Measuring Four Personal Opportunities for Adults with Intellectual and

Developmental Disabilities

Abstract

This study tests an empirically-derived model for measuring personal opportunities for people with intellectual and developmental disabilities (IDD) using National Core Indicators In-Person Survey (NCI-IPS) state and national datasets. The four personal opportunities measured: 1) privacy rights, 2) everyday choice, 3) community participation, and 4) expanded friendships were informed by existing conceptualizations of service as well as NCI-IPS measures. Analyses confirmed the fit of a four-factor model and demonstrated that factors were significantly and positively correlated. To demonstrate the relationships between personal opportunities and personal and environmental characteristics, we estimated a structural equation model that regressed personal opportunities on age, gender, place of residence, and level of intellectual disability. Implications for using personal opportunities for evaluating service quality of IDD systems are discussed.

Keywords: Measurement, privacy, community participation, choice, friendship

**Measuring Four Personal Opportunities for Adults with Intellectual and
Developmental Disabilities**

The Centers for Medicare & Medicaid Services (CMS) partners with states to assure and
improve the quality of Medicaid Home and Community Based Services (HCBS) for adults with
intellectual and developmental disabilities (IDD). The primary service goals are to integrate
people with IDD into their communities, maximizing the quality of life, independence, health
and well-being of people who use HCBS (CMS, n.d.) Depending on their needs and the service
array received, people can experience a range of positive outcomes related to health, safety,
relationship building, and community participation.

Definitions of quality services often vary throughout the United States and consequently
the ways quality is monitored remain relatively diverse. The National Quality Forum has guided
ongoing processes to improve clarity about the conceptualization of quality services (2015;
2016). Quality services enhance human rights such as privacy, dignity and respect while
providing *opportunities* for choice, social connectedness, and community participation
(Friedman, 2018a; National Quality Forum, 2015). Quality services are shaped by and fulfill the
needs and preferences of the service users.

People with IDD experience persistent barriers in their ability to exercise personal rights,
make everyday choices, engage in community activities, and develop meaningful relationships.
These barriers have been addressed at a systems level via litigation, policy, and regulation that
promote independence, full participation, inclusion, and equal opportunity for people with IDD
(Hewitt et al., 2016; Rich et al., 2002). A recent example of this can be seen in the Medicaid
Home and Community-Based Services (HCBS) Final Rule (CMS 2249-F/2296-F). This
regulation is specifically focused on the development and implementation of "innovative

strategies to *increase opportunities* [emphasis added] for Americans with disabilities and older adults to enjoy meaningful community living." In other words, the Final Rule mandates that states work to enhance HCBS service quality.

Opportunities

People are more aware of their capabilities when given opportunities to assess and enact their potential. The administration of high-quality services and supports should accentuate opportunities while lower quality supports can extinguish opportunities (Bradshaw et al., 2018). Health and safety are often provided as a rationale for limiting opportunity, but only through opportunities can people with IDD prove to themselves and others that they can remain safe when making choices regarding their privacy, activities, community participation or relationships (Petner-Array et al., 2015). Reinders and colleagues (2014) reported that opportunities are developed by building on strengths and capabilities, infusing human and legal rights and resulting in personal development.

Opportunity expands as people with IDD are provided with a wider range of options to fully participate in decision making and community life. For example, young people with IDD participating in paid work experiences during high school are more likely than their peers that have no or unpaid work training to attain paid, integrated employment in early adulthood (Carter et al., 2012; Simonsen & Neubert, 2012). Likewise, when people with IDD are given opportunities to make more choices they develop greater self-determination (Wehmeyer & Garner, 2003; Williams-Diehm et al., 2008). More commonly though, people with IDD have limited opportunities to make their own choices, participate in desired activities, or to fully engage in their communities in ways that are typical for people without IDD, making

opportunity, in its own right, an important outcome for people with IDD (Bradley & Moseley, 2007; Shogren et al., 2009).

Measuring quality and opportunity

Ideally, measures of service quality should capture both the nature of the services provided and the opportunities that the services produce. Many existing measures, such as the National Core Indicators In Person Survey (NCI-IPS; HSRI & NASDDDS, n.d.), the Personal Outcome Measures (Friedman, 2018b), and the Money Follows the Person Quality of Life Survey (Sloan & Irvin, 2007), address core domains and subdomains of quality and opportunity including privacy rights, choice, community participation and social relationships. Therefore, efforts to improve the measurement of quality services should use existing measures to construct standardized scales (National Quality Forum, 2016).

The Center for Medicaid and CHIP Services recognized the NCI-IPS as a core measure of quality for adults enrolled in Medicaid services, including HCBS (NASDDDS, 2019). The present study used national NCI-IPS data from 2017-2018 to test measurement models for four empirically generated domains of personal opportunities: privacy rights, everyday choice, community participation, and expanded friendships. These factors were chosen because they represent five subdomains of quality: privacy, personal freedoms and dignity of risk, personal choice and goals, social connectedness and relationships, and resources and settings to facilitate inclusion. These subdomains are among 40 deemed as "the most important areas for quality measurement in HCBS" (National Quality Forum, 2016, p.10). Also, the factors build upon previously operationalized NCI-IPS measures, including Everyday Choice (Lakin et al., 2008), Social Participation and Relationships (Mehling & Tasse 2014a; 2014b), and Home Privacy (Houseworth et al., 2019).

