greater than in 2018, although still smaller than in previous years. In general, the number of case closures for people with intellectual disabilities has declined since 2010, when it was 49,697. The corresponding figure for people with other disabilities was 374,479 in 2019, down from 387,410 in 2018 and 511,441 in 2010, the highest figure reported during the period examined.

Table 7. National Trends in Employment Outcomes²

	Total closures		Received services		Rehabilitation rate		Hourly wage*		Weekly hours*		Got a job in one year	
	ID	Other	ID	Other	ID	Other	ID	Other	ID	Other	ID	Other
2010	49,697	511,441	65%	58%	48%	49%	\$8.78	\$12.49	24	32	33%	37%
2011	47,812	494,273	66%	60%	51%	51%	\$8.57	\$12.11	24	32	32%	36%
2012	46,672	484,330	65%	60%	52%	53%	\$8.51	\$11.95	24	32	30%	35%
2013	48,847	492,247	66%	62%	50%	51%	\$8.44	\$11.79	24	31	30%	34%
2014	45,443	495,293	67%	58%	56%	54%	\$8.39	\$11.68	23	31	30%	33%
2015	47,390	470,289	68%	62%	56%	57%	na	na	23	30	32%	35%
2016	47,595	459,141	70%	63%	55%	57%	na	na	23	30	33%	37%
2017*	38,642	361,601	72%	67%	47%	49%	na	na	23	30	33%	38%
2018	44,152	387,410	78%	72%	47%	48%	\$9.97	\$13.91	23	31	31%	37%
2019	45,108	374,479	77%	71%	46%	46%	\$10.08	\$13.84	22	30	27%	35%
Change	↓	↓	↑	↑	—	—	—	—	↓	↓	—	—

ID = intellectual disabilities; Other = other disabilities.

Hourly wages are in 2019 dollars.

*Includes only 9 months due to a change in the RSA-911 reporting protocol.

1 Intellectual disability refers to code 25 (“mental retardation” in the RSA-911 case report description) as either a primary or secondary cause of an impediment to employment.

5 The program years 2010-2016 refer to the period from October 1 to September 30. The program year 2017 refers to the period from October 1 to June 30 (9 months only). The program years 2018-2019 refer to the period from July 1 to June 30. Each program year refers to the end date of the reported period. For example, the program year 2019 refers to the period July 1, 2018, to June 30, 2019.

The percentage of people receiving VR services increased.

Receiving services from VR is a key step toward an employment outcome. In 2019, 77% of people with intellectual disabilities who exited the VR program received services. This is slightly less than in 2018 (78%), but still among the highest percentage in ten years, confirming a growth trend that started in 2012. The corresponding figure for people with other disabilities was 71%, a meaningful increase compared to earlier years. The most frequent reasons reported for people with intellectual disabilities to exit the program without receiving services in 2019, included the individuals' refusal of services or failure to cooperate (27%), VR counselors' inability to locate or contact the individual (23%), and other reasons, including disability too significant, death, job seeker's relocation, no disability-related need for services, or other non-specified reasons. Similar reasons for exiting the program without receiving services were reported for people with other disabilities.

The rehabilitation rate varied from 46% in 2019 (the lowest level) to 56% in 2014 and 2015.

The rehabilitation rate is the percentage of people who gain employment divided by the total number of people who receive services³. The rehabilitation rate of people with intellectual disabilities was 46% in 2019 from the previous high of 56% in 2014-2015. The corresponding figure for people with other disabilities (46%) reflected a similar pattern.

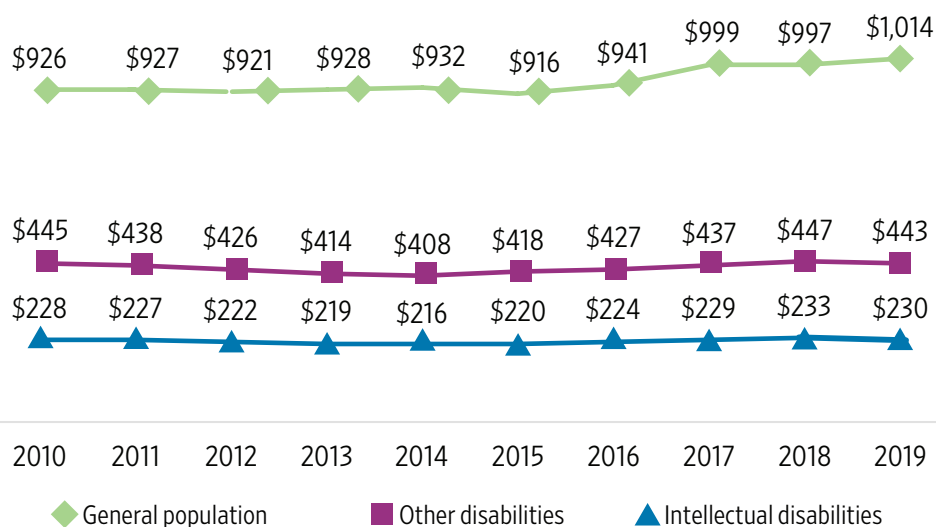
Wages remained largely unchanged after adjusting for inflation.

After five years of steady decline in adjusted hourly wage between 2010 and 2014, there was a substantial increase from \$8.39 per hour in 2014 to \$10.08 per hour in 2019. A similar pattern emerged for people with other disabilities. All figures are adjusted for inflation. Wage data were not available for the years 2015-2017.

Another way to look at earnings is to examine weekly wages. Weekly wages provide a focus on overall earned income and allow comparison with the earned income of the general population. Weekly wages depend on the number of weekly work hours, therefore an increase in hourly wages does not always result in an increase in weekly wages.

Figure 7 compares the trend in weekly wages of people with intellectual disabilities, people with other disabilities (RSA911 data), and the general population without disabilities (American Community Survey data). In 2019, weekly wages of people with intellectual disabilities who exited with an employment outcome remained largely unchanged after adjusting for inflation: \$230 in 2019, compared to \$228 in 2010 in constant 2019 dollars. The weekly wages of people with other disabilities also remained unchanged over time, though this group earned almost twice as much as people with intellectual disabilities (\$443 in 2019). In contrast, the wages of the general population of people without disabilities have been slightly increasing since 2010 (\$926), reaching \$1,014 in 2019.

Figure 7. National Trends in Weekly Wages in Constant 2019 Dollars*



* Earnings of the general population were computed by dividing the annual wages of civilians, ages 16–64, by 52 weeks, using data from the American Community Survey.

³ Rehabilitation rate in 2018= Number of people who “exited after an IPE in competitive and integrated employment or supported employment” divided by (Number of people who “exited after an IPE in competitive and integrated employment or supported employment” + Number of people who “exited after an IPE without an employment outcome”) p. 105 <https://www2.ed.gov/policy/speced/guid/rsa/subregulatory/pd-16-04.pdf>

This is slightly different for years prior to 2018 when the rehabilitation rate = Number of people who “Exited with an employment outcome” divided by (Number of people who “Exited with an employment outcome” + Number of people who “Exited without an employment outcome, after receiving services” + Number of people who “Exited without an employment outcome, after a signed IPE, but before receiving services”) p. 40 <https://www2.ed.gov/policy/speced/guid/rsa/subregulatory/pd-14-01.pdf>

Weekly work hours decreased.

In 2019, people with intellectual disabilities who exited the VR program with employment worked an average of 22 hours per week, a slight decline from 23 hours per week in 2018 and 24 hours per week in 2010. People with other disabilities reported 30 weekly work hours, down from 31 hours per week in 2018 and 32 hours per week in 2010.

Time from application to exit with employment increased between 2018 and 2019 reversing a five year trend.

In 2019, it took people with intellectual disabilities on average about 714 days from application to exit the VR program employed. This is an increase of 30 days from 684 days in 2018, and interrupts five years of steady reduction from the maximum of 718 days in 2013. People with other disabilities also reported a longer timeframe from application to employment: 755 days in 2019 compared to 728 days in 2018. The shortest amount of time was 720 days in 2010.

Another way of looking at this outcome is to examine the percentage of people with disabilities who exited the VR program with employment within one year from application. For people with intellectual disabilities, the figure in 2019 was 27%. A longer time from application to exit with employment is not necessarily an indication of a slow process to employment. For example, some people may have obtained a job within one year from the date of application, but VR postponed closing the case until a later year. One possible reason for delaying the exit from the program, even though employment was achieved, is to resume employment services more rapidly if the job is lost. In 2014, WIOA extended the time frame for the provision of supported employment services from 18 months to 24 months to better support these employment scenarios.

The majority of people with intellectual disabilities are male, white, and transition-age young adults.

The majority of people with intellectual disabilities who exited VR programs in 2019 were male (58%). Similar figures were reported for people with other disabilities (56%; Table 8) and in previous years.

Table 8. National Trends in Demographic Characteristics

	Gender				Race and ethnicity							
	Male		Female		White (Non-Hispanic)		Black (Non-Hispanic)		Hispanic		Other	
	ID (%)	Other (%)	ID (%)	Other (%)	ID (%)	Other (%)	ID (%)	Other (%)	ID (%)	Other (%)	ID (%)	Other (%)
2010	57%	57%	43%	43%	56%	64%	34%	24%	8%	9%	2%	2%
2011	58%	57%	42%	43%	56%	64%	34%	24%	8%	10%	2%	3%
2012	58%	57%	42%	43%	55%	64%	35%	24%	7%	10%	3%	3%
2013	58%	56%	42%	44%	54%	63%	35%	24%	8%	10%	2%	3%
2014	57%	56%	43%	44%	56%	63%	33%	24%	9%	11%	3%	3%
2015	57%	56%	43%	44%	56%	62%	33%	24%	9%	11%	3%	3%
2016	57%	56%	43%	44%	56%	62%	33%	24%	9%	12%	3%	3%
2017	58%	56%	42%	44%	55%	61%	33%	25%	9%	11%	3%	3%
2018	58%	56%	42%	44%	57%	61%	30%	23%	10%	13%	3%	4%
2019	58%	56%	42%	44%	56%	60%	30%	24%	11%	13%	3%	3%

The majority of people with intellectual disabilities who exited VR in 2019 were white non-Hispanic (56%). This is fairly aligned with the figures reported during the past ten years. The second-largest racial group for people with intellectual disabilities in 2019 was Black non-Hispanic. People with other disabilities included a high proportion of white people, 60% in 2019. Also in the case of people with other disabilities, the second largest racial group was Black, 24% in 2019.

