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Abstract

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 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 integrated employment remains elusive for the majority of individuals with intellectual and developmental disabilities. The number of individuals supported in integrated employment by state agencies has remained stagnant for the past fifteen years, participation in non-work services has grown rapidly, and individual employment supports have not been implemented with fidelity (Domin & Butterworth, 2016; Winsor et al., 2017). This article presents preliminary findings from activities completed by the Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities and discusses a framework for organizing state and federal investments in research, practice, and systems change.

Keywords: systems change, employment, intellectual and developmental disabilities

Building an Evidence-Based, Holistic Approach to Advancing Integrated Employment

While there is not one definitive source of data describing labor force participation for individuals with intellectual and developmental disabilities (IDD), the National Core Indicators Project found that, in 2015-16, 19% of working age adults supported by state IDD agencies worked in integrated employment including both individual and group supported employment, with only 14% working in individual competitive or supported jobs (National Core Indicators, 2017). Survey research from the Institute for Community Inclusion (ICI) estimates that 18.6% of individuals receiving day supports from state IDD agencies participated in integrated employment services during FY2015 (Winsor et al., 2017). This percent has declined from a peak of almost 25% in FY2001. Those who are employed typically work limited hours with low wages (Hiersteiner, Bershadsky, Bonardi, & Butterworth, 2016). Data show that people with a cognitive disability who are receiving Supplemental Security Income (SSI), the group most likely to include people who have the most significant cognitive or intellectual disabilities, have the lowest employment rate of all disability subgroups, and are the most likely to live in a household that is below the poverty line (Winsor et al., 2017).

Recent federal policy and strategy promotes employment. The Centers for Medicare and Medicaid Services (CMS) released guidance to the field clarifying their commitment to integrated employment as a priority outcome of employment-related services offered within Home and Community-Based Services (HCBS) waivers, and have issued new rules related to the assessment of community-based employment settings (CMS, 2011; CMS, 2014). The HCBS Settings Rule requires that HCBS services must support integration 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). The

Workforce Innovation and Opportunity Act of 2014 (WIOA) requires that state public vocational rehabilitation (VR) agencies focus on transition services and pre-employment services, and coordinate with the state agency responsible for administering the state Medicaid plan and with state IDD agencies. WIOA also provides a definition of competitive integrated employment and puts into place restrictions on the use of sub-minimum wage and expectations supporting informed choice for individuals currently in or considering this type of employment. Finally, the U. S. Department of Justice has taken action to ensure that the *Olmstead v. L.C.* decision related to the unnecessary segregation of people with disabilities applies to access to competitive integrated employment and community life engagement.

In addition to federal policy under CMS, WIOA, and the Department of Justice, 33 states have established Employment First policy, and 49 states have some form of an Employment First initiative. These initiatives support community employment as the first outcome considered for people with disabilities who receive state services. Employment First represents a commitment by states, and state IDD agencies, to the idea that all individuals with IDD (a) are capable of working 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, Hoff, Freeze, & Mank, 2011; Nord et al., 2015).

The Challenge of Creating Systemic and Enduring Change

While growth in participation in employment for individuals with IDD has been relatively stagnant, there are ample examples of creative individual outcomes, support providers that have substantially transformed their organizations to focus on community employment, and states that have been successful in improving outcomes. Current research and practice suggests

clearly that individuals with IDD want to work, that there are well-established strategies that result in successful employment outcomes, and that states can implement key policy and strategic elements that influence outcomes (Butterworth, Hiersteiner, Engler, Bershadsky, & Bradley, 2015; Hall, Butterworth, Winsor, Gilmore, & Metzel, 2007; Kiernan et al., 2011; Migliore, Nye-Lengerman, Lyons, Bose, & Butterworth, in press; Nord et al., 2015; Nord, Luecking, Mank, Kiernan, & Wray, 2013). These successes suggest a need for a more holistic approach to improving employment outcomes that integrates individual, employment support, and systems factors, and develops a deeper understanding of the elements that influence employment participation. In order to be effective, strategies for outreach and capacity building need to be developed that are both scalable (able to be replicated and expanded to benefit a larger population), and cost-efficient. Areas in need of attention include (a) family involvement, (b) use of promising practices by employment specialists, (c) alignment of community rehabilitation providers' priorities, and (d) integration of agencies across state systems.

