

Using the independent monitoring for quality (IM4Q) program to examine employment in integrated settings in the community for people with IDD over time

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Abstract.

BACKGROUND: Community-based employment is a key step for many adults with intellectual and developmental disabilities (IDD), a group prone to high unemployment, poverty, and dependency. It is also important in order to avoid poverty and progress toward economically stable and independent lifestyles. Increases in community-based employment for individuals with IDD meet the expectations of the HCBS final rule as well as state-wide transition planning requirements and other compliance indicators.

OBJECTIVE: The current study explores changes in employment over time before and after the final rule was issued and other initiatives (e.g., Employment First policy) were adopted. This method provides an important way to detect if the effort is impacting service users with IDD as intended. By comparing three waves of data from the state of Pennsylvania (2013, 2016, and 2019), we can gain insight into changes in employment rates over time among HCBS service users with IDD in light of policy initiatives.

METHODS: We used three waves of IM4Q data to compare the growth in employment among 9,486 individual service users with IDD in the state of Pennsylvania. Repeated measures regression using generalized estimating equations (GEEs) was used to examine employment in an integrated setting in the community over time after controlling for age, support needs, residence type, and community type.

RESULTS: Controlling for the effects of demographic and environmental characteristics, there was a significant increase in community-based employment among IDD service users in Pennsylvania between 2013 and 2019. Other variables were also associated with employment.

CONCLUSION: This study was the first to our knowledge to consider changes in community-based employment across three waves of data for individuals with IDD. The data wave collection periods in Pennsylvania coincided with significant policy changes relevant to service users with IDD. These changes in policy may be effective and warrant both continued exploration of its effects and ways to maximize policy to further integrate adults with IDD into the community.

Keywords: Employment, employment first, intellectual and developmental disability, IDD, community inclusion, longitudinal

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1. Introduction

Community-based employment is a key step for many adults to avoid poverty and progress toward economically stable and independent lifestyles. This reality is particularly true for individuals with intellectual and developmental disabilities (IDD), a group prone to high unemployment rates and poverty. Individuals with self-reported disabilities are significantly more likely to be unemployed, underemployed, or absent from the labor market (O'Brien, 2013). Employment rates for individuals with IDD from 2017-2018 was 18% (National Core Indicators, 2019). This was significantly lower than the employment rate of 75.5% for working-age adults without disabilities in 2018 (Winsor et al., 2020).

Regardless of its economic importance, employment can play a vital role in a person's identity and provide broader access to the community. For many individuals, employment plays a key role in one's social identity within society (Baldrige & Swift, 2013). Altogether, employment can help build a positive social identity for many individuals and a sense of reciprocity within society.

Individuals with IDD engage in a variety of employment-related activities that are facilitated by services, accomplished independently, or accomplished with family support. Examples of these activities include unpaid and paid facility work (workshops) and community-based work. There are arguments that suggest positive roles for facility work (e.g., training opportunities, socialization); despite these potential benefits, there are clear ethical and human rights issues with facility-based work, especially when it can be exempt from federal and state minimum wage laws and often occurs in isolation from the larger community. Therefore, the current study focuses on community-based employment and the effectiveness of recent efforts to increase the involvement of adult service users with IDD in Pennsylvania.

1.1. Factors related to community-based employment

Previous research has indicated that participation rates in community-based employment vary based on the severity of an individual's disability, funding availability, level of choice-making abilities, communication method, and living situation, among other reasons (Bush & Tassé, 2017; Nord et al., 2018).

For the purposes of this study, we focus on levels of disability and living arrangements.

Intellectual disability severity has been correlated with employment rates. Individuals categorized with less severe levels of ID have been associated with higher chances of community-based employment (Bush & Tassé, 2017; Nord et al., 2018).

A recent study suggested significant correlations between employment rates and living situations. Adults with IDD living independently in their own home or apartment have been shown to have the highest rates of community-based employment at 32% (Hiersteiner et al., 2018). Conversely, adults living in institutional settings (e.g., Intermediate Care Facilities (ICF/IDD), nursing homes) had the lowest estimated rates of community-based employment at 8.8%. In between these two extremes, adults living with parents or relatives and those living in group homes (or agency-operated apartment programs) had estimated community-based employment rates of 19.8% and 16.7%, respectively.