The majority (62%) of people with intellectual disabilities who exited the VR program in 2019 were between 16 and 26 years old at application. This percent remained fairly stable between 2010 and 2019, varying between 61% and 63%. In contrast, 41% of the people with other disabilities who exited the program in 2019 were between 16 and 26 years old. This figure increased from 35% during the years 2010-12.

Outcomes varied considerably across states.

As Table 9 shows, services and outcomes varied widely across states. Hawaii reported that 100% of people with intellectual disabilities received services, the highest percentage across states, while New York reported that 60% received services. Kentucky was an outlier in 2019 reporting that only 7% of people received services, however, this figure is not consistent with earlier years (Kentucky reported 67% in 2017). In the case of people with other disabilities, the percentage of people receiving services ranged from a high of 98% in Hawaii to a low of 44% in Montana (excluding the outlier of Kentucky).

The rehabilitation rate is a key indicator of how many people who received services exited the VR program with a job. Washington state reported the highest rehabilitation rate for people with intellectual disabilities (68%), compared to Hawaii, which reported the lowest figure (24%). For people with other disabilities, the highest rehabilitation rate was reported in Mississippi (67%), and the lowest in Hawaii (24%).

The hourly wage of people with intellectual disabilities varied from \$8.42 in Louisiana to \$13.89 in DC. For people with other disabilities, hourly wage varied from \$10.98 in North Carolina to \$22.19 in Connecticut. These figures are likely influenced by local level minimum wage legislation.

In 2019, weekly work hours varied greatly across states as well. People with intellectual disabilities in South Carolina worked the most hours per week (29 on average), whereas their peers in Montana reported the lowest amount of work hours per week (12 on average)⁴. Among people with other disabilities, the highest work hours were reported in Mississippi (36 weekly work hours), and the lowest work hours in Minnesota, Washington state, and Wisconsin (26 weekly work hours).

The highest percentage of people with intellectual disabilities exiting VR with a job within one year from application was reported in South Dakota (52%)⁵. Their peers in Montana and Hawaii were the least likely to exit the program with a job within one year (0%). In regard to people with other disabilities, exiting the VR program with a job within one year was most likely in Michigan (60%), and least likely in Montana (0%).

State VR agencies vary widely in the emphasis on individuals with intellectual disabilities in their caseload. In FY2019, 9% of all closures nationally were individuals with an intellectual disability. This percentage ranged from 3% in Massachusetts to 19% in North Carolina. This figure is influenced by a variety of factors, including the structure of the state service system and interagency roles in the employment process.

⁴ Kentucky also reported that people with intellectual disabilities worked on average 29 hours per week. However, for the state the 2019 reporting year appears to be an outlier when compared to earlier years.

⁵ In Kentucky 100% of the people with intellectual disabilities who exited VR with a job in 2019, exited VR within one year from application. However the 2019 reporting year for the state appears to be an outlier when compared to earlier years.

Table 9. State Outcomes in 2019

	Total Closures		Received Services		Rehabilitation Rate		Hourly Wage		Weekly Hours		Got Job in <1 year	
	ID	Other	ID (%)	Other (%)	ID (%)	Other (%)	ID	Other	ID	Other	ID (%)	Other (%)
Alaska	82	1,078	83%	69%	60%	51%	\$11.92	\$15.37	17	31	32%	35%
Alabama	1,087	8,393	77%	68%	58%	59%	\$8.80	\$12.43	27	32	41%	48%
Arkansas	355	5,250	74%	77%	42%	62%	\$9.69	\$13.39	23	34	12%	34%
Arizona	502	6,965	77%	63%	38%	35%	\$10.92	\$13.44	24	29	32%	24%
California	2,503	28,487	84%	81%	41%	36%	\$12.52	\$15.40	27	30	28%	28%
Colorado	661	5,023	70%	65%	55%	54%	\$11.26	\$15.16	19	30	25%	41%
Connecticut	263	2,645	89%	87%	37%	52%	\$10.85	\$22.19	20	31	16%	57%
DC	238	1,588	92%	87%	31%	35%	\$13.89	\$16.21	26	32	26%	30%
Delaware	233	1,773	82%	85%	56%	54%	\$9.71	\$12.11	24	31	23%	19%
Florida	2,152	18,698	79%	77%	44%	42%	\$9.40	\$12.79	22	30	15%	28%
Georgia	1,389	8,357	66%	65%	33%	27%	\$9.00	\$11.55	26	30	18%	22%
Hawaii	133	956	100%	98%	24%	24%	\$11.42	\$15.29	27	29	0%	1%
Iowa	936	4,925	88%	74%	49%	48%	\$9.77	\$13.13	18	30	13%	13%
Idaho	323	3,750	76%	69%	41%	37%	\$8.80	\$14.25	17	32	25%	42%
Illinois	1,480	12,565	81%	76%	41%	48%	\$10.01	\$12.05	21	28	35%	36%
Indiana	1,189	4,205	82%	88%	43%	37%	\$8.98	\$12.17	20	27	10%	10%
Kansas	405	3,557	81%	70%	50%	42%	\$8.96	\$11.23	22	30	44%	41%
Kentucky	162	1,980	7%	18%	36%	46%	\$8.75	\$15.99	29	33	100%	83%
Louisiana	281	4,170	67%	60%	47%	52%	\$8.42	\$12.81	22	32	42%	48%
Massachusetts	343	10,296	84%	86%	47%	42%	\$11.98	\$15.13	19	28	30%	17%
Maryland	617	5,082	76%	70%	33%	30%	\$10.93	\$13.32	22	27	24%	29%
Maine	336	2,617	85%	77%	42%	35%	\$10.94	\$14.73	13	29	13%	36%
Michigan	1,527	14,006	76%	74%	48%	56%	\$10.06	\$15.22	23	32	39%	60%
Minnesota	899	6,459	90%	82%	47%	44%	\$10.80	\$13.27	20	26	31%	34%
Missouri	1,862	10,470	76%	72%	55%	53%	\$9.66	\$12.09	25	30	45%	53%
Mississippi	367	4,930	63%	81%	29%	67%	\$8.70	\$13.89	27	36	5%	54%
Montana	108	1,300	64%	44%	51%	35%	\$9.50	\$13.50	12	29	0%	0%
North Carolina	4,072	14,174	79%	68%	45%	38%	\$9.09	\$10.98	25	28	26%	32%
North Dakota	145	1,361	81%	76%	56%	50%	\$10.04	\$14.23	19	32	30%	48%
Nebraska	260	1,853	85%	81%	63%	56%	\$11.13	\$14.60	19	33	24%	30%
New Hampshire	131	1,380	74%	70%	67%	44%	\$9.86	\$14.32	17	27	8%	16%
New Jersey	663	9,471	63%	63%	54%	53%	\$9.99	\$13.65	23	29	27%	27%
New Mexico	259	3,058	72%	75%	41%	32%	\$9.46	\$12.94	17	30	35%	35%
Nevada	214	2,060	79%	75%	41%	42%	\$9.84	\$13.45	23	32	36%	42%
New York	2,003	30,899	60%	59%	45%	43%	\$12.09	\$14.69	21	30	37%	24%
Ohio	3,383	14,216	81%	72%	43%	44%	\$9.44	\$12.36	21	28	40%	50%
Oklahoma	651	5,129	71%	53%	32%	35%	\$9.73	\$13.52	26	34	5%	5%
Oregon	1,243	6,154	80%	70%	54%	57%	\$11.51	\$15.05	18	27	33%	50%
Pennsylvania	2,409	19,594	64%	66%	44%	53%	\$9.84	\$14.41	22	32	16%	25%
Rhode Island	138	1,088	93%	84%	50%	39%	\$10.79	\$13.77	17	27	2%	4%
South Carolina	611	12,287	86%	78%	39%	50%	\$9.18	\$14.10	29	35	19%	57%
South Dakota	315	1,948	87%	72%	57%	41%	\$9.79	\$13.93	19	30	52%	45%
Tennessee	990	4,326	74%	68%	45%	43%	\$8.84	\$12.06	22	29	35%	35%
Texas	2,082	29,999	80%	69%	51%	59%	\$10.03	\$14.66	26	33	23%	38%
Utah	538	5,044	78%	71%	51%	52%	\$9.30	\$12.64	19	31	13%	21%
Virginia	1,394	7,278	72%	66%	47%	46%	\$9.81	\$11.84	24	30	8%	19%
Vermont	252	2,680	93%	82%	42%	38%	\$11.40	\$15.02	17	29	42%	52%
Washington	890	6,153	72%	63%	68%	51%	\$12.36	\$15.24	15	26	34%	26%
Wisconsin	1,496	10,426	87%	75%	44%	39%	\$9.62	\$12.89	18	26	15%	29%
West Virginia	426	2,999	83%	84%	30%	33%	\$9.47	\$15.28	23	35	11%	9%
Wyoming	110	1,377	86%	77%	51%	55%	\$9.69	\$14.02	16	31	42%	43%
Average	884	7,343	77%	72%	46%	45%	\$10.16	\$13.88	21	30	26%	33%
Min	82	956	7%	18%	24%	24%	\$8.42	\$10.98	12	26	0%	0%
Max	4,072	30,899	100%	98%	68%	67%	\$13.89	\$22.19	29	36	100%	83%

Note. ID = intellectual disabilities; Other = other disabilities.

Data from Kentucky is dramatically different from previous years, indicating a possible anomaly in the data reporting system.

