**RRTC State of the Science**

**Bringing Employment First to Scale: State systems and policy issues**

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Funding:

The contents of this brief were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR Grant # 90RT5028-01-00) awarded to the Institute for Community Inclusion at UMass Boston, with a subcontract to the University of Minnesota. NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this brief do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

Abstract

The paper provides an overview of the employment policy landscape for people with IDD and describes findings from a series of related research projects that address policies and practices of high performing state employment systems. Research activities included the development of a composite indicator that considers state performance across systems, case study research, and in-depth policy analysis. The discussion focuses on applying the findings to advance our knowledge and refine priority areas for future study.

Introduction

Since the introduction of supported employment in the Developmental Disabilities Act of 1984 and the Rehabilitation Act Amendments of 1986, there has been continued development and refinement of best practices in employment services and supports. Progress includes demonstrations of creative outcomes for individuals with significant support needs, including customized jobs and self-employment, community rehabilitation providers that have shifted emphasis to integrated employment, and states that have made a substantial investment in Employment First policy and strategy. Despite these achievements, the promise of competitive and integrated employment has not been realized for many individuals with IDD. The number of individuals supported in integrated employment by state IDD agencies has remained stagnant for the past fifteen years, participation in non-work services has grown rapidly, and individual employment supports are not implemented with fidelity to a consistent model or expectations (Winsor et al, 2017).

Responding to this need, the Rehabilitation Research and Training Center (RRTC) on Advancing Employment for Individuals with Intellectual and Developmental Disabilities is a research project housed at the Institute for Community Inclusion (ICI) at the University of Massachusetts Boston. It is part of the ICI’s ThinkWork! initiative, a group of projects promoting the vision, values, and implementation of employment in the community for people with IDD. The term “competitive and integrated employment” refers to full 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 coworkers without disabilities (WIOA, 2014).

The RRTC’s work covers 4 main areas:

1.  Sharing knowledge with and supporting individuals and families around employment.

2.  Increasing the effectiveness of employment consultants who work directly with people with IDD to help them find and maintain employment.

3.  Building capacity and supporting organizational change for community rehabilitation providers

4.  Furthering policies and practices of high-performing state employment systems

This paper covers Strand 4: Policies and Practices of High-Performing State Employment Systems. The paper provides an overview of the employment policy landscape, describes findings from a series of related research projects, and a discussion section that focuses on applying the findings to advance our knowledge and refine priority areas for future study. The research questions that guided this strand of research include:

* What are the characteristics of higher-performing employment systems?
* What is the relationship between systems’ characteristics and employment outcomes?

Background

Employment is culturally and economically critical for providing opportunities to thrive as an individual and a community member. State and local efforts, in concert with federal regulations, are aligning to support individuals with intellectual and developmental disabilities to move out of poverty and into the workforce. The U.S. Department of Labor and federal offices that serve people with disabilities are working together to promote Employment First policies (U.S. DOL, no date). “Employment First” means that employment is the first and preferred option when exploring goals and a life path for citizens with disabilities (APSE, 2010). At the time of this writing, almost every state has some type of Employment First initiative, policy, or grassroots effort, with 32 states having an official policy or directive (Hoff, 2016). The introduction of Employment First policies has been an important step toward helping people with disabilities participate fully in society, expand their social and economic capital, and move towards self-sufficiency (Winsor et al, 2017).

At the national level, integrated employment has become a policy priority. Greater expectations are being placed on those charged with delivering employment supports, and disability systems are responding. However, as a SABE representative notes, “just calling your state an ‘Employment First’ state is not enough; it’s when everyone who wants a job, actually has a job.” (SABE, 2016). Data shows that the promise of Employment First has yet to be realized for the majority of individuals with intellectual and developmental disabilities (IDD). The number of individuals supported in integrated employment by state IDD agencies has remained the same since 2000, participation in non-work services has grown rapidly, and promising practices for employment supports identified in the research are not widely implemented.

