

Integrating Research, Training, and Knowledge Translation

What our new center is about

- People with intellectual and developmental disabilities (IDD) can work and want to work--yet the majority don't have jobs.
- State and national policies exist to increase employment, but systems have not aligned to make integrated employment a priority.
- To meet this need, the Institute for Community Inclusion (ICI) at UMass Boston is hosting a new rehabilitation research and training center, or RRTC. It's called the **RRTC on Advancing Employment for Individuals with Intellectual and Developmental Disabilities**.
- Because change is critical at multiple levels, the RRTC integrates four focus areas:
 - 1) individual and family knowledge and engagement,
 - 2) effective employment supports,
 - 3) organizational change for community rehabilitation providers, and
 - 4) state-level policy and strategy.
- In 2015, our products and activities include a webinar series featuring innovative and inspiring speakers, policy papers that target state administrators and individuals with IDD, a review of effective strategies for communicating with families, in-depth interviews with employment consultants about the strategies used to help people find jobs, and findings from a panel of experts about what comprises a "high-performing" community rehabilitation provider.

Background on employment and disability

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.

What is Employment First?

» States that adopt an Employment First policy focus on employment in individual integrated jobs in the typical labor market as the preferred option for all citizens with disabilities. This means that employment is the priority for funding, individual planning, and the supports an individual receives.

Despite these achievements, the promise of 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.¹

What does the data tell us?

There is no direct source for data on labor force participation for individuals with IDD in the general population. However, data from the National Core Indicators Project suggests that, in 2012–2013, only 15% of working-age adults supported by state IDD agencies worked in integrated employment, including both individual and group supported employment, with just 10% working in individual competitive or supported jobs.²

Other ICI survey research estimates that 18% of individuals receiving day supports from state IDD agencies participated in integrated employment services during FY2013. This percent has declined from a peak of almost 25% in FY2001. Those who are employed typically work limited hours with low wages.³ American Community Survey data (2012) shows that people with a cognitive disability who are receiving Supplemental Security Income, the group most likely to include people who have the most significant cognitive disabilities, have the lowest employment rate of all disability subgroups. They are also the most likely to live in a household that is below the poverty line.⁴

How have national and state-level policies responded?

The 2014 Workforce Innovation and Opportunity Act (WIOA) requires that each state public vocational

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A project of

ThinkWork!

at the Institute for Community Inclusion, University of Massachusetts Boston



By the Numbers

4	... PERCENT OF JOB DEVELOPERS' TIME THAT IS SPENT WITH EMPLOYERS
6	... NUMBER OF STATES REPORTING 40% OR MORE OF INDIVIDUALS SERVED IN INTEGRATED EMPLOYMENT SERVICES
9	... PERCENT OF CRP STAFF WORKING ON INTEGRATED EMPLOYMENT
12	... AVERAGE HOURS (PER PERSON) WORKED PER WEEK IN AN INDIVIDUAL SUPPORTED JOB
13.5	... PERCENT OF IDD AGENCY DAY AND EMPLOYMENT FUNDING SPENT ON INTEGRATED EMPLOYMENT
15	... PERCENT OF INDIVIDUALS WORKING IN INTEGRATED EMPLOYMENT
18	... PERCENT OF INDIVIDUALS PARTICIPATING IN AN INTEGRATED EMPLOYMENT SERVICE (OF THOSE RECEIVING A DAY SERVICE FROM STATE IDD AGENCIES)
43	... PERCENT OF INDIVIDUALS WHO ARE IN NON-WORK SERVICES
44	... NUMBER OF STATES THAT HAVE SOME FORM OF EMPLOYMENT FIRST INITIATIVE
47	... PERCENT OF INDIVIDUALS WHO DON'T WORK WHO SAY THEY WANT TO WORK.

rehabilitation program 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 address access to the general workforce development system and One-Stop Career Centers (American Job Centers) for people with disabilities.

In 2011, the Centers for Medicare and Medicaid Services (CMS) released guidance clarifying their commitment to individual integrated employment as a preferred outcome of employment-related services under the home and community-based services waiver program. In

January 2014, CMS released new rules about home and community-based setting requirements. The new rules specify that states must prioritize access to community living in the most integrated setting; additional guidance related to the assessment of community-based employment settings is forthcoming.