1.2. Cost and benefits of community-based employment

Prior research has also explored the costs and benefits of supported community-based employment for people with IDD, particularly in comparison to sheltered workshops. A review of 26 studies that met high quality criteria published between 2000 and 2020 found mostly positive economic effects for community-based employment, while finding largely null or negative effects for sheltered workshops (Taylor et al., 2021). The evidence seems to suggest that while supporting community-based employment has high up-front costs (e.g. job development, seeking, training), these costs are reduced over time and end up paying for themselves in terms of benefits to individuals and taxpayers. Conversely, workshop-based activities retain consistent daily costs over time with little to no later benefits that outweigh those costs. Therefore, community-based employment not only can maximize individual economic opportunities, community inclusion, and social identity for individuals with IDD, but also may be a more economical investment for the larger society.

1.3. HCBS final rule

The Final Rule was issued by the Centers for Medicare and Medicaid Services (CMS) in the U.S. Department of Health and Human Services in 2014.

This regulation mandated states to submit a transition plan to CMS related to the new federal requirements and demonstrate that community-based services funded by CMS are delivered in community-based settings, a new definition of home and community-based (HCBS), to receive service reimbursement (CMS, 2014; Riesen & Snyder, 2019). Such efforts advocated for HCBS users to have full access to the benefits of community living as people without disabilities have. The rule also was developed to ensure that Medicaid funding for HCBS more fully matched the requirements of the Americans with Disabilities Act and the Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999). States are required to develop and submit statewide transition plans (STP) for approval to CMS (Riesen & Snyder, 2019). There is a lot of leeway in what is allowed in these plans, but each state must specify how it will assess the extent to which its regulations, standards, policies, and licensing requirements ensure that settings where people with disabilities receive services comply with the Final Rule. Plans must include specific action steps, including timelines and deliverables. The state of Pennsylvania received initial approval of its transition plan in 2016, a period well placed within the scope of the current study.

Increases in community-based employment for individuals with IDD, as opposed to maintaining or increasing involvement in sheltered workshops or other isolated work/training settings, certainly meets the expectation of the HCBS Final Rule. States would also help meet their transition planning requirements and other compliance indicators by increasing community-based employment of HCBS service users with IDD.

1.4. *Employment first policy*

The Employment First initiative was a national movement in favor of systematic change that prioritized the goal that all citizens, including individuals with disabilities, be able to participate in integrated, community-based employment, and that this should be the primary goal before other options are considered (e.g., workshops, etc.). Employment First operates on the key assumptions that individuals with IDD (like all individuals) (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 other facility-based and non-workday services; and (c) should be paid at minimum or

prevailing wage rates (Kiernan et al., 2011; Rogan & Rinne, 2011). Thirty-eight states have formally joined this initiative by executive orders, state agency policy statements, legislation or combinations of all three (Hoff, 2019).

The state of Pennsylvania, the focus of the current study, formally joined the Employment First movement in 2016 via an Executive Order by the Governor that established a cross-disability Employment First policy (Hoff, 2019). Further, in 2018, the Pennsylvania state legislature passed a law that further dedicated the state to Employment First policy, establishing a Governor's Cabinet for People with Disabilities and an Employment First Oversight Commission (APSE, 2020).

1.5. *The current study*

The current study explores changes in employment before and after the Final Rule was issued and other initiatives (e.g., Employment First policy) were adopted. This longitudinal approach provides an important way to detect if this effort is impacting service users with IDD as intended. It is particularly important as most studies regarding employment and disabilities have been dominated by cross-sectional research, with only 22.2% employing longitudinal methods (Jurado-Caraballo et al., 2020). Longitudinal data are crucial in order to test the effectiveness of implemented policies and inform future decision-making. Unlike cross-sectional research, longitudinal data can be used to follow trajectories, inform on transition periods, and help identify causal relationships (Livermore & Roche, 2011; McConkey et al., 2017). By comparing three waves of data from the state of Pennsylvania (2013, 2016, and 2019), we can gain insight into changes in employment rates over time among HCBS service users with IDD in light of policy initiatives. It is important that we track the effect of the policy intended to improve the lives of people with IDD in terms of key personal outcomes (e.g. employment rates). Such efforts inform policymakers as to what policy should be maintained and what should be changed, which can help maximize the effectiveness of programs such as HCBS.

