

Intellectual and Developmental Disabilities

Using the Independent Monitoring for Quality Program to Examine Longitudinal Outcomes for People with IDD

--Manuscript Draft--

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Dear Dr. Schalock,

We thank you and the reviewers again for the feedback provided and for the opportunity to revise and resubmit our manuscript titled *Using the Independent Monitoring for Quality Program to Examine Longitudinal Outcomes for People with IDD* (Ms. No. IDD-D-22-00021).

In the table below, we list the second round of comments from reviewers we have and how we addressed them. We read and appreciated the positive comments included in the reviews, but focus here on the constructive criticism provided.

Reviewer #1 Critique	Response
General	
The authors have adequately addressed the comments and concerns made in initial draft of the manuscript.	Thank you for your feedback.
Reviewer #2 Critique	Response
General	
As written in the first review, this is an article on an interesting and important theme. The importance of longitudinal studies and the national context of the U.S. are well substantiated. The focus of the article, exploring longitudinal approaches when assessing outcomes for individuals with IDD, is thus more clearly stated. It gives a good insight in the Independent Monitoring for Quality Program. It is an interesting program with, in my view, a good procedure, which works with independent and trained interviewers, with participation of people with disabilities and their families. The sampling procedure is now better described.	<p>Thank you for the feedback on the previous revisions.</p> <p>While addressing reviewer feedback, we also updated the manuscript to APA 7 format per the journal requirement. The table and figures were removed from the body of the text and submitted separately per author instructions.</p>
Abstract	
The abstract mentions 'improvement in all three aspects of focus: more community based living opportunities, more people employed in community based settings, and better everyday choice making'. However this doesn't match with the three themes of focus as mentioned in the article: support related choice, everyday choice and community employment.	This was an error. Thank you for catching it. More community-based living opportunities was removed, and the sentences rewritten to better reflect the themes.

Reviewer #1 Critique	Response
Methodology	
Another remaining remark is that, because the Cronbach scores for Support Related Choice are below .70, perhaps the author could reflect on that.	An error was found in the support-related choice scale. Numbers have been updated and adjusted throughout the manuscript. Additionally, a few sentences explaining the lower than desired alphas have been added in the Variables section under the Choice outcomes.
Results	
Then, in the results section I wonder why community employment is not included in Table 1, while it is in the text.	Community employment is in Table 1. The label was Employed in an Integrated Setting. This has been changed to Community Employment.
Discussion	
... line 8 and 9, the author mentions 'indication of positive trends in moving toward living with relatives or independently in the IM4Q dataset', but I cannot find this in the description of the results.	This was an error. Thank you for catching it. This clause was removed, and the sentences rewritten to accurately reflect the results.
The same with the notice that 'the descriptive data indicate positive trends in community based outcomes' on page 18, line 6.	This was incorrect wording. Thank you for pointing it out. The sentence was rewritten to accurately reflect the study outcomes.

On behalf of our team, thank you considering this revised manuscript for publication in IDD.



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**Using the Independent Monitoring for Quality Program to Examine Longitudinal Outcomes for
People with IDD**

Abstract

The purpose of this study is to lay a foundation for illustrating the importance of longitudinal data collection by sharing the results of the Independent Monitoring for Quality (IM4Q) program in Pennsylvania designed to collect data over time on the quality of services for adults with IDD. In this article, we report on the history and characteristics of the IM4Q program; describe the key variables of interest and highlight the trends in the key variables over three years of data collection (2013, 2016 and 2019). The descriptive results indicate mixed trends for the three areas of focus: comparable rates of people employed in community-based settings; less support-related choice, and better everyday choice-making outcomes.

Key words

Intellectual and developmental disabilities (IDD); Independent Monitoring for Quality (IM4Q) program; Longitudinal

Having national or state longitudinal datasets in which individual and contextual characteristics and outcomes for people with IDD can be studied is essential to promote delivery of equitable and effective services and supports. Electronic data management tools and systems have enabled most European countries (including the UK, Ireland, Denmark, and Sweden), Australia and Canada to develop and maintain longitudinal databases for people with IDD (Ahlström et al., 2020; Burke et al., 2014; Lin et al., 2021; McConkey et al., 2017; Segerlantz et al., 2020). However, such longitudinal studies with identified people with disabilities are limited.

Concerted effort has been put into how to support and improve longitudinal initiatives in these countries. For example, in the UK, the Economic & Social Research Council (ESRC) commissioned an independent international panel to undertake a review of its longitudinal studies and future scientific needs in this area. Series of reports were published in 2017 and 2018 summarizing the results and recommendations for longitudinal data collection in different areas, including aging, poverty, parenting, child development, etc. (Davis-Kean et al., 2017; Townsley, 2017).

In the US, longitudinal studies include the Health and Retirement Study (University of Michigan, 2019), Survey of Income and Program Participation (SIPP, 2021), the Longitudinal Study of Aging (National Center for Health Statistics, 1993), the National Long-Term Care Survey (Manton, 2010), and the National Longitudinal Transition Study-2 (U.S. Department of Education, 2010). These studies, however, do not specifically identify people with IDD or include children, rather than adults.