THE AMERICAN COMMUNITY SURVEY (2018)

The American Community Survey (ACS) offers a broader view of employment outcomes for working-age people with disabilities than system-specific data sources, such as the RSA-911 dataset. The ACS allows for the comparison of employment participation and outcomes for civilian working-age people with and without disabilities, and provides a population estimate that includes people who do not receive formal supports from a human service agency.

“Working-age people” are defined in this chapter as “civilian non-institutionalized people ages 16–64”. The data presented below will emphasize the ACS disability category of cognitive disability as the closest approximation for individuals with intellectual and developmental disabilities. It is important to look at multiple demographic, economic, and employment outcome indicators to get the best understanding of the employment situation for individuals with IDD.

Analysis of the ACS dataset revealed these key findings:

- » People with disabilities are much less likely to work than people without disabilities.
- » People with a cognitive disability who are receiving Supplemental Security Income (SSI) have the lowest employment rate of all people.
- » People with any type of disability have less success in the labor market compared to people with no disability.
- » Among working-age Americans, people with any disability and people with a cognitive disability are more likely to live in a household that is below the poverty line.
- » People with disabilities who are employed are less likely to live in a household that is below the poverty line compared to people with disabilities who are not employed.
- » Individuals with disabilities who are employed on average work fewer weeks per year than their nondisabled counterparts.

Important notes on ACS terminology and definitions for this report

In assessing employment outcomes, it is important to understand how the ACS defines employment categories as well as disability subgroups. Employment categories in the ACS include:

Employed: People with jobs.

Unemployed: People who do not have jobs and have actively looked for work in the past four weeks. These people are considered part of the labor force.

Not in the labor force: People who do not have jobs and have not actively looked for work in the past four weeks.

Employment rate (also referred to as the employment-to-population ratio): Number of people employed / number of people in the working-age population

Unemployment rate: Number unemployed / (number employed + number unemployed)

Questions that allow people to indicate specific disabilities like IDD are uncommon in large national surveys. The method by which ACS collects information on disability is summarized below:

- An individual is categorized as having any disability if they answer “yes” to one or more of six items: hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, self-care difficulty, and independent living difficulty.
- Someone with a cognitive disability has indicated that because of a physical, mental, or emotional condition lasting six months or more, they have difficulty learning, remembering, and concentrating.

People with disabilities are much less likely to work than people without disabilities.

Table 10 displays indicators of labor market success for four groups of working-age individuals: 1) people who do not have a disability, 2) people who indicated they have at least one disability (any disability), 3) people with a cognitive disability, and 4) people with a cognitive disability who received SSI in 2018. People with any disability or a cognitive disability are employed at much lower rates (36.9% and 27.8% respectively) than those without disabilities (75.5%).

People with a cognitive disability who are receiving Supplemental Security Income (SSI) have the lowest employment rate of all people.

People with cognitive disabilities who receive SSI have the lowest employment rate (8.2%). This finding is not surprising given that to be eligible for SSI, an individual needs to demonstrate that their disability is so significant that they cannot reasonably be expected to work for pay. Within the group of people with a cognitive disability, those who also receive SSI are likely to be people who have the most significant cognitive disabilities.

People with any type of disability have less success in the labor market compared to people with no disability.

In order to gain a full understanding of the employment experiences of individuals with disabilities, this report examines 1) the percentage employed, percentage unemployed, and percentage not in the labor force (indicators A, B, and C in Table 10) and 2) the unemployment rate. Individuals with disabilities are significantly less likely to be in the labor force, and those who are in the labor force experience higher levels of unemployment compared to people with no disability, indicating they have more difficulty finding a job.

Table 10. Labor Market Success Indicators by Disability Status in 2018

	No disability	Any disability	Cognitive disability	Cognitive disability with SSI
A. Percentage Employed (Employment Rate)	75.5%	36.9%	27.8%	8.2%
B. Percentage Unemployed	3.7%	4.8%	6.1%	2.4%
C. Percentage Not in the Labor Force	20.9%	58.3%	66.1%	89.4%
Total (A+B+C)	100.0%	100.0%	100.0%	100.0%
Unemployment Rate (number unemployed / number employed + number unemployed)	4.6%	11.6%	17.9%	22%

People with disabilities are more likely to live below the poverty line.

People with any disability and people with a cognitive disability are more likely to be living in a household that is below the poverty line than people without a disability. In 2018, only 10.9% of all working-age people without a disability lived in a household that was below the poverty line, compared with 26% of people with any disability, 30.8% of people with a cognitive disability, and 38.1% of people with a cognitive disability who received SSI payments as part of their income.

Eligibility for the SSI program includes having limited financial resources. Therefore, it is not surprising that people with a cognitive disability who receive SSI payments are more likely to be poor. Nearly fifteen years ago, Stapleton, O'Day, Livermore, and Imparato (2006) described this as living in a "poverty trap". In order to maintain access to health care and support services through Medicare and Medicaid, people with disabilities must prove that they are poor; this leads people either remaining out of the labor force or limiting their employment earnings. Little has changed since their report. A 2017 report by the National Council on Disability described the ongoing issue:

"..., due to the "all or nothing" requirement of the SSA, people with disabilities are faced with choosing between working or receiving needed cash, medical, and other in-kind support. If they choose to work, then they often find themselves in low-paying jobs with little or no benefits. If they select needed benefits, they cannot work and are often faced with the further challenge of navigating a complex system to obtain needed supports." (p. 49).

When people with disabilities are employed, they are less likely to live below the poverty line.

Table 11 compares poverty rates for population subgroups of working-age people who are employed and who are not employed. We ran chi square tests, which determine whether or not there is a statistical relationship between variables, for each subgroup. The chi square test determined there was a relationship between people who are working and people who are not working in terms of living below the poverty line. These tests showed that people with a disability who are working are less likely to be living in a household that is poor than people with a disability who are not working.

The difference in poverty rates between people who are employed and people who are not suggests that work is critical to economic self-sufficiency. Of those people who had a cognitive disability, received SSI payments as part of their income, and were not working, 40.2% were living in a household that was below the poverty line, compared with 14.9% of people in this subgroup who were working.

People in disability subgroups who worked were less likely to be living in poverty than people in the same subgroup who were not working. However, the poverty rates for disability subgroups who did work were still higher than the poverty rates for people with no disabilities who work. This finding suggests that compared to people with no disability, people with disabilities have a greater likelihood of being underemployed, (i.e., working in jobs that do not provide them with sufficient income to exit poverty). This finding supports the conclusions of Stapleton, O'Day, Livermore, and Imparato (2006) and the National Council on Disability 2017 report..

Table 11. Poverty Rates in 2018 for Disability Subgroups by Employment Status

	Percentage living below the poverty line (poverty rate)	
	Not employed	Employed
People with no disabilities	26.4%	6%
People with any disability	35%	10.6%
People with a cognitive disability	36.8%	15.1%
People with a cognitive disability who received SSI	40.2%	14.9%

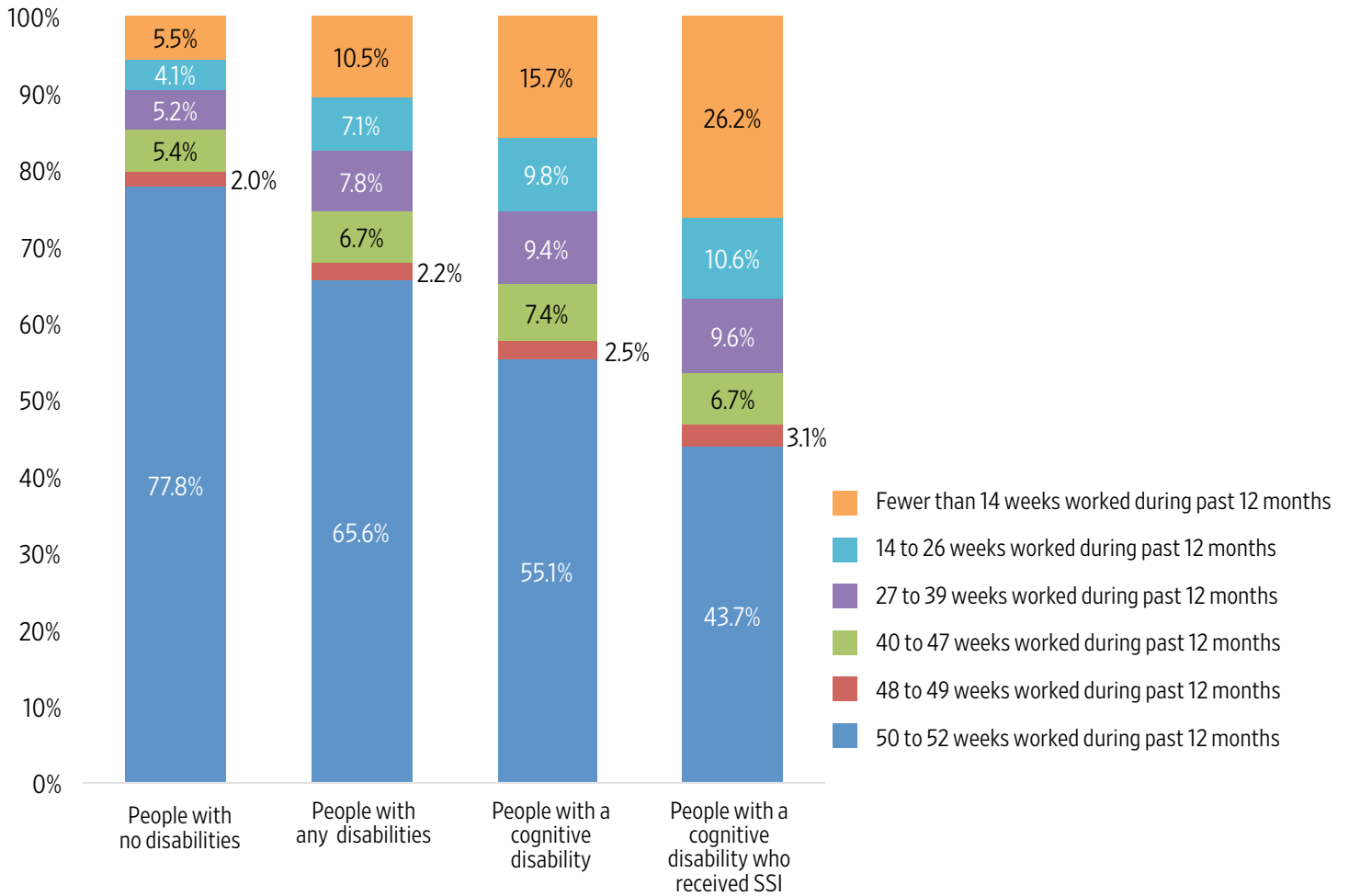
People with disabilities work less than individuals without disabilities.