Family Involvement

Despite the fact that parental expectation is the greatest predictor of paid work experiences, families frequently experience low expectations and support from school programs (Almutairi, 2016; Blustein, Carter, & McMillan, 2016; Henninger & Taylor, 2014). Moreover, families report insufficient information and support to effectively participate in the transition from the education service system to the adult service system (Almutairi, 2016; Hetherington et al., 2010; Winsor, Butterworth, Lugas, & Hall, 2010). Key needs include development of accessible and effective approaches for sharing information with and supporting individuals and their family members in developing individualized goals and planning for employment.

Use of Promising Practices by Employment Specialists

Although well-defined standards for effective employment support exist (e.g., the Association for People Supporting Employment First [APSE] Certified Employment Support Professional credential; the Association for Community Rehabilitation Educators [ACRE] Certificate of Achievement in Employment Services; the National Alliance for Direct Support Professionals Employment Support credential), 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, Butterworth, Nord, Cox, & Gelb, 2012; Migliore, Hall, Butterworth, & Winsor, 2010). Additional research indicates that employment specialists who receive training and mentorship do improve the number and quality of the jobs they develop (Butterworth, Migliore, Nord, & Gelb, 2012); however, job developers have limited opportunities for effective professional development, including both formal and informal chances for learning (Hall, Bose, Winsor, & Migliore, 2014). While there is a robust literature that describes overarching models including supported employment and customized employment (Nord et al., 2015; Wehman, Inge, Revell, & Brooke, 2007), there is limited experimental research that documents the use of such strategies in everyday practice.

Alignment of Community Rehabilitation Providers' Priorities

Research suggests continued variation of services and philosophies across community providers, making the creation of a unified employment vision extremely difficult. Providers who have transformed their services emphasize that ongoing commitment to integrated employment at all levels of their organization is key (Lyons, Timmons, Hall, & LeBlois, in press) and that employment is possible for all, including those with the most significant disabilities. Yet, Inge and colleagues (2009) found that almost 89% of respondents to a national

survey of community 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. Providers also perceive inadequate funding and community resources to provide individual employment (Rogan & Rinne, 2011; Rosenthal et al., 2012). Lastly, front-line staff experience confusion about job development responsibilities, do not feel prepared to engage the mainstream business community, and have limited training in providing appropriate supports to individuals with IDD in community settings (Migliore et al., 2012; Rosenthal et al., 2012; West & Patton, 2010). With rising pressure from CMS and WIOA to expand access to employment and community life engagement (Sulewski et al., 2017), there is a need to develop a better understanding of the key elements of organizations that implement a community integrated approach. Moreover, there is a critical need to develop cost-effective models for supporting organizational transformation so that more individuals with IDD can benefit from community employment.

Integration of Agencies Across State Systems

As previously noted, navigating employment services is confusing for individuals and families, and not well coordinated among education, IDD, and Vocational Rehabilitation agencies and providers. Even with mandates for interagency collaboration, research finds that mechanisms for information-sharing and shared service delivery are not well coordinated. There are gaps in service delivery, a lack of agreement about target populations, and differences in culture and resources (Certo, Luecking, Murphy, Courey, & Belanger, 2008; Martinez et al., 2010; National Council on Disability, 2008; Timmons, Cohen, & Fesko, 2004). The Government Accountability Office (2012) highlighted as barriers the difficulty students and their parents face navigating services across different programs during the transition to adult life, limited

coordination across agencies, and a lack of information about the full range of service options available to young adults with disabilities. While there is growing evidence of policy shifts that emphasize coordination among employment supports, history has shown that policy alone does not enable states to help people with disabilities attain the best possible outcomes. In their state systems research, Hall and colleagues (2007) demonstrate that it is the dynamic interplay of multiple elements, including but not limited to policy changes and interagency mandates, that leads to long-term systems change.