In longitudinal studies, responses for specific individuals can be linked across multiple waves of data collection. Longitudinal studies offer several advantages over cross-sectional research. Having multiple data points for each individual allows the consistency and accuracy of

data to be assessed. Longitudinal data are also needed to test the effectiveness of implemented policies and program sustainability and to inform decision-making. Unlike cross sectional research, longitudinal data can be used to follow developmental trajectories, provide information on transition periods (Livermore & Roche, 2011; McConkey et al., 2017), and help to identify *causal* relationships because people serve as their own controls. Data that are able to establish longitudinal trajectories and identify causal relationship present an important value in social services, healthcare, and policymaking (Townesley, 2017; Ahlström et al., 2020; Segerlantz et al., 2020).

Most recurring assessment tools designed to collect data on people with disabilities in the US are cross-sectional, with a new sample of participants selected for each data collection cycle (e.g., annually). An example of a US-based cross-sectional dataset specific to outcomes of people with IDD is the National Core Indicators In-Person Survey (NCI-IPS; National Association of State Developmental Disabilities Directors, 2019). The NCI-IPS that started in 1997 is administered by the National Association of State Developmental Disabilities Directors and the Human Services Research Institute (Smith & Ashbaugh, 2001). Participating states (currently 46) conduct annual or bi-annual interviews of adults receiving services as part of the state's Developmental Disabilities (DD) system. States use NCI-IPS results to assess outcomes and manage services at the state level.

Other data collection efforts on outcomes of people with IDD in the US, such as the Council on Quality and Leadership (CQL) Personal Outcome Measures (CQL, 2017), a set of 21 quality of life (QOL) indicators clustered into five categories originally developed in 1992 (Gardner et al., 2001), are programs of quality assurance and improvement that require extensive training that leads to a certification, subject to periodic renewals, and substantial effort to link sufficient data to examine cross-sectional or longitudinal outcomes (Rehabilitation

Research and Training Center on HCBS Outcome Measurement, 2020).

Study Purpose

The purpose of the current initiative was to utilize a longitudinal dataset in Pennsylvania (PA), Independent Monitoring for Quality (IM4Q), to investigate the possibilities and challenges of longitudinal data linking and to examine changes in outcomes over time for IM4Q participants. This particular set of data was selected because it has a substantial sample size, a stable set of measures, and enough longevity to produce longitudinal data on outcomes of people with IDD. This data collection effort has been designed to include following the outcomes of people with IDD over time, and thus leading to a well-designed state-level PA longitudinal dataset.

National Context

The Home and Community-Based Services (HCBS) program supports more than three million people with disabilities or who are aging to live in their communities. The Centers for Medicare and Medicaid Services (CMS) funds the HCBS program in partnerships with state governments. HCBS enables people who need help with daily activities to live at home rather than in a nursing home, state institution, hospital, or other institution. The HCBS program has shown steady growth since its inception in 1981. The share of federal funding for HCBS (\$56.5 billion) exceeded spending for the federal share of institutional Long-Term Services and Supports (LTSS) for the first time in 2013 (Eiken et al., 2016). Consumer demand drives the increase in the usage of community based LTSS. Community-based supports offer a desirable alternative to institutional life by helping people stay closer to friends and family and accessing what the community has to offer (Barrett, 2014).

The cornerstone of the HCBS mission is to help LTSS users enjoy the same access and opportunities for social, civic, career, educational, and home life as their peers without disabilities. The importance and scope of this mission and its publicly funded status create an imperative for the responsible government agencies, advocates, and the public to obtain clear and accurate information

about the program's impact through robust measurement and evaluation programs. Current research indicates that HCBS consistently falls short of its mission of supporting adequate community access and opportunities to participate in community life. These sources identify that HCBS users are more isolated, under-employed, and lacking in control over their daily lives when compared with people not receiving services (Butterworth et al., 2015; Heller et al., 1999, 2002; Tichá et al., 2012). Along with addressing these shortcomings and improving quality of life outcomes for people in HCBS, better measures of accountability are essential to monitoring improvement in outcomes as program capacity and the population in the US requiring services continue to grow.

CMS significantly revised its expectations for HCBS providers in 2014. Program rules regarding HCBS settings and practices were revised to assure that supports become more person-centered and that people enjoy more choice and control in their day-to-day lives. States have until March of 2023 (revised from 2022 due to the COVID-19 Pandemic) to ensure that all existing and new HCBS funded supports are fully aligned with the new requirements (CMS, 2016). To evaluate whether the Final Rule changes improve outcomes, measuring HCBS outcomes of people with disabilities is essential. Currently, it is difficult to gather useful information about program challenges systematically because appropriate HCBS "outcome measurement" tools and approaches are not well established in much of the country. Measurement data are not routinely gathered, coordinated, and tracked across settings and over time in all locations in a comparable manner. This inconsistency, along with other measurement issues, creates reasons to doubt that data are reliable (the degree to which information gathered is consistent) or valid (possessing evidence that the information it provides can be used for its intended purposes). Many measures in this field do not take the time to test if basic threshold of reliability and validity have been met.

