Identifying Predictors for Enhanced Outcomes for People with Intellectual and Developmental Disabilities

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Background

As of June 2013, there were an estimated 6.2 million people in the United States (U.S.) with Intellectual or Developmental Disabilities (IDD) (Larson et al., 2016). As the population of people with IDD has grown, so too has the need for services and supports to facilitate their daily living. The primary program through which people with IDD receive long term supports and services (LTSS) in the U.S. is Medicaid (Naylor, Kurtzman, Miller, Nadash, & Fitzgerald, 2015). As of 2013, close to 800,000 people with IDD received LTSS through the Medicaid program (Larson et al., 2016). In an analysis of data from five states from 2008-2013, McDermott and colleagues (2018) found that between 2.3% and 4.2% of Medicaid recipients had IDD.

The investment in Medicaid for supports and services for people with disabilities is significant (Harrington & Kang, 2016; Pollack, 2011). Although beneficiaries with all types of disabilities make up 15% of Medicaid enrollees, they account for more than 40% of total Medicaid spending (Paradise et al., 2015). Per-enrollee, Medicaid spending for people with disabilities is more than five times the level for nonelderly, nondisabled adults and nearly seven times the level for children. With respect to people with IDD, the U.S. spent over $61 billion on IDD publicly funded services in 2013; of this amount, Medicaid funds constituted 78% of total IDD services and support spending in the U.S. (Braddock, Hemp, Rizzolo, Tanis, Haffer, & Wu, 2015).

While there are significant state and national financial commitments for Medicaid IDD services, a concomitant body of research documenting the relationship between individuals' outcomes and Medicaid IDD services is lacking (Kaiser Family Foundation, 2012; Naylor,

Kurtzman, Miller, Nadash, & Fitzgerald, 2015; United Cerebral Palsy, 2016). Additionally, there is a critical need to better understand which individual and service characteristics are related to enhanced outcomes for people with IDD, and how these factors interact with costs and systems change efforts (Tichá, Hewitt, Nord, & Larson, 2013).

Research that links individual, service utilization, and outcome data is an outgrowth of earlier IDD measurement scholarship in areas including quality of life and in the evaluation of service outcomes. A disussion of these efforts will provide context for current research and illustrate the progression of IDD outcomes measurement to date.

Measuring Quality and Outcomes

Currently, there is no one standard way that quality is defined or measured across Medicaid-funded LTSS home and community based services (HCBS) and, while a core set of quality metrics has been developed by the Centers for Medicaid and Medicare Services (CMS), states are not required to use them (National Quality Forum, 2016; Reaves & Musumeci, 2016; United Healthcare, 2016). Often, service "quality" and "outcomes" are considered together and are conceptualized in measures that assess a variety of areas at both "person-referenced level" (i.e., quality of life, self-determination) and at the "system-focused level" (i.e., characteristics of the system, services provided) (Kayne, 2014; Kaye & Harrington. 2015; Shogren et al., 2009).

Quality of Life as a Measurement of Personal Outcomes. Historically, the concept of a person's quality of life (QOL) has been used in the field of IDD as framework for measuring personal outcomes; a social construct to guide system-level quality improvement; and a method for assessing service outcomes (Schalock, Bonham, & Verdugo, 2008; Shalock, Gardner, & Bradley, 2007; Townsend-White, Pham, & Vassos, 2012). The construct of QOL emphasizes the equality of all people and is grounded in the concepts of self-determination, emancipation,

inclusion, and empowerment (Morisse, Vandemaele, Claes, Claes, & Vandevelde, 2013). Using this foundation, QOL has also become a vehicle through which equity, empowerment, and life satisfaction for people with IDD is measured at an individual level to examine personal outcomes as well as outcomes related to service delivery (Brown, 1996; Schalock, Gardner, & Bradley, 2007; Shogren et al., 2009).

Although many QOL models exist in the field of IDD, the one that has emerged with the greatest empirical support was developed by Schalock, Verdugo, & Braddock (2002). This model consists of eight domains structured in three main factors: (1) independence, composed of personal development and self-determination; (2) social participation, composed of interpersonal relations, social inclusion, and rights; and (3) wellbeing, composed of emotional, physical, and material wellbeing (Balboni, Coscarelli, Giunti, & Schalock, 2013). Numerous QOL assessment tools have been developed based on these factors, and measures have been validated in many different countries and cultures (Claes et al., 2012; Schalock et al., 2005; Verdugo, Gomez, Arias, Navas, & Schalock, 2014).

QOL scholarship has made significant contributions to the IDD field. It is widely used for the objective evaluation of people's needs and subjective levels of satisfaction; for informing programs, strategies, and activities aimed at quality improvement; and for collecting information to guide service provision (Bigby, Knox, Beadle-Brown, & Bould, 2014; Buntinx & Schalock, 2010; Gomez et al., 2016; Schalock, Gardner, & Bradley, 2007; van Loon et al., 2013). However, a gap remains between the application of QOL models in program development and service delivery and their use as measurement tools in *systems-level* program evaluation (Brown, Hatton, & Emerson, 2013) and policy development (Conner, 2016).

System Measures of Quality. As the IDD service system has continued to evolve, and with the development of significant Medicaid reform efforts in recent years, there has been an increasing need to develop metrics at a systems level that measure the effectiveness of programs that support people with IDD (Owen et al., 2015). In the past few decades, a growing body of research has emerged to examine IDD system-level outcomes.

Studying aggregate expenditures has been a primary way researchers have documented the impact of policy/programmatic changes (such as people moving from institutional to community settings) on service systems. A frequent finding of this work has been a growth in spending for Home and Community Based Services (HCBS) over institutional spending (see, e.g., Eiken, Sredl, Burwell, & Saucier, 2016; Hemp, Braddock, Tanis, & King, 2013). In a large-scale study spanning four states, Lakin et al., (2008) compared spending patterns for recipients of HCBS and Intermediate Care Facility/Mental Retardation (ICF/MR) services. Results showed that Medicaid expenditures for HCBS recipients were lower than those for ICF/MR residents when controlling for differences in people's level of disability and for congregate settings. Several other teams of researchers have investigated national and state spending trends related to IDD services and obtained similar findings (see Braddock et al., 2016; Bohl, Schurrer, Miller, Lim, & Irvin, 2014, Harrington & Kang, 2016; Lakin, Prouty, & Alba, 2007; Muramatsu & Campbell, 2002; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013; Stancliffe & Lakin, 2005).

Assessing residential outcomes is another way that researchers have examined the effects of changes in disability policy and programs on people's lives. Larson et al., (2016) reported that, although discussions of IDD supports and services are often focused on out-of-home settings, the vast majority of people with IDD (85%) live with relatives. Further, as of 2013,

fewer than 30,000 people who received LTSS in IDD systems lived in state institutional settings. Researchers have also found differences in residential placements based on disability type. For example, Hewitt and colleagues (2017) found that, when accounting for demographic and state difference, people with ASD had higher odds of living with family but lower odds of living in their own home. Likewise, Stancliffe and colleagues (2012) reported that within a sample of 25 states, adults with Down syndrome were less likely to live in institutions or their own home, but they were more likely to live in a family member's home.

Employment outcomes have also been used as a measure of IDD system performance. Multiple national surveys illustrate that the employment rate for people with disabilities is less than half that of those without disabilities (e.g., Butterworth et al., 2014; Bureau of Labor Statistics, March, 2015). Further, the estimated percentage of people participating in integrated employment services has remained nearly stagnant in recent years, while investment in non-work services continues to expand (Butterworth et al., 2016).