Adding more evidence to the claim that people with disabilities are underemployed, individuals with disabilities who are employed work fewer weeks per year on average than individuals without disabilities. Figure 8 shows that in 2018, individuals with any disability were employed for fewer weeks out of the year than their counterparts without disabilities. Across all groups, individuals in disability subgroups are concentrated in the top bar segments.

Slightly more than half of employed people with any disability worked between 50 and 52 weeks in 2018. More than one-third of individuals with a cognitive disability worked fewer than 40 weeks and 46.4% of individuals with a cognitive disability who received SSI worked fewer than 40 weeks in 2018. By contrast, only 14.8% of individuals without a disability worked fewer than 40 weeks.

These data show that the lack of consistency with which individuals with disabilities, and particularly individuals with cognitive disabilities, maintain paid employment (measured here in number of weeks worked per year) is an additional barrier to economic self-sufficiency. To achieve a path to self-sufficiency, individuals with disabilities not only need to be employed at higher rates, but also need to be working in jobs that promote stable and long-term employment.

Figure 8. Number of Weeks Worked in the 12 Months Prior to Responding to the ACS Among Employed Individuals



SOCIAL SECURITY ADMINISTRATION (2010–2018)

The Supplemental Security Income (SSI) program administered by the Social Security Administration (SSA) provides cash assistance to low-income individuals who are seniors, are blind, or have another disability. The SSA also administers Social Security Disability Insurance (SSDI), another form of cash assistance that is designed as a disability insurance program for individuals who have worked and become disabled or, in some cases, are the children of a worker who became disabled or is deceased. While both programs support individuals who are found to be too disabled to work, they serve different purposes and have different rules and structures. SSA policy for both programs provides programs and incentives designed to support individuals to work. While individuals with ID may receive SSI, SSDI, or both, it is common for adults with ID to be SSI participants, and this analysis will focus on that group.

SSA's work incentives for SSI recipients include the Plan to Achieve Self-Support (PASS), Impairment-Related Work Expenses (IRWE), Blind Work Expenses (BWE), section 1619(a) benefits, and section 1619(b) benefits. PASS, IRWE, and BWE allow individuals to set aside money, resources, and expenses to be excluded from total earned income calculations.

PASS allows people to set aside money and resources to pay for education, vocational training, assistive technology that is used for employment-related purposes, and starting a business, as long as the expenses are related to achieving a work goal. IRWE allows people to exclude impairment-related expenses that are necessary for work from their income. Examples include attendant care services, transportation costs, service animals, medical devices, medication, and specialized equipment. BWE allows workers who are blind to exclude expenses related to earning income. These include service animal expenses, transportation to and from work, income taxes, attendant care services, visual/sensory aids, and professional or union dues.

Section 1619(a) of the Social Security Act allows people with disabilities to continue receiving SSI, even if their earned income is at Substantial Gainful Activity (SGA) levels, (i.e., the amount that would normally make them ineligible for SSI). Section 1619(b) of the Social Security Act allows individuals to continue receiving Medicaid benefits if their earnings disqualify them from eligibility for SSI cash payments, but are not enough to allow them to afford medical insurance.

Analysis of the SSA dataset revealed these key findings:

- » In 42 years, there has only been a 3.1% increase in the percentage of blind and disabled SSI recipients who are working.
- » Work incentive programs for SSI recipients with disabilities remain underused.
- » SSI recipients with ID work more than their counterparts with other types of disabilities, but participate in work incentive programs less frequently.
- » Older SSI recipients work less frequently than their younger counterparts, but use work incentive 1619(b) at higher rates.

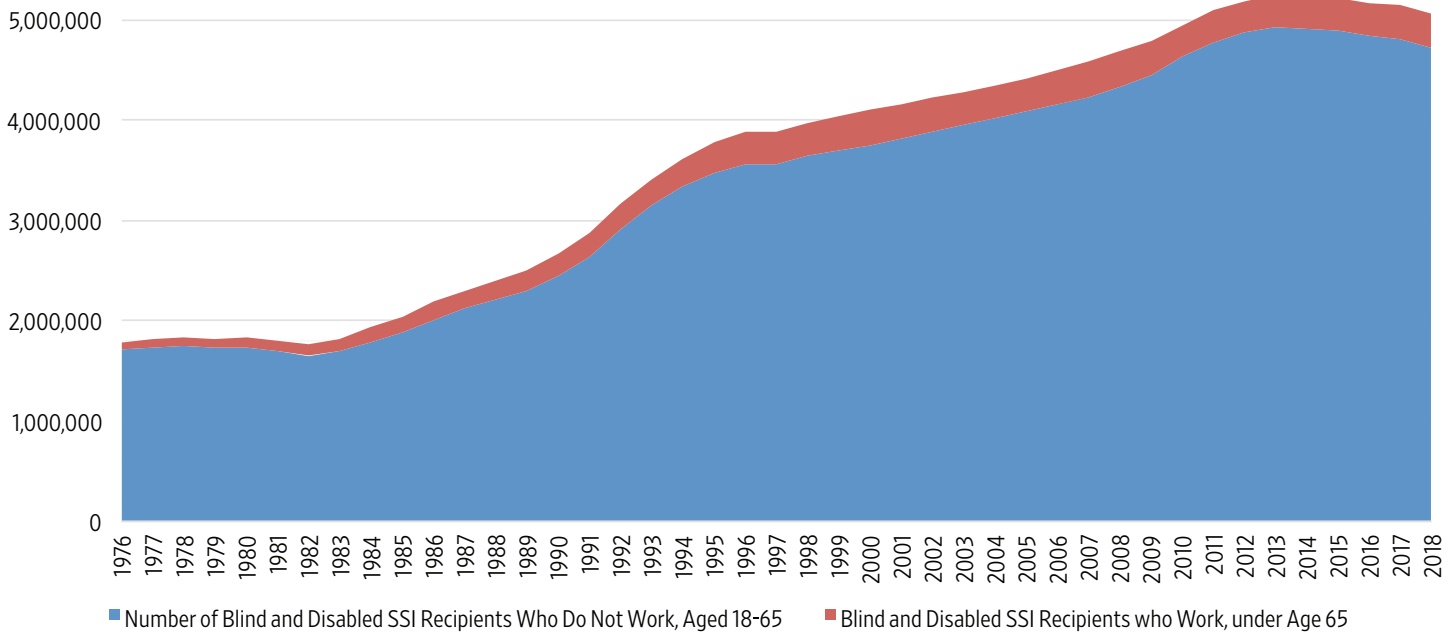
This chapter will discuss the trends in employment rates of SSI recipients from an historical perspective, by disability type and age groups.

A historical perspective on the Supplemental Security Income program.

In the last 42 years, the SSI program has supported between 1.7 and 4.9 million individuals between the ages of 18 and 64 who are blind and disabled. The terminology “blind and disabled recipients” is how the SSA describes SSI recipients. The number of recipients has grown 175% from 1976 to 2018. While the number of recipients increased steadily until 1990, there was a much sharper increase of recipients from 1990 through the mid-1990s.

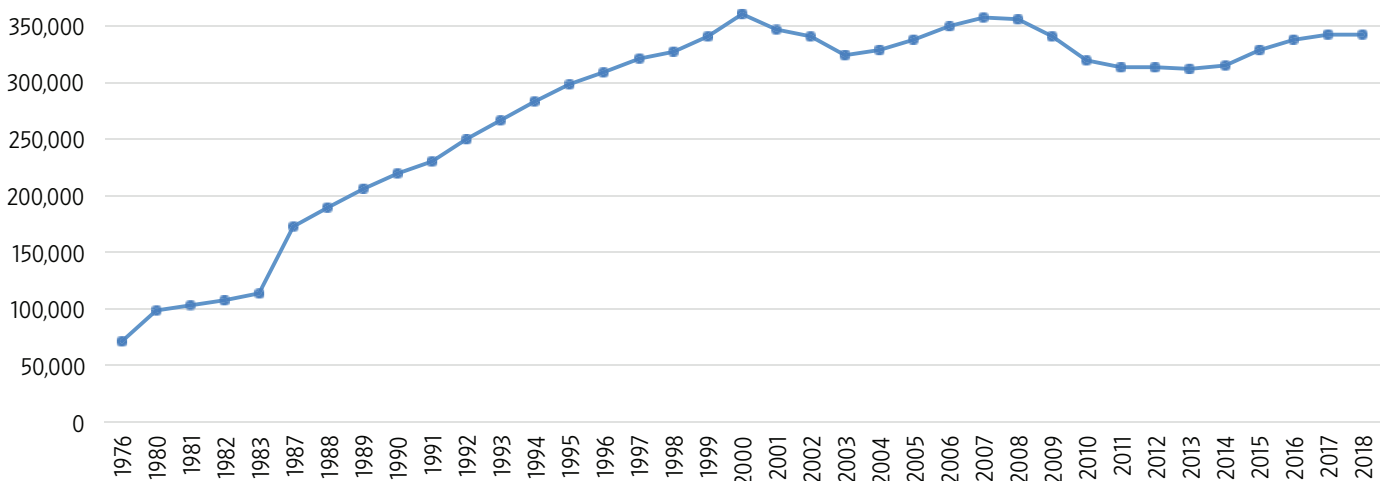
Figure 9 and Table 12 demonstrate that the total number of recipients peaked in 2013, then dropped steadily for the next five years (2014-2018). Data from Tables 4 and 40 SSI Statistical Annual Report 2018 was used to calculate the number of blind and disabled SSI recipients who do not work and are between the ages of 18-65. We subtracted the number of blind and disabled SSI recipients under 65 who work from the number of blind and disabled SSI recipients aged 18-65.