The CMS HCBS Final Rule addresses several sections of Medicaid law under which states may use federal Medicaid funds to pay for home and community-based services (HCBS). The rule

supports enhanced quality in HCBS programs and adds protections for individuals receiving services. In addition, this rule reflects CMS' intent to ensure that individuals receiving services and supports through Medicaid's HCBS programs have full access to the benefits of community living and can receive services in the most integrated setting (CMS, 2014).

In order to fulfill the tenets of the CMS Final Settings Rule, effective data collection strategies are necessary. Initiatives such as National Core Indicators (NCI), IM4Q and the CQL's outcome measures have been developed, at least in part, to measure those efforts at the provider, county, state and national levels.

IM4Q Introduction and Context

The Independent Monitoring for Quality (IM4Q) program grew from a 1997 recommendation from Pennsylvania's Office of Developmental Programs (ODP) Planning Advisory Committee (PAC) to develop a mechanism to monitor the quality of life of individuals receiving services under the auspices of the ODP. The intent of the initiative was to develop the capacity for monitoring that was independent of the typical data collection efforts by the service system. A sub-committee of the PAC included people who use ODP services, family members, advocacy groups, providers, Administrative Entities (AEs, which are counties and other local government units charged with administering DD services on behalf of the state), direct support professionals, union representatives, the PA Developmental Disabilities Council, the Institute on Disabilities at Temple University (PA's University Center for Excellence), the PA Disability Rights Network (the state protection and advocacy agency), and ODP staff. This subcommittee recommended that quality monitoring should be independent, leading to a pilot program being conducted in 1999-2000. This pilot program, summarized in the *2002 State Report of Independent Monitoring for Quality* along with recommendations from the IM4Q Steering Committee, was the basis of developing an action plan (2003 Quality Action Plan) that became the IM4Q program.

There are two critical features of IM4Q: independent monitoring of outcome of adults with IDD and the process of “Considerations.” The interview team is independent, which means they are not from ODP, the county, or the individual’s service provider. The independent teams, primarily consisting of people with disabilities, family members, and interested others, monitor the quality of services for people with disabilities through this systematic effort.

The IM4Q is administered at a local level through each of 48 Administrative Entities (AEs) in Pennsylvania. The AEs select local programs to conduct the interviews. Standards for selecting local programs include being independent of service delivery entities and are required to have consumer and family involvement on governing boards or committees overseeing IM4Q activities. Therefore, the agencies include Centers for Independent Living (CIL), non-service providing chapters of The Arc, consumer satisfaction teams (in the mental health system) and local colleges and universities. The IM4Q local programs must have the participation of individuals receiving supports and families in data collection process (ODP, 2016).

Considerations are a mechanism whereby individuals, their family members, staff or the interview teams (monitors) can make recommendations for change or improvement to services. Considerations are intended to improve the individual’s quality of life. Each local IM4Q Program has developed a process, referred to as "closing the loop" (follow-up) activity with the county with which they contract to ensure that issues related to individuals as well as systemic issues on the provider or county level are addressed through the Considerations process. The independent monitoring team that includes an individual with a disability and or a family member, offers a set of considerations based on the responses to the survey that are transmitted electronically to the supports coordinator at the AE level to address. The supports coordinator responds to the consideration and submits the resolution to their supervisor; once approved, it is sent back to the

local IM4Q program for concurrence or disagreement. Once all parties agree on the resolution to the consideration (including the individual/family) the loop is closed.

The IM4Q Instrument

The IM4Q protocol consists of a Pre-survey form, the Essential Data Elements (EDE) survey, and the Family/Friend/Guardian (F/F/G) survey.

The Pre-survey information is pulled from supports coordination records. It includes contact information, communication details and other information needed to set up the interview.

The EDE is completed by interview and is comprised of the following sections: Satisfaction; Dignity, Respect and Rights; Choice and Control; Relationships; Inclusion; Monitor Impressions; Major Concerns.

- *Satisfaction* – this section is only to be completed based on the responses of the individual receiving supports. Questions are asked about satisfaction with where the individual works and lives, as well as with staff who support the individual.
- *Dignity, Respect and Rights* – this section is also only to be completed based on responses of the individual receiving supports. Questions are asked about whether roommates and staff treated people with respect, whether people were afforded their rights, and whether they had fears at home, at work or in the community.
- *Choice and Control* – the questions in this section are answered by the individual, or by a family member, friend or staff person. Questions are asked about the extent to which individuals exerted choice and control over various aspects of their lives.
- *Relationships* – the questions in this section are answered by the individual, or by a family member, friend or staff person. Questions are asked about friends, family and neighbors, and individuals' opportunity to visit and contact them.

- *Inclusion* – the questions in this section are answered by the individual, or by a family member, friend or staff person. Questions are asked about opportunities for community inclusion.
- *Monitor Impressions* – this section of the survey is completed by the Independent Monitoring team, after they have completed their visit. Questions are asked about staff support and opportunities for growth and development.
- *Major Concerns* – All major concerns with the following issues are to be communicated within 24 hours: physical dangers within a home or place of community activity, significant sanitation problems, evidence of physical abuse or neglect, evidence of psychological abuse, or evidence of human rights violation.

Goreczny et al. (2005) performed an inter-rater reliability analysis of the Essential Data Elements (EDE) instrument used in Pennsylvania's Independent for Monitoring program. Analysis revealed monitor agreement scores of 85% or higher on 73 of the 74 questions in the instrument.

