

# Intellectual and Developmental Disabilities

## The State of Employment for People with IDD: Implications for Practice, Policy and Equity --Manuscript Draft--

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State of Employment for People with IDD

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## State of Employment for People with IDD

### **Abstract**

Meaningful progress in improving employment outcomes for people with intellectual and developmental disabilities continues to be elusive despite 40 years of investment in research, policy, and supports. This manuscript reviews the current state of employment for individuals with intellectual and developmental disabilities (IDD), and describes policy, practice, and individual factors that influence employment outcomes. Research suggests the need for a holistic approach to change that addresses systems level strategy, policy, and fiscal investment while strengthening individual experiences with employment and related day services.

Recommendations address strengthening the implementation of employment policy, developing pathways to employment, and engaging individuals with IDD, and in particular individuals with diverse social characteristics, in reflecting on the quality of their experiences and supports.

Despite over 40 years of investment in developing models for employment support and demonstrating the ability of individuals with intellectual and developmental disabilities (IDD) to succeed in the general workforce, only limited progress has been made toward improving employment outcomes (Mank, 1994; Wehman et al., 2018; Winsor et al., 2022). Improving employment outcomes has been identified as a priority by self-advocates, families, state disability agencies, and federal policy makers. Employment is an essential life outcome that provides a path to opportunity, connects individuals to their community, expands personal relationships, and contributes to personal independence and financial self-sufficiency (Gilson et al., 2022; Taylor et al., 2022). Research suggests that employment also supports health and other quality of life outcomes (Robertson et al., 2019).

Employment services and supports are provided within the context of state and federal disability policy, workforce development policy, income maintenance programs, and healthcare policy. Core supports are funded by state intellectual and developmental disability (IDD) agencies, state vocational rehabilitation (VR) agencies, and local education agencies. This complex array of factors makes the experience of pursuing employment, including the transition from school to employment, challenging for job seekers and families even when they are clear that individual employment is a priority outcome (Kramer et al., 2020; Timmons et al., 2011). The goal of this paper is to review the state of employment as a critical element in community living and to assess factors that have limited improvement in employment outcomes at an individual and systems level. The paper is a product of the State of the Science Conference on Community Living held by the Research and Community Center on Community Living in September of 2022 and incorporates discussion and priorities from the conference's employment strand working group. Discussion at the conference emphasized the importance of a holistic

systems approach to improving employment outcomes and the need for research and practice that addresses access to employment supports and employment outcomes for individuals from marginalized and underserved communities.

### **Introduction**

There are well documented employment disparities between people with and without disabilities. While most data sources that address individuals with an IDD are specific to a service system (i.e., state IDD agencies and VR service participants), the American Community Survey provides a population view of the employment of people with all disabilities and provides context for data that are specific to individuals with an IDD. Estimates from the 2019 American Community Survey suggest that 38% of working-age adults with disabilities are employed, compared with 76% of people without disabilities (Winsor et al., 2022). When people with disabilities are employed, they are more likely to work part time (29%) compared to people without disabilities (16%) (Bureau of Labor Statistics, 2021). In addition to being underrepresented 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). Individuals with disabilities from marginalized racial, ethnic, and cultural communities are often even less likely to be employed (Houseworth et al., 2022; Shepard et al., 2020).

For people with intellectual and developmental disabilities (IDD), these disparities are far greater. Data from the National Core Indicators project suggests that in 2018–2019, only 19% of working-age adults supported by state IDD agencies were employed in a paid job in the community (National Core Indicators, 2020). The percentage working fell to 14% in 2020-2021,

reflecting the impact of the COVID-19 pandemic (National Core Indicators, 2022). 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.