Figure 9. Number of Blind and Disabled SSI Recipients Who Do Not Work Aged 18 - 65 and Blind and Disabled SSI Recipients Who Work Under Age 65, 1976 - 2018



In 1976, almost 71,000 blind and disabled SSI recipients under the age of 65 worked; their numbers peaking at a little over 360,000 in 2000. The next 18 years saw fluctuations in the number of SSI recipients working. There was a drop between 2000 and 2003, then another dip around the time of the 2008 to 2010 recession. Figures 10 and 11 show that the number of SSI recipients working remained flat from 2011 - 2013, and then started to slowly increase from 2014 to 2018 (Table 40 of the SSI Statistical Annual Report, 2018), while the number of total recipients declined slightly during that same time period. With the exception of the last five years, the number of SSI recipients has mostly increased since 1976, while the number of recipients working has been on a slightly different trajectory, and hovering below its peak of 360,427. Throughout its 42-year history, as Figure 10 demonstrates, the percentage of SSI recipients of working age who are working has been a small proportion of all working age recipients (in 2018, 7.2%).

Figure 10. Blind and Disabled SSI Recipients Who Work Under Age 65, 1976 - 2018



Until 1990, the number of SSI recipients was increasing, as was the percentage of SSI recipients working. While SSI recipients continue to increase in numbers, the percentage working started to flatten out in the next decade (1990-2000). To calculate the percentage of all blind and disabled SSI recipients who work under age 65, we divided the number of blind and disabled SSI recipients who work under age 65 by the number of blind and disabled SSI recipients aged 18-65.

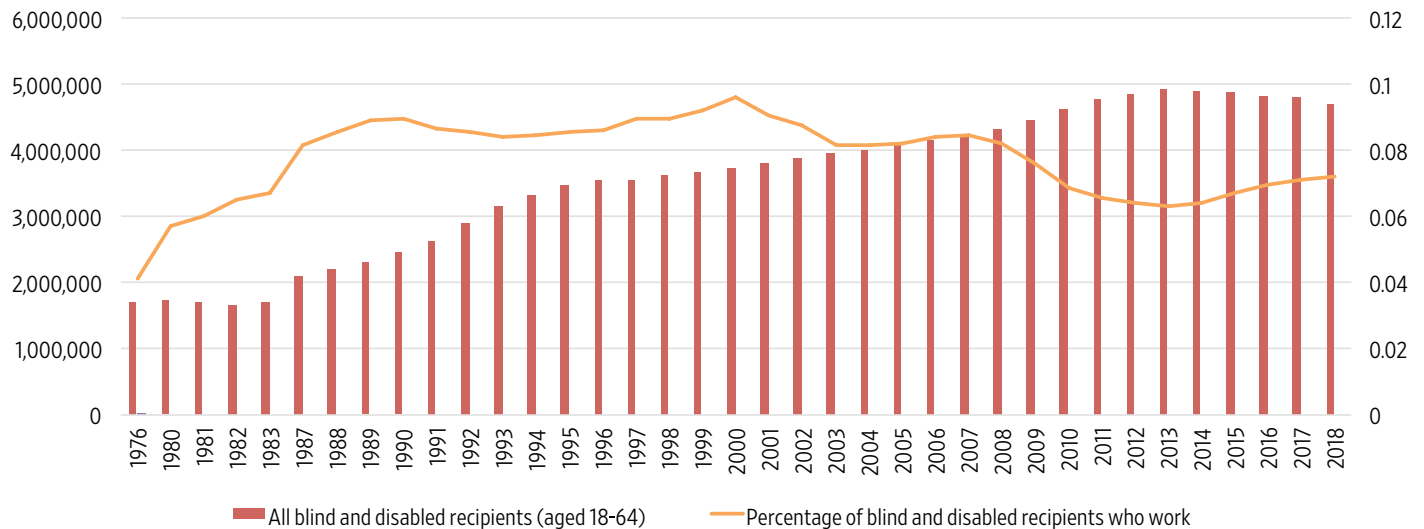
Table 12. Blind and Disabled SSI Recipients, 1976 - 2018

Year	Blind and Disabled SSI Recipients Aged 18-65	Blind and Disabled SSI Recipients Who Work Under Age 65	Percentage of Blind and Disabled SSI Recipients Under 65 Who Work
1976	1,713,594	70,719	4.1%
1977	1,736,879	83,697	4.8%
1978	1,747,126	87,697	5.0%
1979	1,726,553	92,270	5.3%
1980	1,730,847	99,276	5.7%
1981	1,702,895	102,632	6.0%
1982	1,655,279	107,803	6.5%
1983	1,699,774	113,899	6.7%
1984	1,780,459	150,320*	8.4%
1985	1,879,168	162,688*	8.7%
1986	2,010,458	175,056*	8.7%
1987	2,118,710	172,855	8.2%
1988	2,202,714	189,144	8.6%
1989	2,301,926	205,837	8.9%
1990	2,449,897	219,932	9.0%
1991	2,641,524	229,619	8.7%
1992	2,910,016	248,917	8.6%
1993	3,148,413	265,649	8.4%
1994	3,335,255	282,476	8.5%
1995	3,482,256	298,635	8.6%
1996	3,568,393	308,300	8.6%
1997	3,561,625	319,855	9.0%
1998	3,646,020	326,475	9.0%
1999	3,690,970	340,618	9.2%
2000	3,744,022	360,427	9.6%
2001	3,811,494	346,110	9.1%
2002	3,877,752	340,910	8.8%
2003	3,953,248	323,682	8.2%
2004	4,017,108	328,204	8.2%
2005	4,082,870	336,570	8.2%
2006	4,152,130	349,420	8.4%
2007	4,221,920	357,344	8.5%
2008	4,333,096	355,761	8.2%
2009	4,451,288	340,175	7.6%
2010	4,631,507	318,537	6.9%
2011	4,777,010	312,779	6.5%
2012	4,869,484	313,655	6.4%
2013	4,934,272	312,068	6.3%
2014	4,913,072	314,912	6.4%
2015	4,888,555	328,008	6.7%
2016	4,845,735	336,837	7.0%
2017	4,805,112	342,217	7.1%
2018	4,714,234	342,046	7.2%

*Estimates for the number of SSI recipients working in years 1984, 1985, and 1986 were created. SSA does not make data available for those years. The researchers used the linear regression method for estimating missing values. This algorithm uses all non-missing observations in a series to fit a regression line and applies a regression equation to replace the missing values. The timeframe used for the regression was from 1976-1997 because they show a more consistent growth trend compared to the full 40-year series.

Between 2000 and 2010 there was a 2.7% decrease in the percentage of SSI recipients working. Around 2004, the number of SSI recipients continued on its upward trajectory, while the percentage working started to decrease. Around the time of the 2008-2010 recession, the two trend lines took divergent paths (Figure 11).

Figure 11. Number of Blind and Disabled SSI Recipients Aged 18-65 and Percentage of All Blind and Disabled SSI Recipients Who Work Under Age 65



Work incentive programs for SSI recipients with disabilities remain underused.

In 2018, the SSA reported that 324,490 blind and disabled SSI recipients (including section 1619(b) participants) ages 18-64 were working. As shown in Table 13, the number of recipients enrolled nationally in any work incentive program between 2000 and 2018 remains low and has been declining. In particular, the PASS incentive program has seen decreased participation in the last 17 years—a 59% decrease from 2000 to 2018 in the number of individuals who enrolled. Overall, BWE program enrollment declined 75% from 2000 to 2018, and IRWE enrollment declined by 69% in the same time span.

Table 13. Number of People Enrolled Nationally in Work Incentive Programs from 2000–2018 (Even Years Only)

	2000	2002	2004	2006	2008	2010	2012	2014	2016	2018
PASS	1,382	1,721	1,598	1,583	1,559	1,393	1,116	862	692	568
IRWE	9,402	8,047	6,874	5,650	4,572	3,491	3,157	3,040	3,128	2,942
BWE	3,895	3,385	2,827	2,370	1,925	1,847	1,410	1,145	1,068	955

SSI recipients with intellectual disabilities work more than their counterparts with other types of disabilities, but participate in work incentive programs less frequently.

Almost one-fifth of all SSI recipients with disabilities ages 18–64 in 2018 (18.9%) were individuals with ID. With the expansion of additional “mental disorders” categories by the SSA, this is now the largest disability subgroup among SSI recipients. Please view the Methods section for more information.

In 2018, the number of SSI recipients with ID who worked was 112,274. This group has had relative success with employment participation compared to recipients who do not have ID. As noted in Table 14, in 2018, SSI recipients with ID worked at a rate more than twice that of SSI recipients without ID (12.6% versus 5.6%). The rate of employment among SSI recipients with ID was fifth among all diagnostic groups and subcategories, behind people with autism (17.5%), people with childhood and adolescent disorders not elsewhere classified (15.8%), people with congenital anomalies (15.6%), and developmental disorders (13.8%).

Mann et al., (2015) support this finding with their analysis of SSI recipients by primary impairment. They found that “beneficiaries with certain primary impairments are consistently associated with relatively higher or lower employment across program types. Beneficiaries with intellectual disability, visual impairments, hearing impairments, neoplasms,

and HIV/AIDS were most likely to be employed” (p. 32, 2015). The National Beneficiary Survey, of which the primary purpose was to provide information on the work-related activities of SSI and SSDI beneficiaries, found that SSI beneficiaries with ID were more likely to use employment-specific services and reported more interest in working than did beneficiaries with other impairments (Livermore et al., 2017). ICI researchers hypothesize that beneficiaries with ID also may have higher involvement with state agencies that encourage labor participation compared to individuals with other disabilities.