The National Core Indicators (NCI) project has been an important source of systems level outcomes-related research. In the 2014-15 data cycle, 31 states administered the NCI Adult Consumer Survey with a total sample of 25,820 people with IDD (HSRI & NASDDDS, 2016). Selected key findings reveal (a) areas for potential service system improvement (e.g., only 54% of respondents choose where they live, 45% choose with whom they live, and 30% would like to do something else during the day), as well as (b) areas of systems strength – with the vast majority of people reporting that they choose their daily schedule (82%), choose how to spend their free time (91%), and like where they live (90%) (HSRI & NASDDDS, 2016).

Additional studies based on analyses of the aggregate NCI datasets have examined the influence of personal and service system variables on outcomes for people with IDD. For

example, personal characteristics such as level of ID, age, mobility, self-reported ability to communicate verbally, and type of disability have been found to account for significant differences in a variety of outcomes (Bershadsky et al., 2012; Lakin et al., 2008; Mehling & Tassé, 2015; Tichá et al., 2012; Stancliffe et al., 2012). Further, across all outcome areas, people living in their own home, family homes, host family homes, or in small agency residences ranked consistently better in achieving positive outcomes than those living in moderate and large agency residences and institutions (Nord et al., 2013).

Need for Further Research

These existing research efforts helped to develop a picture of how Medicaid services and supports are influencing the lives of people with IDD across the country. However, there is a critical need to extend this important work.

A fundamental challenge with each of the measurement approaches described above is that they lack linkages between system, individual, and outcome data points. As summarized by Tichá et al., (2013), “by better aligning data sets, researchers can more effectively investigate the relationships between costs and services to individual outcomes” (p. 312). Owen (2015) echoed that “research that ties the performance of the system to individually reported outcomes must guide the LTSS system” (p. 234). Additionally, Kaye and Harrington (2015) reiterated the need for analyses that examine expenditures in conjunction with individual outcomes.

With access to more granular level, state-based data linked to IDD system performance, we can begin to address fundamental questions that are of primary importance to people with disabilities, their families, program administrators, and policy makers. This information can, in turn, form the basis for evidence-based program planning and policy decision making (Mosley,

Kleinert, Sheppard-Jones, & Hall, 2013; Tichá et al., 2013) aimed at improving the quality of life for people with IDD.

Research Questions

The overarching goal of this research was to identify factors associated with enhanced outcomes for people with IDD, and to assess the relationships between predictors of enhanced outcomes and costs. Specifically, the study sought to address three main research questions.

1. What is a practicable process by which to integrate major IDD datasets to enable individual-level analyses?
2. How do a person's identified support needs from the Supports Intensity Scale and one's residence type predict an individual's total Medicaid expenditure?
3. How are personal outcomes for people with IDD, based on existing NCI scales, predicted by demographic factors, support needs, and total Medicaid expenditures?

Method

This study was a pilot of a novel method for investigating HCBS system performance for people with IDD. We used three major datasets, merged at the individual level, to develop an understanding about the relationship between Medicaid expenditures, an person's support needs, and commonly studied outcomes for people with IDD. All procedures used in this study were reviewed and approved by the Institutional Review Board at authors' affiliated university.

Data Sources

This pilot study linked three distinct data sources to form a single dataset for analysis. Data were obtained from the state IDD agency and the Medicaid agency in one Mid-Atlantic state.

Medicaid Claims. This study used Medicaid claims data for adults with IDD who used HCBS in FY 2014. The state's Medicaid agency extracted all claims for people who used HCBS, including claims for those people that were not related to HCBS (e.g., acute medical claims). The file containing all Medicaid claims for FY 2014 for people with IDD who used HCBS was securely transferred to the research team for use in this analysis. We engaged in an extensive process to clean the Medicaid data file before analyses began.

For the analyses presented in the results section to follow, Medicaid claims were summed into a single variable representing the total Medicaid expenditure for each person. Though all people included in the analysis used Medicaid to pay for HCBS, the Medicaid expenditure variable contains not only HCBS expenditures, but also all other Medicaid-reimbursed costs for a person with IDD in FY 2014.

National Core Indicators. The National Core Indicators (NCI) Adult Consumer Survey is a nationally-validated instrument administered to adults with IDD in 46 states. Results from one state were used in this study. The NCI is administered in-person, directly with a person with IDD, with some sections of the survey being completed by a parent, case manager, direct support professional in some instances. NCI surveys that were administered on the timeline corresponding to Medicaid FY 2014 were eligible for inclusion in this study.

The NCI has several sections, seeking general demographic information, data about a person's physical and behavioral health, and a range of personal outcomes. For the purpose of this study, the authors used previous literature to construct four main outcome variables from the NCI. Specifically, we constructed scaled variables, based on previous literature, for Community Inclusion, Social Participation and Relationships, Everyday Choices, and Rights, each of which is described in more detail below. We chose to construct variables based on scales that were

validated in previous literature because individual items in the NCI sometimes offer limited range in responses, since many items are answered dichotomously. The scaled variables allowed for greater discrimination and range in responses.

The Community Inclusion variable was constructed based on previously published findings from the National Core Indicators (2012) project. It was constructed by summing four items from the NCI, each representing the number of times the respondent reported engaging in a particular activity in the month preceding the NCI interview: went shopping, did errands, went out for entertainment, or went out to eat. The result was a simple frequency count of how many times the individual engaged in those four activities in the month leading to NCI participation.

Social participation was constructed based on the work on Mehling and Tasse (2014). It includes seven items from the NCI: (a) whether the person went shopping in the previous month, (b) whether they did errands in the previous month, (c) whether they went out for entertainment in the previous month, (d) whether they went out to eat in the previous month, (e) Whether they took a vacation in the previous year, (f) whether they have friends other than staff or family, and (g) whether they have a best friend. Responses were dummy coded as follows: if a person answered affirmatively to all seven items, score = 2, 4-6 affirmative responses = 1, and 0-3 affirmative responses = 0.

Everyday Choices was constructed based on the National Core Indicators (2012). It was based on three items from the NCI: how much choice a person has to determine their daily schedule, how much choice they have in determining how to use their personal spending money, and how much choice they have to determine how to use their free time. In each of these three items, coding was as follows: Makes the decision by one’s self = 2, the person has some input in

the decision=1, the decision was made by someone else=0. Thus, total scores for the Everyday Choices variable ranged from 0 to 6.

Finally, Rights was constructed based on the previous work of Neely-Barnes, Marcenko, and Weber (2008). The Rights variable was developed from three items from the NCI, each with dichotomous scoring: whether someone else could open the person's mail (scored Yes=0, No=1), whether the person can use the phone when desired (Yes=1, No=0), and whether the person can be alone when desired (Yes=1, No=0). The total score could range from 0 to 3.

Additionally, demographic characteristics (i.e., age, gender, type of residence) of the sample were taken from the NCI, since the self-reported or proxy-reported demographics from Part I of the NCI were thought to be more accurate than demographic variables that could be extracted from Medicaid data.

Supports Intensity Scale. The Supports Intensity Scale (SIS) is a nationally-normed widely used tool that is used in many states to assess the level of support needs a person with IDD has in multiple domains. For this analysis, SIS data corresponding to the state's FY 2014 Medicaid data were utilized. In this study, the authors used a seven-tiered rating system used by the state where the study was conducted, based on a person's SIS score to create a predictor variable for overall level of support needs. People who were determined to have extraordinary medical support needs or extraordinary behavioral support needs were also noted.