There is growing advocacy to emphasize competitive integrated employment over alternatives including employment at less than minimum wage, sheltered or center-based employment, group supported employment, and non-work services (Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities, 2016; Self Advocates Becoming Empowered, 2009). Improving access to employment and the quality of employment outcomes is a priority for self-advocates. The position statement on employment from Self Advocates Becoming Empowered calls for equal opportunities for equal pay for all people, an end to subminimum wage and sheltered workshops, and improving the quality of jobs and career paths (Self Advocates Becoming Empowered, 2009). Federal legislation and policy such as the Workforce Innovation and Opportunity Act (2014) and the Home and Community Based Settings Rule (Centers for Medicare and Medicaid Services, 2014) support this position. At the state level, Employment First policies have been adopted by most states over the past 15 years and further the priority.

### **Infrastructure for Employment Services Legislation and Policy**

Legislation and regulation governing Medicaid Home and Community-Based Services (HCBS) and workforce development services clarify federal intent and pave the way to supporting opportunities for people with disabilities to have meaningful jobs in their communities. HCBS guidance in 2011 and in the 1915(c) HCBS waiver 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. Medicaid guidance 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” (Centers for Medicare and Medicaid Services, 2011; 2019). 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 as individuals not receiving Medicaid HCBS” (Centers for Medicare and Medicaid Services, 2014).

The Workforce Innovation and Opportunity Act of 2014, the guiding legislation for Federal workforce investments, establishes competitive integrated employment as the expected outcome of vocational rehabilitation services and strengthened the definition of competitive integrated employment. The Rehabilitation Services Administration (RSA) has clarified that, in general, competitive integrated employment refers to jobs that are “typically found in the community” and “open to all applicants.” Additional criteria address compensation that is comparable to coworkers performing similar work, interaction with coworkers, customers, and vendors who are not individuals with disabilities, and opportunities for advancement (Rehabilitation Services Administration, 2021).

The legislation also dramatically expands the role of state vocational rehabilitation (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, the

Workforce Innovation and Opportunity Act places new restrictions on the use of subminimum wage under Section 511. As of July 2016, this Section requires that individuals under the age of 24 must first be provided pre-employment transition services, be determined ineligible for VR services or have an unsuccessful VR closure and receive career counseling and referrals to assist with achieving competitive integrated employment before working in a job that pays less than minimum wage. In addition, individuals of any age who work 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.

Over the past 15 years, state level Employment First policies and initiatives have been developed to emphasize that employment in integrated settings in the community is the priority outcome and goal of government funds for people with disabilities, including people with IDD. According to the Association of People Supporting Employment First, “Employment First means that employment in the general workforce should be the first and preferred option for individuals with disabilities receiving assistance from publicly funded systems” (Association of People Supporting Employment First, 2023). As of February 2022, thirty-nine states have enacted formal Employment First policy through legislation, governor’s executive orders, or state agency policy (Hoff, 2022; Rogan & Rinne., 2021).

### **Employment Services**

State IDD agencies are the primary source of long-term funding and support coordination for adults with IDD. They provide, fund, and monitor a wide range of day and employment services including employment supports, center-based work services, non-work center-based services, and community integration services. Funding for state IDD agency day and employment services

is primarily through Medicaid Home and Community Based Services (HCBS) waivers, with some services supported by state or local general funds (Houseworth et al., 2022). Employment support is provided as part of, and competes with, an array of day and employment services that include facility-based support for non-work activities (day habilitation), support for community-based non-work activities, and facility-based or sheltered employment.

State VR agencies are also an essential part of the pathway to employment in most states, and fund job development and job entry. Because Medicaid waiver regulations require that VR services be used by job seekers first if they are available, most individuals with an IDD receive supports from both state agencies during their employment journey, with early job exploration and career planning supported by the state IDD agency, a transition to VR funded services for the job search and job entry, and another transition back to IDD agency funded employment services for ongoing employment support. Job seekers may also receive career and employment related supports through the public education system if they are still in school, postsecondary education, and American Job Centers. Benefits counseling services to address the intersection of earned income, Medicaid, Medicare, Supplemental Security Income and Social Security Disability Insurance income assistance, and other public benefits are available through the Social Security Administration's Work Incentives Planning and Assistance Programs or other sources. The need to manage supports and services across service systems and other publicly funded supports is often unwieldy and a challenge for job seekers and families (Carter et al., 2023).