Overview of Research Conducted by the Center

The field of IDD is at a crossroads. More than three decades of research has found that integrated employment outcomes can only improve if supports provided by state IDD agencies and their partners prioritize employment for all, if individuals and families have clear and useful access to information that supports their full engagement, and if individuals receive effective and research-based supports. This article presents preliminary findings from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) funded Rehabilitation Research and Training Center on Advancing Employment for Individuals with IDD. The Center recognizes that employment outcomes are influenced by an array of factors, including characteristics of the community and labor market, workplace structure and culture, and federal policy. Center research is focusing on the development of strategies that can be implemented at a state and local level to expand employment in four strands: (a) individuals and families, (b) employment supports (employment consultants who work directly with individuals with disabilities), (c) community rehabilitation provider practices, and (d) state policy and strategy. This section provides a brief overview of preliminary findings and themes from each of these areas (see Table 1 for an overview of studies conducted).

Individuals and Families

The findings from the Center's individual and family engagement research revealed inconsistency between the essential role of families in supporting a pathway to employment and the perceived effectiveness of "the system/s" (typically referred to as the vocational rehabilitation system, the school system, and the state IDD agency system) in engaging families in employment planning and implementation (Kramer, 2017; Kramer, Bose, & Winsor, in press). Three key themes emerged from the Center's research activities.

Families can play an important role with respect to a person's future employment expectations and opportunities. Early on in an individual's life, family members' modeling of roles and expectations can shape positive experiences of employment for people with IDD, and build a proactive vision. Findings indicate that the service system should connect with families as early as possible to influence employment expectations. Modeling of work roles by family members has a positive impact on employment for people with IDD, and family members' early expectations are powerful for shaping this vision.

Findings also suggest that systemic engagement with families leads to employment-focused decisions. When family members have advanced knowledge about the service system and partner with service professionals, employment outcomes increase. There is an important role for engaged families, in particular for those who understand the transition process and have a sense of ownership and commitment to their role in the process.

Families have identified multiple systemic barriers to employment outcomes. Families perceived confusing guidance by the service system (Vocational Rehabilitation, education, and the IDD state agency system), and lack of alignment between agencies as major challenges. Families also observed limited cohesion and varying sets of rules, expectations and

opportunities across the different agencies with which they were interacting. There was a palpable sense of futility in continuing to “chase” government funded employment-related support. Part of the frustration came from the lack of progress, despite many repeated attempts at accessing services.

In addition, the perception of low expectations of staff about what individuals could accomplish were pervasive. Families felt that the tools used to understand their family member’s strengths and needs did not offer the full picture of an individual’s potential. This could negatively impact the array of possibilities and opportunities that employment consultants would consider relative to employment planning and vocational goals.

Self-advocates described achieving positive outcomes when relying on themselves and family members, and not solely on employment services. While some families reported feeling that government-funded service programs are seen as the one-and-only option for people with disabilities seeking employment, an additional theme that emerged was the resilience of those families and individuals who remained committed to employment. People with IDD and their families drove the employment process, learned about funding sources and networked with other families for advice and information about services. Individuals and families did their own process of discovering their strengths, skills and interests and envisioned and planned for employment before engaging the service system and/or used the system as needed. Family members expressed both that the current system feels like it may never be able to meet demand, and that employment can happen with perhaps no system help or, at the very least, much lighter involvement.

