Research

“Get Us Real Jobs:” Supported Employment Services for People with Intellectual and Developmental Disabilities in Medicaid Home and Community Based Services Waivers
“Get us real jobs.” Supported Employment Services for People with Intellectual and Developmental Disabilities in Medicaid Home and Community Based Services Waivers

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Citation:
Abstract

BACKGROUND: Despite their interest in and ability to work in integrated settings the majority of adults with intellectual and developmental disabilities (IDD) in the United States are funneled into segregated settings.

OBJECTIVE: Because of the essential role Medicaid 1915(c) Home and Community Based Services (HCBS) waivers play in providing both long-term supports and supported employment services the aim of this study was to examine how HCBS waivers allocated supported employment services in fiscal year 2014. This included an examination of hourly reimbursement rates and annual service prevision per participant as well as variance across states.

METHODS: Supported employment services in Medicaid 1915(c) HCBS waivers for people with IDD were analyzed to determine trends, service utilization, and projected expenditures.

RESULTS: Although HCBS waivers play a critical role in providing supported employment services for people with IDD, we found wide variability across services and states in terms of projected total spending, projected spending per participant, and service rates.

CONCLUSIONS: Expansion of supported employment services is important so people with disabilities can access employment in the most integrated settings possible in alignment with the Americans with Disabilities Act and the Olmstead v L.C. decision.

Keywords: Supported Employment, Intellectual and Developmental Disabilities, Medicaid Home and Community Based Services Waivers
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People with disabilities have a deep and historied relationship with employment. In fact, some disability scholars (e.g., Barnes, 1997; Charlton, 1998; etc.) argue that the shift in modes of production from feudalism to capitalism was one of the first times people with disabilities were defined as a class. While feudalism offered some opportunities to work for people with disabilities, the shift to capitalism centered around productivity, thereby most excluding people with disabilities from wage labor (Erevelles, 2001; Goodley, 2011). Although people with disabilities are still often excluded from employment, more recent United States policy has worked to decrease this employment discrimination. For example, Sections 501 and 503 of the Rehabilitation Act bar employment discrimination; in doing so this policy not only recognized the right people with disabilities have to employment but also the value people with disabilities have to the employment industry (Fleischer & Zames, 2001). The Americans with Disabilities Act (ADA) (1990) has also contributed to the reduction of discrimination people with disabilities face in relation to employment.

Despite these improvements and the ability and interest in work, people with disabilities are employed at significantly lower rates than nondisabled people (Office of Disability Employment Policy, 2013; Russell, 2000). In fact, employment is one of the largest gaps between people with and without disabilities (Rogan & Rinne, 2011). Moreover, those people with disabilities that are employed are often underemployed (Parker Harris, Renko, & Caldwell, 2014). These employment disparities highlight the effect of traditional expectations barriers, and persistent social and culture stereotypes that equate disability with unemployability (Parker Harris, Renko, & Caldwell, 2013; Parker Harris, Renko, & Caldwell, 2014). Underemployment
and unemployment of people with disabilities can also be “directly linked” to other inequalities such as “income, access to health care, and socialization” (Rogan & Rinne, 2011, p. 248).

People with intellectual and developmental disabilities (IDD) often have even more trouble with employment systems than people with other disabilities. Instead of integrated employment settings, the majority of people with IDD are funneled into segregated services such as day habilitation, or prevocational sheltered workshops. Day habilitation services are “regularly scheduled activities…such as assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills that enhance social development and develop skills in performing activities of daily living and community living” while prevocational services are “services that provide learning and work experiences, including volunteer work, where the individual can develop general, non-job-task-specific strengths and skills that contribute to employability in paid employment in integrated community settings” (Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services, 2015, p. 148-151). Eighty-one percent of people with IDD were in day programs and sheltered workshops in fiscal year (FY) 2013 (Braddock et al., 2015). The skills taught in segregated settings such as prevocational placements can be problematic because they rarely translate to integrated employment settings (Nazarov, Golden, & von Schrader, 2012). People with IDD who receive prevocational services before job placement, rather than just job placement, are also more likely to receive lower wages in integrated employment (Nazarov et al., 2012). Nazarov et al. (2012) suggest this may be because prevocational services may reduce provider and employer expectations about productivity and ability.
In contrast to segregated systems such as prevocational placements, supported employment services allow people with IDD, especially those who are considered not otherwise employable, to work in integrated settings with the proper supports (Braddock et al., 2015). Examples include individual job placements, small businesses, work crews, and enclaves within industry (Braddock et al., 2015; Wehman, Inge, Revell, & Brooke, 2007). As a result of both initial and continual supports people with IDD are “more able to bridge the gap between their skills and the requirements of their job to maintain competitive integrated employment” (Braddock et al., 2015, p. 45). Even those with high support needs can work in integrated employment settings with the right support (Center for Medicare and Medicaid Services, 2011; Migliore at al., 2007; Rogan & Rinne, 2011). Not only does supported employment provide higher quality of life than sheltered employment, people are also more engaged and more likely to interact with nondisabled people (not support staff) in these settings (Jahoda, Kemp, Riddell, & Banks, 2008; Kilsby & Breyer, 1996; Verdugo et al., 2005). In addition to these benefits the majority of people with IDD working in sheltered workshops report preferring employment in the community (Migliore at al., 2007; Rogan & Rinne, 2011).