1.6. *Research question*

The current study is designed to answer the following research question: *Controlling for demographic and environmental characteristics, have there been increases in community-based employment between*

2013 and 2019 among service users with IDD in Pennsylvania? The answer to this question will provide valuable insight into changes that many stakeholders believe are important consequences of the push to increase community-based employment opportunities for persons with IDD.

2. Method

2.1. Overview of IM4Q

The purpose of IM4Q is to improve satisfaction and everyday living outcomes for the individuals who receive services through the gathering, reporting and analysis of satisfaction and other outcome data. Temple University's Institute on Disabilities issues an annual statewide summary report containing aggregate findings. The inclusion criteria for IM4Q is determined by the state Office of Developmental Programs; they determine the sample size and composition of the sample from a pool of individuals receiving services and supports from the state through its Intellectual/Developmental Disabilities Agency.

There are 23 Local Programs that are contracted to collect IM4Q data and enter it into the database. Data is collected through in-person interviews of the individual with IDD and other respondents. A person with a disability (or a family member) must be part of each interview team.

An Annual Statewide Training is held for the various participants of IM4Q: Monitors, Local Programs, County/Administrative Entity staff, Supports Coordinators, Technical Advisors, and Office of Developmental Program staff. Based on the information provided at the Annual Statewide Training and other materials shared by the technical advisors for IM4Q, the Local Programs do annual training of their data collectors. In addition, HSRI offers National Core Indicator training that monitors attendance when required. IM4Q Technical Advisors also do periodic training on the instrument when major changes in the instrument occur.

2.2. Approach to data collection

Data were collected from people with IDD receiving services during a single in-person visit and entered into the online HSRI data entry system, ODESA. Participation is voluntary, and if an individual elects not to participate, they are replaced in the sample with another individual. The interviews

were conducted at the home of the individual unless they preferred that the interview take place in another location, at which point other arrangements were made. The interview was private unless the individual wanted to have others present. If the individual could not respond for themselves, the interview proceeded with those sections where a proxy/surrogate response was permitted.

2.3. IM4Q sample, recruitment, data collection

Sampling each year was random; however, many individuals were selected for interviews every other year or every three years. In FY 2018-2019, the sampling strategy was changed to reflect the ODP service system more closely by including more individuals living with their families. IM4Q data collection monitors 5,000 to 6,500 consumers of services in Pennsylvania annually.

2.4. Current study participants

Three years of data (2013, 2016, and 2019) were chosen with the desire of selecting a time point before the HCBS Final Settings Rule (2014) went into effect, one shortly thereafter, and one a few years after it went into effect. There were 5,840 participants in 2013, 5,216 in 2016, and 5,326 in 2019. The data sets have a common consumer identification number which allowed them to be linked together. A variable was created to determine the number of years of data each participant had. There were a total of 13,851 unique participants: 11,570 (83.5%) with a single year of data, 1,987 (14.3%) with two years of data, and 294 (2.1%) with three years of data. There were 819 (59%) who had no employment data, reducing the sample to 13,032. Of those, 24% were missing one variable of interest, 3% were missing two variables, and <1% were missing three variables. Due to listwise deletion in the GEE model, the analytic sample was 9,486 participants with employment data.

2.5. Measures

The IM4Q protocol consists of three parts: (1) the pre-survey which includes basic demographics and contact information; (2) the Essential Data Elements (EDE), which has sections for Satisfaction; Dignity, Respect, and Rights; Choice and Control; Relationships; Inclusion; Monitor Impressions; Major Concerns; and (3) the Family/Friend/Guardian Survey. Goreczny et al. (2005) performed an inter-rater

reliability analysis of the Essential Data Elements and found monitor agreement scores of 85% or higher on 73 of the 74 questions in the instrument.

The Supports Intensity Scale (SIS) is used to measure the level of support needed by individuals with IDD in Pennsylvania. The SIS has excellent inter-rater reliability, and multiple sources have found evidence that the SIS is a reliable and valid measure of the level of support needed (Thompson et al., 2004; Verdugo et al., 2020).

2.6. Variables

Predictor variables included the personal characteristics of community type, residential type, the SIS, and age in years. The outcome of interest was employment in integrated settings in the community.

2.6.1. Personal characteristics

2.6.1.1. Community type. Community type was a single variable with three categories including rural, urban, and suburban. The groups were created by modifying the work done by the Center for Rural Pennsylvania (2021) on county population density, and the variable was added to the data set. The referent group was urban.

