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Examining Choice and Control for People with IDD Over Time

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All authors declare that they have no competing interests.

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Ethics approval statement

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

Key words: People with IDD; longitudinal data analysis; choice-making; HCBS Final Settings Rule

Abstract

Choice-making is an important aspect of everyone’s life in terms of fully becoming an adult within a democratic society. People with intellectual and developmental disability (IDD) are at risk for diminished choice-making due to various factors, including guardianships, dependence on supports that are not person-centered, and in some cases, limited capacity to express one’s desires effectively. Independent Monitoring for Quality (IM4Q) data for 9,195 and 9,817 for adult services users with IDD were analyzed across two types of choice. Repeated measures mixed regression examined choice over time after controlling for age, support needs, residence type, and community type. We found significant increases in everyday choice-making among IDD service users in Pennsylvania, but not in support-related choice.

The following study is the first to our knowledge to consider change in choice-making, an important indicator of rights and inclusion for persons with IDD. By comparing three waves of data from the state of Pennsylvania (2013, 2016, and 2019), we were able to detect changes in choice-making over time among home and community-based service (HCBS) users with IDD.

Examining Choice and Control for People with IDD Over Time

Introduction

Choice-making is an important aspect of everyone’s life in terms of fully becoming an adult within a democratic society. No one has control over all aspects of life, but some control in everyday and key life decisions is a marker of good quality of life. People with intellectual and developmental disability (IDD) are at risk for diminished choice-making due to various factors, including guardianships, dependence on supports that are not person-centered, and in some cases, limited capacity to express one’s desires effectively.

In comparison to individuals without IDD, individuals with IDD have reported having less choice (Sheppard-Jones, Prout, & Kleinert, 2005). Further, people with IDD have clearly indicated that choice is very important to them (Miller, Cooper, Cook, & Petch, 2008). Finally, choice is both a key component of quality of life (Schalock & Verdugo, 2012) and an important indicator of self-determination (Abery & Stancliffe, 2003a, 2003b).

Support-related and everyday choice

Previous research has utilized data from the National Core Indicators-In Person Survey (NCI-IPS), a similar survey to the one explored in the current study, to explore choice-making of adults with IDD. The NCI-IPS is a survey administered to persons with IDD, case managers, family members, and other knowledgeable persons as to the quality of services and important life outcomes (e.g., employment) of persons with IDD receiving home and community-based services (HCBS) (Tichá et al., 2012; Houseworth et al., 2018). The support-related choice scale included five choice items: who to live with, where to live, staff members, case manager, and type of day/work activity. The everyday choice scale included three choice items: one’s daily schedule, free time, and minor purchases. Complimentary research by Bush and Tassé (2017) found a similar clustering of items, differing only in calling the two scales long-term and short-term choice-making. Further, research from Ireland found a similar structure using questions like those on the NCI-IPS calling them everyday and “key life” decisions (O’Donovan et al., 2017). Thus, the dichotomy between everyday and support-related choice, though sometimes termed differently, has been established in the literature and is how we conceptualized choice in the current study.

In comparing these two types of choices, service users with IDD make more everyday choices than support-related choices (Heller et al., 1999; Lakin et al., 2008; Sheppard-Jones et al., 2005). Support-related choices may be constrained by funding, regulations, and the tendency for service providers and caregivers to assert a degree of control over these choices. For example, where and with whom a person lives can be heavily influenced by service providers, regulations, and funding, particularly so in group homes (Stancliffe et al., 2011). O’Donovan et al. (2017) and Bush & Tassé (2017) refer to support-related choice as “key life” and “long-term” choice respectively, which further reflects the higher level consequence to these decisions and why others may feel more impulse to intercede.

Conversely, everyday choices can be accomplished more independently of service delivery via individual motivation. Considering the change in these two types of choices over time, especially in light of system-wide efforts such as the HCBS final rule, is an important way to mark progress or the lack thereof in this important aspect of quality of life.