Despite the higher employment rate, Table 14 also shows that SSI recipients with ID participate in the 1619(a) and 1619(b) work incentive programs at lower rates than SSI recipients with other disabilities: 3.2% vs. 5.0% in 1619(a) and 20.7% vs. 31.6% in 1619(b). SSI recipients with ID participate in the IRWE program at the same rates as recipients with other disabilities (0.9%). This is also confirmed by Mann et al., (2015), who found that “the primary impairments that are positively correlated with employment are not always positively correlated with being in a higher earnings category or with having earnings above the annualized SGA level. This result suggests heterogeneity across primary-impairment types in the ability to work a certain number of hours at a given wage level or the ability to obtain a higher wage level” (p. 32, 2015).

A number of factors could explain differences in 1619(a) and 1619(b) participation. Analysis of other data sources, (e.g., the RSA-911), has shown that people with ID often work fewer hours and earn less than individuals from other disability subgroups. Using the most recent data available, in 2017, people with intellectual disabilities worked an average of 23 hours per week while people with other disabilities reported working 30 hours. In 2014, people with ID earned \$200 per week, and people with other disabilities reported earning \$379 per week (Winsor et al., 2018). As a result, individuals with ID who work are less likely to have earnings close to SGA and may be at lower risk of losing access to benefits because of earnings.

Table 14. Employment Outcomes and Participation in Work Incentives for SSI Recipients with Disabilities 2018

	Intellectual disability	All other disabilities
Percentage of SSI recipients with disabilities who work	12.6%	5.6%
Percentage of working SSI recipients who participate in 1619(a)	3.2%	5.0%
Percentage of working SSI recipients who participate in 1619(b)	20.7%	31.6%
Percent of working SSI recipients who participate in IRWE	0.9%	0.9%

The low rates of participation in work incentive programs by SSI recipients with ID should not overshadow the overall impact of these programs. For instance, in 2018, section 1619(b) benefits allowed 23,207 individuals with ID to work and to continue receiving Medicaid benefits. Better explanations of incentives and greater encouragement of participation in incentive programs by employment and disability services professionals could lead to higher rates of employment and better employment outcomes for individuals receiving SSI. While research on the value of work incentives for individuals with ID is scarce, the benefits of working outweigh the alternative of not working (Shapiro et al., 2017).

Older SSI recipients work less frequently than their younger counterparts, but use work incentive 1619(b) at higher rates.

According to the Social Security Administration (SSA), in 2018, there were a total of 4,804,535 blind and disabled recipients (including section 1619(b) participants) aged 18-64 receiving SSI benefits (Table 43 of the SSI Statistical Annual Report, 2018). Out of the almost 5 million people receiving benefits, 324,490 (6.8%) worked. Out of those who worked, 90,301 were enrolled in 1619(b) (Social Security Administration, 2019).

Adults with disabilities between the ages of 40 and 64 constitute almost two-thirds of SSI recipients in 2018 (n=3,072,976, 64%). However, only 3.7% of SSI recipients with disabilities between the ages of 40 and 64 work. Out of those recipients who work, 31% participate in 1619(b). Younger SSI recipients—those between the ages of 18 and 39—were three times more likely to be working than SSI recipients 40 and older (12.2% compared to 3.7%) in 2018. Interestingly, their participation in 1619(b) was lower (26%) compared to the 40-64 age group (31.2%). The lowest participation was reported among 18- to 22-year-olds at 10.3%, but increases to 24.6% for the 22-25 age group. The highest use of section 1619(b) is among the 40-49 age group at 32.1%. There is not sufficient research to conclude why this age group has the highest usage of 1619(b). Researchers should consider examining the reasons for this phenomena.

REFERENCES

- Administration for Community Living. (2015). Report to the President—Leveling the playing field: Improving technology access and design for people with intellectual disabilities.
- The President's Committee for People with Intellectual Disabilities. <https://acl.gov/sites/default/files/programs/2017-03/PCPID-2015-Report-to-President.pdf>
- Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities. (2016). Final report to the honorable Thomas E. Perez, United States Secretary of Labor, the United States Senate Committee on Health, Education, Labor and Pensions, the United States Committee on Education and the Workforce. Retrieved from https://www.dol.gov/odep/topics/pdf/ACICIEID_Final_Report_9-8-16.pdf
- Almutairi, R. A. (2016). Parent perceptions of transition services effectiveness for students with intellectual disabilities. *International Interdisciplinary Journal of Education*, 5(6), 1–9.
- Barrows, M., Billehus, J., Britton, J., Hall, A. C., Huereña, J., LeBlanc, N., . . . Topper, K. (2016). The truth comes from us: Supporting workers with developmental disabilities. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion. Retrieved from http://scholarworks.umb.edu/ici_pubs/17/
- Blustein, C. L., Carter, E. W., & McMillan, E. D. (2016). The voices of parents: Post-high school expectations, priorities, and concerns for children with intellectual and developmental disabilities. *Journal of Special Education*, 50(3), 1–14. doi:0.1177/0022466916641381
- Bose, J., & Winsor, J. E. (2018). State employment first policies #1: Development and goals. Research to Practice Brief, Issue No. 56. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Brault, M. W. (2010). Disability among the working age population: 2008 and 2009. ACSBR/09-12. Washington, DC: U.S. Census Bureau.
- Bureau of Labor Statistics. (2020). Economic news release: Persons with a disability: Labor force characteristics summary—2019. Retrieved from <https://www.bls.gov/news.release/pdf/disabl.pdf>
- Butterworth, J., Hall, A., Timmons, J. & Winsor, J. (2020). Key findings and lessons learned from research on integrated employment for individuals with IDD. <https://www.thinkwork.org/key-findings-and-lessons-learned-research-integrated-employment-individuals-idd>
- Butterworth, J. (10/1/2020). Taking stock: A Conversation About Employment Trends and Employment During COVID. Presentation at the Annual Meeting of the State Employment Leadership Network.
- Butterworth, J., Migliore, A., Nye-Lengerman, K., Lyons, O., Gunty, A., Eastman, J., & Foos, P. (2020). Using data-enabled performance feedback and guidance to assist employment consultants in their work with job seekers: An experimental study. *Journal of Vocational Rehabilitation*, 53, 189-203.
- Butterworth, J., & Migliore, A. (2015). Trends in employment outcomes of young adults with intellectual and developmental disabilities, 2006–2013. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Butterworth, J., Migliore, A., Bose, J., Lyons, O., & Nye-Lengerman, K. (2017). Assisting job seekers with intellectual and developmental disabilities: A guide for employment consultants. Bringing Employment First to Scale, Issue 13. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Butterworth, J., Fesko, S. L., & Ma, V. (2000). Because it was the right thing to do: Changeover from facility-based services to community employment. *Journal of Vocational Rehabilitation*, 14(1), 23–35.
- Butterworth, J., Migliore, A., Nord, D., & Gelb, A. (2012). Improving the employment outcomes of job seekers with intellectual and developmental disabilities: A training and mentoring intervention for employment consultants. *Journal of Rehabilitation*, 78(2), 20–29.
- Callahan, M., Butterworth, J., Boone, J., Condon, E., & Luecking, R. (2014). Ensuring employment outcomes: Preparing students for a working life. In M. Agra, F. Brown, C. Hughes, C. Quirk, & D. Ryndak (Eds.), *Equity and full participation for individuals with severe disabilities: A vision for the future* (pp. 253–274). Baltimore, MD: Paul H. Brookes.
- Carter, E., Ditchman, N., Sun, Y., Trainor, A., Swedeen, B., & Owens, L. (2010). Summer employment and community experiences of transition-age youth with severe disabilities. *Exceptional Children*, 76(2), 194–212.
- Carter, E., Austin, D., & Trainor, A. A. (2011). Factors associated with the early work experiences of adolescents with severe disabilities. *Intellectual and Developmental Disabilities*, 49(4), 233–247.
- Centers for Medicare and Medicaid Services. (2011). CMCS informational bulletin: Updates to the §1915 (c) waiver instructions and technical guide regarding employment and employment related services. Retrieved from <http://downloads.cms.gov/cmsgov/archived-downloads/CMCSBulletins/downloads/CIB-9-16-11.pdf>
- Centers for Medicare and Medicaid Services. (2014). Medicaid program; state plan home and community-based services, 5-year period for waivers, provider payment reassignment, and home and community-based setting requirements for community first choice (Section 1915(k) of the Act) and home and community-based services (HCBS) waivers (Section 1915(c) of the Act). Retrieved from <https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>
- Centers for Medicare & Medicaid Services. (2015). Application for a Section 1915(c) home and community-based waiver: Instructions, technical guide and review criteria. Retrieved from www.medicare.gov/medicaid-chip-program-information/by-topics/waivers/downloads/technical-guidance.pdf
- Centers for Medicare & Medicaid Services. (2015). Medicaid employment: Options and incentives. 2015 HCBS Conference, September 3, 2015.
- Certo, N. J., Luecking, R. G., Murphy, S., Brown, L., Courey, S., & Belanger, D. (2008). Seamless transition and long-term support for individuals with severe intellectual disabilities. *Research & Practice for Persons with Severe Disabilities*, 33(3), 85–95.