The Family/Friend/Guardian survey is completed after the interview, either by phone or mail. It gives family members an opportunity to express their view of the services and supports provided to their relative.

Approach to Data Collection

Interview teams, each including a person with a disability or a family member of a person with a disability, are carefully selected and thoroughly trained before the interviewing begins. When there are significant changes to the instrument, training is provided by research coordinators at Temple University and often by members of the NCI staff. In intervening years, the training is provided by the local programs; local programs may request training from the Temple team as the need arises, particularly when there is a new program or a number of new monitors. In addition to regional and

statewide training, individual programs provide training to their monitoring teams based on need at the local level.

Participation in the interview is voluntary. If an individual refuses to participate, the individual is replaced in the sample with another individual. The interview takes place at the home of the individual, but if they prefer that the interview take place elsewhere, alternate arrangements are made. The interview is conducted in private whenever possible unless the individual expresses a desire to have others present. More recently, online and phone options were added due to COVID-19. If the individual is unable to respond on their own behalf, the interview proceeds with those who know the individual well in those sections where a surrogate/proxy response is permitted.

Sampling

A random sample, stratified by county/administrative entity, is pulled by an ODP consultant from the Home and Community Services Information System (HCSIS) at the state level each year. On average, one-third of individuals receiving residential supports were selected each year; hence, the entire residential population was expected to be interviewed over a three-year cycle. Sampling is done each year without replacement, indicating that those individuals sampled in year one are not eligible to be a part of the sample in year 2.

The sampling methodology used for IM4Q has changed over time. The original methodology was a random sample stratified by county/administrative entity of individuals receiving residential supports. Over time the methodology was revised to a random sample of service recipients, which more closely represents the service system. The main impact of this sampling change was that individuals receiving service who lived with their families were a larger segment of the sample. Before the sample was drawn each year, individuals who were interviewed in the previous two years were removed from the sampling pool. The sampling methodology did not have longitudinal analysis as a consideration.

Data Collection Across Three Data Points

The years chosen for the analysis were primarily based on disability policy in Pennsylvania (HCBS, Employment First). With about 5,000 individuals in each wave of data, it seemed logical that a certain portion of the participants would have multiple data points. Ultimately, 2% of the participants had all three waves of data, and 14% had two waves of data.

Method

IM4Q data are collected annually. Data sets currently exist for years 2000 to 2022. For the purposes of this illustration, three waves of data (2013, 2016, and 2019) were selected as our time points of interest.

Participants

The three IM4Q data sets share a consumer identification number which allowed matching together of the three time points. A variable was created to determine the number of years of data each participant had. There were 11,570 (83.5%) with a single wave of data, 1,987 (14.3%) with two waves of data, and 294 (2.1%) who had all three waves of data. The focus of this illustration is those with all three waves of data.

Variables

Variables of interest included the following characteristics of people with IDD: gender, age, and residential setting. Outcomes of interest were support-related choice, everyday choice, and community employment. These variables are explained in detail below.

Personal Characteristics

- **Age** was a continuous measure at the earliest year of data available.
- **Gender** was a single item with two categories, female and male, at the earliest year of data available.

- **Residential Type** was a single item with six categories including community homes, relatives' home, private ICF, family living/life sharing, own residence, and other residence. Other residences included state-operated ICF/ID, 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 type.

Outcomes

- **Support-related Choice** was a 4-item measure representing the level of choice an individual has related to support-related decisions. Items include: choosing where you live, choosing your housemates, choosing your paid staff, and choosing what you do during the day. Each had a 3-point response scale (someone else chose, the individual chose with help, and the individual made the choice). The mean was computed across the four items, and scores ranged from 0 to 2. A higher score represents greater choice around support-related decisions. Psychometric analyses were conducted for each year of data. For 2013, $\alpha = 0.68$ with corrected item-total correlations ranging from 0.3910 to 0.518. Principal Components factor analysis produced a single factor explaining 51% of the variance with factor loadings ranging from 0.641 to 0.765. For 2016, $\alpha = 0.65$ with corrected item-total correlations ranging from 0.374 to 0.486. Principal Components factor analysis provided a single factor explaining 49% of the variance with factor loadings ranging from 0.634 to 0.750. For 2019, $\alpha = 0.69$ with corrected item-total correlations ranging from 0.423 to 0.518. Principal Components factor analysis provided a single factor explaining 52% of the variance with factor loadings ranging from 0.668 to 0.763.
- **Everyday Choice** was a 3-item measure representing the level of choice an individual has related to everyday decisions. Items included: having enough choice about their daily schedule, having choice about free time, and being able to choose what to buy with their

money. Response options were a 3-point response scale (someone else chose, the individual chose with help, and the individual made the choice). The mean was computed across the three items, and scores ranged from 0 to 2. A higher score represents greater choice around everyday decisions. For 2013, $\alpha = 0.74$ with corrected item-total correlations ranging from 0.551 to 0.572. Principal Components factor analysis produced a single factor explaining 66% of the variance with factor loadings ranging from 0.801 to 0.818. For 2016, $\alpha = 0.73$ with corrected item-total correlations ranging from 0.531 to 0.591. Principal Components factor analysis provided a single factor explaining 65% of the variance with factor loadings ranging from 0.789 to 0.832. For 2019, $\alpha = 0.50$ with corrected item-total correlations ranges from 0.275 to 0.396. Principal Components factor analysis provided a single factor explaining 52% of the variance with factor loadings ranging from 0.615 to 0.796.