### **Employment Outcomes**

Although there is no direct source for labor force participation for individuals with IDD in the general population, the percent of individuals who receive any day or employment service from a state IDD agency that receive a service that supports integrated employment declined

between 2001 and 2012 after reaching a peak of almost 25% in fiscal year 2001 and has only recently begun to show signs of modest growth. Nationally, an estimated 21.5% of individuals receiving day supports from state IDD agencies participated in integrated employment services in FY2019 (Winsor et al., 2022). Data from the National Core Indicators Project indicate that in 2018–2019, only 19% of working-age adults supported by state IDD agencies worked in some form of community employment including individual jobs, group supported jobs, or jobs in community businesses that primarily hire people with disabilities, and only 14% worked in an individual competitive job. The percent in community employment fell to 14% in 2020-2021, and recovered to 16% in 2021-2022, reflecting the impact of the COVID-19 pandemic (National Core Indicators, 2020; National Core Indicators, 2022; National Core Indicators, 2023). Of those individuals who were working in individual jobs with publicly funded supports in 2021-2022, individuals worked an average of 14 hours per week and earned an average of \$12.05/hour). Only 29% of individuals received paid time off (National Core Indicators, 2023).

The majority of individuals who receive day and employment supports from a state IDD agency participate in non-work day habilitation services or prevocational services (Friedman, 2016; Friedman & Nye-Lengerman, 2018). Friedman found that in fiscal year 2014 the projected spending for day habilitation services was \$5.6 billion supporting a projected 380,000 participants, while an additional \$748 million was projected for prevocational services supporting 87,500 individuals. While prevocational services are intended to lead to competitive integrated employment, the authors found substantial variability in the location and type of services that were provided. These findings are consistent with data from Winsor et al. (2022) who found that in fiscal year 1999, 79% of individuals who participated in state IDD day and employment services participated in facility-based and non-work activities including day

habilitation and prevocational services, representing 88.7% of the funding reported by state IDD agencies for day and employment services.

Despite these low rates of labor force participation and limited outcomes when employed, individuals with IDD express a desire to fully participate in the typical labor force (Barrows et al., 2016). Substantial research documents the desire of individuals with IDD to be employed in the community (Migliore et al., 2007; Gilson et al., 2022; Timmons et al., 2011). About half of people who receive services from state IDD agencies and who are not working in the community report that they want a community job (National Core Indicators, 2023). Data also suggest that there is a gap between individuals' stated interest in employment and the supports they receive. The National Core Indicators In-Person Survey found that while half of the people who were not working in the community in 2021-2022 want a job in the community, only 25% of those who wanted a job had this goal documented in their service plan (National Core Indicators, 2023).

### **State Outcomes Differ**

There is increasing acknowledgement in the field that improving employment outcomes requires change at the state systems level that integrates policy, implementation, and evaluation (Nord et al., 2013; Shogren et al., 2017; Winsor et al., 2023). An estimated 658,000 individuals received a day or employment support from state IDD agencies in fiscal year 2019, and there are considerable state-to-state differences in participation in employment services (see Figure 1, Winsor et al., 2022). In fiscal year 2019, seven state IDD agencies reported that 40% or more of individuals receiving a funded employment or day support participated in integrated employment services, while 5 states reported 10% or fewer individuals participated in integrated employment services (Winsor et al., 2022). Research has shown that differences in employment participation between states can be explained by state policy and investments, outcome measurement and

goals, the quality of employment supports, the quality of interagency collaboration, and investments in service innovation (Hall et al., 2007; Nord et al., 2020; Winsor et al., 2023). Case study research on state IDD agencies with higher participation rates or higher rates of growth in integrated employment services identified seven elements that transmit and maintain commitment to the goals of community inclusion and integrated employment including leadership, policy and goals, interagency collaboration, financing, training and technical assistance, service innovation, and outcome data. Higher performing states maintained a consistent and holistic focus on employment across each of these elements (Hall et al., 2007; Winsor et al., 2023). More recent research on the model emphasizes the role of a shared cross-agency investment in supporting employment outcomes, with a common emphasis on youth (Winsor et al., 2023).