States provide supported employment services to people with IDD through a number of means including through IDD agencies, Vocational Rehabilitation, and special education (Braddock et al., 2015; Hall, Freeze, Butterworth, & Hoff, 2011). Medicaid 1915(c) Home and Community Based Services (HCBS) waivers – the largest funding system of long term supports and services for people with IDD in the United States (Rizzolo, Friedman, Lulinksi-Norris, & Braddock, 2013) – also play “an essential” role in supported employment services for people with IDD (Braddock et al., 2015). HCBS waivers allow states to ‘waive’ the main provisions of the Social Security Act in order to deliver integrated community-based services tailored to
certain populations (U.S. Department of Health and Human Services, 2000). Braddock et al. (2015) reports HCBS waivers were responsible for more than two-thirds of all supported employment spending for people with IDD in fiscal year (FY) 2013. Yet, in FY 2013 Medicaid HCBS IDD waivers projected spending almost nine times more money on segregated day programs – day habilitation and prevocational services – than supported employment (Friedman & Rizzolo, 2014a).

Because of the role of federal funding systems in facilitating these supported employment models for people with IDD, and the importance of integrated employment to community inclusion, the aim of this study is to examine how Medicaid 1915(c) Home and Community Based Services (HCBS) waivers allocate supported employment services. To do so we analyzed FY 2014 HCBS IDD waivers providing supported employment services to determine service utilization and expenditure projections. This included an examination of hourly reimbursement rates and annual service prevision per participant as well as variance across states. Moreover, as they determine how supported employment is defined and what is provided, supported employment service definitions were analyzed and compared.

**Methods**

This study focused specifically on Medicaid HCBS 1915(c) waivers because they are the most prevalent funding mechanism for the long-term supports of people with IDD (Rizzolo et al., 2013). Over a 24-month period (June 2013 to June 2015) we obtained HCBS 1915(c) waiver applications from the Centers for Medicare and Medicaid (CMS) Medicaid.gov website for waivers that specified the inclusion of people with IDD: intellectual disability (ID), “mental retardation” (MR), developmental disability (DD), and/or autism (ASD). (See figure 1 for a

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1 The term “mental retardation” is considered outdated however was a necessary search term because it remains in use in some waiver applications.
detailed tree of methodology.) No age limitations were imposed. Waiver applications that did not include 2014 were then excluded. To do so, the waiver year that most closely aligned with FY 2014 (July 1, 2013 and June 30, 2014) was used. Most often this was the state fiscal year (FY) however other states used the federal fiscal year of October 1, 2013 to September 30, 2014. A few other waivers others used the 2014 calendar year (January–December). For consistency, fiscal year is used throughout this article. This resulted in FY 2014 data from 110 HCBS waivers (45 states and the District of Columbia).

All waiver applications are required to describe: CMS assurances and requirements; levels of care; waiver administration and operation; participant access and eligibility; participant services, including limitations and restrictions; service planning and delivery; participation direction of services; participant rights; participant safeguards; quality improvement strategies; financial accountability; and cost-neutrality demonstrations. We used this information to organize services into a taxonomy similar to the one developed by Thompson Reuters and Mathematica (Eiken, 2011), and Rizzolo et al.’s (2013) FY 2010 taxonomy that was specifically tailored to IDD waivers. Sorting services into taxonomy categories allowed us to explore employment related services more in depth.

Once data were organized, service definitions were qualitatively analyzed to determine service patterns and trends. We then quantitatively analyzed data related to service expenditures to determine projected spending, the projected number of users, and service allotment. States are required to submit this information to CMS to demonstrate cost neutrality (Rizzolo et al., 2013).