Literature review

With an increasing emphasis on integrated employment and an Employment First philosophy, the nation is poised for transformation that could put impoverished Americans with disabilities on a path to self-sufficiency. However, there remains a significant gap in employment rates between people with and without disabilities. The 2014 American Community Survey (ACS) estimates that 33.7% of working-age adults with disabilities are employed, compared with 72.9% of people without disabilities (Butterworth et al., 2016). Labor force statistics from the Bureau of Labor Statistics for March, 2017 estimate that 20.4% of individuals with disabilities ages 16 to 64 are employed, compared with 68.7% of those without disabilities.

For people with intellectual and developmental disabilities (IDD), the disparity in employment participation widens further. Data from the National Core Indicators Project suggest that in 2014–2015, only 16% of working-age adults supported by state IDD agencies were employed in a paid job in the community (Hiersteiner, Bershadsky, Bonardi, & Butterworth, 2016). ICI research shows that an estimated 19% of individuals receiving day supports from state IDD agencies participated in integrated employment services during FY2014 (Butterworth et al., 2016). This number has slowly declined after reaching a peak of almost 25% in FY2001. 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 (Nord et al., 2016; Butterworth et al., 2015; Domin & Butterworth, 2012).

Many factors affect the national landscape around integrated employment. The Centers for Medicare and Medicaid Services (CMS) released guidance to the field clarifying their commitment to integrated employment as an outcome of employment-related services under the Home and Community-Based Services waiver, and have issued new rules related to the assessment of community-based employment settings (CMS, 2014). Notable in a 2011 bulletin from CMS is the amount of values-based language it contains. The bulletin urges investment in person-centered planning, and points out the ways in which Medicaid funds should support opportunities to increase employment outcomes compared to historically segregated options: “Work is a fundamental part of adult life for people with and without disabilities. It provides a sense of purpose, shaping who we are and how we fit into our community.”

The HCBS “Final Rule,” which took effect in March, 2014, creates more clarity in the definitions of home and community-based settings, rather than defining them based solely on location, geography, or physical characteristics (CMS, 2014). The rule requires that all HCBS settings must be integrated within and facilitate access to the community, optimize autonomy and independence, be chosen by the individual, and provide an opportunity to work in the community (HCBS Advocacy Coalition, 2015). In May of 2017, CMS announced a three year extension for states to meet the settings requirements. This extension is in response to states’ request for more time to comply with the requirements in ways that are “collaborative, transparent, and timely” (CMS, 2017). States now have until March, 2022 to comply with the rule.

In July 2014, the Workforce Innovation and Opportunity Act (WIOA) required that state’s public vocational rehabilitation (VR) agency focus on transition services and pre-employment services, coordinate with the state agency responsible for administering the state Medicaid plan and with state IDD agencies, and focus on the general workforce development system and One-Stop Career Centers (also called American Job Centers). WIOA also puts into place restrictions on the use of sub-minimum wage. As of 2016, the legislation incorporates a series of steps that individuals must go through before being placed in a position that pays less than minimum wage.

In multiple states, the U.S. Department of Justice has extended the Olmstead vs. L.C. decision related to the unnecessary segregation of people with disabilities. As recently as October 2016, the Department of Justice issued further clarification on the how the ADA’s integration mandate and Olmstead should be applied to publicly-funded employment services. The memo statement clarifies the definition of “most integrated setting” and the importance of informed choice for individuals with disabilities, who have traditionally been steered towards more segregated service options. Guidance around access to competitive employment services addresses individualization of services, intensity and duration of services, and access to integration and necessary supports during non-work hours (U.S. Department of Justice, 2016).

## How states are responding

State and even federal policies can make an important contribution to raising expectations, improving outcomes, and increasing self-sufficiency for individuals with intellectual and developmental disabilities. However, research suggests that while the existence of a policy is important to provide a vision for practice and expectations, the existence of the policy by itself does not guarantee that more people with disabilities will become employed.

In order for change to be sustainable, it must be occur with a comprehensive approach to change that recognizes the need to achieve consistent messaging, goals, and policy across a complex network of services and programs. The Higher Performing States model, described below, emphasizes the relationship among strategy, policy, and culture in implementing systems change.