Demographic Variables. In addition to Medicaid expenditures, level of support needs, and the outcome variables, all of which were described in the preceding paragraphs, our model for analysis also included variables for residence type and age. Residence type was based on the most common living settings that were used by HCBS users with IDD in the state where the

study was conducted. Age was collected from the NCI and was entered as an ordinal variable for our analysis, with age ranges as displayed in the regression results to follow.

Data Management and Integration

A hallmark of this study was the ability to integrate Medicaid claims, the NCI, and the SIS at the individual level to create a unified dataset representing a person's Medicaid claims, personal outcomes and assessed support needs. In the state where the study was conducted, a person's Medicaid number is collected on all three data sources, so this was used as a unique individual-level identifier to guide the integration of all three datasets. Once the merger of datasets was complete, the Medicaid number was removed and replaced by a different unique identifier before analyses commenced. All data were stored on an encrypted, password-protected server, and were available only to authorized members of the research team.

The process of merging datasets occurred in three stages. The researchers began with all people with an NCI Adult Consumer Survey on file for FY 2014 (n=931). To those data, we then added Medicaid claims. Of the 931 people with a valid NCI, 601 also had Medicaid claims related to HCBS in FY 2014. Finally, and again using Medicaid numbers to guide the merger process at the individual level, the researchers added SIS data. The final file for analysis contained 522 people with IDD who had all three data sources valid for the 2014 fiscal year.

Sample

The final sample for this study contained records for 522 people, all of whom were identified as having IDD. Selected sample characteristics are summarized in Table 1. The category for support level listed in Table 1 is based on categories used by the state where the

study took place, which uses a seven-tiered assessment of needs, and includes categories for people with extraordinary behavioral support needs and extraordinary medical support needs.

In addition to the demographic factors listed in Table 1, other characteristics of the sample were also worth noting. Over half of respondents (*n*=250, 56.2%) reported some type of psychiatric disorder (such as mood disorders, anxiety, psychotic disorders, etc.), and 57.7% of the sample (*n*=286) reported taking medications to treat such a disorder. Seizure disorders (*n*=144, 31.6%), autism spectrum disorder (*n*=87, 19.4%), and cerebral palsy (*n*=78, 17.4%) were the most commonly reported disability types among the sample, based on NCI records.

Results

Regression with hierarchical model building was used to examine associations between NCI outcomes and Medicaid expenditures and demographic characteristics and support needs. Regression models were developed for each of five separate outcomes: 1) Medicaid expenditures in 2014, 2) community inclusion, 3) everyday choices, 4) rights, and 5) social participation. Because these outcome variables had differing measurement characteristics as described in the methods section, several types of regression approaches were required to model the data appropriately.

Summaries of each regression model are presented by outcome in Table 2. To best synthesize the results, only the estimates from the final model are included and discussed below. Full model results, including coefficient estimates for each step in the hierarchical model building process can be found in the Appendix. Because these results come from multiple regression analyses with a number of covariates, all significant estimates should be interpreted as occurring while controlling for all other variables in the model.

Outcome 1: Medicaid Expenditures

Several predictors were found to be significantly associated with Medicaid expenditures, including all SIS levels, and all residence types. Results appear in Table 3. For the SIS seven-level assessment framework, the coefficient estimates for all levels were positive and significant when compared to those in SIS level 1 (people with the least support needs). Practically, this means that Medicaid expenditures tended to increase along with assessed support needs. Estimates of cost increases over what would be expected for people at SIS Level 1 were the highest for respondents with exceptional medical needs (B = 33.0, or $33,000, $p < .001$) or exceptional behavioral needs (B = 25.3, or $25,300, $p < .001$). These estimates do not represent total costs, but rather the difference in expenditures between each group and those needing the least support (i.e., the "reference category").

All estimates for residence type were found to be significant and negative when compared to participants living in congregate housing with 4 or more beds (the reference category for residence). Estimates of Medicaid expenditures for those living in congregate housing with less than 4 beds (-$7,680 as compared to congregate residential with 4 or more beds), those living independently (-$39,400), those with parents (-$52,800) or in sponsored/host homes (-$10,900) were significantly lower than those in the reference category (all p values < .05).

Outcome 2: Community Inclusion

As noted earlier, scores on Community Inclusion were calculated by summing the number of times people participated in four specific community activities during the last month. Coefficient estimates for this outcome can be interpreted as "expected counts," or the predicted number of community events in which a participant might take part in a typical month.

Results as listed in Table 4 suggest that SIS level, age, and gender are not significantly associated with community inclusion. Residence type, however, is associated to the outcome for two groups – those living with a parent/relative and those living in sponsored/host homes. Participants living with a parent or relative would be predicted to take part in .25 more inclusive activities over the course of a month (or about 3 more activities per year) compared to participants living in a congregate setting with four or more beds (the reference category) ($p < .05$). Similarly, participants living in sponsored/host homes would be expected to take part in .50 more activities over the course of a month (or about 6 more activities per year) compared to participants living in a larger congregate setting ($p < .001$).

Outcome 3: Everyday Choices

The Everyday Choices outcome was based on NCI survey questions that asked participants how much input they had on everyday decision making in three areas as described in the scale. Results were collapsed into three categories – those who had no input, those who had input on some choices but not all, and those who had input on all choices. Estimates are interpreted as odds ratios, representing the proportional change in odds associated with a given predictor variable.

Only one SIS level was found to be significant in this model as indicated in Table 5. Participants who received extraordinary medical support were predicted to have 89% lower odds of making everyday choices than participants with the least support needs (the reference category) (O.R. = .11, $p < .01$). Residence type was also found to be significant, with participants living independently predicted to have over four times the odds of making everyday choices compared to participants in larger congregate residential settings (O.R. = 4.16, $p < .05$). Medicaid expenditures were also found to be significant in this model, with odds of making more

everyday choices predicted to decrease by about 1% for every additional $1,000 of costs (O.R. = .99, $p < .05$). Thus, people with greater Medicaid costs were predicted to have less choice. Age and gender were not found to be significantly associated with the odds of making everyday choices.

Outcome 4: Rights

Rights was modeled based on participants' responses to three NCI questions: whether or not their rights were respected to be alone, use the phone, and not have others open their mail. Model results can be interpreted as the proportional change in odds of feeling respected in all three situations associated with a given variable.

As outlined in Table 6, SIS level, residence type, and Medicaid expenditures were not found to be significantly associated with feeling one's rights were respected. Age was found to be a significant predictor, with participants who were age 55-64 predicted to have more than twice the odds of feeling their rights were respected compared to participants age 18-39 (the reference group) (O.R. = 2.20, $p < .05$). Participants over age 64 were also significantly different from the reference group, with more than four times the odds of feeling their rights were respected (O.R. = 4.84, $p < .01$).

Outcome 5: Social Participation

Social Participation was operationalized as a three-category ordinal variable for regression modeling. Here, participants were given a 2 if they answered yes to all 7 subcategories of social participation (e.g., shopping, errands, vacation), a 1 if they answered yes to 4-6 subcategories, and a 0 if they responded yes to 0-3 categories. Ordinal logistic regression was then used to model this outcome. Estimates of effects in this type of regression are

interpreted as odds ratios, or the proportional change in odds of increased social participation associated with a given variable.

Results as detailed in Table 7 indicated that age, gender, and Medicaid expenditures were not significantly associated with level of social participation. Participants with “moderate to high” or “high to maximum” support needs according to the SIS seven-level assessment framework had significantly lower odds of social participation (64% lower and 89% lower, respectively, both p values < .05) compared to participants with the least support need. Type of residence was also significant. Participants who lived with a parent or relative had odds of social participation that were 70% lower than participants who lived in a large congregate setting (the reference group) (O.R. = 0.30, $p < .001$). Participants who lived in sponsored/host homes had more than twice the odds of full social participation compared to the reference group (O.R. = 2.13, $p < .05$).