**Findings**

We found 86 waivers (78.18%) offered supported employment services in FY 2014 through 225 services. Supported employment services aimed at supporting individuals with IDD
in a competitive integrated workplace where the majority of employees do not have disabilities. These services were particularly aimed at people with IDD who would likely not be able to hold competitive employment without these supports. These services are often provided both in the form of preparation for these settings, such as specific job skills training, and for participation in them, such as supervision. Supported employment services are provided prior to the job, while arranging the employment opportunity, and ongoing during the job.

Prior to the job, supported employment services may include: teaching participants basic job skills, such as work-related personal safety skills; discovery of participants’ skills, strengths, and vocational desires; and, development of a career plan. Pre-job supported employment training may also include instruction on work-related equipment, meal planning, and fostering financial skills.

Supported employment services also provided assistance with setting up the employment opportunity. In addition to job placements, this may include a job site analysis where participants’ needs are matched with job sites. Once employed supported employment services can assist with negotiations with employers and human resources, and develop job accommodations and assistive technology. This can also include co-worker training for natural supports and accommodations as well as educating the participant about the role of self-advocacy in the workplace. Ongoing employment support is also provided within supported employment services. For example, this may include job-coaching, advocacy to resolve problems, support with job retention and advancement, and documentation of employment progress. As it is critical to maintain employment, in many waivers this also included providing transportation to and from the participant’s employment.
Waivers specified supported employment services could be provided in a number of different settings. In addition to the setting where participants were employed, supported employment services were provided in agency settings, in participants’ homes, and/or in the community. A few waivers also allowed supported employment services to be provided through mobile work crews, where participants performed work in a variety of settings under a supervisor or job coach. Although there was flexibility to where these services could be furnished, waivers often directly specified that these services should not be provided in facility-based settings, such as sheltered workshops, or specialized facilities not part of a general workplace.

In addition to more traditional employment structures, a number of waivers also used supported employment services to assist participants in self-employment, micro-enterprises, and entrepreneurship. In doing so, assistance was often provided for identifying potential business opportunities, business planning including assistance with identifying potential sources of business financing and other assistance in developing and launching a business, identification of the supports that are necessary in order for the participant to operate the business, and ongoing assistance, counseling, and guidance once the business is in operation. (Alaska People with Intellectual and Developmental Disabilities waiver)

Waivers that described these unique employment methods were very clear that the supported employment funds must not be used for business start up or operating costs.

Although a large number of waivers provided supported employment services many waiver noted that supported employment services could not take the place of or duplicate services from the Division of Vocational Rehabilitation. Although supported employment services “may only be furnished to a [1915(c)] waiver participant to the extent that they are not available as vocational rehabilitation services funded under section 110 of the Rehabilitation Act of 1973” (Centers for Medicare and Medicaid, 2011, p. 4), not all waivers mentioned this
requirement in their service definitions. Nine out of the 86 waivers specified that Vocational Rehabilitation services must be used first, participants must have exhausted Vocational Rehabilitation, and/or participants must be ineligible for Vocational Rehabilitation services. For example, Maine Home and Community Services for Adults with Intellectual Disabilities or Autistic Disorder waiver’s “Employment Specialist Services” explained,

if Vocational Rehabilitation denies services under the Rehabilitation Act and the participant is unable to benefit from Vocational Rehabilitation then the participant may receive Employment Specialist Services for job development. Current documentation of ineligibility from Vocational Rehabilitation is required.

Other waivers (n = 7) specified that Vocational Rehabilitation could not be used simultaneously with the supported employment services provided by the waiver. Still other waivers (n = 6) mentioned people with IDD utilizing supported employment services may be referred back to Vocational Rehabilitation. For example, Indiana Community Integration and Habilitation Waiver’s “Supported Employment” service said,

Depending on each participant's circumstances, the time limit may need to be extended or the participant may need to be referred to, or back to, Vocational Rehabilitation for services and reimbursement, in which case, concurrent reimbursement for Supported Employment Follow-Along and Vocational Rehabilitation Services will not be allowed. Extensions are currently granted to anyone who is still making efforts toward employment.

It should be noted that although not all waivers’ service definitions specified exclusions related to Vocational Rehabilitation the absence of language could simply suggest they did not specify such provisions to that extent and does not necessarily reflect not following the CMS requirements.