Implications. These themes confirm the importance of family engagement in employment planning, but also indicate families’ feelings of frustration with the process. It is

likely that, as employment systems continue to be challenged by budget shortfalls and competing priorities, parents and other family members may be expected to know more and engage in greater advocacy towards successful employment outcomes. It is possible that capacity for family engagement may be related to differences in demographic and socioeconomic life course variables (Wagner, Newman, & Lavitz, 2014). Family members with fewer financial resources may not have the time or social capital to contribute to employment planning as compared to family members with greater access to resources. Building on these findings that highlight the resilience and success of some families, future research studies should focus on potential differences in experiences and interactions with employment services among families from varying socioeconomic environments.

Employment Supports

Our research on employment supports focused on how employment consultants implement support practices and make decisions about supports, and how intervention strategies can be developed at a provider and state systems level to support fidelity to best practice and improve outcomes (Migliore et al., in press; Nye-Lengerman & Timmons, 2017). Strengthening the effectiveness of employment services for job seekers with disabilities is key for improving their opportunities for employment and financial self-sufficiency. Center findings based on qualitative and quantitative analysis delve into not only what strategies employment consultants use, but also how much time is spent on each support strategy, as well as on administrative tasks. (Migliore, 2018). Findings from the Center's work in this area suggest two major themes.

Building trust, getting to know job seekers, and optimizing a job match. Engaging in actions and activities to build trust with job seekers was a key component for connecting with a job seeker and ensuring their openness and candor about their true preferences and deeper

aspirations. In turn, knowing this information was essential to increase the chances of identifying the best job match, thus maximizing job satisfaction, minimizing support after hire, and optimizing job retention. While building trust occurs across all activities of the employment process, findings show the importance of being intentional about allocating time for relationship building from day one.

Understanding job seekers' deep motivations was described as an individualized process focused on learning about job seekers' passions, values, strengths, challenges, vision for themselves, dislikes, non-negotiables, and other motivating factors. It was about seeing an individual's gifts, talents, and interests rather than focusing on disability labels, poor work history, or behavioral challenges. Respondents emphasized the importance of "what," "why," and "how come" questions, and being a good listener. Every desire expressed by a job seeker, even if perceived as hard to attain, was welcomed as an opportunity for digging deeper into a job seeker's aspirations.

This fundamental knowledge of individuals they are supporting allows employment consultants to develop a range of activities designed to anticipate the job seeker's support needs once employed. These included assisting them with improving work and social skills, planning for transportation to and from work, planning for communication and technology supports, and facilitating work incentive planning. A focus on looking for tasks, rather than for jobs openings, within a prospective place of employment allows employment consultants to match the job seekers' preferences and skills with opportunities that add value to a business.

Understanding time investment in supports that lead to hire. Findings suggest that although the above activities are consistent with the literature on best practices in employment support (Nord et al., 2015; Wehman et al., 2007), employment consultants only spend about 30%

of their time in activities and supports that can lead to hire (Migliore, 2018). Other time is spent on non-employment related supports, supports after hire that can support job retention and advancement, and administrative tasks. In fact, survey results indicate that almost one-third of an employment consultant's work day was spent on administrative tasks including handling service authorizations, billing reporting, completing forms, case notes and other documentation, or attending meetings

Implications. Investing more time in supports that lead to hire is key for allowing employment consultants to develop the needed expertise for handling the job seekers' individual support needs while ensuring that the employers' business needs are met. It is important for employment consultants and their supervisors to reflect on how to simplify administrative tasks including minimizing unnecessary paperwork, and increasing the use of technology—e.g., adopting mobile devices, using software for billing and authorizations. Future research should continue to investigate exactly how effective employment consultants spend their time, with a focus on disseminating information to the field that ensures that employment consultants have the tools to implement effective employment support practices.

Community Rehabilitation Provider Practices

Employment supports occur in the context of the culture, policy, and structure of a community rehabilitation provider. This strand of research investigates the most important features necessary for building a successful organization that supports competitive integrated employment (Lyons et al., in press). Building on previous work (Butterworth, Gandolfo, Revell, & Inge, 2007), the Center conducted two studies (i.e., a Delphi panel of experts as well as in-depth case studies with organizations that have closed sheltered workshops) that resulted in the identification of 10 critical elements for organizational transformation in ranked order.