**Insert Figure 1 About Here**

State VR agencies provide job placement supports to individuals with disabilities, and based on Medicaid HCBS policy are in most cases the first funder for job placement supports. In program year 2019, 45,110 individuals with an intellectual disability (ID) exited VR services and 15,873 (35%) were “closed” (reporting as exiting VR services) into integrated employment. Over time the number of individuals with an ID who exit VR with an integrated employment outcome has declined gradually from over 20,000 in FY 2002 to 15,898 in FY 2012, paralleling a similar decline for all individuals who receive supports from state VR agencies (Winsor et al., 2022). As with state IDD agencies, state VR agencies vary widely in the percent of individuals who exit the VR program with an integrated employment outcome. In program year 2020 the percent who worked in integrated employment at closure after receiving services from the state VR agency (the rehabilitation rate) ranged from 25% to 64% (Winsor et al., 2022).

Finally, there is considerable variation across states in the number of individuals who are employed at less than minimum wage. Section 14(c) of the Fair Labor Standards Act authorizes employers to pay certain employees with disabilities less than minimum wage. Participation in subminimum wage jobs has declined from an estimated 210,689 workers in 2013 to only 59,537 workers in 2022 as this regulation and its use have come under increasing pressure from advocates and policymakers (Butterworth & Edelstein, 2023). As of July 2022, ten states reported that they did not have any 14(c) workers, but nine other states reported that they each had over 2,000 14(c) workers. A total of 13 states have established legislation or regulation that eliminates subminimum wage, and additional states are developing legislation or policy that prohibits subminimum wage employment for individuals receiving state-funded support (Association of People Supporting Employment First, 2023, May 1). Legislation and state policy related to subminimum wage represent an additional explanation for the differences in state employment outcomes.

Efforts to end the use of subminimum wage employment are viewed as a human rights issue by many, although the movement continues to generate controversy (Lysaght et al., 2020; U.S. Commission on Civil Rights, 2020). A recent systematic review of the relationship between segregated employment, the dominant source of subminimum wage employment, did not find evidence of a positive association between segregated employment, vocational training, and meaningful competitive integrated employment outcomes (Taylor et al., 2023). They conclude that there is evidence that participation in segregated vocational services reduced individual's potential for future competitive integrated employment.

## **Impact of Social Characteristics on Employment Outcomes**

A particular emphasis of the State of the Science Conference on Community Living was attention to disparities in outcomes. Family, culture, language, immigration, and poverty status are important contextual factors when studying employment of people with disabilities (Francis et al., 2018). It's not surprising that there is a strong relationship between disability and work and poverty. People with disabilities are much more likely to live in a household that is below the poverty line, and, as previously described, are less likely to work. According to American Community Survey data, just 10% of people without disabilities live in a household that is below the poverty line. That figure jumps to 24% for people with any disability, and 28% for people with a cognitive disability (Winsor et al., 2022). Poverty affects one's networks when looking for work, it affects one's ability to have flexibility, get to a job interview, have the right clothing, and make the right connections, including connection to employment and career development services. It's a critical part of the overall context of a person's relationship to the labor market.

Factors like race, culture, ethnicity, language, poverty, and gender have a multiplying effect. The overwhelming impact on employment outcomes is disability, but there is an additional level of disparity as the field begins to examine additional personal characteristics. In an analysis of National Core Indicators data, Houseworth et al. (2022) found that people with an IDD who were not white or people identified as female were less likely to participate in community-based work and more likely to participate in unpaid day activities and facility-based work. Similarly, compared with white workers with disabilities, average annual earnings, employment overall and in community jobs, and rehabilitation rates are all lower for Black workers with any disability and black workers with an IDD, according to American Community Survey, National Core Indicators, and VR data, and these patterns extend across racial and ethnic groups (Shepard et al.,

2020):

- Individuals with any disability and individuals with a cognitive disability who are Black, Native American, or identify as Hispanic are less likely to work and they earn less if they do work (Data source: American Community Survey).
- Individuals with IDD who are Black, Asian, or a Pacific Islander, or who identify as Hispanic, are less likely to work in integrated jobs (Data source: National Core Indicators).
- Individuals with any disability and individuals with an intellectual disability who are Black, Native American, Native Hawaiian, or identify as Hispanic are less likely to be employed following VR services (Data source: Rehabilitation Services Administration 911).