- **Community Employment** was a single, dichotomous item asking if the participant works in a community integrated setting. Response options are yes and no.

The choice and employment variables were based on previous work with NCI data at the national level (Bush & Tassé, 2017; Tichá et al., 2012; Houseworth et al., 2018). This study uses those scales specific to the IM4Q program in Pennsylvania. The support-related and everyday choice scales had limited response options (3 choices rather than the typical 5-7 point Likert scale) and were composed of a fewer items (3-4 items). With these limitations, some alphas were lower than desired, but acceptable (Novick & Lewis, 1967; Carmines & Zeller, 1979).

Analysis

Using SPSS version 27 (IBM Corporation, 2020), descriptive analysis of the variables of interest for each dataset were conducted to examine patterns of missing data and variable distributions.

Results

Descriptive statistics were examined to understand the composition of the sample. An illustration of IM4Q used longitudinally was provided.

Descriptive Analysis

Of the 294 participants in the IM4Q survey in all three years, 60% were male, 78% lived in community homes, 11% in a relative's home, 2% in a private ICF, 6% in family living/life sharing arrangement, 2% in their own residence, and 1% in another residence type. The average age was 48 years (SD = 13 years, range 15 to 81 years). For support-related choice, the 2013 average score was 0.75 (SD = 0.61, range 0 to 2), the 2016 score was 0.80 (SD = 0.59, range 0 to 2), and the 2019 score was 0.69 (SD = 0.56, range 0 to 2). For everyday choice, the 2013 average score was 1.54 (SD = 0.48, range 0 to 2), the 2016 score was 1.55 (SD = 0.46, range 0 to 2), and the 2019 score was 1.79 (SD = 0.33, range 0 to 2). For community employment, 8% were employed in 2013, 5% in 2016, and 8% in 2019.

Insert Table 1

Illustrative Example

The benefit of longitudinal data is the capacity to examine trends over time. Figures 1 and 2 show the average support-related and everyday choice scores for 2013, 2016, and 2019. Figure 3 shows the percent of participants involved in community employment for 2013, 2016 and 2019. We can look at just one point in time, but also see how the scores or percentages move over time. The trends we see for participants who have IM4Q 2013, 2016 and 2019 data show a slight decrease in support-related choice (0.75 to 0.69) and an increase in everyday choice (1.54 to 1.79). For community employment, there was a decrease from 8% in 2013 to 5% in 2016 with a rebound to

8% in 2019. IM4Q in PA possesses the unique ability to track individuals over time; this is the only database of which we are aware that allows for that type of tracking analysis. In most/all other NCI states, the data are collected without the ability to track individuals over time – data are collected without the use of unique identifiers.

Insert Figures 1, 2, and 3

Discussion

Longitudinal data has the potential to highlight trends in the outcomes and contextual factors in the lives of people with disabilities, including potential impact of policies. Such information, while available in some countries, is not easily available in the US, specifically for people with IDD. This study has been designed to begin to fill this gap, using the IM4Q Pennsylvania data. The IM4Q data has an established track record for over two decades and can be analyzed longitudinally for selected participants who participated in data collection across multiple years. The results of this descriptive study provide a summary of trends of the cases available across three years (2013, 2016, 2019) in the IM4Q dataset, indicating stable trends for working in community employment settings, a slight decrease in support-related choice, and a positive trend is demonstrated by increased everyday choice-making over time.

The results of this secondary data analyses reflect a national trend toward greater community inclusion of people with IDD examined in this study, including the movement of people to small community-based settings (living with family or independently), more people engaging in community-based employment, and an increase in choice-making (Larson & Lakin, 2012; Houseworth et al., 2018).

Trends reported using NCI data between 2013, 2016 and 2019 noted similar increases in residential settings regarding people with IDD living in their own homes, but a steady trend when examining people living with family (NCI, 2014, 2017, & 2020). At a national level, the trend of people living with family and on their own respectively has changed from 38% and 12% in 2013 to 35% and 20% in 2016 to 38% and 18% in 2019. Regarding employment, there was similarity in the general increase in community-based employment over time. In 2013, 15% of people with IDD had a paid community job, compared to 19% in 2016 and 2019. National trends in choice-making using NCI data also demonstrated an increasing trend both for everyday and support-related choice respectively from 86% and 56% in 2013 to 88% and 67% in 2016 to 89% and 66% in 2019. One difference between the national NCI data and IM4Q PA results reported here is that there was a greater increase in the PA data in 2019 in all aspects of the studies compared to the national trends reported in NCI (NCI, 2014, 2017, & 2020).