The U.S. Department of Justice has extended enforcement of the Olmstead decision to address employment outcomes in states including Rhode Island, Oregon, Georgia, and Virginia. This places pressure on all states to move individuals from segregated settings to more community-based models of support. The Rhode Island settlement agreement establishes strong standards for employment participation, quality employment outcomes, and access to integrated community activities during non-work hours.⁵

At least 44 states have some form of Employment First initiative, and 32 have a formal state-level policy or directive,⁶ which is nationally recognized as a policy path towards integrated employment for people with IDD. Employment First policy establishes clear guiding principles and practices through state statute, regulation, and operational procedures. Employment First represents a commitment by states to the propositions that all individuals with IDD (a) are capable of performing work in typical integrated employment settings; (b) should receive, as a matter of state policy, employment-related services and supports as a priority over facility-based and non-work day services; and (c) should be paid at minimum or prevailing wage rates.⁷

Six causes of poor employment outcomes

State IDD agencies have inconsistent and competing priorities.

#1

State IDD agencies remain the primary source of long-term funding and service coordination, including managing Medicaid Home and Community-Based Services waivers. The agencies provide, fund, and monitor a wide range of services, including employment supports, facility-based options (sheltered workshops and non-work day habilitation programs), community integration services, and self-directed supports.

State IDD agency investment in integrated employment varies widely, with between 5% and 86% of all individuals participating in integrated employment services. Despite the national mean of 18% in integrated employment, six states report that over 40% of individuals participate in integrated employment, suggesting substantial opportunity for policy change and redirection of resources.

Non-work services are growing and competing with integrated employment.

#2

Participation in non-work services is growing. While the most common service of this type is day habilitation (facility-based non-work), concern for a meaningful day has led to growth in supports for community-based non-work and community life engagement. These services compete with integrated employment for resources⁸ and have grown steadily for state IDD agencies that report non-work as a service.⁹

Survey research found that 16.4% of individuals with IDD participate in community-based non-work services.¹⁰ These services are loosely defined with respect to requirements, activities, populations served, and goals, which further complicates prioritizing resources.¹¹

Interagency integration of services is limited.

#3

Navigating employment services is confusing for individuals and families, and not well coordinated by state agencies. Despite 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.¹²

The Government Accountability Office 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 after high school.¹³

Individuals and families lack accurate knowledge to make informed choices.

#4

Young adults with IDD express a strong expectation that they will work in adulthood,¹⁴ and almost 50% of adults served by state IDD agencies who are not working say that they want an integrated job.¹⁵ This preference is rooted in the principles of self-determination and informed choice,¹⁶ and is expressed regardless of the severity of disability.¹⁷ Collectively, self-advocates have made integrated employment (“real jobs”) a stated national policy objective, citing work as a hallmark of inclusion in society.¹⁸

Families can be influential in the decision-making process.¹⁹ Research has shown that people with IDD are most likely to be employed when their parents want them to and believe they can work,²⁰ and that parental expectation was the most predictive factor of paid work experience.²¹ Despite findings that emphasize family engagement,

research shows that parents lacked adequate knowledge to support their child’s transition to adult life. Family factors found to influence outcomes include lack of information about work incentives and fear of losing benefits.²² In fact, such misinformation negatively impacts the expectations of parents about work in general.²³

Community rehabilitation providers’ priorities have not re-aligned to emphasize employment.

#5

Community rehabilitation providers (CRPs) and their staff are the primary source of day and employment supports for people with IDD. Survey findings reveal that only 8.7% of CRP staff have time dedicated to integrated employment.²⁴ Continued service and philosophical variation within the provider community makes the creation of a unified vision for service delivery difficult.²⁵

Research shows that almost 89% of respondents to a national survey of CRP administrators believe that facility-based programs are essential for individuals with disabilities who are having difficulty getting or maintaining real work in the labor force, and only 47% had a formal plan to expand integrated employment.²⁶ Providers perceive inadequate funding and community resources for individual employment.²⁷ Front-line staff experience confusion about job development responsibilities, do not feel prepared to engage the mainstream business community, and have little training in providing appropriate supports to individuals with IDD in community settings.²⁸

Best practices in job supports are not consistently implemented.

#6

The successful transition of job seekers to employment depends in large part on the knowledge, skills, and abilities of employment consultants to develop, match, and support jobs that meet both the job seeker’s and the employer’s interests and needs.²⁹ Research suggests that employment consultants inconsistently use established promising practices, including investing in discovery or career planning, spending time with individuals in community settings, working with families, and negotiating job responsibilities with an employer.³⁰

Findings also suggest that job developers have limited opportunities for professional development, including both formal and informal chances for learning.³¹ However, employment specialists who do receive appropriate training and mentorship improve the number and quality of the jobs they develop.³²

How will our new center address these issues?