2.6.1.2. Residential type. Residential type was a single item with six categories. They were: community homes (agency-managed group homes), a relative's home (living with their family), private ICF, family living/life sharing (living with qualified adults who provide supports in their home), their own residence, and other residences. The referent group was community homes. The most recent wave of participant data was used for residential types.

2.6.1.3. SIS. SIS was a single item with four categories including significant need, modest need, moderate need, and mild need. The referent group was in mild need. The Office of Developmental Programs (ODP) also uses SIS. This measure was created by American Association on Intellectual and Developmental Disabilities (AAIDD) to describe and assess the pattern and intensity of supports an individual needs to have in order to meet the demands of their environment. SIS scores from 2018–2020 were collected for participants and added to the data set.

2.6.1.4. Age. Age was a continuous measure used as a time-varying covariate.

2.6.2. Outcome

2.6.2.1. Community employment. Community employment is work performed on a full- or part-time basis for which a person earns at least minimum wage at a location in the community where the employee works and interacts with people without disabilities. It is a single, dichotomous item which asks whether the participant works in a community-integrated setting. The response options were yes and no. The referent group was no.

2.7. Analysis

Using SPSS version 27 (IBM Corp., Armonk, NY, USA), data were reshaped into long format for the purposes of running repeated measures regression using generalized estimating equations (GEEs). This method changed the analysis to a univariate method. Independence of data points was no longer an issue, and measurement points did not have to be in the same interval. Listwise deletion was used; however, one of the advantages of using GEE models is that all available data are used for each participant. While participants had to have all of the variables in the model to be included in the analytic sample, they could have a different number of observations within the variables (i.e. they had to have at least one instance (observation) with a valid value of the variable to be included in the model. This allowed for less data loss due to missing data points. We also purposefully included three time points (2013, 2016, and 2019) in order to allow more participants to be included and better test the change that occurred from 2013 to 2019. Model estimates were interpreted as odds or means applicable to an “average” participant in this group of individuals with IDD, as GEE models were “marginal” or “population averaged models” (Liang & Zeger, 1986). This approach allowed the flexibility to select the appropriate covariance structure, in this case first-order autoregressive (AR1). All analyses were evaluated using the alpha level ($\alpha = 0.05$).

3. Results

First, the characteristics of those who had data on community employment were examined descriptively. Then, a repeated measures regression using generalized estimating equations (GEEs) was run to examine the change over time on individuals' employment in integrated settings in the community, after controlling for demographic variables.

Table 1
 Characteristics of individuals with community employment data

Categorical variables				
Type of residence	N	%		
Community homes	4,239	44.7		
Relative home	3,561	37.5		
Private ICF	223	2.3		
Family living/Life sharing	556	5.9		
Own residence	634	6.7		
Other residence	273	2.9		
Total	9,486	100.0		
Community type	N	%		
Urban	5,051	53.2		
Suburban	1,747	18.5		
Rural	2,688	28.3		
Total	9,486	100.0		
Supported need	N	%		
Significant	2,114	22.6		
Moderate	2,032	21.4		
Modest	2,537	26.8		
Mild	2,773	29.2		
Total	9,486	100.0		
Employment in integrated setting in community 2013	N	%		
Yes	272	8.6		
No	2,881	91.4		
Total	3,153	100.0		
Employment in integrated setting in community 2016	N	%		
Yes	369	8.8		
No	3,813	91.2		
Total	4,182	100.0		
Employment in integrated setting in community 2019	N	%		
Yes	597	15.5		
No	3,257	84.5		
Total	3,854	100.0		
Continuous variables				
	N	Mean	SD	Range
Age in years 2013	3,153	44.5	15.4	9 to 92
Age in years 2016	4,182	43.3	16.4	7 to 95
Age in years 2019	3,854	41.2	14.8	18 to 88

Note. Other residences included state-operated ICF/MR, state mental health hospital, homeless, temporary shelter, incarcerated, nursing home/nursing facility, domiciliary care, personal care home, children's facility, approved private school, and other unlisted residential types.