HCBS Final Rule

The Centers for Medicare and Medicaid Services (CMS) in the U.S. Department of Health and Human Services issued a final rule in 2014. The final rule requires states to demonstrate that community-based services funded by CMS are delivered in settings that meet a clarified definition of home and community-based or they will not be reimbursed for those services. This new rule specifically states that HCBS users should have access to the full benefits of community living, which begins with receiving services in the most integrated setting. This process begins with person-centered planning, which leads to what kind of HCBS a person receives. The goal is to ensure Medicaid funding and policy support needed strategies for states in their efforts to meet their obligations under the Americans with Disabilities Act and the Supreme Court decision in Olmstead v. L.C., 527 U.S. 581 (1999). More specifically, the final rule specifies that states:

- Optimize individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact, and
- facilitate individual choice regarding services and supports, and who provides them.

The intent of the current study was to measure changes in choice-making, both in terms of everyday and service-related choices, over a time before and after the final rule was issued. This information provides important context for learning about the impact of the rule on services users with IDD.

Purpose and Research Question

This study seeks to explore the change in choice over time in the ability of service users with IDD to make choices, especially because policy changes have encouraged an increase in the benefits of community living in lieu of more institutional settings.

Choice has underlying concepts behind it and can bring to mind a few different concepts, especially in reference to individuals with IDD. One key underlying concept is the degree to which a person has the necessary skills and abilities to engage in choice-making. From this perspective, choice-making could refer to those skills or abilities. We do not conceptualize our results from this perspective: we control for the level of ID for each individual in order to narrow our results to the actual expression of choice-making.

Another related concept is decision-making, a potentially complex process involving both skills and abilities along with opportunities and agency. Our data and results must be interpreted in terms of who is the one who actually makes the "choice" or "decision" in the end, regardless of this overall decision-making process. For the purposes of the current study, choice-making may be considered most directly as "who decides" or "who chooses". In fact, interviewers who administer the IM4Q survey may use those two phrases interchangeably. We do not have information available on this survey as to the larger, more complex decision-making processes, but do find our results important in terms of the end result of choice-making.

Further, the current study explores two types of choice-making: support-related and everyday choice. While our overall intention is to track changes in two indicators of choice-making over time, these two scales provide an important opportunity to explore the differences between the two. These are two related (inter-correlated) but distinct choice-making scales that serve as indicators of different aspects of autotomy over one's life, one perhaps more malleable than the other based on previous theory (i.e. everyday choice).

The current study is designed to answer the following research question:

Controlling for demographic and environmental characteristics, have there been increases in support-related and everyday choice between 2013 and 2019 among services users with IDD in Pennsylvania?

The answer to this question will provide valuable insight into changes over time that many stakeholders believe are important consequences of the push to increase the human rights and community inclusion of persons with IDD.

Method

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. 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 who are contracted to collect IM4Q data and enter it into the database. Data is collected through in-person interview 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 attend, when required. IM4Q Technical Advisors also do periodic training on the instrument, when major changes in the instrument occur.

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.

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 family. IM4Q data collection monitors 5,000 to 6,500 consumers of services in Pennsylvania annually.

Current Study Participants

Three years of data (2013, 2016, and 2019) were selected for this study to include a time point before the HCBS Final Settings Rule (2014) went into effect, one shortly thereafter, and one a few years later. In 2013, there were 5,840 participants, 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 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. Repeated measures mixed regression models were the analytic method. Unlike traditional repeated measures, this approach tolerates missing data with reshaping of the data into a long format meaning any participant who had at least one score of the time-varying measures is included. There were 9,888 participants who had at least one support-related choice or one everyday choice score. Due to listwise deletion with this approach, the analytic sample for support-related choice was 9,195 and 9,817 for everyday choice.

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 supports 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 supports needed (Thompson, et al., 2004; Verdugo et al., 2020).

Variables

Predictor variables included the personal characteristics of age, residential type, community type, and the Supports Intensity Score (SIS). The outcomes of interest were support-related choice and everyday choice.