        This study expands on previous work by describing the relationship between these factors

and providing examples of personal and service characteristics that predict opportunities. The

analytical steps that were employed provide a simple heuristic for developing and using quality

measures from the NCI-IPS to support quality monitoring and improvement.

        This study addresses the following three research questions:

1. Does a state-derived model of personal opportunities fit data from a national sample?

2. Are personal opportunities correlated and how?

3. In what way do basic contextual variables predict personal opportunities?

Method

        All methods described in the following section were reviewed and approved by the

Virginia Commonwealth University Institutional Review Board.

Data Source

        The National Core Indicators (NCI) are a collection of nationally-validated surveys of

people with IDD, their family members, and support workers that was developed by the National

Association of State Directors of Developmental Disabilities Services (NASDDDS) and the

Human Service Research Institute (HSRI). This study used the NCI-IPS, formerly known as the

Adult Consumer Survey, which was administered in 35 states and the District of Columbia in

2017/2018.

        The NCI-IPS is administered in an interview format with people with IDD aged 18 and

older who use at least one public IDD service in addition to case management. The survey has

multiple sections. A background section collects demographic and basic health status

information and is often completed by a case manager or other individual with access to

administrative file information. The in-person portion of the NCI-IPS is administered directly

with the person with IDD by a trained interviewer. The first part of the in-person section of the

NCI-IPS must be answered by the person with IDD directly, but the second part permits proxy

response, if needed.

Procedure

The development of the personal opportunities measures began by examining NCI-IPS

data from [name of state redacted for peer review]. Items from previously developed NCI-IPS

factors were used to build measurement models. Included were various measures of choice:

Everyday Choice (Lakin et al., 2008), Choice (Neely-Barnes et al., 2008), and Social

Determination (Mehling & Tasse, 2014b); rights: Rights (Neely-Barnes et al., 2008), Home

Privacy (Houseworth et al., 2019); and community and social inclusion: Social Participation and

Relationships (Mehling & Tasse, 2014b), Relationships, Community Inclusion (Neely-Barnes et

al., 2008). Confirmatory factor analysis was used to test item loadings and the fit of models to

state NCI-IPS data. The process and results used for arriving at the four-factor model of personal

opportunities are outlined in the supplementary information

(https://osf.io/5jk7h/wiki/home/?view_only=b821d9a3f906455f88f2036879f2612e). Permission

was sought and granted from HSRI and NASDDDS to determine the fit of the four-factor model

to the 2017/2018 national NCI-IPS data.

Variables

Privacy Rights

Two variables were used to construct the privacy rights factor, both of which came from

Part II of the IPS, a section completed by the person with IDD or by a proxy respondent (i.e.,

friend/family, staff, other). The two variables in this grouping asked a) whether a person with

IDD had a key to their home; and b) whether the person could lock their bedroom door when

desired. Both had three response options (yes; maybe; no). We dichotomized responses to 1=
"no" and 2= "yes and maybe." Uneven group sizes across response categories drove the choice
to dichotomize responses. Dichotomization was used in order to facilitate more robust analyses
while maintaining the overall meaning of the variables.

Everyday Choice

The daily choices variables all come from Section II and were answered either by a
person with IDD or a proxy respondent. Three variables exist in this grouping: (a) whether the
person with IDD reported having choice over their daily schedule, (b) whether the person can
choose how to spend free time, and (c) whether the person can choose what to buy. These are the
same items used previously to measure "short-term decision making" (Bush & Tasse, 2017) and
everyday choice (e.g., Lakin et al., 2008). Each item relied on three primary response options
which we rescaled as 1= "Someone else chose", 3= "Person had some input", and 2= "Person
made the choice." The "some input" option for choosing what to buy with one's spending money
varied slightly and was "person has help choosing what to buy, or has set limits (such as can buy
small items, but not big items)". Responses were dichotomized under the same rationale that
was applied to Privacy Rights (1= "someone else chose" and 2= "made choice or had input in the
choice").

Community Participation

Many of the variables in the community participation grouping have been included in
previously formed measures such as "community inclusion" (e.g., Neely-Barnes et al., 2008) and
"social participation and relationships" (Mehling & Tasse, 2014b). Measured in this way,
community participation is akin to physical integration and is not the same as terms such as

community inclusion, social inclusion, or social participation, though they are sometimes used

interchangeably.

The four variables in this section all come from Part II of the IPS. The four variables

were how often: (a) did the person with IDD go out shopping in the past month, (b) did the

person with IDD go out for errands in the past month, (c) did the person go out for entertainment

in the past month, and (d) did the person go out to eat in the past month. All responses related to

frequency of participation in a community activity in the past month and ranged from 1 (0 times)

to 4 (More than 5 times).

Expanded Friendships

Friendship items comprised the final group in the Personal Opportunities model. In

addition to frequency of participation in community activities, the IPS (Part II) included items to

capture with whom respondents usually participated in community activities in the month prior.

Response options included alone, friends, family, housemates or co-workers, staff or others. We

used the dichotomous response (1=no; 2=yes) of "friends" for seven community activities. The

activities considered were: (a) shopping, (b) errands or appointments, (c) going to community

groups, (d) going out for entertainment, (e) going to restaurants or coffee shops, (f) attending

religious services or spiritual practices, and (g) going on vacation.

This factor also included a friendship item used previously to determine if friendship of

NCI respondents were 'limited' or 'expanded.' (Giordano et al., 2016). This item asked "Do you

have friends you like to talk to or do things with?" and we recoded the response options to be

1="No, does not have friends," 2="Yes, all friends are staff or family," or 3= "Yes, has friends

who are not staff or family." A response of 1 indicated limited friendships and a response of 2,

along with the other items in the factor, when affirmative, were indicative of expanded friendships.