- Domin, D., Landim, L., & Narby, C. (2017). Career center success: The critical role of benefits counseling. *Tools for Inclusion*, Issue No. 26. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Domin, D., & Timmons, J. (2017). Despite some gains, Social Security Administration data show a low level of workforce participation among SSI recipients. *DataNote Series*, Data Note 58. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Domin, D., & Butterworth, J. (2016). The 2014–2015 national survey of community rehabilitation providers. Overview of services, trends, and provider characteristics. *Research to Practice Brief*, Issue No. 55. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Domin, D., & Butterworth, J. (2013). The role of community rehabilitation providers in employment for persons with intellectual and developmental disabilities: Results of the 2010–2011 national survey. *Intellectual and Developmental Disabilities*, 51(4), 215–225.
- Domin, D., & Butterworth, J. (2012). The 2010–2011 national survey of community rehabilitation providers. Overview of services, trends and provider characteristics. *Research to Practice Brief*, Issue No. 52. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Eckstein, A., Sevak, P., & Wright, D. (2017). Personal characteristics of vocational rehabilitation applicants: Findings from the Survey of Disability and Employment. *Journal of Vocational Rehabilitation*, 46(2), 177–185.
- Friedman, C., & Rizzolo, M. C. (2017). “Get us real jobs”: Supported employment services for people with intellectual and developmental disabilities in Medicaid Home and Community Based Services Waivers. *Journal of Vocational Rehabilitation*, 46(1), 107–116.
- Gilson, C., Carter, E., Bumble, J., & McMillan, E. (2018). Family perspectives on integrated employment for adults with intellectual and developmental disabilities. *Research and Practice for Persons with Severe Disabilities*, 43(1), 20–37.
- Grigal, M., Hart, D., & Migliore, A. (2011). Comparing the transition planning, postsecondary education, and employment outcomes of students with intellectual and other disabilities. *Career Development for Exceptional Individuals*, 34(1), 4–17.
- Haber, M. G., Mazzotti, V. L., Mustian, A. L., Rowe, D. A., Bartholomew, A. L., Test, D. W., & Fowler, C. H. (2016). What works, when, for whom, and with whom: A meta-analytic review of predictors of postsecondary success for students with disabilities. *Review of Educational Research*, 86(1), 123–162.
- Hall, A. C., Butterworth, J., Winsor, J., Gilmore, D., & Metzler, D. (2007). Pushing the employment agenda: Case study research of high performing states in integrated employment. *Intellectual and Developmental Disabilities*, 45(3), 182–198.
- Hall, A. C., Freeze, S., Butterworth, J., & Hoff, D. (2011). Employment funding for intellectual/developmental disability systems. *Journal of Vocational Rehabilitation*, 34(1), 1–15.
- Hall, A. C., Bose, J., Winsor, J., & Migliore, A. (2014). Knowledge translation in job development: Strategies for involving families. *Journal of Applied Research in Intellectual Disabilities*, 27, 489–492.
- Hall, A. C., Butterworth, J., Winsor, J., Kramer, J., Nye-Lengerman, K., & Timmons, J. (2018). Building an evidence-based, holistic approach to advancing integrated employment. *Research & Practice for Persons with Severe Disabilities*, 43(3), 207–218.
- Hall, J., Shartzler, A., Kurth, N., & Thomas, K. (2018). Medicaid Expansion as an employment incentive program for people with disabilities. *American Journal of Public Health*, 108(9), 1235–1237.
- Haines, K., Domin, D., & Butterworth, J. (2013). The 2010–2011 National Survey of Community Rehabilitation Providers: Estimating the number of community rehabilitation providers in the United States. *Research to Practice Brief* (53). Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Henninger, N. A., & Taylor, J. L. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Intellectual and Developmental Disabilities*, 52(2), 98–111.
- Hetherington, S. A., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., Taylor-Brown, S., & Tuttle, J. (2010). The lived experiences of adolescents with disabilities and their parents in transition planning. *Focus on Autism & Other Developmental Disabilities*, 25(3), 163–172.
- Hewitt, A., & Larson, S. (2007). The direct support workforce in community supports to individuals with developmental disabilities: Issues, implications, and promising practices. *Mental Retardation and Developmental Disabilities Research Reviews: Special issue: Public policy aspects of developmental disabilities*, 13(2), 178–187.
- Hiersteiner, D., Butterworth, J., Bershadsky, J., & Bonardi, A. (2018). Working in the community: The status and outcomes of people with intellectual and developmental disabilities in integrated employment—Update 3. *NCI Data Brief*, April 2016. Cambridge, MA: Human Services Research Institute.
- Hoff, D. (2011). Changing the culture and message about benefits: A comprehensive approach for promoting employment. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Hoff, D. (2017). Career center success: Using the power of the Ticket to Work program. *Tools for Inclusion*, Issue No. 30. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Hoff, D. (2019). SELN working document: Employment first guide. Retrieved from <http://static.smallworldlabs.com/umass/content/SELN%20Employment%20First%20resource%20list-spring-2019.pdf>
- Inge, K. J., Wehman, P., Revell, G., Erickson, D., Butterworth, J., & Gilmore, D. S. (2009). Survey results from a national survey of community rehabilitation providers holding special wage certificates. *Journal of Vocational Rehabilitation*, 30(2), 67–85.
- Johnson, D. R., Nye-Lengerman, K.M., & Gunty, A. L. (2020). Moving ahead with PROMISE: Lessons learned from six model demonstration projects through the Promoting Readiness of Minors in Supplemental Security Income project. Minneapolis, MN: Institute on Community Integration, University of Minnesota.

- Kennedy-Lizotte, R., & Freeze, S. (2012). Medicaid and employment guidance to states. Association of People Supporting Employment First. [Conference presentation.] Crystal City, VA, June 2012.
- Kiernan, W. E., Hoff, D., Freeze, S., & Mank, D. M. (2011). Employment first: A beginning not an end. *Intellectual and Developmental Disabilities*, 49(4), 300–304.
- Kramer, J., Bose, J., Shepard, J., & Winsor, J. (2020). Engaging Families in Employment: Individuals and Families' Retrospective Transition Experiences With Employment Services. *Intellectual and Developmental Disabilities*, 58(4), 314–327.
- Landim, L., Domin, D., & Narby, C. (2017). Career center success: Services and practices made possible by the DEI grant. *Tools for Inclusion*, Issue No. 29. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Livermore, G., Bardos, M., & Katz, K. (2017). Supplemental Security Income and Social Security Disability Insurance beneficiaries with intellectual disability. *Social Security Bulletin*, 77(1), 17–40.
- Lulinski, A., Timmons, J., & Leblois, S. (2017). From sheltered work to competitive integrated employment: Lessons from the field. *Bringing Employment First to Scale*, Issue 11. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Lyons, O., Timmons, J., Hall, A., Enein-Donovan, L., & Kamau, E. (2020). The Benefits of Active, Person-centered Job Placement: Results From Service Providers Undergoing Organizational Transformation Away From Sheltered Employment [Manuscript submitted for publication]. Institute for Community Inclusion, University of Massachusetts Boston.
- Lyons, O., Timmons, J., Hall, A., & Leblois, S. (2018). The essential characteristics of successful organizational transformation: Findings from a Delphi panel of experts. *Journal of Vocational Rehabilitation*, 49(2), 205–216.
- Lyons, O., Migliore, A., Nye-Lengerman, K., Nord, D., & Butterworth, J. (2016). Who are employment consultants? Characteristics of the workforce that connects job seekers with intellectual and developmental disabilities to employment. *Bringing Employment First to Scale*, Issue 6. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Lyons, O., & Hall, A. (2015). Community life engagement: Data sources, definitions, and measurement. *Engage Series*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Mamun, A., Patnaik, A., Levere, M., Livermore, G., Honeycutt, T., Kauff, J., . . . Gionfriddo, B. (2019). Executive summary: Promoting Readiness of Minors in SSI (PROMISE) evaluation: Interim services and impact report. Washington, D.C.: Mathematica Policy Research. Retrieved from <https://www.mathematica-mpr.com/our-publications-and-findings/publications/es-promoting-readiness-of-minors-in-ssi-promise-evaluation-interim-services-and-impact-report>
- Mank, D., Cioffi, A., & Yovanoff, P. (2003). Supported employment outcomes across a decade: Is there evidence of improvement in the quality of implementation? *Mental Retardation*, 41(3), 188–197.
- Mann, D. R., Mamun, A., & Hemmeter, J. (2015). Employment, earnings, and primary impairments among beneficiaries of Social Security disability programs. *Social Security Bulletin*, 75(2), 19–40.
- Martinez, J., Fraker, T., Manno, M., Baird, P., Mamun, A., . . . Wittenburg, D. (2010). The Social Security Administration's youth transition demonstration projects: Implementation lessons from the original projects. Washington, D.C.: Mathematica Policy Research.
- Mazzotti, V. L., & Plotner, A. J. (2016). Implementing secondary transition evidence-based practices: A multi-state survey of transition service providers. *Career Development and Transition for Exceptional Individuals*, 39(1), 12–22.
- Migliore, A., & Landa, C. (2017). Reasons for exiting VR services without employment. *DataNote Series*, Data Note 59. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Migliore, A., Nwangwu, U., & Butterworth, J. (2016). Time from VR application to closure in employment for adults with intellectual disabilities. *Data Note 56*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Migliore, A., Mank, D., Grossi, T., & Rogan, P. (2007). Integrated employment or sheltered workshops: Preferences of adults with intellectual disabilities, their families, and staff. *Journal of Vocational Rehabilitation*, 26(1), 5–19.
- Migliore, A., Hall, A., Butterworth, J., & Winsor, J. (2010). Job development: What do employment specialists really do? A study on job development practices. *Research and Practice for Persons with Severe Disabilities*, 35(1–2), 15–23.
- Migliore, A., Butterworth, J., Nord, D., Cox, M., & Gelb, A. (2012). Implementation of job development practices. *Intellectual and Developmental Disabilities*, 50(3), 207–218.
- Migliore, A., Nye-Lengerman, K., Lyons, O., Bose, J., & Butterworth, J. (2018). A comprehensive model of employment supports for job seekers with intellectual and developmental disabilities. *Journal of Rehabilitation*, 84(2), 3–13.
- Mitra, S., & Kruse, D. (2016). Are workers with disabilities more likely to be displaced? *International Journal of Human Resource Management*, 27(14), 1–30.
- Moseley, C. (2009). *Workers first*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services. Retrieved from http://www.nasddds.org/Publications/special_pubs.shtml
- Narby, C., Domin, D., & Landim, L. (2017). Career center success: Effective case management for job seekers. *Tools for Inclusion*, Issue No. 27. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- National Core Indicators (2019). In-person survey, 2017-2018 Final Report. Cambridge, MA: Human Services Research Institute. Retrieved from https://www.nationalcoreindicators.org/upload/core-indicators/17-18_IPS_National_Report_PART_I_update_CA_entitlement.pdf
- National Council on Disability. (2017). *National Council on Disability: A Progress Report*. Washington, D.C. Retrieved from https://ncd.gov/sites/default/files/NCD_A%20Progress%20Report_508.pdf