Personal Characteristics

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

Residential Type. Residential type was a single item with six categories including: community group homes, a relative’s home, private ICF, family living/life sharing, own residence, and other residence. Community group homes was the referent group. Residential type came from the participant's most recent wave of data.

Community Type. Community Type was a single item with three categories including urban, suburban, and rural. Groups were created using modifications to the work done by the Center for Rural Pennsylvania (2021) on county population density. Urban was the referent group.

Supports Intensity Scale (SIS). SIS was a single item with four categories, including mild need, modest need, moderate need, and significant need. Mild was the referent group. The ODP uses the SIS developed by the American Association on Intellectual and Developmental Disabilities (AAIDD). The SIS is designed to assess and describe the pattern and intensity of supports an individual needs in order to meet the demands of their environment. SIS scores came from 2018-2020.

Outcomes

Support-related Choice. This measure represents the level of choice an individual has related to support-related decisions. Four questions including whether the participant had enough choice in choosing: where they live, their housemates, their paid staff, and what they do during the day were combined to form this measure. The items were on a 3-point response scale: someone else chose, the individual chose with help, and the individual made the choice. Scores were computed using a mean across the four items, and scores ranged from 0 to 2. A higher score indicates the individual has greater choice around support-related decisions. Factor analysis verified unidimensionality. Cronbach's alpha established internal consistency (2013 α = 0.68; 2016 α = 0.65; 2019 α = 0.69) using the study data.

Everyday Choice. This measure represents the level of choice an individual has related to everyday decisions. Three questions including whether the participant had enough choice in choosing: their daily schedule, what to do in their free time, and what to buy with their money, were combined to form this measure. The items were on a 3-point response scale: someone else chose, the individual chose with help, and the individual made the choice. Scores were computed using a mean across the three items, and scores ranged from 0 to 2. A higher score indicates the individual has greater choice around everyday decisions. Factor analysis verified unidimensionality. Cronbach's alpha established internal consistency (2013 $\alpha = 0.74$; 2016 $\alpha = 0.73$; 2019 $\alpha = 0.50$) using data from this study.

These scales were based on previous work done using NCI data at the national level (Bush & Tassé, 2017; Tichá et al., 2012; Houseworth et al., 2018). The current study is using those measures for a single state (PA). The choice scales were composed of a few items (3-4 items) and response options were limited (3 choices rather than the typical 5-7 point Likert scale). Given these limitations, some alphas were lower than desired but acceptable (Novick & Lewis, 1967; Carmines & Zeller, 1979).

Analysis

Using SPSS version 27 (IBM Corp, 2020), descriptive statistics were run on all variables of interest. Additionally, data were reshaped into a long format for the purposes of running repeated measures mixed regression analysis. This method changes the analysis to a univariate method. Independence of data points is no longer an issue, and measurement points do not have to be the same interval. Listwise deletion is still used; however, the effect is different in that participants can have a different number of observations. This allows for less data loss due to missing data points. The mixed approach allows the flexibility to select the appropriate covariance structure, in this case first order autoregressive (AR1). Maximum likelihood estimation was used as the sample was not small (UCLA: Statistical Consulting Group, accessed July 19, 2021). All analyses were evaluated using the alpha level of 0.05.

Results

First, we examined the variables of interest descriptively. Then, repeated measures mixed regressions were run to examine change over time on individual’s support-related and everyday choice, respectively, after controlling for demographic variables.

Descriptive Analysis

As seen in Table 1, of the 9,888 participants who had either support-related or everyday choice scores, 44.6% lived in community homes, 37.4% in the home of a relative, 2.3% in private ICFs, 5.9% in family living/life sharing arrangements, 6.8% in their own residence, and 3.0% in another residence type. 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 type. With respect to community type, over half (53.6%) were in urban settings, 18.1% suburban settings, and 28.3% in rural settings. For SIS support needs, 22.7% of participants had significant support needs, 21.3% moderate support needs, 26.9% modest support needs, and 29.1% mild support needs.