Personal Characteristics and Residential Context

Gender, age, level of intellectual disability and type of residence were collected using the background information section of the NCI-IPS which was completed by referring to existing records. Age was calculated from date of birth. Gender response options were male, female, or other. We recoded this variable so female was 1 and male was 0. The "other" category had only three responses nationally and were not included in analyses.

Level of intellectual disability was a follow-up question to an item which asked whether the person had been diagnosed with ID (1=No; 2=Yes; 99=Don't know). When initial responses were affirmative then the level of ID noted in personal records were recorded as either (1) mild, (2) moderate, (3) severe or (4) profound. Additional responses included "no ID diagnosis," "unspecified level of ID" or "ID diagnosis unknown."

The NCI-IPS included 15 residence types, including "other" and "unknown." Our data did not include people living in institutions such as intermediate care facilities. We combined host homes for one individual with a disability with host homes for two or more individuals with disabilities to create a single host home category. Final categories included 2-3 bed group homes, 4-6 bed group homes, 7-15 bed group homes, living with family, living independently, and host homes.

Sample

As highlighted earlier, the development of the Personal Opportunities Scale began by examining NCI-IPS data from [name of state redacted for peer review]. To validate the scale with a larger, more diverse sample we used the national 2017/2018 NCI-IPS dataset, which

contained a total of 25,671 participants from 35 states and the District of Columbia. Many states

contributed approximately 400 IPS responses, since this was the minimum number

recommended in guidance from NASDDDS and HSRI.

Nationally, participants in the 2017/2018 NCI-IPS dataset had a mean age of 42 years

and 59% were male. The sample's racial composition was 67% White, 16% Black, and 10%

Latinx, with other racial identities present in smaller numbers. The majority of participants in the

national sample ranged in age from 26 to 58 years. The youngest participants were 18 years old

and the oldest was 95 years old. Additional information about the NCI-IPS sample, both

nationally and in [name of state redacted] is available in the 2017/2018 IPS Report (HSRI and

NASDDDS, 2019).

Analysis

Data analysis was carried out in three phases, corresponding to the three primary research

aims of the study. First, confirmatory factor analysis (CFA) was used to test the relative fit of a

series of factor models for personal opportunities. For each CFA, we tested a tau equivalent

model, where item loadings were fixed to be equal, and a congeneric model, where all item

loadings were allowed to freely vary except the first item, which was fixed at one to scale the

latent variable. This approach, recommended by Brown (2015), allowed us to test the relative fit

of models with increasing complexity, both in terms of the dimensionality of the latent construct

(one vs. four factors) and in terms of the weighting of each item.

Data analysis was conducted using Mplus Version 7.11 (Muthén and Muthén, 1998-

2017) with the mean- and variance-adjusted weighted least squares estimator (WLSMV) for all

CFA SEM models. To explore missing data patterns, Little's MCAR test (Little, 1988) was used

as an omnibus test to determine whether the data could be assumed missing completely at

random (MCAR). The results of this test suggested that the data could not be treated as MCAR, thus requiring estimation procedures that are more robust to missing data.

To address potential bias due to missing data, we compared our preferred estimates above with model results estimated via full information maximum likelihood (FIML) using the MLR estimator in Mplus. Overall, rates of missingness were quite low for most survey questions, with more than 90% of individuals recording a response for community participation, everyday choice, and privacy rights. Missingness was higher for "Do you have friends you like to talk to or do things with?" which necessitated that we compare our preferred results with those generated via FIML in order to ensure that potential bias due to missing data had not occurred. Estimates did not differ in terms of magnitude or significance and are available from the authors on request.

Data Assumptions and Model Fit/Parsimony

We used the mean- and variance-adjusted weighted least squares estimator (WLSMV in MPlus) and Satorra-Bentler's (2001) scaled chi-square (S-B χ 2) to examine model fit for all CFA and SEM models. In addition to the S-B χ 2, we also used the comparative fit index (CFI), standardized root-mean-square residual (SRMR), and root-mean-square error of approximation (RMSEA) with a 90% confidence interval to assess model fit. We adopted Hu and Bentler's (1999) guidelines for assessing acceptable model fit, which include CFI $\geq$ .95, SRMR $\leq$ .08, and RMSEA $\leq$.06. In cases where the CFI value was below the suggested threshold, we then used Hu and Bentler's (1999) recommendations to simultaneously evaluate SRMR and RMSEA, with RMSEA $\leq$ .06 and SRMR $\leq$ .10 indicating an acceptable model fit.

Latent Correlations

To estimate the latent correlations between our personal opportunity factors, we used the TECH4 procedure in MPlus (Muthén and Muthén, 1998-2017). This is a diagnostic routine that provides a covariance matrix, correlation matrix, and corresponding *p*-values for all latent variables specified in a given model.

Impact of Personal Characteristics and Residential Contexts

To determine the relationship between personal characteristics, residential contexts, and the personal opportunity scales, we estimated a structural equation model that included factors for all four personal opportunities and regressed those factors on to a set of predictors including the demographic and personal characteristics described above. This is similar to running a multivariate regression model with four simultaneous outcomes, in that we were able to account for each individual's correlation between each of the four measures of personal opportunity. Further, by fitting this model in an SEM framework, we were able to account for measurement error at the item and construct levels while obtaining our regression estimates.