**The High Performing States Model.** The large variation in employment participation across state IDD agencies suggests that examining state agency policy and practice is vital for understanding employment outcomes.

Figure 1: Higher Performing States Model



The High Performing States model was developed from research that examined common strategies and approaches across state IDD agencies with high levels of integrated employment outcomes, and identifies seven elements that communicate commitment to the goals of community inclusion and integrated employment.

Developed over ten years ago, this model has been used as a strategic planning tool with 30 states to guide systems change towards greater integrated employment outcomes within state IDD agencies. Given the current and increasing emphasis on a cross-systems focus and interagency collaboration, this model is evolving to encompass the systems interactions, relationships, and partnerships that characterize higher performing states.

The focus of the current work is to understand how state systems are paving the way for more individuals with IDD to experience integrated employment options while building new paths for economic self- sufficiency and meaningful roles in their communities. These changes must directly tie back to the key system drivers outlined earlier in partnership with the authoring federal entities. The drivers clarify the importance of individuals achieving their employment goals in concert with federal expectations, and not in spite of such influences. State systems must use the available opportunities to determine whether current investments are producing the intended outcomes, and if not, provide the strategic leadership to adapt as necessary to reach intended goals.

Findings

Through the work of the Rehabilitation Research and Training Center on Advancing Employment for People with IDD, we consider the practices, needs, and goals of state employment systems. This project explores how state agencies and their partners are working to implement Employment First policies that enable people with IDD to attain integrated employment. Building on a foundation of work on state systems and employment, project staff and partners in this research are exploring the relationships between state strategy and employment outcomes, with the goal of producing a framework where systems intentionally align practices with a priority for employment. We use several tools including secondary analysis of national data sets (National Core Indicator analysis and the Employment Composite Indicator analysis), case studies of higher-performing state systems, and policy analyses that describe challenges and strategies of states as they respond to national priorities.

*National Core Indicator Analysis*

Understanding what services and supports individuals with IDD receive and the outcomes of those services is an important step for developing long-term, sustainable system change. This study explored the characteristics of individuals with IDD who receive services in relation to their involvement in different day and employment settings. National Core Indicators (NCI) data from 25 states in 2012–2013 were analyzed to identify and describe individual demographic characteristics and outcomes related to four different day and employment settings: individual community, group community, facility-based, and no paid job.

Findings indicate that basic demographic characteristics of people who receive services (age, gender, and significance/severity of disability), and support needs characteristics (mode of expression, mobility, and guardianship status), are possible indicators for type of day and employment setting. In particular, younger individuals were less likely to be in any employment setting, females were the most underrepresented group in the paid employment group, and those that had legal guardians were less likely to be employed (Nye-Lengerman, Pettingell, Nord, & Hewitt, under review). In general, individuals with IDD continue to receive services in non-work or facility-based employment programs at significantly higher rates than in community employment.

This analysis highlights two important points. First, findings of this study suggest a gender-based disparity between men and women in the area of community-based employment. More research is needed to understand why women seem to be underrepresented among people with IDD who are employed in community-based settings. This research also highlights an important correlation between legal guardianship and employment for people with IDD. Understanding why guardianship may represent a barrier to integrated employment can help providers, policymakers, and advocates engage effectively with guardians in order to support improved employment outcomes for individuals with IDD. In general, guardianship does not necessarily reflect or neatly correspond to an individual’s degree of intellectual impairment. Rates of guardianship for people with IDD vary significantly across different states (Pettingell, raw data), and the requirements for guardianship vary according to state law (Whitenack, n.d.). Guardians often have significant influence over the lives of people with IDD, and thus it may be necessary to explore whether and where legal guardians are able to access information about integrated employment, and whether there might be observable gaps or misalignment between guardians’ expectations and individuals’ employment goals (Narby, in press).

*The State Employment System Performance Composite Indicator*

The State Employment System Performance Composite Indicator was developed through a broad, data-driven effort. Researchers used data representing employment outcomes for state IDD agencies, state VR agencies, and state public education systems to create a composite indicator representing overall state employment system performance rankings. Results of composite indicator analysis revealed that some states’ employment systems achieve a relatively higher performance when compared with other states.