Table 1

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 year (median = 43.0, SD = 16.4, range 7 to 95), and for participants in 2019 was 42.2 years (median = 40.0, SD = 15.4, range 18 to 92). For participants who answered support-related choice items, the average support-related choice 2013 score was 0.79 (median = 0.75, SD = 0.66, range 0 to 2), the average support-related choice 2016 score was 0.80 (median = 0.75, SD = 0.64, range 0 to 2), and the average support-related choice 2019 score was 0.90 (median = 1.00, SD = 0.70, range 0 to 2). For participants who answered everyday choice items, the average everyday choice 2013 score was 1.52 (median = 1.67, SD = 0.52, range 0 to 2), the average everyday choice 2016 score was 1.52 (median = 1.67, SD = 0.52, range 0 to 2), and the average everyday choice 2019 score was 1.75 (median = 2.00, SD = 0.40, range 0 to 2).

Repeated Measures Mixed Regression Analysis

Repeated measures mixed regression examined support-related choice over time after controlling for age, support needs, residence type, and community type. A second repeated measures mixed regression was run to examine everyday choice over time controlling for the same covariates.

Support-related Choice

Age [F(1,8855) = 17.196, p < 0.001], support needs [F(3,8467) = 207.856, p <0.001], residence type [F(5,8958) = 161.768, p <0.001], and community type [F(2,8558) = 24.119, p < 0.001] were all statistically significant predictors. Survey year [F(2,8071) = 0.771, p = 0.462] was not significant (Table 2).

Table 2

As seen in Table 3, neither 2013 and 2016 support-related choice scores (mean = 0.83 and mean = 0.84) were significantly lower than 2019 scores (mean = 0.83). Means on support-related choice scores were significantly lower for those with significant support needs (mean = 0.71), moderate support needs (mean = 0.67), and modest support needs (mean = 0.86) compared with those having mild support needs (mean = 1.09). For residence type, participants living in private ICFs or other residences had significantly lower support-related choice scores (mean = 0.48 and mean = 0.57, respectively) compared to those in community homes (mean = 0.67). Additionally, those living in their own residence (mean = 1.23), the home of a relative (mean = 0.91), and family living/life sharing arrangements (mean = 1.13) had significantly higher support-related choice scores than those living in community homes (mean = 0.67). Participants living in suburban communities (mean = 0.76) had significantly lower support-related choice scores than those living in urban communities (mean = 0.76). And, for every year increase in age the expected value of support-related choice increased by 0.01 points (Table 3).

Table 3

Everyday Choice

Age [F(1,9740) = 29.608, p < 0.001], survey year [F(2,8429) = 257.205, p <0.001], support needs [F(3,9366) = 459.009, p <0.001], residence type [F(5,9725) = 28.980, p <0.001], and community type [F(2,9418) = 150.496, p < 0.001] were all statistically significant predictors (Table 4).

Table 4

As seen in Table 5, both 2013 and 2016 everyday choice scores (mean = 1.46 and mean = 1.46) were significantly lower than 2019 scores (mean = 1.65). Means on everyday choice scores were significantly lower for those with significant support needs (mean = 1.36), moderate support needs (mean = 1.36), and modest support needs (mean = 1.59) compared with those having mild support needs (mean = 1.78). For residence type, participants living in private ICFs (mean = 1.36), a relative's home (mean = 1.50) or other residences (mean = 1.46) had significantly lower everyday choice scores compared to those in community homes (mean = 1.58). Additionally, those living in their own residence (mean = 1.63) had significantly higher everyday choice scores than those living in community homes. Participants living in suburban communities (mean = 1.39) had significantly lower everyday choice scores than those living in urban communities, while those in rural communities (mean = 1.60) had significantly higher everyday choice than those living in urban communities (mean = 1.58). And, for every year increase in age, the expected value of everyday choice increased by 0.01 points (Table 5).