Results

Correlations

Table 1 presents item-level polychoric correlations between all items used in this study. Polychoric correlation is used to determine the strength of association between two ordinal variables with two or more categories (Jöreskog 1994; Olsson 1979). This approach is especially preferred when conducting CFA with ordinal variables composed of less than five categories (Rhemtulla et al. 2012), which is often the case when working with NCI data. A number of individual correlations occurred in the .30-.50 range. No items demonstrated consistently weak correlations below .10, and no items demonstrated exceedingly large correlations above .80 that may hinder the detection of distinct and interpretable factors.

Investigating Alternative Factor Structures

Having examined the polychoric correlation matrix and finding it suitable for factor analysis, we then used CFA to investigate the underlying factor structure of the selected items. The initial working hypothesis was that the items would best be represented by four latent factors, PRIVACY RIGHTS, EVERYDAY CHOICE, COMMUNITY PARTICIPATION, and EXPANDED FRIENDSHIPS. To confirm this, we began by testing a model that included all factors in one latent factor (a plausible rival hypothesis), then tested the four-factor model. For each class of model, we compared a tau-equivalent model with a congeneric model in order to best represent the underlying item loading patterns.

Four separate CFA models were tested. Model fit and parsimony statistics are available in Table 2. Model 4, the four-factor model with congeneric item loadings demonstrated the best model fit and parsimony according to the guidelines suggested by Hu and Bentler (1999). In contrast, the one-factor model with tau-equivalent items demonstrated the worst fit and parsimony. Chi-square difference tests were significant for the comparisons between models 1 and 2, 2 and 3, and 3 and 4, respectively (all ps < .001). Therefore, the four-factor model with congeneric items appears to be a more accurate representation of the underlying constructs. Figure 1 shows a path diagram representing model 4, the best-fitting model that was tested.

Factor Correlations and Regressions

Factor Correlations

Correlations between the four personal opportunities are shown in Table 3. All of the factors were significantly and positively correlated as expected for factors conceptually related. The relationships between latent factors varied in strength. Some correlations were weak (CHOICE with COMPAR; CHOICE with FRIENDS), some were moderate (RIGHTS with

COMPAR; RIGHTS with FRIENDS; COMPAR with FRIENDS) and one was strong (RIGHTS

with CHOICE).

Personal Characteristics and Residential Contexts

Basic personal characteristics (age, gender, level of intellectual disability) and place of

residence were included as predictors of personal opportunities in four multiple regression

models. Complete results are displayed in Table 4.

Gender. Participants' gender predicted personal opportunity factors, except for everyday

choice. Gender had a small but significant contribution to models for privacy rights, community

participation, and friendship. Women had fewer privacy rights than men but had more

community participation and friendship.

Age. In the regression models, age significantly predicted all personal opportunities.

Older participants reported more rights and everyday choice, factors which tended to vary

together. However, older adults were also more isolated than their younger counterparts; younger

participants reported more friendships and community participation.

Level of Intellectual Disability. Disability status was the strongest predictor of everyday

choice and privacy rights, which are two closely related personal opportunities. Between each

level of ID – from mild to profound – everyday choice decreased pointedly. Decreases in

opportunity for everyday choice and privacy rights were most pronounced between mild and

moderate and moderate and severe, with smaller decreases between severe and profound ID. For

community participation, differences between mild and moderate were significant. The

differences in community participation for people with mild ID compared with severe and

profound ID were much larger. The relationship between level of ID and friendship differed

from the other variables. Those with mild ID had more expansive friendships, while those with

moderate, severe, and profound ID had friendships that were similarly constricted.

Type of Residence. Residence type broadly predicted personal opportunities. Those

living independently showed the strongest outcomes for privacy rights, everyday choice, and

friendships, though friendships were somewhat similar among people who lived with their

families. People living in host homes had the most community participation. There were no

statistical differences in community participation when comparing the different group home sizes

(e.g., 2-3 bed, 4-6 bed, or 7-15 bed). People living with their families or living independently in

their own home or apartment participated in the community at greater frequencies than people

living in group homes of any size, although not as frequently as those living in host homes.

Those with the least everyday choice lived with their families or in 4-6 bed group homes and

those with the fewest privacy rights also lived in 4-6 bed group homes. People living in larger

group homes had more expansive friendships than those in 2-3 bed group homes.

Discussion

This research responded to a national call to configure components of existing measures

to monitor fundamental characteristics of quality HCBS (National Quality Forum, 2016). We

used national NCI data to evaluate the factorial validity of a state-constructed model of personal

opportunities consisting of 4 latent factors: privacy rights, everyday choice, community

participation, and expanded friendship. We confirmed that the state-level structure of personal

opportunities demonstrated good fit with national NCI-IPS data (RQ1) and the model

demonstrated better fit than a single factor model. These results add to ongoing efforts at quality

measure development, and can be used to better understand, evaluate, and strengthen personal

opportunities for HCBS users with IDD.

Latent Factor Correlations

The study also examined relationships between four personal opportunities. Pairwise correlations between latent factors, each representing a personal opportunity, were all positive and significant (RQ2). These results support the possibility that personal opportunities share common contextual origins, even when opportunities represent seemingly distinct quality domains. These contexts can range from a person's adaptive behaviors to the training that direct support professionals receive to broaden rather than constrain opportunities (Qian et al., 2015).