The field of IDD is at a crossroads. More than three decades of research by the ICI has found that integrated employment outcomes only improve if all policies and practices are aligned to support employment as the first goal for service recipients, and if individuals and families have clear and useful access to information and supports.³³

To help make integrated employment a real option for all adults with IDD, our new RRTC will integrate research, dissemination, and knowledge translation. The center will:

- Develop and test a comprehensive information, outreach, and support framework for individuals and families.
- Assess a cost-effective strategy for improving employment support practices by integrating online training, data-based performance feedback, and facilitated peer supports.
- Develop and test an evidence-based intervention to support organizational transformation and resource rebalancing across networks of CRPs.
- Analyze state employment systems' policies and practices and their relationship to individual outcomes at a multi-agency level, and define policies and practices of high-performing state employment systems.

The center is part of a rich network of research and systems change initiatives, including ICI's consulting relationships with 45 states and the extensive work of partners including The Arc of the United States, the University of Minnesota, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), Self-Advocates Becoming Empowered (SABE), and APSE (the Association of People Supporting Employment First). Participation of a network of advisors and dissemination partners, including people with IDD and their families, will extend the effectiveness and use of our project findings and resources.

What's next?

For the 2015 project year, products and activities include:

- The launch of a social media campaign and website.
- A webinar series that features innovative and inspiring leaders in our field.
- A detailed review of strategies for individual and family engagement and knowledge translation.
- Qualitative interviews with employment consultants about their use of evidence-based strategies for helping job seekers find employment.
- Policy papers from our partners at NASDDDS and SABE.
- A Delphi panel around organizational transformation of CRPs.

Sources

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- ² NCI, 2014; Butterworth et al., in press
- ³ Boeltzig, Timmons, & Butterworth, 2008.
- ⁴ Butterworth et al., 2014.
- ⁵ U.S. v. State of Rhode Island, 2014.
- ⁶ APSE, 2014.
- ⁷ Moseley, 2009; APSE, 2014.
- ⁸ Sulewski, 2010.
- ⁹ Butterworth et al., 2014.
- ¹⁰ Domin & Butterworth, 2012.
- ¹¹ Sulewski, Butterworth, & Gilmore, 2008.
- ¹² Timmons, Cohen, & Fesko, 2004; Certo et al., 2008; Martinez et al., 2010; NCD, 2008.
- ¹³ U.S. Government Accountability Office, 2012.
- ¹⁴ Wagner, Newman, Cameto, Garza, & Levine, 2005.
- ¹⁵ Bradley et al., 2015; Butterworth et al., in press.
- ¹⁶ Wehmeyer, 2005.
- ¹⁷ Migliore et al, 2007.
- ¹⁸ Self Advocates Becoming Empowered, 2011.
- ¹⁹ Dixon & Reddacliff, 2001; Timmons et al., 2011; Whiston & Keller, 2004.
- ²⁰ Dixon & Reddacliff, 2001; Freedman & Fesko, 1996; Taylor & Hodapp, 2012.
- ²¹ Carter et al., 2011.
- ²² Winsor, Butterworth, Lugas, & Hall, 2010; Hall & Kramer, 2009; Luecking & Wittenburg, 2009.
- ²³ Timmons et al., 2011; Carter et al., 2010; Lindstrom, Doren, & Miesch, 2011.
- ²⁴ Inge et al., 2009.
- ²⁵ ODEP, unpublished.
- ²⁶ Inge et al., 2009.
- ²⁷ ODEP, unpublished; West & Patton, 2010; Rosenthal et al., 2012.
- ²⁸ Butterworth & Fesko, 2001; West & Patton, 2010; Migliore et al., 2011; Rosenthal et al., 2012.
- ²⁹ Hewitt & Larson, 2007; Migliore et al., 2012.
- ³⁰ Migliore et al., 2012; Migliore, Hall, Butterworth, & Winsor, 2010.
- ³¹ Hall, Bose, Winsor, & Migliore, 2014.
- ³² Butterworth et al., 2012.
- ³³ Hall, Butterworth, Winsor, Gilmore, & Metzel, 2007; Butterworth et al., 2014; Timmons et al., 2011.

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ThinkWork!

Advancing employment and opportunity for people with intellectual and developmental disabilities



Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities is a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston. ThinkWork! is a resource portal offering data, personal stories, and tools related to improving employment outcomes for people with intellectual and developmental disabilities.

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