Table 5

Discussion

Tracking outcomes of people with IDD over time is important for several reasons, including measuring the impact of supports and services the person may be receiving, finding out to what extent people feel included in the community, and as an indicator of overall quality of life over time. Unlike in other countries (e.g., Sweden, Ireland, Australia), the US does not have a consistent way of collecting longitudinal data on the outcomes of people with IDD. The purpose of this study was to utilize a unique source of data in Pennsylvania, IM4Q, that allows for tracking a subgroup of participants with IDD longitudinally.

The main research question of this study was: Controlling for demographic and environmental characteristics, have there been increases in support-related and everyday choice between 2013 and 2019 among services users with IDD in Pennsylvania? The following results suggest that for everyday choice there has been an increase but not for support-related choice. For everyday choice, the 2019 wave of data showed growth in choice-making over time in comparison to the 2013 and 2016 waves. We emphasize that while our results do not generalize to the full complexity of the decision-making process (e.g. issues with abilities and skills), they do relate to an important aspect of this process: who ultimately chooses.

Regarding the demographic characteristics included in the models, we found higher support needs were associated with less choice-making across both types of choice. Particularly those with mild support needs indicated higher levels of choice than those with modest, moderate, or significant support needs. This finding has been consistent across research in this area (Lakin et al., 2008; Tichá et al., 2012; Houseworth et al., 2018), though measured differently via the proxy of level of intellectual disability.

Regarding environmental characteristics, both residential and community type were associated with choice-making. Those living in community homes expressed more support-related choices than those living in private ICFs and other residence types, while expressing less choice than those living in their own, a relative’s home or a family/life sharing residence. Similarly, those living in community homes expressed more everyday choice than those living in private ICFs, a relatives' home, and other residence types, while expressing less choice than those living in their own residence. It is interesting to note the primary difference is that everyday choices appear to be more limited in a relatives' home while support-related choices appear to be more accessible in family living/life sharing residences. A similar general trend has been found in that living in smaller, community-based settings, particularly in one's own home, is associated with choice-making while living with relatives is associated with more support-related choice-making, but not everyday choice-making (Tichá et al., 2012; Houseworth et al., 2018).

Those living in urban settings were more likely to make support-related and everyday choices compared to those in suburban settings. It may be that urban settings provide better and more varied transportation options to facilitate the actualization of choice for persons with IDD than is the case in suburban settings. Rural settings may rely more on familial transportation and/or have different dynamics when it comes to choices and expectations. For everyday choices only, those living in urban settings expressed less choice than those in rural settings. Again, this may have to do with a different dynamic in terms of expectations in rural environments that primarily effect the day-to-day flow of activities and choice related to those activities.

Above and beyond the effects of these demographic and environmental characteristics, we found significant increases in everyday choice-making among IDD service users in Pennsylvania. This finding suggests that in Pennsylvania, there may be changes between 2013 and 2019 that influenced increases in everyday choice-making. Next, we discuss how policy changes may be an impactful factor due to the timing of data wave collection.

HCBS Final Rule and other policy changes

The HCBS final rule was issued in 2014 by CMS. The final rule requires states to demonstrate that community-based services funded by CMS are delivered in settings that meet a clarified definition of being home and community-based or they will not be reimbursed for those services. The process for compliance with the final rule begins with person-centered planning, which is designed to assist the individual to achieve personally defined goals and, more importantly for the current study, ensure delivery of services in a manner that reflects personal preferences and choices (Centers for Medicare and Medicaid Services, 2014).

Each state is required to submit a transition plan to CMS related to the new federal requirements for reimbursement under the final rule (The Arc, 2014; Riesen & Snyder, 2019). The state of Pennsylvania completed its initial draft to CMS in 2016 and received initial approval in that same year. As of July 2020, 21 states had received final approval from CMS for their transition plan. Thus, while Pennsylvania has not received final approval, the state has cooperated with CMS to plan/implement changes to move toward the requirements of the rule.