For example, privacy rights and everyday choice were the two most strongly correlated opportunities. Similar findings have been reported elsewhere (e.g., Jones et al., 2018). Although there are many possible reasons why choice and privacy rights are highly correlated, one potential explanation can be attributed to the culture of one's home environment. In the context of IDD services and supports, Bigby & Beadle-Brown (2016) describe culture simply as the way things are done within the home environment. Both the privacy rights and choice factors are concerned with issues of access, such as whether people are given options to choose their daily schedule or to lock their bedroom door. When high-quality residential services promote a culture of respect, autonomy, or empowerment, then greater opportunities for everyday choice and privacy rights may co-develop in parallel. Conversely, more restrictive living environments may limit access to everyday choice and privacy rights.

A significant relationship between community participation and everyday choice is supported by existing literature (Heller et al., 2002; Verdonschot et al., 2009). However, in our analysis, this relationship, while statistically significant, was fairly weak. Differences in individual preferences may account for the relatively weak relationship between community participation and choice (Carter et al., 2013). While explanations for this are not entirely clear, it

is possible that some people may exert choice by opting not to engage in community activity. Another possible explanation is that community participation often requires additional resources (i.e., transportation, spending money, supporter's time) necessary to engage in activities such as shopping or going out to eat (Simplican et al., 2015).

External factors may similarly account for the relatively weak, positive relationship between expanded friendship and everyday choice. Supporters, including paid staff and family, often play a pivotal role in helping people with IDD to foster and maintain friendships (Clifford et al., 2016; Friedman & Rizzolo, 2018). As seen with community participation, additional support requires increased external investment. Although quality HCBS should advance social inclusion through supporting opportunities for relationships to develop between people, friendships often survive or fail by the mutual efforts of two parties. Investments of time, interest, respect, and support are needed to build and maintain friendship outcomes.

Contexts and Personal Opportunities

The degree to which contextual factors impact personal opportunities was tested empirically. We modeled how systems can use latent scores from personal opportunities measures to explore differences in opportunities among HCBS users. This is important because quality services should improve rights and opportunities. However, we were able to show that service contexts (i.e., type of residence) and personal characteristics (e.g. age, gender, and level of intellectual disability) were predictive of greater opportunities (RQ3).

Type of residence predicted most outcomes, but the variable's relationship to privacy rights showed particularly discernable patterns. Smaller residences that best approximated home environments were the best predictors of more privacy rights. People who lived independently had the most control of their residential privacy and people living with their families or in host

homes also had more privacy rights than people living in group homes. Privacy among people with IDD living in group homes may be influenced by a combination of personal characteristics and contextual elements, such as changes in support persons, which may be more stable for people living in host homes or with their families (Qian et al., 2019).

Many of these patterns held across personal opportunities. Findings echoed Friedman's (2017; 2019) studies, which found that people living in group homes had less community, friendships, and social capital than those living independently or with families. People living in group homes of all sizes had lower levels of community participation and friendships compared to those living independently or with parents. People living independently had more personal opportunities than those in group homes, and like previous studies (Lakin et al, 2008; Ticha et al, 2012), we found everyday choice was greatest for those living independently. However, there was not a direct linear relationship between size of residence and everyday choice. We found that people living in 7-15 bed group homes reported more everyday choice than people who lived in smaller group homes and people living with family.

Overall findings indicated that level of ID is a powerful predictor of personal opportunities, which is in line with extant literature (Houseworth et al., 2018; Lakin et al., 2008; Nord et al., 2018; Ticha et al., 2012). With each increase in level (e.g., mild compared to moderate ID), indicators of personal opportunity typically decreased. This inequitable access to opportunities between people with different levels of ID demands that HCBS and other service systems review their procedures and make direct efforts to minimize disparities. Opportunity measures provide systems with a mechanism to further identify and address disparities based on a range of characteristics such as race, urbanicity, co-occurring behavior health conditions, to

assure increased equity among people who use supports and services to participate in their

communities.

Limitations and Future Research

Our recommended measures for assessing personal opportunities capture many important

outcomes, but our model of personal opportunities is not an exhaustive encapsulation of all

forms of opportunity related to HCBS. The four factors that were the focus of this study –

privacy rights, everyday choice, community participation, and expanded friendships – represent

just a modest proportion of HCBS quality areas that have been identified as critical to measure

(National Quality Forum, 2016). Future work ought to address and include meaningful activities

(e.g., employment), self-direction, and long-term choices related to supports and services.

Additionally, systems intending to use the measures of personal opportunities presented

for planning and evaluation are advised to examine whether the measure maintains acceptable fit

with their state's NCI-IPS data. Nationally validated measures that have appeared in the

literature were evaluated as part of this research team's state-based analyses (e.g., Mehling &

Tasse, 2014b). Most of these measures showed poor fit to our state's data over multiple years,

driving our development and validation of measures that fit our state's data and national data.

The effects of proxy responses in section II of the NCI-IPS should also be further explored

because it is possible that the factor structure of certain personal opportunities could vary

depending on respondent.

Like previous studies, level of intellectual disability was often related to personal

outcomes. People with mild ID always fared better than people with greater support needs.

Dinora and colleagues (2020) recently provided a more thorough examination of relationships

between outcomes and support needs by merging NCI-IPS data with more sensitive measures of

support needs, such as the Supports Intensity Scale (SIS; Thompson et al., 2004). By merging

NCI data with SIS data researchers can support their systems in identifying adaptive behaviors,

rather than level of ID, that best predict improved personal outcomes.