In addition, supported employment services did not cover payment for changes required of businesses in compliance with the ADA. Supported employment services also could not serve as incentive pay to encourage employers to participate in integrated employment.
Service Expenditures

Our analysis of 110 HCBS IDD waivers found that $813.15 million of spending was projected for the supported employment services of 94,012 projected participants in FY 2014. Supported employment service projected spending amounted to only 3% of all FY 2014 HCBS IDD projected spending ($31.39 billion) (Friedman & Rizzolo, 2015). Although on average waivers projected spending $3.61 million for supported employment services, total projected spending varied widely by waiver, from $122 for New Mexico Developmental Disabilities Waiver Program’s “Supported Employment, Level 1, Group, Exception (Old)” (1 participant) to $64.76 million for New York OPWDD Comprehensive Renewal Waiver’s “Supported Employment (SEMP)” (11,002 participants). Table 1 shows this variance by detailing projected spending by state.

An average of $6,693 of spending was projected per participant for supported employment services. However, average projected spending per participant also varied widely by service with 51% of services (n = 115) projecting between $1 and $5,000 on average per participant annually; 26% (n = 59) between $5,001 and $10,000; 13% (n = 29) between $10,001 and $15,000; 5% (n = 12) between $15,001 and $20,000; 2% (n = 4) between $20,001 and $25,000; and, 3% (n = 6) above $25,000.

States offered multiple service rates depending on the types of services. The majority of supported employment services were paid using an hourly rate (n = 183 services), however other used daily (n = 17 services) or monthly rates (n = 14 services), while still others (n = 11 services) used different units such as “each,” “block,” “item,” or “unit.” The average hourly rate projected for supported employment services was $29.00. Yet, hourly rates ranged from $6.80 for Louisiana New Opportunities Waiver’s “Employment Related Training” to $203.18 for New
Mexico Developmental Disabilities Waiver Program’s “Supported Employment, Individual (Old).” Figure 2 details projected supported employment hourly rates by service. For those employment services paid by daily rate the average rate was $63.97. Of those services providing supported employment by daily rates 18% of services \((n = 3)\) projected daily rates of $1 to $20, 12\% \((n = 2)\) $21 to $40, 18\% \((n = 3)\) $41 to $60, 18\% \((n = 3)\) $61 to $80, and, 12\% \((n = 2)\) $81 to $100, and 24\% \((n = 4)\) $101 and above. The average monthly rate was $458.56 for services that provided supported employment monthly. These rates also varied widely with 14\% of services \((n = 2)\) projecting monthly rates of $1 to $200, 36\% \((n = 5)\) $201 to $400, 36\% \((n = 5)\) $401 to $600, 7\% \((n = 1)\) $601 to $800, and, 7\% \((n = 1)\) $801 and above.

The average number of supported employment services participants received in a year (FY 2014) was 292 hours for services provided hourly; see Figure 3. For those services provided daily, the average participant received 179 days of supported employment services annually. 19\% of services \((n = 3)\) provided between 1 and 100 days annually, 56\% \((n = 9)\) between 101 and 200, 13\% \((n = 2)\) between 201 and 300, 6\% \((n = 1)\) between 301 and 400, and, 6\% \((n = 1)\) between 401 and 500. For those services provided monthly, the average participant received 8 months of supported employment services annually; 29\% of services \((n = 4)\) provided 6 months annually, 14\% \((n = 2)\) 7 months, 21\% \((n = 3)\) 8 months, and, 36\% \((n = 5)\) 11 months.

**Discussion**

Supported employment services operate under the understanding that:

working is the normal expectation of adults in our society and should not be bypassed because of a disability. No one is excluded who wants to participate – level of disability is not a barrier and all individuals who express the desire for work are to be assessed and supported to be employed. (Alabama Home and Community-Based Waiver for Persons with Intellectual Disabilities)
Supported employment services in Medicaid 1915(c) HCBS waivers are used to support people with IDD entering the workforce and maintaining integrated employment. Through our analysis of FY 2014 Medicaid HCBS waivers we found that although $816.12 million of funding was allocated for supported employment services, it is only a very small percent (3%) of total HCBS projected spending for people with IDD. For comparison, 18% of FY 2014 HCBS IDD spending ($5.61 billion) was projected for day habilitation services (Friedman, under review; Friedman & Rizzolo, 2015).

Across the United States, in FY 2014 HCBS waivers projected spending $2.52 per capita on supported employment services. For comparison, Braddock et al. (2015) found state IDD agencies across the country spent $2.76 per capita on supported employment services in FY 2013. These rates suggest that in addition to employing Vocational Rehabilitation states utilize a comparable combination of IDD agencies and HCBS waivers to provide supported employment services for people with IDD. Thus, our findings suggest that HCBS waivers play a critical role in providing supported employment services for people with IDD.