Another policy change in Pennsylvania over this same time period was the addition and approval of a new waiver called the Community Living Waiver designed to comport with the definitions laid out by the final rule. This new HCBS waiver was approved in 2018. It provides additional resources for supports other than 24/7 residential services, another potential change that could increase choice-making opportunities for people with disabilities.

The requirements of Pennsylvania's initially approved plan to CMS include efforts to "optimize(s) individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact and facilitate(s) individual choice regarding services and supports, and who provides them" (Medicaid.gov). In this study, we found indications related to choice-making may be manifesting in the lives of service users with IDD in Pennsylvania (https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/83086). Longitudinal data analysis allows for clearer conclusions with respect to change in outcomes over time. While we cannot be sure that the improvement of choice-making over time by people with IDD in PA is solely due to its response to the final rule, we can conclude that the trend in this important aspect of community inclusion has a positive trajectory.

Support-related vs. everyday choice

In interpreting the main finding, that only everyday choice of people with IDD increased in Pennsylvania over the time frame assessed in this study, recall that previous research has strongly suggested service users with IDD make more everyday choices than support-related choices (Heller et al., 1999; Lakin et al., 2008; Sheppard-Jones et al., 2005). This trend would suggest there is more potential growth for policy to increase those support-related choices people with IDD make. This trend would also suggest efforts to increase everyday choices may be more easily accomplished. This appears to be the case in terms of the current study.

Support-related choices may be constrained by both funding and regulations along with the tendency for service providers and caregivers to assert more control over these choices (Stancliffe et al., 2011; O'Donovan et al., 2017; Bush & Tassé,2017). We suggest policies, such as the Final Rule may increase efforts to provide individuals with IDD more choice, but may still be constrained by some of the same funding and regulatory limitations that would make changes in support-related choice more difficult to achieve for many individuals. Further, policy changes such as the Final Rule may take longer to change the culture of decision-making in which longer-term choices of more significance (e.g. where one will live) come with a stronger tendency for the system and other stakeholder (e.g. family) to intercede.

Therefore, our results may reflect the more difficult task for policy to increase the ability for individuals to make support-related choices independently in a system with these constraints with tendencies to be protective of the long-term consequences of those decisions. It may take more flexibility within the system and shift in the culture in terms of expectations for people with IDD that current policy does not directly address or will take more time to manifest in the reality of people’s lives.

Limitations

One important limitation to consider is that we only assessed one state. It may be that change in choice-making over this same time period is inconsistent across states, thus challenging the generalizability of our findings here nationwide.

Similarly, not all IM4Q participants were included in each wave of data collected. Therefore, we have a sample limited to those who chose to participate in all three waves of data. It may be that if larger efforts were made to include the same people in each wave (a more truly longitudinal design), results would differ.

Next, we were limited to the items available on the IM4Q instrument and their capacity for forming reliable scales. Therefore, our ability to explore choice-making was limited to those scales, limited our ability to explore other aspects of and theoretical definitions of choice-making that may be of importance.

Finally, we do not have a direct measure or indicator of how or to what degree the policy changes that may explain increases in choice-making actually impacted our sample versus other potential explanations. Other changes unrelated to HCBS policy could impact the degree of choice-making among HCBS services users. Therefore, casual conclusions cannot be made.

Conclusion

The following study is the first to our knowledge to consider change in choice-making over time, an important indicator of rights and inclusion of persons with IDD. By comparing three waves of data from the state of Pennsylvania (2013, 2016, and 2019), we were able to detect changes in everyday choice-making among HCBS services users with IDD, a period before and after significant policy initiatives related to the quality of life of this population. The same cannot be said for support-related choices, choices of more long-term consequences perhaps more resistant to change due to funding and other constraints. However, we have indications policy changes have encouraged an increase in the benefits of community living for people with IDD similar to those without IDD. We have found indications this policy may have effectively explored a method by which future studies can continue to examine the effects of policy changes in disability research.