Implications for Inclusion

The results of this work extend a growing body of research that uses NCI-IPS datasets to

measure important constructs related to service quality (see Houseworth et al.2019; Lakin et al.,

2008; Mehling & Tasse, 2014a; Neely-Barnes et al., 2008), but stakeholders need access to more

reliable and valid measures to evaluate IDD service system performance (Tichá et al., 2013).

Policymakers are also in need of these data to inform decisions regarding the considerable public

investment in HCBS. As stated by Owen and colleagues (2015), data must form the basis for

policy decisions in long-term services and supports so that limited resources can be used to

achieve the best outcomes for people with IDD. Our measure of personal opportunities is

intended to provide reliable, sound measurement about a fundamental expectation of IDD service

systems that can be used in conjunction with other compliance and personal outcome measures

to inform programmatic and policy decision making.

Because opportunities influence a variety of personal outcomes for people with IDD (see

Carter et al., 2015; Wehmeyer, 1997), this measure may have particular utility as a macro-level

indicator in the context of evaluating state-based policy or service system change over time. The

HCBS final settings rule and other recent regulations have a particular mandate to increase

opportunity for people with IDD to be full, contributing members of their communities.

Measures of personal opportunities can also provide high-level indicators of progress towards

primary objectives of U.S. policy, such as the Olmstead decision (1999) and the Integration

Mandate of Title II of the Americans with Disabilities Act. The enforcement of these regulations

assures that people with IDD can live, work, and fully participate in their communities, much

like people without disabilities, and measures such as the ones presented may be used to

benchmark progress made when people are given a chance.

References

Bigby, C., & Beadle-Brown, J. (2016). Culture in better group homes for people with intellectual

disability at severe levels. *Intellectual and Developmental Disabilities*, *54*(5), 316–331.

https://doi.org/10.1352/1934-9556-54.5.316

Bradley, V. J., & Moseley, C. (2007). National Core Indicators: Ten Years of Collaborative

Performance Measurement. *Intellectual and Developmental Disabilities*, *45*(5), 354–358.

https://doi.org/10.1352/0047-6765(2007)45[354:ncityo]2.0.co;2

Bradshaw, J., Beadle-Brown, J., Richardson, L., Whelton, B., & Leigh, J. (2018). Managers'

views of skilled support. *Journal of Applied Research in Intellectual Disabilities*, *31*(5),

873–884. https://doi.org/10.1111/jar.12444

Brown, T. A. (2015). *Confirmatory factor analysis for applied research*. Guilford.

Bush, K. L., & Tassé, M. J. (2017). Employment and choice-making for adults with intellectual

disability, autism, and down syndrome. *Research in Developmental Disabilities*, *65*, 23–

34. https://doi.org/10.1016/j.ridd.2017.04.004

Carter, E. W., Austin, D., & Trainor, A. A. (2011). Predictors of postschool employment

outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies*,

23(1), 50–63. https://doi.org/10.1177/1044207311414680

Carter, E. W., Harvey, M. N., Taylor, J. L., & Gotham, K. (2013). Connecting youth and young

adults with autism spectrum disorders to community life. *Psychology in the Schools*,

50(9), 888–898. https://doi.org/10.1002/pits.21716

Carter, E. W., Kleinert, H. L., LoBianco, T. F., Sheppard-Jones, K., Butler, L. N., & Tyree, M. S.

(2015). Congregational participation of a national sample of adults with intellectual and

developmental disabilities. *Intellectual and Developmental Disabilities*, *53*(6), 381–393.

https://doi.org/10.1352/1934-9556-53.6.381

Centers for Medicare and Medicaid Services. (2020). *Request for information: Recommended measure set for Medicaid-funded Home and Community Based Services*. https://www.medicaid.gov/medicaid/quality-of-care/quality-improvement-initiatives/measuring-and-improving-quality-home-and-community-based-services-hcbs/index.html

Clifford, C. J., Lauer, E., Dutra, C., & Pirog, R. (2016). *Fostering social inclusion and community engagement*. University of Massachusetts Medical School, Eunice Kennedy Shriver Center, Center for Developmental Disabilities Evaluation Research.

Dinora, P., Bogenschutz, M., & Broda, M. (2020). Identifying predictors for enhanced outcomes for people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, *58*(2), 139–157. https://doi.org/10.1352/1934-9556-58.2.139

Friedman, C. (2017). Community integration of people with intellectual and developmental disabilities: A national longitudinal analysis. *Disability and Health Journal, 10*(4), 616-620. https://doi.org/10.1016/j.dhjo.2016.12.018

Friedman, C. (2017). Self-Advocacy services for people with intellectual and developmental disabilities: A national analysis. *Intellectual and Developmental Disabilities*, *55*(6), 370–376. https://doi.org/10.1352/1934-9556-55.6.370

Friedman, C. (2018a). The personal outcome measures ®. *Disability and Health Journal*, *11*(3), 351–358. https://doi.org/10.1016/j.dhjo.2017.12.003

Friedman, C. (2018b). *Building the Framework for IDD quality measures*. Towson, Chicago, and Omaha: The Council on Quality and Leadership, the Institute for Public Policy for People with Disabilities, and Mosaic.