Age is also an important factor impacting employment outcomes, and there is a growing emphasis on services during the transition from school to adult life that support employment. Despite this emphasis, research shows continuing disparities between employment outcomes of young adults with and without disabilities. American Community Survey data suggest 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 young adults without a disability employed, compared to 41% of youth with a cognitive disability. Only 7% of young adults who receive services from a state IDD agency age 18-21 and 17% of young adults age 22-30 worked in a community job (Butterworth & Migliore, 2015). Nord et al. (2020) also found that younger adults (18-24) with IDD experience lower employment outcomes compared to their older counterparts (25-55) (Nord et al., 2020) but reported that the effects of age were minimized in

states with higher fiscal investment as measured by the ratio between spending on integrated employment services and spending on all day and employment services. These findings reinforce the importance of consistency across policy goals and state investment decisions.

Examining transition-age youth with disabilities using the National Health Interview Survey on Disability, Hasnain and Balcazar (2009) found that in addition to race, ethnicity, and gender, living above the poverty threshold, having more than a high school education, and having a higher per capita income all increased the likelihood of employment in a community-based work setting for young adults with disabilities.

Level of support need has also been identified as an individual characteristics that affect employment participation. Houseworth et al. (2022) found that people with a more significant intellectual disability or communication or mobility challenges were less likely to be employed, and individuals with a legal guardian were less likely to be employed.

### **Emerging Research on Employment Disparities and Social Characteristics**

There is emerging research on the transition from school to work that is useful in understanding people's experiences within the contexts of the communities they live in. For example, when Courtney Wilt of the University of Kansas and colleagues interviewed 36 family members with diverse cultural and racial identities, including low-income and rural white family members, it was striking how infrequently people felt that the school played a significant role in preparing their kids for adulthood (Wilt et al., 2021). Low expectations, a well-known issue, was an even stronger concern for families who reside in under-resourced communities. Families reported having limited opportunities for career development and work-related experiences, often because engaging with the schools or the adult support system was extremely challenging. Some families were able to compensate using their power of personal capital and community

relationships that respected who they were, and this resulted in some positive outcomes.

In a study exploring the experiences of caregivers supporting family members with disabilities, Francis and colleagues talked to family members from Hispanic households about their experiences that led to their distrust of educators (Francis et al., 2018). Poor transition planning overall was discussed, but there were other factors specifically related to families from underserved communities. The overwhelming nature of service systems and the discomfort people feel in trying to operate within them was significant. Language barriers and lack of federally mandated interpreters and translation supports, along with microaggressions experienced along the way, complicated everything. Families reported being questioned about citizenship and eligibility as something that pushed them away from potentially helpful services to which they were legally entitled. Families also reported a lack of respect for cultural differences. Families with a strong cultural focus on interdependence, for example, encountered conflicts with the education and service system's emphasis on independence. Families, particularly those in poverty or working in low-wage jobs, often struggled to maintain regular communication with schools and attend individualized education plan meetings. In turn, this resulted in individuals and families having limited information about resources and supports available to them.

### **The Role of Employment Supports**

Despite over 40 years of continuous innovation in high quality employment supports, research suggests that staff providing employment supports (employment specialists) do not consistently use established promising practices, including spending time with individuals in community settings, working with families, and negotiating job responsibilities with the employer (Migliore et al., 2012; Migliore et al., 2010; Inge et al., 2022).