Future Directions

Future research should seek to include more states and participants in assessing the impact of policy longitudinally. The reason the current study is unique and only included one state is due to the lack of longitudinal data that track the same people over time in the US. Building high-quality databases of information on the quality of life of HCBS service users would allow for better assessment of the effectiveness of policy and policy changes on the lives of people with IDD. This research would help to maximize the effectiveness of money spent on services by ensuring better causal inferences and a person-centered approach to this assessment.

Future research should include a range of outcomes related to quality of life (e.g., employment, community inclusion) to provide a more complete picture of change over time before and after significant policy changes, such as the HCBS final rule.

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Table 1

Descriptive statistics for Variables of Interest (N=9,888)

Categorical variables				
Type of Residence	N	%		
Community homes	4,410	44.6		
Relative home	3,691	37.4		
Private ICF	231	2.3		
Family living/Life sharing	583	5.9		
Own residence	674	6.8		
Other residence*	399	3.0		
Total	9,888	100.0		
Community Type	N	%		
Urban	5,302	53.6		
Suburban	1,785	18.1		
Rural	2,801	28.3		
Total	9,888	100.0		
Supported Need	N	%		
Significant	2,248	22.7		
Moderate	2,104	21.3		
Modest	2,658	26.9		
Mild	2,878	29.1		
Total	9,888	100.0		
Continuous Variables				
Age	N	Mean	SD	Range
Age in Years 2013	3,220	44.5	15.4	9 to 92
Age in Years 2016	4,327	43.3	16.4	7 to 95
Age in Years 2019	4,249	42.2	15.4	18 to 92
Support-related Choice 2013	3,304	0.79	0.66	0 to 2
Support-related Choice 2016	4,108	0.80	0.64	0 to 2
Support-related Choice 2019	3,853	0.90	0.70	0 to 2
Everyday Choice 2013	3,497	1.52	0.52	0 to 2
Everyday Choice 2016	4,332	1.52	0.52	0 to 2
Everyday Choice 2019	4,181	1.75	0.40	0 to 2

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 type.

Table 2

Support-related Choice Repeated Measures Mixed Regression Summary (N=9,195)

				95% Confidence Interval		
Variables	Estimate	SE	t	Lower Bound	Upper Bound	p
Age in Years	0.01	0.00	4.15	0.00	0.01	**<0.001**
Survey 2013	0.00	0.01	0.09	-0.03	0.03	0.930
Survey 2016	0.01	0.01	1.095	-0.01	0.04	0.273
Survey 2019*						
Significant Support Needs	-0.38	0.02	-20.69	-0.42	-0.35	**<0.001**
Moderate Support Need	-0.42	0.02	-22.85	-0.45	-0.38	**<0.001**
Modest Support Need	-0.23	0.02	-13.75	-0.26	-0.20	**<0.001**
Mild Support Need*						
Other Residence	-0.10	0.03	-2.95	-0.17	-0.03	**0.003**
Own Residence	0.56	0.03	21.24	0.51	0.61	**<0.001**
Family Living/Life Sharing	0.46	0.03	18.23	0.41	0.51	**<0.001**
Private ICF	-0.19	0.04	-4.75	-0.26	-0.11	**<0.001**
Relative Home	-0.24	0.02	14.71	0.21	0.27	**<0.001**
Community Home*						
Rural	0.02	0.01	1.37	-0.01	0.05	0.171
Suburban	-0.10	0.02	-6.105	-0.13	-0.07	**<0.001**
Urban*						
Constant	0.89	0.03	31.61	0.82	0.92	**<0.001**

Note. * Referent group ** Age F(1,855) = 17.196; Survey year F(2,8071) = 0.771; Support Needs F(3,8467) = 207.856; Residence F(5,8958) = 161.768; Community Type F(2,8558) = 24.119. The estimate of the residual was 0.36, and the 2 log likelihood = 19,586.563 for 16 parameters.