Discussion

This study was significant for two main reasons: (a) it developed and implemented a novel method for integrating complex datasets at the individual level and (b) it provided insights into outcomes for HCBS users with IDD, based on their assessed support needs and Medicaid expenditures. Understanding the relationship between service costs and personal outcomes for people with IDD, accounting for support needs, is important since this understanding can illuminate where a IDD support system is performing efficiently in improving the lives of people with IDD, and where outcomes are in the greatest need of improvement, relative to fiscal investments.

Costs and Outcomes

This study found that Medicaid expenditures generally rose along with the support needs of a person with IDD, as assessed in the state's seven-level framework using the SIS. Of particular note was the finding that people with extraordinary medical needs ($33,000 more annual expenditures per person compared with HCBS users with the lowest support needs) and extraordinary behavioral needs ($25,300 more Medicaid expenditures per person) utilized more services than other people in the sample. Despite the fact that these people comprise a relatively small portion of all HCBS users with IDD, the costs associated with meeting their needs make them a particularly important population to understand. The prevalence of behavioral health concerns in the sample, and significant use of psychotropic medications also suggests that more research should be done to understand the expenditure patterns of people with comorbid IDD and mental health conditions and how those expenditures correspond to personal outcomes.

Consistent with findings from previous analyses (Lakin et al., 2008), participants in our sample had higher overall Medicaid expenditures when they lived in congregate settings of four people or more, as compared with those people living in settings with three or fewer people, with family, independently, or in sponsored homes. While this finding was expected considering trends from past research, it nevertheless underscores the fiscal benefits of smaller-sized community living arrangements. The finding may also raise questions about the specific support needs profiles of individuals with IDD who live in each type of residential arrangement. For example, if people with higher behavioral and medical support needs tend to reside in larger congregate settings, it would stand to reason that Medicaid expenditures for people who use such facilities would be high.

The outcome of social participation was of particular interest in this study. While it appeared reasonable that people with IDD who had higher assessed support needs, based on SIS score tended to have lower social participation, findings pertaining to social participation and residence type may require more exploration. Our analysis found that people who live with family tended to have significantly less social participation than people who lived in the study's largest congregate settings, a finding that may seem at odds with the prevailing logic that people have more opportunity to engage in social activities when they live in smaller community settings. Precise explanations for this finding are unclear based on the analysis, and may warrant closer study in the future. This finding is suggestive, however, of the need for public policy to focus more attention on the needs of family caregivers so they may more readily gain access to resources they need to support the community integration of their family members with IDD. For instance, recent research indicates that neither policymakers (DeCarlo, Bogenschutz, Hall-Lande, & Hewitt, 2018) nor family members (Bogenschutz, Hewitt, Hall-Lande, and LaLiberte, 2010) report that self-directed supports for people with IDD, a commonly used service modality for family caregivers, place much emphasis on social integration.

When examining the community inclusion outcome, which was exclusively a count of the number of activities in which a respondent participated, outcomes appear to be weaker for people living in congregate settings with four or more people, than for people living with family or in sponsored/host homes. Based on our analysis, these differences are not large, but they are statistically notable, suggesting that congregate care may still lag behind other models of service provision when it comes to supporting the community inclusion of people with IDD. Interestingly, individual characteristics such as SIS level, extraordinary medical or behavioral needs, age, and gender were not found to be statistically associated with community inclusion

outcomes. However, the system variable, “type of residence” was found to have a significant effect. With 40 percent of the sample living in congregate settings of four or more people with primarily 24-hour support, it will be important to continue to examine if and how individual characteristics play a role in community inclusion when a greater diversity of community based residential options are considered in analyses.

With regards to everyday choices, only one individual characteristic, “extraordinary medical needs,” was negatively associated with everyday choices, meaning the more medical supports one needs, the less likely he or she is to make everyday choices. This is not a surprising finding. However, what is notable is that the SIS level, extraordinary behavioral needs, age, and gender had no effect. Further, the service system characteristic “type of residence” was again significantly related to everyday choices. People living independently were predicted to have over four times the odds of making everyday choices than those living in larger congregate residential settings. This finding reinforces public policy related to enhancing independent living options for people with IDD and is also consistent with findings for the community inclusion measure.

Finally, the outcome of rights shared little similarity to the other outcomes examined. The only significant relationship identified for this outcome was a person’s age: the older a person is, the more that they feel their rights are respected. While we can speculate about possible explanations for these findings, further study is needed to examine if these results remain consistent over time and to try to understand the context for these findings.

Individual-Level Analyses

This study is perhaps most significant for its process. It is the first known study to integrate the NCI and SIS with Medicaid claims data to gain a comprehensive look at how

Medicaid expenditures relate to outcomes for people with IDD, while accounting for their identified support needs. Merging these three datasets at an individual level provides an opportunity for in-depth study of outcomes and expenditures that has not been possible in previous research. Though this study should be considered a pilot due to the relatively small cross-sectional sample, the research team was successful in developing a process by which to manage and merge these three complex datasets in a way that will be a model for forthcoming longitudinal study.

The significance of this novel approach to administrative data usage could be widespread, but most applicable to the policy arena. At a policy level, this approach to data usage can enable states to understand the performance of their disability systems with greater precision, and could serve as a useful approach to quality assurance and data-driven policy decision making. It will also enable policymakers and IDD service administrators to gain an understanding of how policy or program changes affect costs and outcomes for people with IDD, especially if this pilot's data handling procedure is applied longitudinally.

Limitations and Future Research

The main limitation facing this cross sectional analysis was related to the available sampling frame and data sources. During the FY 2014 data cycle [name of state] was not yet fully administering the SIS. Since our analyses required the presence of all three datasets (Medicaid claims, NCI and SIS), we were limited in the amount of people who could be included in the study. With the SIS now at full implementation in the state, analyses of data from subsequent years should be more robust. Our analyses were also constrained, to some extent, by the variables available to us in these datasets. For instance, while the NCI does provide a well-rounded look at outcomes for people with IDD, it sometimes lacks the robust nuance to construct

variables to represent the full spectrum of how an idea like social inclusion is often understood in the field. In addition, the limitations in our sampling frame resulted in less representation of people with particular characteristics, including people who live independently and people with very high support needs. While our sample largely represents the population characteristics of the state, we would like to look more closely at the relationship between Medicaid expenditures and outcomes for some sub-populations in future studies.

In addition, while this study did help to define and identify sub-populations of people with IDD who are particular interest due to their high levels of Medicaid expenditure, we did not specifically examine many outcomes for those individuals. Targeted analysis of people with IDD with co-occurring behavioral health diagnoses or who have extraordinary medical support needs were absent from this study, but will make important contributions to the field's knowledge in the future.

Finally, while cross sectional analyses have utility in their own right, the greatest impact from this novel method of data integration is likely to come from longitudinal study. Doing so will enable an understanding of system performance over time as policy and program shifts occur. Additionally, if data are integrated at the individual, as in this study, we may begin to understand how the service needs of a person change over time and how changes in expenditure relate to outcomes for people with similar support needs profiles.