While the design of this study does not lend itself to making any causal conclusions, the descriptive data indicate stable trends in community employment, a slight decline in support-related choice, and a positive uptick in everyday choice for people with IDD in PA after the HCBS final settings rule came into effect in 2014. Undoubtedly, there are numerous factors that have contributed to the improvement in community inclusion outcomes of people with IDD (e.g., increase in funding for community-based services – residential and employment; higher expectations to be included in education and after-school activities; better supports in employment for people with disabilities, Employment First state, etc.) (Hiersteiner & Butterworth, 2018; Houseworth et al., 2018; Winsor et al., 2020). Nevertheless, the trends demonstrated using IM4Q longitudinal data are encouraging in relation to the state implementation of the final settings rule.

The findings of this descriptive study highlight the potential of the IM4Q to fill the gap in longitudinal analysis of quality life outcomes for people with IDD in PA and beyond (nationally).

Given that the IM4Q data collection efforts have an established practice, there is a lot that can be learned from the program when designing similar initiatives, including data collection procedures, separation of the program from the service system, and using the data to make changes in people's supports and services.

This manuscript serves as one in a series of manuscripts using IM4Q data across three time points. The manuscript lays out foundational information about the IM4Q program (its purpose and structure) and provides descriptive information as well as trends using the selected variable across 2013, 2016, and 2019. The accompanying manuscripts focus on inferential analysis of the choice and employment outcomes across the three years of IM4Q data.

Conclusion

Evaluation of trends in community inclusion of people with IDD over time requires longitudinal data. This study provides an opportunity to examine IM4Q data in PA over three years (2013, 2016 and 2019) collected mostly with the same individuals. Thus, this study provides a unique contribution in the US context by examining longitudinal trends in living arrangement, community-based employment, and choice making for adults with IDD. This publication is accompanied by related inferential studies by the same research team, examining predictive factors in addition to studying changes over time in employment and choice outcomes for people with IDD in the US.

Limitations

While this study is an important step in performing longitudinal analysis on outcome data of adults with IDD, the IM4Q data was not originally designed for this specific purpose, but rather to monitor quality of services in PA. There were missing data across the waves for the same individuals across the three years, thus reducing the sample size and limiting the true longitudinal

nature of the study. In addition, this analysis represents findings only in one state, thus having limited generalizability.

Future directions

More intentional efforts are needed in collecting and analyzing longitudinal data on quality-of-life outcomes of adults with IDD in the US. This is important because unlike with cross-sectional data, longitudinal findings can provide more reliable and predictive information about trends in outcomes of adults with IDD in the context of changing policies, funding and other federal and local factors.

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Figure 1. Support-related Choice Over Time