Staff have historically reported they have little training in providing appropriate supports to individuals with IDD in community settings (Migliore et al., 2012; Rosenthal et al., 2012). This becomes more pronounced when placing individuals with IDD in community employment, particularly those with high support needs (Rogan & Rinne, 2011). Researchers have begun to explicitly articulate and translate the latest practices into clear, more easily communicated elements to expand opportunities for employment consultants to improve their skills. 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 for the individual (Migliore et al., 2018). Self Advocates Becoming Empowered have developed similar recommendations for employment support professionals that emphasize respect, empowerment, and quality outcomes (Barrows et al., 2016). Finally, an emerging body of research is focusing on implementation support for employment professionals. Butterworth et al. (2012) found that when employment specialists received training supplemented by in-person coaching, more individuals entered jobs, individuals had higher wages and work hours, and there was a shorter time to placement. In a more recent study, data-based feedback paired with coaching for managers that supports integrating the data into a team's workflow for planning and goal setting showed promise for improving employment outcomes (Butterworth et al., in press). Research on customized employment is validating competencies and developing fidelity scales to support implementation (Inge et al., 2023; Riesen et al., 2023).

### **Discussion**

Despite significant advancements in policy and research and over 40 years of innovation in employment supports, there have not been significant national improvements in employment outcomes for individuals with an IDD. At the same time, data describe considerable variability at

the state level in both services and individual outcomes suggesting that some states have been successful at prioritizing employment in IDD and VR services and in ending or reducing reliance on subminimum wage employment. The growing demand for employment opportunities from advocates, strengthening federal and state policy, and development in our understanding of employment implementation creates an opportunity to accelerate change, but also requires changes in strategy and investment. Research findings emphasize the need for a holistic approach to systems change that better connects stated policy goals with strategy and fiscal investments. Simultaneously, there is a need to strengthen individual experiences with employment supports and address inequities in access to employment including extending existing research and innovation in employment supports to support individuals from underserved and marginalized communities.

*Strengthen implementation of employment policy.* In a cross-disability review, community-wide environmental characteristics such as urbanicity, governance, and the socioeconomic environment did not reveal a relationship to employment outcomes for people with disabilities (Fortune et al., 2022), however there is an increasing emphasis in the literature on understanding systems change and the elements that contribute to successful outcomes (Nord et al., 2020; Shogren et al., 2017; Winsor et al., 2023).

The wide variation in employment participation and outcomes across state IDD and VR agencies suggests that state level systems change efforts are an important element of improving employment outcomes. Evidence suggests that states that have made robust and holistic investments in employment policy implementation and strategy and that emphasize accountability are able to achieve substantially different outcomes (Hall et al., 2007; Winsor et al., 2023). Systems change requires attention to data-based management and strengthening policy

implementation by ensuring dedicated employment leadership, funding models that support competitive integrated employment as a preferred outcome, operational policies such as person-centered planning that prioritize employment, quality management, and investments in capacity building, innovation, and interagency collaboration (Hall et al., 2014; Winsor et al., 2023). Nord et al. (2020) highlight the importance of fiscal effort. Nationally, despite state Employment First policy, state IDD agencies only reported spending on average 11.3% of all day and employment spending on integrated employment services, although state investments vary widely (Winsor et al., 2022). Consistency in evaluation measures, fiscal effort, and messaging are essential elements of change. While research into the policy and state service system elements of improving employment outcomes is relatively new, data suggest that systems implementation is more influential than larger environmental factors and greater emphasis should be placed on these issues at the state and federal levels.

*Develop meaningful pathways from facility-based work and non-work services to employment.* While there has been considerable research that addresses employment outcomes, there has been limited emphasis on the quality of facility-based work and non-work services and supporting a pathway from non-work to employment. Systems change efforts need to provide direct access to services that are known to improve integrated employment outcomes such as career exploration, benefits planning, job development, and referral to vocational rehabilitation.