Conclusion

This report recounted the results of a pilot for a novel approach to the use of major datasets of importance to the IDD field: the NCI, SIS, and Medicaid claims, which were merged at the individual level. The pilot provided a roadmap for the procedure to be scaled up in future studies. Findings suggested that support needs as assessed by the SIS were predictive of

Medicaid expenditures, with people with extraordinary medical and/or behavioral supports needs incurring significantly higher costs than people with IDD with only minimal support needs, based on their SIS score. Analyses of variables related to the NCI yielded mixed results in this pilot, though findings often suggested that type of resident and level of support needs were often solid predictors of individual outcomes. More study, especially of a longitudinal nature, is likely to be of utility to policymakers and advocates for people with IDD.

References

Balboni, G., Coscarelli, A., Giunti, G., & Schalock, R. L. (2013). The assessment of the quality of life of adults with intellectual disability: The use of self-report and report of others assessment strategies. *Research in Developmental Disabilities*, *34*, 4248-4254.

Bershadsky, J., Taub, S., Engler, J., Moseley, C. R., Lakin, K. C., Stancliffe, R. J., … Bradley, V. (2012). Place of residence and preventive health care for intellectual and developmental disabilities services recipients in 20 states. *Public Health Reports*, *127*(5), 475–485. https://doi.org/10.1177/003335491212700503

Bigby, C., Knox, M., Beadle-Brown, J., & Bould, E. (2014). Identifying good group homes: Qualitative indicators using a quality of life framework. *Intellectual and Developmental Disabilities*, *52*, 348-366. https://doi.org/10.1352/1934-9556-52.5.348

Bogenschutz, M., Hewitt, A., Hall-Lande, J., & LaLiberte, T. (2010). Status and trends in the direct support workforce in self-directed supports. *Intellectual and Developmental Disabilities*, *48*(5), 345-360.

Bohl, A., Schurrer, J., Miller, D., Lim, W., & Irvin, C. V. (2014, October). The changing medical and long-term care expenditures of people who transition from institutional care to home and community-based services. *Report from the Field*, 15.

Braddock, D., et al. (in preparation). *The state of the states in intellectual and developmental disabilities*, 2016.

Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E., S., Haffer, L., & Wu, J. (2015). The state of the states in intellectual and developmental disabilities: Emerging from the great recession. Washington, DC: *American Association on Intellectual and Developmental Disabilities*.

Brown, I., Hatton, C., & Emerson, E. (2013). Quality of life indicators for individuals with intellectual disabilities: Extending current practice. *Intellectual and Developmental Disabilities 51*, 316-332.

Brown, R. I. (1996). *Quality of life for people with disabilities. Models, research and practice*. Cheltenham, UK: Stanley Thornes.

Buntinx, W. H., & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, *7*, 283-294.

Bureau of Labor Statistics. (2015). *Economic news release: The employment situation-January 2015.* Retrieved from www.bls.gov/news.release/empsit.nr0.htm

Butterworth, J, Smith, F. A., Hall, A.C.,Migliore, A., Winsor, J., & Domin, D.(2014). *StateData: The national report on employment services and outcomes.* Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

Claes, C., Vandevelde, S., Van Hove, G., van Loon, J., Verschelden, G., & Schalock, R. (2012). Relationship between self-report and proxy ratings on assessed personal quality of liferelated outcomes. *Journal of Policy & Practice in Intellectual Disabilities*, 9(3), 159-165.

Conner, B. L. (2016). *A systematic rewire of quality of life assessment tools for adults with intellectual and developmental disabilities. (Master's Thesis*). Retrieved from http://digitalrepository.unm.edu/cgi/viewcontent.cgi?article1000&contextpadm_etds.

DeCarlo, M. P., Bogenschutz, M. D., Hall-Lande, J. A., & Hewitt, A. S. (2018). Implementation of Self-Directed Supports for People With Intellectual and Developmental Disabilities in the United States. *Journal of Disability Policy Studies*, 1044207318790061.

Eiken, S., Sredl, K., Burwell, B., & Saucier, P. (2016). Medicaid expenditures for long-term services and supports (LTSS) in FY 2014. Report to US Department of Health and Human Services, Centers for Medicare & Medicaid Services, *Truven Health Analytics*. Retrieved from https://www.medicaid.gov/medicaid/ltss/downloads/ltss-expenditures2014.pdf.

Gómez, L. E., Alcedo, M. Á., Arias, B., Fontanil, Y., Arias, V. B., Monsalve, A., & Verdugo, M. Á. (2016). A new scale for the measurement of quality of life in children with intellectual disability. *Research in Developmental Disabilities, 53*, 399-410.

Harrington, C., & Kang, T. (2016). Disparities in service use and expenditures for people with intellectual and developmental disabilities in California in 2005 and 2013. *Intellectual and Developmental Disabilities*, 54(1), 1–18. https://doi.org/10.1352/1934-9556-54.1.1

Hemp, R., Braddock, D., Tanis, E., & King, M. (2016). US disability services and spending. *NCSL legisbrief, 24*(18), 1.

Hewitt, A. S., Stancliffe, R. J., Hall-Lande, J., Nord, D., Pettingell, S. L., Hamre, K., & HallasMuchow, L. (2017). Characteristics of adults with autism spectrum disorder who use residential services and supports through adult developmental disability services in the United States. *Research in Autism Spectrum Disorders, 34*, 1-9.

Human Services Research Institute (HSRI) and National Association of State Directors Of Developmental Disabilities Services (NASDDDS) (2016). Adult consumer survey 2014-15 final report. Retrieved from https://www.nationalcoreindicators.org/resources/reports/2016/#reports-adult-consumer-survey-final-reports

Kaiser Family Foundation. (2012). *People with disabilities and Medicaid managed care: Key issues to consider*. Menlow Park, CA. Retrieved from https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8278.pdf

Kaye, H. S., & Williamson, J. (2014). Toward a model long-term services and supports system: State policy elements. *The Gerontologist*, 54(5), 754-761.

Kaye, H. S., & Harrington, C. (2015). Long-term services and supports in the community: Toward a research agenda. *Disability and Health Journal, 8*(1), 3-8.

Lakin, K. C., Doljanac, R., Byun, S. Y., Stancliffe, R. J., Taub, S., & Chiri, G. (2008). Factors associated with expenditures for Medicaid home and community based services (HCBS) and intermediate care facilities for persons with mental retardation (ICF/MR) services for persons with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 46,* 200-214. https://doi.org/10.1352/2008.46:200-214

Lakin, K. C., Prouty, R., & Alba, K. (2007). Medicaid institutional and home and communitybased services expenditures for persons with ID/DD within the overall Medicaid program. *Intellectual and Developmental Disabilities, 45*, 418-421.

Larson, S. ., Hallas-Muchow, L., Aiken, F., Taylor, B., Pettingell, S., Hewitt, A., … Fay, M.L. (2016). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2013*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from https://risp.umn.edu

McDermott, S., Royer, J., Cope, T., Lindgren, S., Momany, E., Lee, J.C., … Armour, B. (2018). Using Medicaid data to characterize persons with intellectual and developmental disabilities in five U.S. states. *American Journal on Intellectual and Developmental Disabilities, 123*(4), 371-381. http://doi.org/10.1352/1944-7558-123.4.371.

Mehling, M. H., & Tassé, M. J. (2015). Impact of choice on social outcomes of adults with ASD. *Journal of Autism and Developmental Disorders, 45*, 1588–1602. https://doi.org/10.1007/s10803-014-2312-6

Moseley, C., Kleinert, H., Sheppard-Jones, K., & Hall, S. (2013). Using research evidence to inform public policy decisions. *Intellectual and Developmental Disabilities*, 51(5), 412- 422.