3.1. Descriptive analysis

As seen in Table 1, of the 9,486 participants who had valid responses to the community employment item, 44.7% lived in community homes, 37.5% in the home of a relative, 2.3% in private ICFs, 5.9% in family living/life sharing arrangements, 6.7% in their own residence, and 2.9% in another residence type. Other residences included state-operated ICF/IDD, state mental health hospitals, nursing homes/nursing facilities, temporary shelters, incarceration, domiciliary care, children's facilities, personal care homes, approved private schools, and other unlisted residential types. With respect to community type, over half (53.2%) were in urban settings, 18.5% in suburban settings, and 28.3% in rural settings. For SIS support needs, 22.6% of

participants had significant support needs, 21.4% had moderate support needs, 26.8% had modest support needs, and 29.2% had mild support needs.

The average age of participants in 2013 was 44.5 years (median = 45.0, SD = 15.4, range 9 to 92), for participants in 2016 was 43.3 years (median = 43.0, SD = 16.4, range 7 to 95), and for participants in 2019 was 41.2 years (median = 39.0, SD = 14.8, range 18 to 88). For participants who answered employment in an integrated setting in the community item, 8.6% were employed in 2013, 8.8% were employed in 2016, and 15.5% were employed in 2019.

3.1.1. Repeated measures GEE analysis

Repeated measures regression using generalized estimating equations (GEEs) examined employment

Table 2
Community employment repeated measures GEE regression summary (N=9,486)

Variables	Estimate	SE	OR	95% confidence interval		p
				Lower bound	Upper bound	
Age in years	-0.03	0.01	0.98	0.97	0.98	<0.001
Survey 2013	-0.42	0.08	0.66	0.56	0.77	<0.001
Survey 2016	-0.40	0.07	0.67	0.58	0.77	<0.001
Survey 2019*						
Significant support needs	-1.94	0.12	0.14	0.11	0.18	<0.001
Moderate support need	-2.35	0.14	0.10	0.07	0.13	<0.001
Modest support need	-1.43	0.09	0.24	0.20	0.29	<0.001
Mild support need*						
Other residence	0.25	0.21	1.29	0.85	1.96	0.240
Own residence	0.54	0.12	1.72	1.35	2.19	<0.001
Family living/life sharing	0.42	0.15	1.52	1.13	2.04	0.006
Private ICF	0.02	0.32	1.02	0.55	1.89	0.958
Relative home	-0.14	0.09	0.87	0.72	1.04	0.121
Community home*						
Rural	-0.27	0.08	0.77	0.65	0.90	0.001
Suburban	0.20	0.09	1.22	1.03	1.44	0.024
Urban*						
Constant	0.17	0.15	1.18	0.88	1.59	0.259

Note. *Indicates the referent group. Wald $\chi^2(1) = 100.474$; Survey Year Wald $\chi^2(2) = 38.984$; Support Needs Wald $\chi^2(3) = 569.688$; Residence Wald $\chi^2(5) = 44.676$; Community Type Wald $\chi^2(2) = 21.622$. The Goodness of Fit QIC = 6,587.463.

Table 3
Repeated measures community employment estimated means

Variables	Mean community employment	SE	95% confidence interval	
			Lower bound	Upper bound
Survey 2013	0.07	0.01	0.06	0.08
Survey 2016	0.07	0.01	0.06	0.08
Survey 2019	0.10	0.01	0.09	0.12
Significant support needs	0.05	0.01	0.04	0.06
Moderate support need	0.03	0.01	0.03	0.04
Modest support need	0.08	0.01	0.07	0.09
Mild support need	0.26	0.02	0.24	0.29
Other residence	0.08	0.20	0.06	0.12
Own residence	0.11	0.01	0.09	0.13
Family living/life sharing	0.10	0.01	0.08	0.12
Private ICF	0.07	0.02	0.04	0.12
Relative home	0.06	0.01	0.05	0.07
Community home	0.07	0.01	0.06	0.08
Rural	0.06	0.01	0.05	0.07
Suburban	0.10	0.01	0.08	0.11
Urban	0.08	0.01	0.07	0.09

in an integrated setting in the community over time after controlling for age, support needs, residence type, and community type.

3.1.2. Employment in an integrated setting in the community

Age [$\chi^2(1) = 100.474$, $p < 0.001$], survey year [$\chi^2(2) = 38.984$, $p < 0.001$], support needs

[$\chi^2(3) = 569.688$, $p < 0.001$], residence type [$\chi^2(5) = 44.676$, $p < 0.001$], and community type [$\chi^2(2) = 21.622$, $p < 0.001$] were all statistically significant predictors (Table 2).