1. *Clear and consistent goals.* An explicit commitment to increasing competitive integrated employment is essential. Goals must be measurable, compelling, easy to grasp, directly reflective of the core mission, modifiable, specific to an established time frame, and reflect the needs of individuals.
2. *An agency culture that values inclusion.* A culture must be established that values supporting individuals in the community rather than in facilities, positive thinking, learning, creativity, innovation, and continuous quality improvement.
3. *An active, person-centered job placement process.* Proactive job-finding should occur one person at a time. This “just do it” approach creates momentum as successful employment outcomes are achieved and celebrated.
4. *A strong internal and external communications plan.* Successful organizations must communicate clear, authentic expectations for competitive integrated employment. Internally, this includes all levels of staff, individuals, families, and board members and externally, this refers to marketing services in the community.
5. *Reallocated and restructured resources.* Active and ongoing investment in realigning all fiscal, material, and staff resources is required in order to put into place the supports and services needed for increasing competitive integrated employment.
6. *An ongoing investment in staff professional development.* Frequent and ongoing training, continuing education, conference participation, and mentorship opportunities are needed to develop and maintain staff’s core competencies and to implement best practices.
7. *A focus on customer engagement.* Organizations must engage with customer groups including individuals, families, funders, and other community partners, as well as with new and existing business partners, in order to meet both individual and market needs.

8. *Effective employment performance measurement, quality assurance, and program oversight.* A clear framework must be established for implementing and measuring administrative, management, and program strategies over defined periods of time in order to determine the impact and success of efforts.
9. *A holistic approach.* Consideration must be given to the whole person with wrap-around life supports, and use of a career planning process that involves staff, parents, and friends, and includes any accommodations, including assistive technology.
10. *Multiple and diverse community partnerships:* Partnerships are needed with school districts, state agency offices such as vocational rehabilitation, faith-based and/or civic organizations, and transportation resources.

Implications. This research provides the foundation for future work around organizational transformation. The case study data adds a richness to the description of the ten characteristics, which is featured in a practical toolkit and technical assistance package that is currently being used in an intervention with providers. The intervention is testing the utility of these elements as a roadmap for organization transformation. Future research should explore the effectiveness of organization and management structures to support employment, including the cost effectiveness of new staffing and support models, performance measurement approaches that drive decision-making, and meaningful organizational communication strategies that promote integrated employment as the priority goal.

State-level Policy and Strategy

Investigating the connection between interagency collaboration and employment outcomes, Center researchers developed the State Employment System Performance Composite Indicator using data representing employment outcomes for state IDD agencies, state VR

agencies, and state public education systems (Smith, Winsor & Hall, 2018; Winsor & Hall, 2017). Because people with IDD may use the services of multiple state agencies throughout their lifetimes, the study investigated the employment outcomes produced across agencies within each state. Thus, “state employment system performance” refers to how a state performs in terms of employment outcomes for people with IDD across three different systems (IDD, VR, and education). The ten states with the highest State Employment System Performance Composite Indicator scores in 2013 in ranked order were Maryland, New Hampshire, Vermont, Oregon, Washington, Iowa, Oklahoma, South Dakota, Colorado, and Delaware. Six of the states with the highest composite scores were top performers in the IDD system: Maryland, New Hampshire, Vermont, Oregon, Washington, and Oklahoma. Four of the top 10 scoring states, Maryland, South Dakota, Colorado, and Delaware, were in the top 10 in terms of VR system performance. Four of the top 10 scoring states were in the top 10 in terms of education system performance: New Hampshire, Iowa, South Dakota, and Colorado. No single state scored in the top 10 in all categories.