Morisse, F., Vandemaele, E., Claes, C., Claes, L., & Vandevelde, S. (2013). Quality of life in persons with intellectual disabilities and mental health problems: An explorative study. *The Scientific World Journal*, 2013.

Muramatsu, N., & Campbell, R. T. (2002). State expenditures on home and community based services and use of formal and informal personal assistance: a multilevel analysis. *Journal of Health and Social Behavior, 43*(1), 107.

National Core Indicators. (2012, April*). Using National Core Indicators (NCI) data for quality improvement initiatives*. National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Retrieved from http://www.nationalcoreindicators.org/upload/coreindicators/using_national_core_indicators_data.pdf

Naylor, M. D., Kurtzman, E. T., Miller, E. A., Nadash, P., & Fitzgerald, P. (2015). An assessment of state-led reform of long-term services and supports. *Journal of Health Politics, Policy, and Law, 40*, 531–574.

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,* 12-26.

Nord, D., Luecking, R., Mank, D., Kiernan, W., & Wray, C. (2013). The state of the science of employment and economic self-sufficiency for people with intellectual and developmental disabilities. *Intellectual and developmental disabilities, 51*(5), 376-384.

Owen, R., Bonardi, A., Bradley, V., Butterworth, J., Caldwell, J., Cooper, R., … Terrill, C. F. (2015). Long-term services and supports. *Inclusion, 3*(4), 233–241. https://doi.org/10.1352/2326-6988-3.4.233

Paradise, J., Lyons, B., & Rowland, D. (2015). Medicaid at 50. Menlow Park, VA: The Henry J. Kaiser Family Foundation. Retrieved from http://files.kff.org/attachment/reportmedicaid-at-50

Rizzolo, M. C., Friedman, C., Lulinski-Norris, A., & Braddock, D. (2013). Home and Community Based Services (HCBS) Waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities, 51*(1), 1-21.

Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, M., Wehmeyer, M., Jiancheng, X., & Lachapelle, Y. (2005). Cross-cultural study of quality of life indicators. *American Journal on Mental Retardation, 110*(4), 298-311.

Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning, 31*, 181–190.

Schalock, R. L., Gardner, J. F., & Bradley, V. J. (2007). *Quality of life for people with intellectual and other developmental disabilities. Applications across individuals, organizations, communities, and systems*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schalock, R. L., Verdugo, M. A., & Braddock, D. L. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.

Shogren, K. A., Bradley, V. J., Gomez, S., Yeager, M. H., Schalock, R. L., Borthwick-Duffy, S., et al. (2009). Public policy and the enhancement of desired outcomes for persons with intellectual disability. *Intellectual and Developmental Disabilities, 47*, 307–319.

Stancliffe, R. J., & Lakin, K. C. (2005). *Costs and outcomes of community services for people with intellectual disabilities*. Paul H Brookes Publishing.

Stancliffe, R. J., Lakin, K. C., Larson, S. A., Engler, J., Taub, S., Fortune, J., & Bershadsky, J. (2012). Demographic characteristics, health conditions, and residential service use in adults with Down syndrome in twenty-five U.S. states. *Intellectual and Developmental Disabilities, 50*(2), 92–108. DOI: 10.1352/1934-9556-50.2.92

Tichá, R., Lakin, K. C., Larson, S. A., Stancliffe, R. J., Taub, S., Engler, 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*, 486–504. https://doi.org/10.1352/1934-9556- 50.06.486

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, 298–315. https://doi.org/10.1352/1934-9556-51.5.298

Townsend-White, C., Pham, A. N. T., & Vassos, M. V. (2012). Review: a systematic review of quality of life measures for people with intellectual disabilities and challenging behaviors. *Journal of Intellectual Disability Research, 56*(3), 270-284.

United Cerebral Palsy. (2016). The case for inclusion. Retrieved from http://cfi.ucp.org/wpcontent/uploads/2014/03/Case-for-Inclusion-2016-FINAL.pdf

van Loon, J. H., Bonham, G. S., Peterson, D. D., Schalock, R. L., Claes, C., & Decramer, A. E. (2013). The use of evidence-based outcomes in systems and organizations providing services and supports to persons with intellectual disability. *Evaluation and Program Planning, 36*, 80-87. http://dx.doi.org/10.1016/j.evalprogplan.2012.08.002

Verdugo, M. A., Gomez, L. E., Arias, B., Navas, P., & Shalock R. L. (2014). Measuring quality of life in people with intellectual and multiple disabilities: Validation of the San Martin scale. *Research in Developmental Disabilities, 35*(1), 75-86.

Table 1
Selected Sample Demographics (n=522)

		n	percent
Gender	Female	217	41.6
	Male	305	58.4
Race	Black/African American	148	28.4
	White	329	63
	Other	22	4.3
	Not Reported	23	4.4
Age	18-39	247	47.3
	40-54	157	30.1
	55-64	76	14.6
	65+	42	8
Residence Type	Congregate 4+ beds	210	40.2
	Congregate < 4 beds	54	10.3
	Independent home/share apartment	17	3.3
	Parent/relative home	164	31.4
	Foster care	77	14.8
Support Level[1]	Least Support Needs	27	5.2
	Modest or Moderate	231	44.3
	Least/moderate with some behavioral	16	3.1
	Moderate to high	171	32.8
	High to maximum	15	2.9
	Extraordinary medical support	20	3.8
	Extraordinary behavioral support	21	4
	Record needs validation	21	4

[1]Based on state's Support Intensity Scale assessment categories

Table 2
Summary of Regression Results, by Outcome

Predictor Variable	Outcome 1: Medicaid Expenditures	Outcome 2: Inclusion	Outcome 3: Everyday Choices	Outcome 4: Rights	Outcome 5: Social Participation
SIS Level (Ref = Least Support Needs)					
Modest or Moderate	11.1*	0.22	1.19	0.73	0.82
Least/Moderate w/ some Behavioral	14.8*	0.15	1.53	0.62	1.40
Moderate to High	18.2***	0.14	0.67	0.70	0.36*
High to Maximum	20.2**	-0.08	0.32	0.33	0.19*
Ext. Medical	33.0***	0.05	0.11**	0.96	0.25
Ext. Behavioral	25.3***	0.36	0.77	1.79	0.54
Needs Verification	23.3***	0.09	0.80	0.27	0.69
Residence Type (Ref = Congregate, 4 or more beds)					
Congregate, < 4 beds	-7.68*	0.17	1.13	0.71	1.50
Independent	-39.4***	0.29	4.16*	2.10	0.42
Parent/Relative	-52.8***	0.25*	0.51	0.78	0.30***
Foster Care	-10.9***	0.50***	1.13	0.61	2.13*
Total Expenditures, $1000s	N/A	0.00	0.99*	1.00	1.00
Age (Ref = 18-39)					
40 to 54	-3.37	-0.07	1.38	1.67	0.79
55 to 64	-6.90*	-0.07	1.37	2.20*	0.77
65 or older	-1.26	-0.15	1.34	4.84**	0.54
Female	1.81	0.03	1.22	0.71	1.41
Observations	522	506	493	342	483

Notes. For outcome 1, results are presented as predicted dollars, measured in $1,000s. For outcome 2, results are presented as predicted counts of inclusive activities. For outcomes 3, 4, and 5, results are presented as odds ratios.
*** $p < .001$. ** $p < .01$. * $p < .05$.