- National Council on Disability. (2018). National disability employment policy, from the new deal to the real deal: Joining the industries of the future. National Council on Disability. https://ncd.gov/sites/default/files/Documents/NCD_Deal_Report_508.pdf
- National Council on Disability. (2020). Policies from the past in a modern era: The unintended consequences of the AbilityOne Program & Section 14(c). National Council on Disability.
- Niemiec, B., Lavin, D., & Owens, L. A. (2009). Establishing a national employment first agenda. Retrieved from <http://www.apse.org/policy/index.cfm>
- Nonnemacher S. L., & Bambara, L.M. (2011). "I'm supposed to be in charge": Self-advocates' perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities*, 49(5), 327–340.
- Nord, D., Butterworth, J., Carlson, D., Grossi, T., Hall, A., & Nye-Lengerman, K. (2016). Employment of people with IDD: What do we know and where are we going? In *Critical issues in intellectual and developmental disabilities: Contemporary research, practice, and policy* (pp. 71–88). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Nord, D., Grossi, T., & Andresen, J. (2020). Employment equity for people with IDD across the lifespan: The effects of state funding. *Intellectual and Developmental Disabilities*, 58(4), 288–300. <http://doi.org/10.1352/1934-9556-58.4.288>
- Oertle, K. M., & Seader, K. J. (2015). Research and practical considerations for rehabilitation transition collaboration. *Journal of Rehabilitation*, 81(2), 3–18.
- Office of Disability Employment Policy. (2014). Evaluation of the employment first state leadership mentoring program. Unpublished raw data.
- Rogan, P., & Rinne, S. (2011). National call for organizational change from sheltered to integrated employment. *Intellectual and Developmental Disabilities*, 49(4), 248–260.
- Rosenthal, D. A., Hiatt, E. K., Anderson, C. A., Brooks, J., Hartman, E. C., Wilson, M. T., & Fujikawa, M. (2012). Facilitators and barriers to integrated employment: Results of focus group analysis. *Journal of Vocational Rehabilitation*, 36(2), 73–86.
- Rusch, F. R., & Braddock, D. (2004). Adult day programs versus supported employment (1988–2002): Spending and service practices of mental retardation and developmental disabilities state agencies. *Research and Practice for Persons with Severe Disabilities*, 29, 237–242.
- Sannicandro, T. (2016). The effect of postsecondary education on employment and income for individuals with intellectual disabilities (Doctoral dissertation). Brandeis University, Waltham, MA.
- Schur, L., Kruse, D., Blasi, J., & Blank, P. (2009). Is disability disabling in all workplaces? Workplace disparities and corporate culture. *Industrial Relations*, 48(3), 381–409.
- Self-Advocates Becoming Empowered, Green Mountain Self-Advocates, & ThinkWork! at the Institute for Community Inclusion at UMass Boston. (2018). A purpose in life: Why employment first matters to self-advocates. Retrieved from <https://www.thinkwork.org/purpose-life-why-employment-first-matters-self-advocates>
- Shapiro, I., Greenstein, R., Trisi, D., & Dasilva, B. (2017). It pays to work: Work incentives and the safety net. Center on Budget and Policy Priorities. Retrieved from www.cbpp.org/research/federal-tax/it-pays-to-work-work-incentives-and-the-safety-net
- Shepard, J., Migliore, A., Butterworth, J. & Winsor, J. (2020). *Employment and Economic Outcomes by Race, Ethnicity, and Gender for Individuals With and Without Disabilities, 2017*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National Longitudinal Transition Study-2. *Intellectual and Developmental Disabilities*, 50(1), 16–30.
- Social Security Administration. (2018). SSI Annual Statistical Report, 2017. Retrieved from www.ssa.gov/policy/docs/statcomps/ssi_asr/
- Social Security Administration. (2017). 2017 red book: A summary guide to employment supports for persons with disabilities from the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs. Retrieved from www.ssa.gov/redbook/
- State Employment Leadership Network. (2019). SELN Accomplishments Report, 2019. Retrieved from <http://static.smallworldlabs.com/umass/content/Public%20Docs/SELN-annual-report-2019.pdf>
- Stapleton, D. C., O'Day, B. L., Livermore, G. A., & Imparato, A. J. (2006). Dismantling the poverty trap: Disability policy for the twenty-first century. *The Millbank Quarterly*. 84(4), 701–732.
- State of the States in Intellectual and Developmental Disabilities: State profiles. University of Colorado Department of Psychiatry. Retrieved from <https://stateofthestates.org/create-idd-chart/state-profiles/>
- Stevenson, B. S., & Fowler, C. H. (2016). Collaborative assessment for employment planning: Transition assessment and the discovery process. *Career Developmental and Transition for Exceptional Individuals*, 39(1), 57–62.
- Sulewski, J.S., Timmons, J.C., Lyons, O., & Hall, A.C. (2019). Guideposts for High-Quality Community Life Engagement Supports: Results of Expert Interviews. *Inclusion* 7(4), 254–268.
- Sulewski, J. S., Timmons, J. C., Lyons, O., Lucus, J., Vogt, T., & Bachmeyer, K. (2017). Organizational transformation to integrated employment and community life engagement. *Journal of Vocational Rehabilitation*, 46(3), 313–320.
- Sulewski, J. S., & Timmons, J. C. (2015). Introduction to community life engagement. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Sulewski, J. S. (2010). In search of meaningful daytimes: Case studies of community-based nonwork supports. *Research and Practice for Persons with Severe Disabilities*, 35(1–2), 39–54.
- ThinkCollege. (2019). Post-secondary education updates. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion. Retrieved from <https://thinkcollege.net/college-search>
- Timmons, J. C., Hall, A. C., Bose, J., Wolfe, A., & Winsor, J. (2011). Choosing employment: Factors that impact employment decisions for individuals with intellectual disability. *Intellectual and Developmental Disabilities*, 49(4), 285–299.

- Timmons, J., & Lyons, O. (2016). Essential elements in organizational transformation: Findings from a Delphi panel of experts. *Bringing Employment First to Scale*, Issue 8. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Timmons, J. C., & Sulewski, J. S. (2016). High-quality community life engagement supports: Four guideposts for success. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Timmons, J., Lyons, O., Lulinsky, A., Hall, A., Kamau, E. . . . Lucas, J. (2018). Agency change toolkit: Ten elements of organizational transformation. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Timmons, J. C., Kamau, E., Lyons, O., & Enein-Donovan, L. (2019). Provider strategies on ten elements of organizational transformation. *Journal of Vocational Rehabilitation*, 50, 307-316.
- U.S. Commission on Civil Rights. (2020). Subminimum wages: Impacts on the civil rights of people with disabilities. [U.S. Commission on Civil Rights 2020 Statutory Enforcement Report]. <https://www.usccr.gov/files/2020-09-17-Subminimum-Wages-Report.pdf>
- U.S. Department of Education. (2013). Department awards \$211 million for the Promoting the Readiness of Minors in Supplemental Security Income (PROMISE) initiative. Retrieved from <http://www.ed.gov/news/press-releases/departments-awards-211-million-promoting-readiness-minors-supplemental-security-i>
- U.S. Department of Justice. (2016). Statement of the Department of Justice on application of the integration mandate of Title II of the Americans with Disabilities Act and *Olmstead v L.C.* to state and local governments' employment service systems for people with disabilities. Retrieved from https://www.ada.gov/olmstead/olmstead_guidance_employment.htm
- U.S. Department of Labor, Employment and Training Administration. (2020). PY2018 Wagner Peyser Act Data Book. Retrieved from https://www.doleta.gov/performance/results/WIASRD/PY2018/PY_2018_WIOA_and_Wagner-Peyser_Data_Book.pdf
- U.S. Department of Labor. (2018). Disability Employment Initiative. Retrieved from <https://dei.workforcegps.org/>
- Walker, A. (2011). Checkmate! A self-advocate's journey through the world of employment. *Intellectual and Developmental Disabilities*, 49(4), 310-312.
- West, E. A., & Patton, H. A. (2010). Case report: Positive behavior support and supported employment for adults with severe disability. *Journal of Vocational Rehabilitation*, 35(2), 104-111.
- Wehmeyer, M. L. & Shogren, K. A. (2013). Establishing the field of applied cognitive technology. *Inclusion*, 1(2), 91-94. <https://doi.org/10.1352/2326-6988-01.02.91>
- Winsor, J., Timmons, J., Butterworth, J., Migliore, A., Domin, D., Shepard, J., & Zalewska, A. (2020). StateData: The national report on employment services and outcomes through 2018. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Winsor, J., Lyons, O., Butterworth, J., & Kennedy-Lizotte, R. (2017). A systematic approach to revising Florida's integrated employment funding system. Prepared for Florida Developmental Disabilities Council. Institute for Community Inclusion and the National Association of State Directors of Developmental Disabilities Services. Retrieved from <https://www.fddc.org/sites/default/files/A%20Systematic%20Approach%20to%20Revising%20Florida.Final.10.9.17.pdf>
- Winsor, J., Butterworth, J., Lugas, J., & Hall, A. (2010). Washington State Division of Developmental Disabilities Jobs by 21 partnership project report for FY 2009. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.