Friedman, C. (2019). Intimate relationships of people with disabilities. *Inclusion*, *7*(1), 41–56. https://doi.org/10.1352/2326-6988-7.1.41

Friedman, C., & Rizzolo, M. C. (2017). Friendship, quality of life, and people with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities*, *30*(1), 39–54. https://doi.org/10.1007/s10882-017-9576-7

Giordano, S., Hiersteiner, D., & Pell, E. (2016). *National Core Indicators data brief: What do NCI data show about friendship and life outcomes for adults with intellectual and developmental disabilities?* https://www.nationalcoreindicators.org/upload/core-indicators/NCI_DataBrief_Friendship_final_041416.pdf

Heller, T., Miller, A. B., & Hsieh, K. (2002). Eight-Year follow-up of the impact of environmental characteristics on well-being of adults with developmental disabilities. *Mental Retardation*, *40*(5), 366–378. https://doi.org/10.1352/0047-6765(2002)040<0366:eyfuot>2.0.co;2

Houseworth, J., Stancliffe, R. J., & Tichá, R. (2018). Association of state-level and individual-level factors with choice making of individuals with intellectual and developmental disabilities. *Research in Developmental Disabilities*, *83*, 77–90. https://doi.org/10.1016/j.ridd.2018.08.008

Houseworth, J., Stancliffe, R. J., & Tichá, R. (2019). Examining the National Core Indicators' potential to monitor rights of people with intellectual and developmental disabilities according to the CRPD. *Journal of Policy and Practice in Intellectual Disabilities*, *16*(4), 342–351. https://doi.org/10.1111/jppi.12315

Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A*

Multidisciplinary Journal, *6*(1), 1–55. https://doi.org/10.1080/10705519909540118

Human Services Research Institute, & The National Association of State Directors of

Developmental Disability Services. (n.d.). *About National Core Indicators*.

https://www.nationalcoreindicators.org/about/

Human Services Research Institute, & The National Association of State Directors of

Developmental Disability Services. (2019). *In-Person survey: 2017-18 final report*.

https://www.nationalcoreindicators.org/upload/core-indicators/17-

18_IPS_National_Report_PART_I_update_CA_entitlement.pdf

Jones, J. L., Shogren, K. A., Grandfield, E. M., Vierling, K. L., Gallus, K. L., & Shaw, L. A.

(2018). Examining predictors of self-determination in adults with intellectual and

developmental disabilities. *Journal of Developmental and Physical Disabilities*, *30*(5),

601–614. https://doi.org/10.1007/s10882-018-9607-z

Jöreskog, K. G. (1994). On the estimation of polychoric correlations and their asymptotic

covariance matrix. *Psychometrika*, *59*(3), 381–389. https://doi.org/10.1007/bf02296131

Lakin, K. C., Doljanac, R., Byun, S.-Y., Stancliffe, R., Taub, S., & Chiri, G. (2008). Choice-

making among Medicaid HCBS and ICF/MR recipients in six states. *American Journal

on Mental Retardation*, *113*(5), 325–342. https://doi.org/10.1352/2008.113.325-342

Little, R. J. A. (1988). A test of missing completely at random for multivariate data with missing

values. *Journal of the American Statistical Association*, *83*(404), 1198–1202.

https://doi.org/10.1080/01621459.1988.10478722

Mehling, M. H., & Tassé, M. J. (2014a). Empirically derived model of social outcomes and

predictors for adults with ASD. *Intellectual and Developmental Disabilities*, *52*(4), 282–

295. https://doi.org/10.1352/1934-9556-52.4.282

Mehling, M. H., & Tassé, M. J. (2014b). Impact of choice on social outcomes of adults with

 ASD. *Journal of Autism and Developmental Disorders*, *45*(6), 1588–1602.

 https://doi.org/10.1007/s10803-014-2312-6

Muthén, L.K. and Muthén, B.O. (1998-2012). Mplus User's Guide. Seventh Edition.

 Los Angeles, CA: Muthén & Muthén

National Association of State Directors of Developmental Disability Services. (2019). *National*

 core indicators (NCI) added to the Medicaid adult core health care quality measure set

 and the CMS Medicaid scorecard website. https://www.nationalcoreindicators.org/-

 upload/aidd/NASDDDS_Press_Release.pdf

National Quality Forum. (2015). *Addressing performance measure gaps in home and*

 community-based services to support community living: Initial components of the

 conceptual framework. http://www.qualityforum.org/Projects/h/Home_and_Community-

 Based_Services_Quality/2nd_Interim_Report_for_Comment.aspx

National Quality Forum. (2016). *Quality in home and community-based services to support*

 community living: Addressing gaps in performance measurement.

 https://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-

 Based_Services_to_Support_Community_Living__Addressing_Gaps_in_Performance_

 Measurement.aspx

Neely-Barnes, S., Marcenko, M., & Weber, L. (2008). Does choice influence quality of life for

 people with mild intellectual disabilities? *Intellectual and Developmental Disabilities*,

 46(1), 12–26. https://doi.org/10.1352/0047-6765(2008)46[12:dciqol]2.0.co;2

Nord, D., Hamre, K., Pettingell, S., & Magiera, L. (2018). Employment goals and settings:

 Effects of individual and systemic factors. *Research and Practice for Persons with*

Severe Disabilities, *43*(3), 194–206. https://doi.org/10.1177/1540796918785352

Olsson, U. (1979). Maximum likelihood estimation of the polychoric correlation coefficient. *Psychometrika*, *44*(4), 443–460. https://doi.org/10.1007/bf02296207

Owen, R., Bonardi, A., Bradley, V., Butterworth, J., Caldwell, J., Cooper, R., Eisenberg, Y., Ford, M., Hewitt, A., Larson, S. A., Rizzolo, M. K., Rotholz, D., Stewart, C., Terrill, B., & Ficker Terrill, C. (2015). Long-term services and supports. *Inclusion*, *3*(4), 233–241. https://doi.org/10.1352/2326-6988-3.4.233