States with higher-performing state systems in 2013, in ranked order, were Maryland, New Hampshire, Vermont, Oregon, Washington, Iowa, Oklahoma, South Dakota, Colorado, and Delaware. Not surprisingly, due to a weighting criteria developed through an expert review and ranking of systems’ indicators, states that had higher IDD system performance rose to the top of the list for the State Employment System Performance rankings. Six of the higher-performing states had IDD systems that were in the top 10 in terms of IDD system score: Maryland, New Hampshire, Vermont, Oregon, Washington, and Oklahoma. Four states, Maryland, South Dakota, Colorado, and Delaware, were in the top 10 in terms of VR system performance. Four of the higher-performing states were in the top 10 in terms of education system performance: New Hampshire, Iowa, South Dakota and Colorado.

Next, researchers will apply the findings from these analyses to understand why some states showed indications of higher performance. Researchers are creating a multivariate analytical model that looks at the various inputs and attributes that contribute to state employment system performance. This will help us to understand systems more holistically and identify the qualitative differences between higher performing states and their lower performing counterparts.

*Evolution of the Higher Performing Framework*

The goal of this research is twofold: to understand what collaborative interagency policies and practices are being implemented in states with relatively high rankings in integrated employment, and to contribute to the evolution of the research-based Higher-Performing States Employment Framework (see Figure 1 presented earlier in this paper).

This study builds on the existing framework of a higher-performing IDD system, and explores the elements within and among collaborating systems (VR and education) that support employment for people with IDD. Through this lens, the framework investigates the conditions that allow stakeholders to bring these practices to scale across states.

Since Maryland identified as having achieved the highest ranking in the composite indicator analysis, researchers chose this state for the first case study. Initial findings suggest that Maryland’s employment system has matured, and emphasizes collaboration across agencies, within agencies, and among individuals. This approach helps create long-standing personal relationships that keep employment outcomes as a key focus in the system. Further analysis will focus on communication, culture, and the more granular elements of collaboration within the system.

*Diving deeper: Highlights from policy analyses*

RRTC staff and partners conducted two in-depth policy analyses of priority and emerging policy topics that impact employment outcomes and services for individuals served by state IDD agencies. Based on the importance of regulations and guidance from the Centers for Medicaid and Medicare and their impact on long-term supports for individuals with IDD, the first topic chosen was how states are applying the 2011 CMS guidance regarding the intent and outcome of pre-vocational services. The second paper analyzed the developments and potential strategies to embed employment as a priority for support coordination/ case management in service plan development, implementation and follow-up. This topic was of particular importance because of the focus on IDD system infrastructure and internal strategy and policy and alignment with overall mission and goals. The third topic chosen focused on multi-system collaboration and supporting individuals across the lifespan.

To examine the first topic, we considered findings from Colorado, New Jersey, and Vermont, where themes emerged in the policies, practices, and strategies being used to increase integrated employment. Each state demonstrated strong leadership, and promoted the value of integrated employment. Leadership is evident through setting values and direction, making and communicating commitments, focusing on collaborative action, and creating systemic change that supports employment as a priority. These states were able to articulate the importance of employment, moved ahead regardless of state budget issues, and created the infrastructure within their systems for innovations. States shared power with stakeholders, encouraging leadership to develop at all levels.

In considering the second topic, we drafted a paper focused on support coordination strategies that impact employment outcomes. Support coordinators assist individuals with IDD to obtain and maintain employment. Their jobs are complex, with multiple responsibilities. As Cooper (2016) notes, “Case managers engage in high quality, person-centered planning that keeps the full focus on the person. But how case managers engage with individuals and families is critical to setting expectations about the services system and the opportunities--and limitations--within the system” (as cited in NASDDDS, 2016).