Table 3

Repeated Measures Support-related Choice Estimated Means

Variables	Mean Support-related Choice	SE	95% Confidence Interval Lower Bound	95% Confidence Interval Upper Bound
Survey 2013	0.83	0.01	0.80	0.85
Survey 2016	0.84	0.01	0.81	0.87
Survey 2019	0.83	0.01	0.80	0.85
Significant Support Needs	0.71	0.02	0.68	0.74
Moderate Support Need	0.67	0.02	0.64	0.71
Modest Support Need	0.86	0.02	0.83	0.89
Mild Support Need	1.09	0.01	1.06	1.12
Other Residence	0.57	0.03	0.50	0.63
Own Residence	1.23	0.02	1.18	1.27
Family Living/Life Sharing	1.13	0.02	1.08	1.18
Private ICF	0.48	0.04	0.41	0.56
Relative Home	0.91	0.01	0.88	0.93
Community Home	0.67	0.01	0.65	0.69
Rural	0.88	0.01	0.85	0.90
Suburban	0.76	0.02	0.73	0.79
Urban	0.86	0.01	0.83	0.88

Table 4

Everyday Choice Repeated Measures Mixed Regression Summary (N=9,817)

				95% Confidence Interval		
Variables	Estimate	SE	t	Lower Bound	Upper Bound	p
Age in Years	0.01	0.01	5.44	0.00	0.01	**<0.001**
Survey 2013	-0.19	0.01	-18.57	-0.21	-0.17	**<0.001**
Survey 2016	-0.20	0.01	-20.95	-0.21	-0.18	**<0.001**
Survey 2019*						
Significant Support Needs	-0.41	0.01	-31.19	-0.44	-0.39	**<0.001**
Moderate Support Need	-0.42	0.01	-32.18	-0.44	-0.39	**<0.001**
Modest Support Need	-0.18	0.01	-14.87	-0.20	-0.15	**<0.001**
Mild Support Need*						
Other Residence	-0.11	0.03	-4.61	-0.17	-0.07	**<0.001**
Own Residence	0.05	0.02	2.63	0.01	0.09	**0.009**
Family Living/Life Sharing	0.03	0.02	1.43	-0.01	0.06	0.154
Private ICF	-0.21	0.03	-7.43	-0.27	-0.16	**<0.001**
Relative Home	-0.08	0.01	-6.86	-0.10	-0.06	**<0.001**
Community Home*						
Rural	0.03	0.01	2.71	0.01	0.05	**0.007**
Suburban	-0.18	0.01	-15.63	-0.21	-0.16	**<0.001**
Urban*						
Constant	1.94	0.02	98.03	1.90	1.98	**<0.001**

Note. * Referent group ** Age F(1,9740) = 29.608; Survey Year F(2,8429) = 257.205; Support Needs F(3,9366) = 459.009; Residence F(5,9725) = 28.980; Community Type F(2,9418) = 150.496. The estimate of the residual was 0.19, and the 2 log likelihood = 13,661.092 for 16 parameters.

Table 5

Repeated Measures Everyday Choice Estimated Means

Variables	Mean Everyday Choice	SE	95% Confidence Interval Lower Bound	95% Confidence Interval Upper Bound
Survey 2013	1.46	0.01	1.44	1.48
Survey 2016	1.46	0.01	1.44	1.48
Survey 2019	1.65	0.01	1.63	1.67
Significant Support Needs	1.36	0.01	1.34	1.39
Moderate Support Need	1.36	0.01	1.33	1.38
Modest Support Need	1.59	0.01	1.58	1.62
Mild Support Need	1.78	0.01	1.76	1.80
Other Residence	1.46	0.03	1.41	1.51
Own Residence	1.63	0.02	1.60	1.66
Family Living/Life Sharing	1.61	0.02	1.57	1.64
Private ICF	1.36	0.03	1.31	1.42
Relative Home	1.50	0.01	1.48	1.52
Community Home	1.58	0.01	1.57	1.59
Rural	1.60	0.01	1.58	1.62
Suburban	1.39	0.01	1.37	1.42
Urban	1.58	0.01	1.56	1.59