Most individuals who receive day or employment supports from a state IDD agency are engaged in unpaid facility-based or community activities, and the most frequent service continues to be facility-based non-work services (Friedman, 2016; Winsor et al., 2022). Research has begun to define factors at the program level that support stronger community engagement for people with IDD (Sulewski et al., 2019), and recent federal guidance has addressed the

relationship between community engagement and employment (U.S. Department of Education, 2022). There has been little examination of the role of state policy in supporting community life engagement supports and outcomes. At the federal level there is a need to strengthen guidance and oversight of implementation of the community rule within state HCBS waiver implementation and ongoing monitoring. At the state level, identifying outcomes and building policy related to community life engagement that emphasizes the connection between employment for working age adults and their ability to engage in activities in their community would be a first step to building capacity and defining expectations.

*Building capacity.* Systems change requires increasing the capacity of the system to provide high quality employment supports. To do this states must encourage the significant transformation of provider business models and facilitate the expansion of a workforce of skilled professionals who can implement employment supports with fidelity (Remund et al., 2023; Timmons et al., 2019). States can directly impact through these factors by investing in training and technical assistance. For example, Remund et al. (2022) describe Utah's tiered training structure for employment support professionals and recommend the need for long term investments from the IDD, VR, and other systems in training and evaluation including ongoing technical assistance to employment professionals.

At a policy level, an increasing number of states are adopting provider qualifications that include completion of training such as training certified through the Association of Community Rehabilitation Educators (ACRE) or attaining a Certified Employment Support Professional (CESP) credential through the Association of People Supporting Employment First (Association of Community Rehabilitation Educators, 2022; Association of People Supporting Employment First, 2019). The field's limited fidelity to research-based practice also suggests that investments

in capacity building need to go beyond training and emphasize implementation support including fidelity assessments, coaching, and data-based feedback (Butterworth et al., in press; Riesen et al., 2023). States including Washington and New Mexico have funded technical assistance and training models that support employment specialists to implement best practice and problem solve in the field (Nye-Lengerman et al., 2021). Research also supports using a systems approach to organizational transformation that supports employment and community life engagement services (Lyons et al., 2022), and states are beginning to increase investment in consultation that supports provider capacity and effective business models.

*Early engagement and planning.* Individuals with IDD have made it clear that they want to work. Given that youth employment outcomes continue to lag behind their peers despite state and federal policy a key strategy needs to be ensuring that youth and young adults have experiences that support them to make an informed choice about employment. 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), lack of long-term follow-up of graduates following transition to employment (Callahan et al., 2014), and limited diffusion of evidence-based transition practices in schools (Mazzotti & Plotner, 2016).

Individuals and families report limited engagement in the transition planning process despite the import role families play in future planning (Kramer et al., 2020). A recent comprehensive literature review confirmed the importance of family engagement to employment outcomes (Kramer et al., 2018). Other research has found that 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 (Timmons et.al. (2011)). Families also report experiencing low expectations from state agencies that fund supports, difficulty finding providers of effective employment services, and insufficient system capacity and skills. Despite these challenges, family engagement has a significant impact on individual outcomes, and families are critical advocates in the employment process (Carter et al., 2016; Wilt et al., 2021).

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 (Bose et al., 2021). When family members have advanced knowledge about the service system and develop partnerships with service professionals, individual outcomes are stronger (Kramer et al., 2020; Timmons et al., 2011).

*Improving interagency coordination.* 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; 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). While state level policy is changing to improve these issues, there is limited knowledge about the impact of specific efforts. Winsor et.al. (2023) found that factors such as formal interagency collaboration

structures and organizations, long-term relationships between staff at different agencies, and focus on transition age youth and young adults across each state impact both youth and older employment seekers with IDD.

*Addressing equity and inclusion.* Access to employment services and outcomes vary widely based on social characteristics, and efforts to improve the employment services and supports individuals with IDD receive must address the diversity of the IDD community. While person-centeredness is a core tenant of services for people with IDD, racial, ethnic, linguistic, and socio-economic issues have not been adequately addressed as part of supporting individuals to obtain employment. While disparities in employment outcomes have been documented (Francis et al., 2018; Houseworth et al., 2022), there has been limited research that addresses the experiences of individuals from diverse communities and the supports needed to help individuals and families navigate complex systems and achieve personal goals.