The person centered planning and settings components of the HCBS Final Rule can provide a strong foundation for support coordinators to further meaningful conversations with individuals, families, and teams. States are finding new ways to improve the person-centered planning process that involve guidance, questions, and potential action steps for support coordinators to use with teams when a person is not working and has not expressed interest in a job, is not working but would like a job, or is working and seeking growth opportunities.

There is no one way to determine how the pathway is developed and implemented in a state, but developing guidance with a stakeholder group, analyzing what can be done to embed the pathway into the person-centered planning process, and looking at how pathway guidance assists during different life stages were identified as promising practices. The next policy analysis will address strategies for interagency collaboration, with the goal of seamless transition throughout systems and across the lifespan.

Discussion

The 2015 National Goals Conference facilitated discussion and papers that identified: points of contention in the field of employment for people with IDD; methodological challenges to researching employment and economic self-sufficiency; unanswered questions; and the next big ideas and paradigm shifts that would advance employment outcomes (Nord et al, 2016). Participants called for an “improved, comparative understanding of related policy (and) practice…inputs, (and their) resulting outcomes” and emphasized the need for alignment among systems. This alignment will result in more people entering the workforce, earning higher wages and working more hours. The current research takes steps to address this challenge by studying state employment systems’ policies and practices and their relationship to individual outcomes, and defining strategies of high-performing, collaborative state employment systems.

The composite indicator research that ranks state employment systems provides a foundation for understanding how well states perform in comparison to one another. The research does not attempt to identify a benchmark states should achieve in terms of system or individual employment outcomes. Rather, it enables the identification of states that are performing higher relative to others, so that that as a field we can identify and seek to replicate promising practices. This is the backbone and intent of our research: bringing these practices “to scale” so that more people with IDD and their communities can benefit from systems change efforts.

The higher performing systems case studies seeks to expand and give context to the contextual factors that support state IDD, VR, and ED agencies to support a high percentage of individuals with IDD in employment. The description of policies and practices that occur within individual state agencies and across state agencies provides valuable information to support the implementation of the both federal and state laws and initiatives to improve the economic outcomes of individuals with IDD. Preliminary findings from the first case study suggests that there is a longitudinal component to state’s success that depends on a cadre of stakeholders within state government, the service provider community, and the advocacy community to maintain a focus on individual integrated employment as a priority. Additional findings from the initial case study also suggest that state agency policy and practices that specifically address how services and supports for individuals will evolve over time is an important component of building an Employment First culture.

While the current research seeks to answer many questions, it also brings up areas for future study. National Core Indicator data analysis suggests that the type of setting in which a person receives services may be related to specific demographic characteristics. Understanding the influence of these demographic factors can assist in the development of targeted training, interventions, and supports throughout multiple areas in a service system. As states identify their strategies for responding to new policies and regulations regarding employment of people with IDD, knowing the influence of demographics on employment profiles can be useful in developing the most effective programs that will enable all people with disabilities, regardless of gender, level of disability, or guardianship status, to have the best opportunity for community employment.

The outcomes of the in-depth policy analyses of priority and emerging policy topics ties together and provides specifics that can help states build not only their employment service systems but help those systems better respond to individuals unique life circumstances. The higher performing systems case studies have identified the importance of evolving expectations for employment and developing a culture of integrated employment; the first policy paper on how states are applying the 2011 CMS guidance regarding the intent and outcome of pre-vocational services provides replicable strategies to help states go beyond following a policy but truly embracing the long term possibilities of supporting individuals to move to employment in the community. Paralleling this, the second policy papers focus on strategies to embed employment as a priority for support coordination/ case management in service plan development, implementation and follow-up. The third policy analysis topic chosen focuses on multi-system collaboration and supporting individuals across the lifespan which provides fodder for changes at the state agency level but also connects to the findings of this project’s family engagement research (see Kramer et al, 2017) related to the ways in which individuals and families are supported across the life span to facilitate obtaining their goals.

The implications of the findings across this research strand focus on suggest that systems change is a commitment that requires a long term dedication to reframing how services are designed to support individuals to obtain their goals. This reframing will require changes not only across the IDD, VR, and ED service systems but within community providers and throughout their direct support workforce who are implementing these services.

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