In-depth case study research with the state with the highest overall score, Maryland, (Winsor, Landa, Narby, & Hall, in press) sheds light on how its employment system (which includes education, VR, and the state IDD agency) collaborates to focus on integrated employment for individuals with IDD. State administrators emphasize collaboration across agencies, within agencies, and among local leaders. Success over the long term has depended on a cadre of stakeholders and their personal relationships and commitment to employment. Leadership is not only at the highest levels of the administration, but was discussed as most effective when distributed across multiple levels of responsibility. In addition to strong leadership, consistent allocation of funds for long-term services for youth exiting schools has

been critical and has cemented expectation for collaboration between school and adult service systems. Capacity-building efforts have spread this consistent message of employment, and have focused on building a statewide understanding of goals and service outcomes, methods to enhance and monitor service quality, and ensure best practice.

Implications. Stakeholders in the field have called for research that leads to an improved understanding of the relationships between policy, practice, and outcomes (Nord et al, 2015). Characteristics of state IDD agencies that support stronger employment outcomes have been defined by Hall et al. (2007), but given the multi-system influence on expectations and access to services, including substantial engagement with education and vocational rehabilitation, as well as other community and health care resources, there is a need to extend research to address multi-agency models for improving employment outcomes.

State agency policy and strategy influence individual and family expectations when engaging with case managers, the definition of and access to services, quality improvement and management priorities, and the qualifications of service providers. In a similar vein to previous discussions on the future of the field of employment research (Nord et al., 2015), participants called for an improved understanding of the relationship between policy, practice and outcomes. Future research should further explore alignment among agencies and innovative strategies states use to respond to an evolving federal landscape.

Conclusion

The substantial overlap in themes identified across the strands of research in the Center support the need for an integrated, holistic approach to systems change. For example, concerns raised by families, such as the capacity of the partnering agencies as well as their expectations, are addressed by an intentional investment in building trust (employment supports) and by

organizations that are committed to communication, customer engagement, and staff development (organizational transformation). At a state policy level, the effectiveness of case managers helps inform families and ensures that a high level of expectations is communicated. Improving the quality of employment supports will be driven by resource allocation, staff development, and a focus on outcomes and performance measurement at the organizational level, and by factors including funding, service definitions, and provider qualifications at the state level.

The findings also support the need for interventions that go beyond local communities and can be replicated and expanded to benefit a greater number of people. Research is clear that best practice is not consistently implemented, that families receive mixed messages and are not supported in building dreams, and that employment is not yet consistently valued as a priority outcome. Previous research indicates that providers invest in transformation because of organizational values and commitment, and not necessarily because of state policy and performance standards (Butterworth, Fesko, & Ma, 2000; Rogan & Rinne, 2011). The growth of the Employment First movement and federal policy changes are shifting this dynamic, but meaningful change in employment outcomes is not yet evident.

In the context of previous research, the Center's findings highlight the need to develop practical and replicable strategies to implement best practice that recognize the scope of change required. Underlying themes emphasize the need for a holistic perspective on change that integrates individual experience, employment supports, and policy, and the need for interventions that are efficient and scalable, able to be integrated throughout individuals' lives and the practices of systems of support.

Over 600,000 individuals receive day or employment supports from state IDD agencies that are provided by over 8,000 community organizations and an estimated 35,000 employment consultants and job coaches (Winsor et al, 2017). In 2014–2015, over 1,000,000 children ages three to 21 identified with an intellectual disability, autism, or multiple disabilities received special education services (Snyder, de Brey, & Dillow, 2018). Addressing the scope of change requires not only policy change, but cultural change and competency development across the diverse array of professionals who interact with individuals with IDD and their families including teachers, adult service providers, therapists, case managers, and medical professionals (Timmons et al., 2011). Strategies are needed for continuous, frequent engagement with families and individuals that supports a personal vision for employment; efficient approaches to building the skills of employment consultants that include both training and implementation support, such as mentoring and data-informed supervision; and the use of strategies that enable providers to transform services to a community based model. States need to ensure high standards of quality and ready access to supports. The ongoing work of the Center is testing interventions in each of these areas over the coming years, yielding important implications for bringing Employment First to states and their communities across the country.

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