### **Future Research**

Creating meaningful change in employment outcomes and opportunities is a complex problem that requires significant investments across the focus areas highlighted above (Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities, 2016; Hall et al., 2018). Extending research on the systems factors that influence outcomes at an individual, community provider, and state level is an ongoing priority, including extending our understanding of the role of specific policy elements such as provider qualifications, person-centered planning, and fiscal effort.

At an individual level there is a substantial need for research that addresses cost-effective and practical strategies for improving outreach and support to individuals and families and supports a pathway to employment. Research documents widespread confusion and frustration of

individuals and families as they engage with both school and adult service systems (Kramer, 2020). Discussion at the State of the Science Conference on Community Living particularly highlighted research questions that support equitable access to employment. Questions identified by the employment strand workgroup include:

1. What cultural contexts, backgrounds and experiences should be understood to work with a person to find out what employment means to them and what they want out of it?
2. What does culturally competent mean in the context of employment supports? What is the impact of culturally competent employment specialists on outcomes?
3. How do people from marginalized groups get information about employment? Does the source of information affect outcomes? What are the best ways for people to hear about employment services and options?

Addressing these questions and strengthening outreach and supports requires engaging individuals with IDD in framing research, understanding their lived experiences, and developing new policy and strategy.

Improving the quality of employment services requires attention to the capacity of the service system and the quality of implementation of employment supports. While there is research that addresses factors that support organizational transformation to emphasize integrated employment and community life engagement (Sulewski et al., 2017; Timmons et al., 2019), and evidence that states are embracing their role in capacity building, further research is needed to identify the elements of state policy and practice that ensure that state investments and strategies for facilitating and supporting quality services achieve their intended goals.

One significant impact of advocacy related to increasing employment opportunities for people with IDD has been the movement toward reducing the role of facility or sheltered based

work options and, in many states, ending the use of subminimum wage for individuals with disabilities. Similarly, the HCBS Settings Rule has accelerated movement from non-work and unpaid center-based services to supports that are delivered in community settings. Research is needed that describes the short- and long-term changes in individual outcomes, how services evolved to support these changes, and describes the characteristics of systems that are successful in supporting improvements in individual outcomes as individuals move from facility-based and non-work services to community settings. Concurrent with this work, there is a growing need to develop measures that address the outcomes of community life engagement services, (Sulewski et al., 2019).

### **Conclusion**

Improving employment participation requires a holistic approach that considers individual experience, family, support practices, and state policy and strategy. Most states lack an integrated approach that balances desired outcomes with investments. In addition, there has been limited investment in research, capacity building, and policy that supports a pathway to employment from facility-based and non-work services. An essential part of capacity building is strengthening supports for the 80% of individuals who engage in facility-based and non-work services and developing outcome expectations and pathways to employment.

Discussion at the State of the Science meeting reflects this breadth, and in addition emphasized the need to better engage individuals with IDD in framing and implementing research, and having authentic opportunities to reflect on the quality of their experiences and supports. A particular theme was the need to move beyond secondary data analysis that simply describes inequities in employment participation across race, culture, language, and community to more fully understanding individual and community experiences (including intersectionality)

that influence these differences in outcomes.

It is time to examine how employment supports for people with IDD have developed into the services that exist today, and explicitly include the perspectives and experiences of people with IDD from diverse communities. The conversations at the State of the Science Conference reveal the need for policymakers to explore and perhaps reconsider the meaning and primary purpose of work for individuals with different social characteristics. This examination should inform the continued evolution and innovation of employment-related services for people with IDD, as well as communication strategies for sharing information that reflects the breadth and depth of the IDD community. The challenges people with disabilities and their families experience in accessing simple and culturally relevant information about employment services was raised by participants at the State of the Science meeting and is also reflected in the literature. A clear understanding of the support options available is essential for people with IDD and their families to be able to make the best choices for their needs and situations.

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Figure 1. Percent participating in integrated employment services of those who receive an employment or day service from a state IDD agency