Table 3

Full Results for Linear Regression Predicting Medicaid Expenditures

Predictors	Entry Block 1					Entry Block 2					Entry Block 3				
	B	*SE B*	β	LL	UL	*B*	*SE B*	β	LL	UL	*B*	*SE B*	β	LL	UL
SIS Level (Ref = Least Support Needs)															
Modest or Moderate	18.4**	6.36	0.29	5.90	30.91	10.6*	4.43	0.16	1.93	19.32	11.1*	4.42	0.17	2.40	19.78
Least/Moderate w/ some Behavioral	30.0**	9.87	0.16	10.60	49.38	15.3*	6.87	0.08	1.83	28.82	14.8*	6.86	0.08	1.29	28.25
Moderate to High	25.2***	6.48	0.37	12.46	37.92	17.7***	4.52	0.26	8.81	26.56	18.2***	4.52	0.27	9.36	27.13
High to Maximum	13.0	10.08	0.07	-6.80	32.79	19.7**	7.03	0.10	5.92	33.53	20.2**	7.01	0.11	6.42	33.98
Ext. Medical	36.1***	9.23	0.22	18.01	54.28	32.9***	6.42	0.20	20.34	45.55	33.0***	6.42	0.20	20.42	45.65
Ext. Behavioral	35.7***	9.10	0.22	17.82	53.59	25.3***	6.34	0.16	12.84	37.74	25.3***	6.33	0.15	12.82	37.69
Needs Verification	36.2***	9.10	0.22	18.33	54.10	23.3***	6.32	0.14	10.91	35.74	23.3***	6.31	0.14	10.89	35.66
Residence Type (Ref = Congregate, 4 or more beds)															
Congregate, < 4 beds						-7.23*	3.31	-0.07	-13.73	-0.72	-7.68*	3.33	-0.07	-14.24	-1.13
Independent						-39.3***	5.51	-0.22	-50.12	-28.48	-39.4***	5.52	-0.22	-50.29	-28.61
Parent/Relative						-51.7***	2.28	-0.75	-56.17	-47.20	-52.8***	2.33	-0.76	-57.36	-48.18
Foster Care						-10.1***	2.91	-0.11	-15.84	-4.41	-10.9***	2.93	-0.12	-16.63	-5.13
Age (Ref = 18-39)															
40 to 54											-3.37	2.24	-0.05	-7.76	1.02
55 to 64											-6.90*	2.89	-0.08	-12.58	-1.23
65 or older											-1.26	3.73	-0.01	-8.58	6.06
Female											1.81	1.95	0.03	-2.03	5.65
Constant	60.49	6.02	--	48.66	72.32	87.47	4.41	--	78.81	96.12	88.96	4.54	--	80.04	97.87
Observations			522					522					522		
Adjusted R^2			0.05					0.55					0.55		

*** p<0.001, ** p<0.01, * p<0.05

Table 4

Full Results for Negative Binomial Regression Predicting Inclusion

Predictors	Entry Block 1				Entry Block 2				Entry Block 3				Entry Block 4			
	B	*SE B*	LL	UL	*B*	*SE B*	LL	UL	*B*	*SE B*	LL	UL	*B*	*SE B*	LL	UL
SIS Level (Ref = Least Support Needs)																
Modest or Moderate	0.23	0.14	-0.05	0.50	0.24	0.14	-0.03	0.50	0.22	0.14	-0.05	0.49	0.22	0.14	-0.05	0.49
Least/Moderate w/ some Behavioral	0.17	0.22	-0.25	0.59	0.19	0.21	-0.22	0.60	0.17	0.21	-0.25	0.58	0.15	0.21	-0.27	0.56
Moderate to High	0.19	0.14	-0.09	0.47	0.16	0.14	-0.11	0.43	0.14	0.14	-0.14	0.42	0.14	0.14	-0.14	0.42
High to Maximum	0.04	0.23	-0.40	0.49	-0.06	0.22	-0.49	0.38	-0.07	0.22	-0.51	0.36	-0.08	0.22	-0.52	0.35
Ext. Medical	0.15	0.21	-0.26	0.57	0.09	0.21	-0.32	0.50	0.05	0.21	-0.36	0.47	0.05	0.21	-0.36	0.47
Ext. Behavioral	0.39*	0.20	0.00	0.78	0.40*	0.19	0.02	0.78	0.37	0.20	-0.01	0.75	0.36	0.20	-0.03	0.74
Needs Verification	0.14	0.20	-0.26	0.53	0.13	0.20	-0.25	0.52	0.10	0.20	-0.29	0.5	0.09	0.20	-0.31	0.48
Residence Type (Ref = Congregate, 4 or more beds)																
Congregate, < 4 beds					0.16	0.10	-0.04	0.36	0.16	0.10	-0.04	0.36	0.17	0.10	-0.04	0.37
Independent					0.27	0.17	-0.06	0.60	0.31	0.17	-0.03	0.65	0.29	0.18	-0.06	0.64
Parent/Relative					0.23**	0.07	0.09	0.37	0.28**	0.10	0.10	0.47	0.25*	0.10	0.06	0.44
Foster Care					0.50***	0.09	0.33	0.68	0.51***	0.09	0.34	0.69	0.50***	0.09	0.33	0.68
Total Expenditures, $1000s									0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Age (Ref = 18-39)																
40 to 54													-0.07	0.07	-0.21	0.07
55 to 64													-0.07	0.09	-0.25	0.11
65 or older													-0.15	0.11	-0.37	0.08
Female													0.03	0.06	-0.09	0.15
Constant	2.58***	0.13	2.32	2.84	2.41***	0.14	2.14	2.67	2.31***	0.18	1.96	2.66	2.36***	0.18	2.00	2.72
Observations		506				506				506				506		
Pseudo R-squared		0.001				0.01				0.01				0.01		
Log-likelihood		-1852				-1835				-1834				-1833		

*** p<0.001, ** p<0.01, * p<0.05

Table 5

Full Results for Ordered Logistic Regression Predicting Everyday Choices

Predictors	Entry Block 1				Entry Block 2				Entry Block 3				Entry Block 4			
	B	*SE B*	LL	UL	*B*	*SE B*	LL	UL	*B*	*SE B*	LL	UL	*B*	*SE B*	LL	UL
SIS Level (Ref = Least Support Needs)																
Modest or Moderate	0.89	0.43	0.34	2.28	1.06	0.53	0.39	2.85	1.25	0.64	0.45	3.43	1.19	0.62	0.43	3.31
Least/Moderate w/ some Behavioral	0.98	0.72	0.23	4.14	1.23	0.94	0.28	5.48	1.56	1.21	0.34	7.10	1.53	1.19	0.33	7.02
Moderate to High	0.47	0.24	0.18	1.27	0.56	0.30	0.20	1.58	0.73	0.39	0.25	2.11	0.67	0.37	0.23	1.96
High to Maximum	0.18	0.16	0.03	1.01	0.22	0.20	0.04	1.34	0.31	0.28	0.05	1.85	0.32	0.29	0.05	1.89
Ext. Medical	0.07***	0.05	0.02	0.27	0.08***	0.06	0.02	0.33	0.12**	0.09	0.03	0.54	0.11**	0.09	0.03	0.50
Ext. Behavioral	0.43	0.32	0.10	1.85	0.55	0.43	0.12	2.51	0.77	0.61	0.16	3.66	0.77	0.61	0.16	3.68
Needs Verification	0.63	0.47	0.15	2.74	0.59	0.45	0.13	2.65	0.82	0.64	0.18	3.79	0.80	0.63	0.17	3.73
Residence Type (Ref = Congregate, 4 or more beds)																
Congregate, < 4 beds					1.31	0.50	0.61	2.78	1.17	0.46	0.55	2.52	1.13	0.45	0.52	2.44
Independent					6.87***	3.67	2.41	19.56	4.25*	2.41	1.40	12.93	4.16*	2.39	1.35	12.80
Parent/Relative					0.91	0.26	0.52	1.58	0.46*	0.18	0.21	1.00	0.51	0.21	0.23	1.12
Foster Care					1.29	0.45	0.65	2.56	1.14	0.40	0.57	2.28	1.13	0.40	0.56	2.27
Total Expenditures, $1000s									0.99*	0.01	0.98	1.00	0.99*	0.01	0.98	1.00
Age (Ref = 18-39)																
40 to 54													1.38	0.38	0.81	2.37
55 to 64													1.37	0.49	0.68	2.76
65 or older													1.34	0.58	0.57	3.13
Female													1.22			
Constant cut1	-3.68***	0.51	-4.69	-2.67	-3.45***	0.56	-4.55	-2.36	-4.61***	0.74	-6.06	-3.16	-4.37***	0.76	-5.86	-2.88
Constant cut2	1.31***	0.45	0.42	2.20	1.62***	0.51	0.62	2.63	0.53	0.67	-0.78	1.85	0.80	0.70	-0.58	2.18
Observations		493				493				493				493		
Pseudo R-squared		0.04				0.06				0.07				0.08		
Log-likelihood		-290				-283				-280				-278		