Petner-Arrey, J., & Copeland, S. R. (2014). "You have to care." Perceptions of promoting autonomy in support settings for adults with intellectual disability. *British Journal of Learning Disabilities*, *43*, 38–48. https://doi.org/10.1111/bld.12084

Qian, X., Larson, S. A., Tichá, R., Stancliffe, R., & Pettingell, S. L. (2019). Active support training, staff assistance, and engagement of individuals with intellectual and developmental disabilities in the United States: Randomized controlled trial. *American Journal on Intellectual and Developmental Disabilities*, *124*(2), 157–173. https://doi.org/10.1352/1944-7558-124.2.157

Qian, X., Tichá, R., Larson, S. A., Stancliffe, R. J., & Wuorio, A. (2014). The impact of individual and organisational factors on engagement of individuals with intellectual disability living in community group homes: A multilevel model. *Journal of Intellectual Disability Research*, *59*(6), 493–505. https://doi.org/10.1111/jir.12152

Reinders, H. S., & Schalock, R. L. (2014). How organizations can enhance the quality of life of their clients and assess their results: The concept of QOL enhancement. *American Journal on Intellectual and Developmental Disabilities*, *119*(4), 291–302. https://doi.org/10.1352/1944-7558-119.4.291

Rhemtulla, M., Brosseau-Liard, P. É., & Savalei, V. (2012). When can categorical variables be

    treated as continuous? A comparison of robust continuous and categorical SEM

    estimation methods under suboptimal conditions. *Psychological Methods*, *17*(3), 354–

    373. https://doi.org/10.1037/a0029315

Rich, R. F., Erb, C. T., & Rich, R. A. (2003). Critical legal and policy issues for people with

    disabilities. *DePaul Journal of Health Care*, *6*(1). https://doi.org/10.2139/ssrn.394644

Satorra, A., & Bentler, P. M. (2001). A scaled difference chi-square test statistic for moment

    structure analysis. *Psychometrika*, *66*(4), 507–514. https://doi.org/10.1007/bf02296192

Shogren, K. A., Bradley, V. J., Gomez, S. C., Yeager, M. H., Schalock, R. L., Borthwick-Duffy,

    S., Buntinx, W. H. E., Coulter, D. L., Craig, Ellis(Pat)M., Lachapelle, Y., Luckasson, R.

    A., Reeve, A., Snell, M. E., Spreat, S., Tassé, M. J., Thompson, J. R., Verdugo, M. A., &

    Wehmeyer, M. L. (2009). Public policy and the enhancement of desired outcomes for

    persons with intellectual disability. *Intellectual and Developmental Disabilities*, *47*(4),

    307–319. https://doi.org/10.1352/1934-9556-47.4.307

Simonsen, M. L., & Neubert, D. A. (2012). Transitioning youth with intellectual and other

    developmental disabilities. *Career Development and Transition for Exceptional

    Individuals*, *36*(3), 188–198. https://doi.org/10.1177/2165143412469399

Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of

    people with intellectual and developmental disabilities: An ecological model of social

    networks and community participation. *Research in Developmental Disabilities*, *38*, 18–

    29. https://doi.org/10.1016/j.ridd.2014.10.008

Sloan, M., & Irvin, C. (2007). *Money follows the person quality of life survey*. Mathematica

    Policy Research, Inc.

https://files.nc.gov/ncdma/documents/files/MFP_QOL_Survey_12_2018_0.pdf

Thompson, J. R., Bryant, B. R., Campbell, E. M., Craig, E. M., Hughes, C. M., Rotholz, D. A., Schalock, R. L., Silverman, W. P., Tasse, M. J., & Wehmeyer, M. L. (2004). *Supports Intensity Scale: Standardization and users manual.* American Association on Mental Retardation.

Tichá, R., Hewitt, A., Nord, D., & Larson, S. (2013). System and individual outcomes and their predictors in services and support for people with IDD. *Intellectual and Developmental Disabilities*, *51*(5), 298–315. https://doi.org/10.1352/1934-9556-51.5.298

Tichá, R., Lakin, K. C., Larson, S. A., Stancliffe, R. J., Taub, S., Engler, J., Bershadsky, J., & Moseley, C. (2012). Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states. *Intellectual and Developmental Disabilities*, *50*(6), 486–504. https://doi.org/10.1352/1934-9556-50.06.486

Verdonschot, M. M. L., de Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Impact of environmental factors on community participation of persons with an intellectual disability: A systematic review. *Journal of Intellectual Disability Research : JIDR*, *53*(1), 54–64. https://doi.org/10.1111/j.1365-2788.2008.01128.x

Wehmeyer, M. (1997). Self-determination as an educational outcome: A definitional framework and implications for intervention. *Journal of Developmental and Physical Disabilities*, *9*(3), 175-209. https://doi.org/10.1023/A:1024981820074

Wehmeyer, M. L., & Garner, N. W. (2003). The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning. *Journal of Applied Research in Intellectual Disabilities*, *16*(4), 255–265.

https://doi.org/10.1046/j.1468-3148.2003.00161.x

Williams-Diehm, K., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., & Garner, N. W. (2008).

Self-Determination and Student Involvement in Transition Planning: A Multivariate

Analysis. *Journal on Developmental Disabilities*, *14*(1). https://oadd.org/wp-

content/uploads/2008/01/williamsdiehmEtAl.pdf