As seen in Table 3, both 2013 and 2016 employment in an integrated setting in the community (mean = 7.0% both years) were significantly lower than 2019 employment (mean = 10.0%). Means on

employment in an integrated setting in the community were significantly lower for those with significant support needs (mean = 5.0%), moderate support needs (mean = 3.0%), and modest support needs (mean = 8.0%) compared with those having mild support needs (mean = 26%). For residence type, participants living in their own residence (mean = 11.0%) and family living/life sharing arrangements (mean = 10%) had significantly higher employment in the community compared to those in community homes (mean = 7.0%). Participants living in suburban communities (mean = 10.0%) had significantly higher employment in the community than those living in urban communities (mean = 8.0%), while those living in rural communities had significantly lower (mean = 6.0%) employment in the community than those in urban communities. Additionally, for every year of increase in age, the expected value of employment in an integrated setting in the community decreased by 2%.

4. Discussion

Our main research question was: *Controlling for demographic and environmental characteristics, have there been increases in community-based employment between 2013 and 2019 among service users with IDD in Pennsylvania?* The current study suggests there has been an increase in the studied outcome: the 2019 wave of data was associated with more community-based employment in comparison to both the 2013 and 2016 waves.

The level of support needed was associated with community-based employment. People with mild support needs were more likely to be employed than all the other categories that had more extensive support needs. This finding is consistent with previous research (Bush & Tassé, 2017; Nord et al., 2018) and suggests that current employment supports may be primarily effective for those with the mildest levels of support needs. However, adults with moderate support needs had worse outcomes in terms of employment than those with significant support needs. We suggest that since both moderate and significant are the two highest groups with support needs out of four considered in this analysis, there may be a point at which “enough” support needs are “enough” to make outcomes such as employment difficult to obtain with currently available services compared to those with mild support needs. Therefore, this difference may not be of practical significance.

Residential setting was also associated with community-based employment. People with IDD living in their own residence and family living/life sharing arrangements were more likely to be employed than those living in community homes. Previous research has found a similar pattern, particularly in terms of individuals living in their own residence having the highest rates of employment while those living in community homes having a lower rate of employment (Hiersteiner et al., 2018). It appears there is a potentially reciprocal relationship between living more independently and community-based employment in that one may increase the likelihood of the other. Overall, community homes also appear to be less effective at supporting community-based employment than living independently, which may reflect the importance of informal supports and self-determination in gaining such employment. Next, we note that people living in relatives' homes appear to fare worse than the reference group, people living in community homes. We suggest family-based living arrangements can sometimes supplant choice for adults with IDD in ways they cannot in other living arrangements.

Finally, people with IDD living in urban communities were more likely to be employed in community-based settings than those living in rural communities, but less likely to be employed than those living in suburban communities (Rural < Urban < Suburban). This result is different than found in a manuscript under review that used NCI-IPS data from 35 states in which researchers found that persons living in smaller, more rural settings were more likely to be employed in the community compared to those in urban settings, with no difference between suburban and urban settings (Houseworth et al., 2022) (Urban < Rural). It is unclear why these different patterns exist. We know of no other study that compared these residential setting types in relation to employment for service users with IDD.

When controlling for the effects of these demographic and environmental characteristics, there was a significant increase in community-based employment among IDD service users in Pennsylvania between 2013 and 2019. Participation in integrated employment for individuals with IDD who received services from a state IDD agency in the U.S. ranged between 11%–19% from 2008 to 2016 (Nord et al., 2018; Giordano & Bradley, 2018; Bush & Tassé, 2017). In comparison, the overall employment rate in the U.S. in 2018 was estimated at 63% (US Bureau of Labor Statistics). There are many reasons for this

gap. Given the benefits community-based employment confers upon individuals and society, efforts to close this gap are highly desirable to many stakeholders. We discuss in the next section how policy may have been a causal factor given when these waves of data were collected.

4.1. HCBS final rule, employment first, and other policy changes

The time frame of this study allowed us to look at changes in community-based employment within the context of service system policy changes. The two main policies related to community-based employment that we highlighted here are the HCBS Final Rule and Employment First policy. The Final Rule was developed to ensure HCBS users have access to the full benefits of community living as people without disabilities do, and to ensure states meet the requirements of the Americans with Disabilities Act and the Supreme Court decision in *Olmstead v. L.C.* (Riesen & Snyder, 2019). Pennsylvania received initial approval in 2016, in the middle of the waves of data collected in this study.