*** p<0.001, ** p<0.01, * p<0.05

Table 6

Full Results for Logistic Regression Predicting Rights

Predictors	Entry Block 1				Entry Block 2				Entry Block 3				Entry Block 4			
	B	*SE B*	LL	UL	*B*	*SE B*	LL	UL	*B*	*SE B*	LL	UL	*B*	*SE B*	LL	UL
SIS Level (Ref = Least Support Needs)																
Modest or Moderate	0.78	0.38	0.30	2.01	0.77	0.38	0.29	2.01	0.80	0.40	0.30	2.12	0.73	0.37	0.27	1.96
Least/Moderate w/ some Behavioral	0.54	0.39	0.13	2.23	0.53	0.39	0.13	2.22	0.55	0.41	0.13	2.34	0.62	0.46	0.14	2.65
Moderate to High	0.76	0.38	0.28	2.03	0.78	0.40	0.28	2.14	0.82	0.43	0.30	2.28	0.70	0.37	0.24	1.98
High to Maximum	0.31	0.32	0.04	2.30	0.34	0.35	0.04	2.58	0.35	0.36	0.05	2.68	0.33	0.34	0.04	2.59
Ext. Medical	0.93	0.79	0.18	4.86	1.07	0.91	0.20	5.64	1.19	1.04	0.22	6.55	0.96	0.87	0.16	5.63
Ext. Behavioral	1.71	1.36	0.36	8.15	1.61	1.30	0.33	7.82	1.80	1.48	0.36	9.04	1.79	1.48	0.35	9.07
Needs Verification	0.35	0.25	0.09	1.40	0.29	0.21	0.07	1.22	0.31	0.23	0.07	1.33	0.27	0.20	0.06	1.18
Residence Type (Ref = Congregate, 4 or more beds)																
Congregate, < 4 beds					0.67	0.26	0.32	1.44	0.65	0.26	0.30	1.40	0.71	0.29	0.32	1.57
Independent					2.19	1.50	0.57	8.39	1.92	1.38	0.47	7.84	2.10	1.53	0.50	8.78
Parent/Relative					0.66	0.19	0.38	1.16	0.55	0.23	0.25	1.23	0.78	0.34	0.33	1.85
Foster Care					0.55	0.18	0.29	1.05	0.53	0.18	0.28	1.02	0.61	0.21	0.31	1.19
Total Expenditures, $1000s									1.00	0.01	0.99	1.01	1.00	0.01	0.99	1.01
Age (Ref = 18-39)																
40 to 54													1.67	0.46	0.98	2.86
55 to 64													2.20*	0.78	1.10	4.40
65 or older													4.84**	2.91	1.49	15.71
Female													0.71	0.17	0.44	1.13
Constant	2.14	0.98	0.87	5.26	2.70*	1.34	1.02	7.15	3.61	2.47	0.95	13.76	2.37	1.72	0.57	9.85
Observations		342				342				342				342		
Pseudo R-squared		0.01				0.03				0.03				0.06		
Log-likelihood		-224				-221				-221				-214		

*** p<0.001, ** p<0.01, * p<0.05

Table 7

Full Results for Logistic Regression Predicting Social Participation

Predictors	Entry Block 1				Entry Block 2				Entry Block 3				Entry Block 4			
	B	*SE B*	LL	UL	*B*	*SE B*	LL	UL	*B*	*SE B*	LL	UL	*B*	*SE B*	LL	UL
SIS Level (Ref = Least Support Needs)																
Modest or Moderate	0.98	0.41	0.44	2.22	0.81	0.35	0.35	1.87	0.83	0.36	0.36	1.95	0.82	0.36	0.35	1.92
Least/Moderate w/ some Behavioral	1.95	1.24	0.56	6.79	1.42	0.94	0.39	5.20	1.49	1.00	0.40	5.52	1.4	0.94	0.38	5.20
Moderate to High	0.49	0.21	0.21	1.14	0.35*	0.16	0.15	0.85	0.37*	0.17	0.15	0.90	0.36*	0.17	0.15	0.90
High to Maximum	0.21*	0.16	0.05	0.90	0.18*	0.13	0.04	0.75	0.19*	0.14	0.04	0.83	0.19*	0.14	0.04	0.80
Ext. Medical	0.32	0.22	0.08	1.25	0.25*	0.17	0.06	0.97	0.27	0.19	0.07	1.10	0.25	0.18	0.06	1.05
Ext. Behavioral	0.68	0.44	0.19	2.44	0.52	0.34	0.14	1.89	0.55	0.37	0.15	2.07	0.54	0.37	0.14	2.04
Needs Verification	1.00	0.62	0.30	3.35	0.68	0.44	0.19	2.41	0.73	0.48	0.20	2.63	0.69	0.45	0.19	2.49
Residence Type (Ref = Congregate, 4 or more beds)																
Congregate, < 4 beds					1.58	0.52	0.83	3.02	1.55	0.51	0.81	2.96	1.5	0.50	0.78	2.90
Independent					0.52	0.31	0.16	1.69	0.47	0.29	0.14	1.59	0.42	0.27	0.12	1.45
Parent/Relative					0.42***	0.11	0.25	0.69	0.36**	0.13	0.18	0.71	0.30***	0.11	0.15	0.61
Foster Care					2.36**	0.68	1.34	4.15	2.29**	0.67	1.29	4.06	2.13*	0.64	1.19	3.83
Total Expenditures, $1000s									1.00	0.00	0.99	1.01	1.00	0.00	0.99	1.01
Age (Ref = 18-39)																
40 to 54													0.79	0.19	0.49	1.25
55 to 64													0.77	0.24	0.42	1.41
65 or older													0.54	0.21	0.25	1.16
Female													1.41	0.29	0.94	2.10
Constant 1	-2.70**	0.42	-3.52	-1.88	-3.20*	0.47	-4.12	-2.29	-3.45***	0.62	-4.67	-2.23	-3.68***	0.65	-4.95	-2.41
Constant 2	0.99*	0.39	0.22	1.76	0.74	0.43	-0.10	1.58	0.49	0.59	-0.66	1.64	0.30	0.61	-0.90	1.50
Observations		483				483				483				483		
Pseudo R-squared		0.02				0.05				0.05				0.06		
Log-likelihood		-382				-364				-364				-361		

*** p<0.001, ** p<0.01, * p<0.05