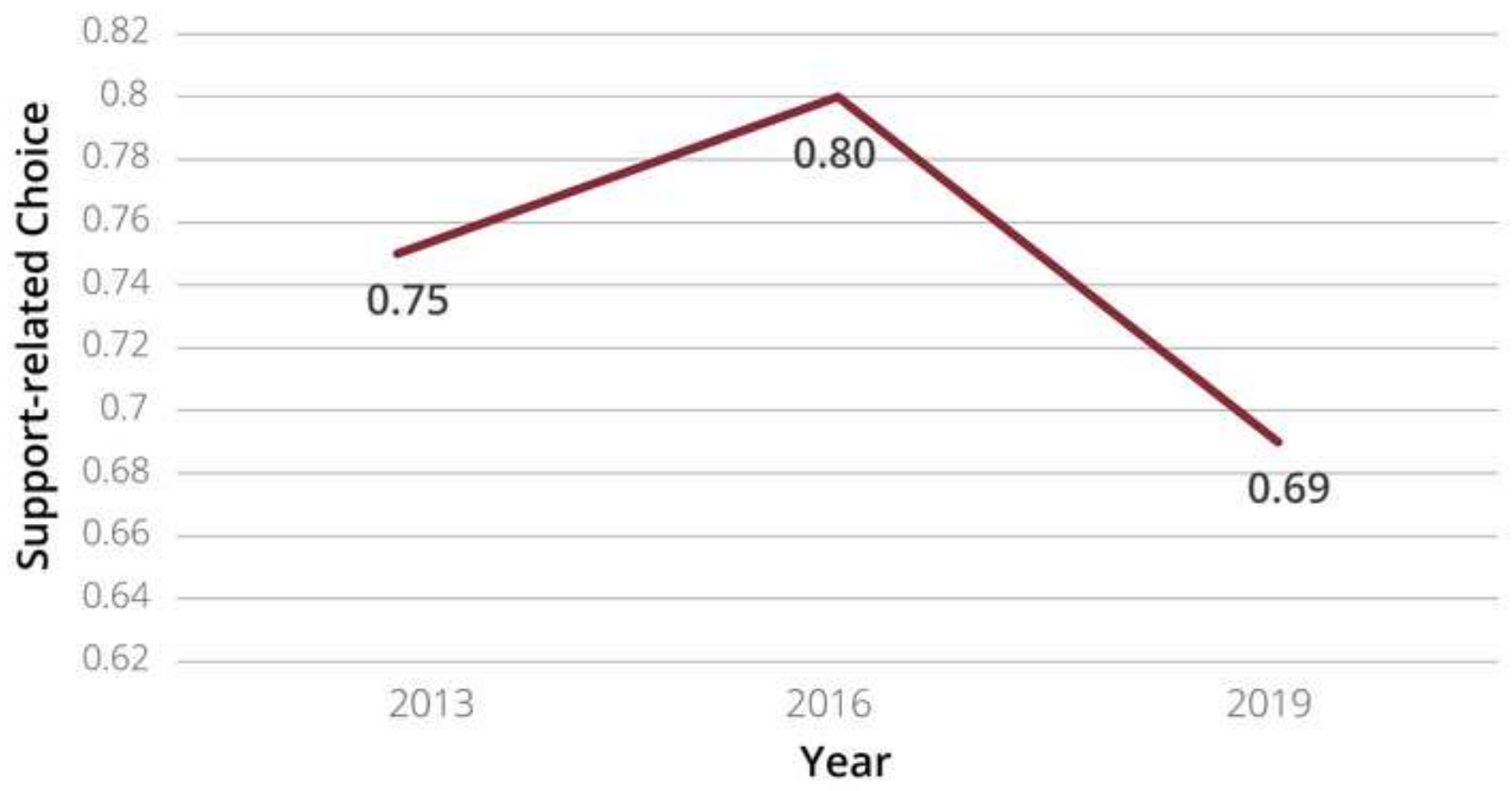


Figure 2. Everyday Choice Over Time

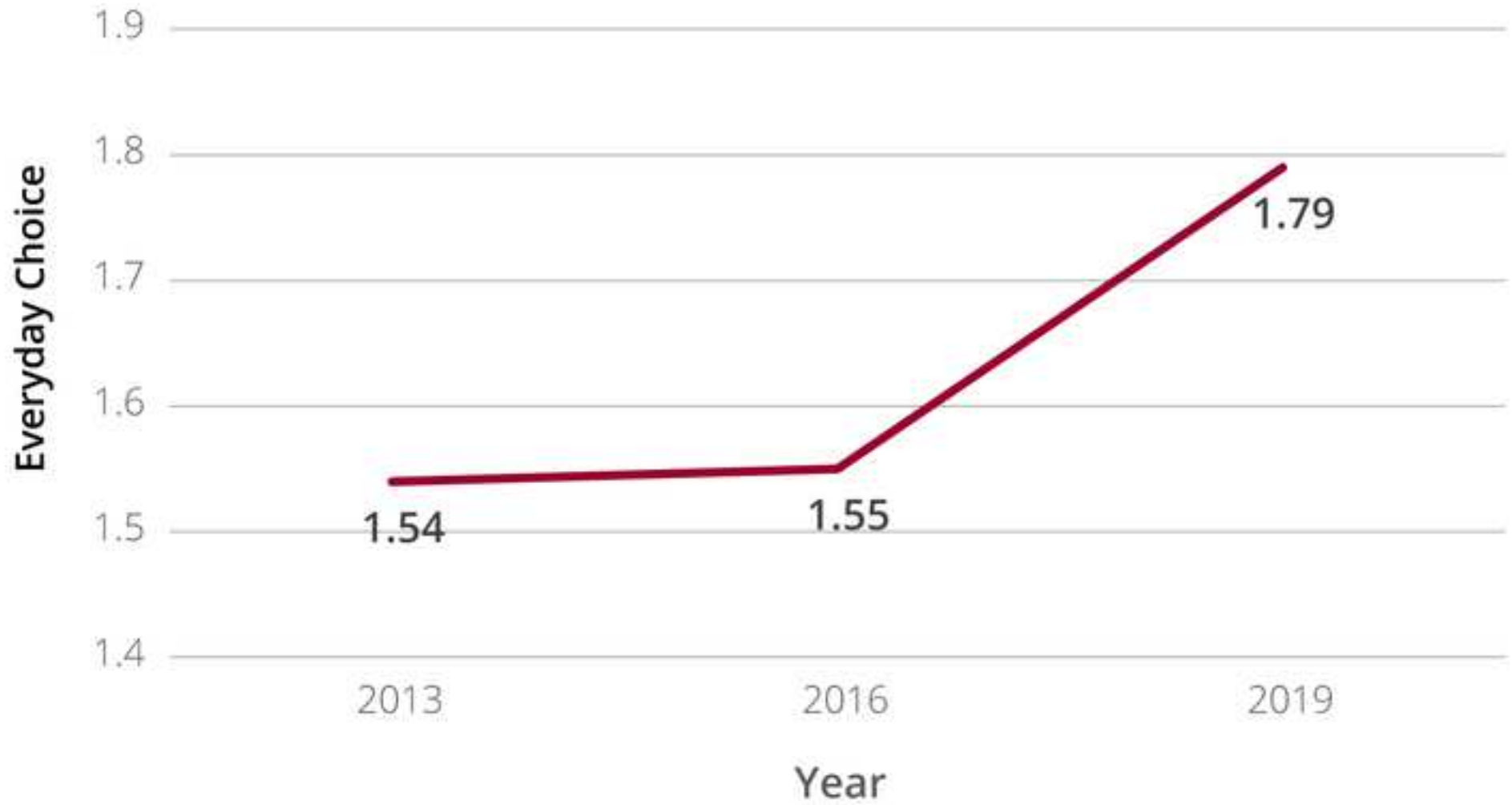


Figure 3. Community Employment Over Time

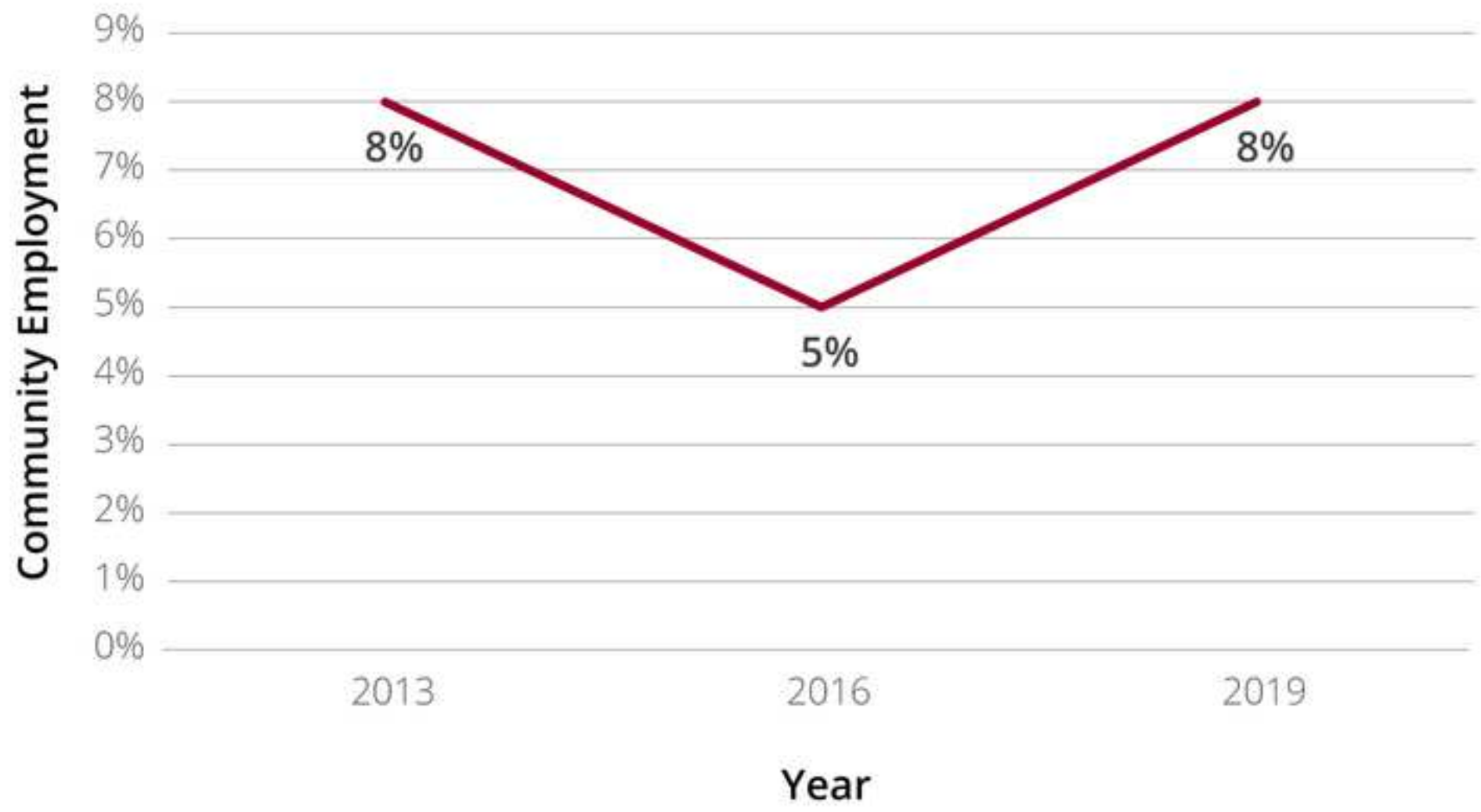


Table 1.*Descriptive Statistics*

Categorical variables					
Gender	N	%			
Female	116	40.0			
Male	178	60.0			
Total	294	100.0			
Type of Residence	N	%			
Community homes	229	78.0			
Relative's home	31	11.0			
Private ICF	7	2.0			
Family living/Life sharing	16	6.0			
Own residence	7	2.0			
Other residence	4	1.0			
Total	294	100.0			
Community Employment 2013	N	%			
Yes	18	8.0			
No	220	92.0			
Total	238	100.0			
Community Employment 2016	N	%			
Yes	12	5.0			
No	226	95.0			
Total	238	100.0			
Community Employment 2018	N	%			
Yes	19	8.0			
No	219	92.0			
Total	238	100.0			
Continuous Variables					
	N	Mean	SD	Range	
Age in years	294	48.0	13.00	15 to 81	
Support-related Choice 2013	274	0.75	0.61	0 to 2	
Support-related Choice 2016	274	0.80	0.59	0 to 2	
Support-related Choice 2019	274	0.69	0.56	0 to 2	
Everyday Choice 2013	282	1.54	0.48	0 to 2	
Everyday Choice 2016	282	1.55	0.46	0 to 2	
Everyday Choice 2019	282	1.79	0.33	0 to 2	