Another policy implemented during this time frame was the Employment First policy. The Employment First initiative is a national movement in favor of systematic change that prioritizes the ability to participate in integrated, community-based employment for all citizens, including individuals with disabilities. This initiative posited that community-based employment should be the primary goal before other options are considered (e.g., workshops). The state of Pennsylvania, the focus of the current study, formally joined the Employment First movement in 2016 via an Executive Order by the Governor that established a cross-disability Employment First policy (Hoff, 2019). Further, in 2018, the Pennsylvania state legislature passed a law that further dedicated the state to Employment First policy (APSE, 2020).

In the state of Pennsylvania more specifically, the policy initiatives that promoted employment in Pennsylvania were likely due to a range of initiatives. First, the Workforce Innovation and Opportunities Act (WIOA, 2014) began implementation in 2015. Section 511 of WIOA required that people in sheltered workshops receive information annually about competitive integrated employment (CIE); in addition, the school-to-workshop pipeline was changed by requiring high school graduates to go to the Office of Vocational Rehabilitation (OVR) and try

pre-employment training supports before going into a sheltered workshop. In 2014, the OVR started “Early Reach”, a program requiring schools to get students linked with OVR early.

Interagency discussions (between the Department of Human Services, the Office of Developmental Programs, Office of Vocational Rehabilitation, etc.) lead to the promotion of changes to promote competitive-integrated employment. For example, new staff qualifications were required for agencies to perform waiver-funded employment services including education in the established universal competencies in employment. Other similar changes include service changes related to employment. For example, a new service called Community Participation Supports was added, marking the first time such services were permitted outside licensed vocational facilities and adult training facilities. Such training and experience in community-based settings likely helps explain the rise in community-based employment detected.

Study results indicate a significant increase in community-based employment between 2013–2019 in Pennsylvania. This suggests that such efforts may be impacting service users in the intended manner. In particular, shifts to service provision in the most integrated settings available due to the HCBS Final Rule and redirection of day/employment services to community-based employment due to the Employment First policy may be impacting Pennsylvania service users.

4.2. Limitations

First, the current study only assessed the employment of people with IDD in one state. It may be that the change we detected in community-based employment is unique to Pennsylvania. Thus, our results are limited in generalizability.

Next, we were only able to track a limited number of IM4Q participants across the waves of data we assessed. We included a sample limited to those invited and who chose to participate in 2 or 3 waves of data collection only. Results could vary if a different sample was included or if a higher percent of participants were included in all 3 waves.

Finally, the conclusion about HCBS policy and changes in employment must be taken tentatively. Without a truly experimental design, other factors that we were unable to control could explain the increases in employment across these years (e.g., increase in employment opportunities).

5. Conclusion

5.1. Future directions

Future research should include more states when examining changes in employment patterns for people with IDD. The current study was only able to assess this outcome in Pennsylvania. This limitation was due to a lack of available longitudinal data at a national level. More state and/or a national database(s) should be built to track quality of life improvements for service users with IDD following policy changes. Such databases would allow for more accurate assessments of service effectiveness. Other outcomes beyond employment (e.g., community inclusion) should be explored in a similar manner as policy, such as the HCBS Final Rule, is not limited to improvements in community-based employment for adults with IDD. Other important community opportunities such as social inclusion, choice-making, and residential and other types of self-determination are important to track as well. The field of disability research overall would highly benefit from databases that collect person-centered information on the same set of people over time (longitudinal) across the U.S. Such databases can be used to explore how changes in policy affect persons with disabilities. We also suggest multi-level modeling to explore how state differences and/or other community factors relate to personal outcomes such as employment.

To our knowledge, this is the first study to consider changes in community-based employment over three waves of data for individuals with IDD. These data waves were collected during times that overlapped with significant policy change initiatives related to service users with IDD. These changes in policy priorities may be effective and call for continued exploration of their effect and how to maximize policy to further integrate adults with IDD into the community.

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Conflict of interest

None of the authors have any competing interests to declare.

Ethics statement

The University of Minnesota's institutional review board (IRB) reviewed this research and granted a waiver of ongoing IRB review and approval.

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Informed consent

Due to the nature of the study, informed consent was not necessary.

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