Despite being a valuable source of supported employment services for people with IDD, HCBS supported employment services were far from standardized; we found wide variability across services and states in terms of projected total spending, projected spending per participant, and service rates. For example, hourly rates for supported employment ranged from $6.80 an hour, which is below the federal minimum wage, to $203.18 an hour. Another example of this large variability was average annual spending per participant, which ranged from $122 to $40,779. This variance may appear extreme but is not uncommon among HCBS waiver services. Our examination of other HCBS 1915(c) IDD waiver services (i.e., community support support services (Friedman, & Spassiani, under review); dental services (Friedman, Rizzolo, &
Schindler, 2014); electronic monitoring services (Friedman & Rizzolo, under review); family support services (Friedman & Rizzolo, 2014b); mental/behavioral health services (Friedman, Lulinski, & Rizzolo, 2015); services that pay families as personal care providers (Friedman & Rizzolo, in press-b); and, transportation services (Friedman & Rizzolo, in press) has revealed that this variability is a hallmark of the HCBS waiver. The HCBS waivers’ ability to be flexible and tailored to support unique populations also allows states great leeway in terms of what services they provide and how they provide those services (Friedman & Rizzolo, in press-b).

One limitation must be considered when interpreting our findings; the current study was based on state projections made to the federal government rather than actual HCBS utilization. However, they are a reasonably accurate proxy of IDD waiver services because they are based on previous years’ actual utilization (Rizzolo et al., 2013). Moreover, Rizzolo et al. (2013) found HCBS waiver projections congruent with spending patterns identified by researchers at Mathematica (Irvin, 2011, September) who used 2008 Medicaid Statistical Information Systems (MSIS) claims data from 44 states and Washington, DC, to determine trends in waiver expenditures across the states (pp. 19-20).

Moreover, another limitation of our data is service expenditures and utilization alone are not necessarily good metrics of success. Thus we suggest future research examine how successfully these services promote community integration, especially in comparison to day habilitation services.

Although a significantly larger proportion of funding was projected for day habilitation than supported employment services for people with IDD in FY 2014, we are encouraged by the HCBS waivers’ use of supported employment for unique employment models such as self-employment, micro-enterprises, and entrepreneurship. We would suggest waivers continue to develop these unique models as literature has found they not only aid people with disabilities
entry into the workforce, they also can serve as an anti-poverty strategy (Parker-Harris, Caldwell, & Renko, 2014; Parker-Harris, Renko, & Caldwell, 2014). In addition, the support provided through these services can help compensate for the extra barriers people with disabilities have in entrepreneurship when compared to nondisabled people, such as the lack of business education and smaller start-up support teams (Parker-Harris, Renko, & Caldwell, 2013; Renko, Parker-Harris, & Caldwell, 2015). Furthermore, entrepreneurship also allows people with disabilities the opportunity to focus on trades they are passionate about.

The ADA (1990) requires providing people with disabilities services in the most integrated settings possible. As a result of the Olmstead v. LC (1999) decision the United States Department of Justice has strengthened enforcement of this mandate including in the area of segregated employment settings and day programs (Novak, 2015). These settings often violate the ADA by “unnecessarily segregat[ing] people with disabilities” (Novak, 2015, p. 100). Supported employment is more integrated and by design more consumer directed than prevocational or day settings. As the Centers for Medicare and Medicaid (2011) explain, “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” (p. 3). Research has found that with the right supports most people with disabilities can work successfully in the community (Butterworth et al., 2007; Centers for Medicare and Medicaid, 2011). Supported employment should be based on consumer’s choices not job-readiness or ability (Nazarov et al., 2012). As Bagenstos (2015) argue, people with IDD “spend the first two decades of their lives preparing to be full members of the community. We should not break that promise just as it is about to be achieved. A guarantee of supported employment services would help to keep that promise” (p. 67).
Acknowledgments

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Olmstead v. LC, No. 98-536, 527 581 (Supreme Court 1999).


Table 1. HCBS supported employment services for people with IDD in FY 2014.

Figure 1. Process for identification of included HCBS 1915(c) IDD employment services.

Figure 2. Hourly rates for supported employment services.

Figure 3. Yearly service units per participant for hourly supported employment services.
Table 1

<table>
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<tr>
<th>State</th>
<th>IDD Waivers Providing These Services</th>
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<th>Spending per Capita</th>
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*Note. For detail about particular services contact the lead author.*
Figure 1. Process for identification of included HCBS 1915(c) IDD employment services.
Figure 2. Hourly rates for supported employment services.
Figure 3. Yearly service units per participant for hourly supported employment services.