Title: State and Individual Differences and Choice-Making among Individuals with IDD: Familial Contexts Matter

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Introduction: Researchers have begun to conceptualize environmental factors, such as (state) disability policy goals, as inputs, with individual outcomes as outputs. Shogren, Luckasson, and Shalock (2015) proposed a logic model that aligns disability policy goals, systems of supports, and personal outcomes. This model is in the spirit of Bronfenbrenner’s Ecological Model of Human Development in which micro, meso, and macrosystems interact to influence individual outcomes (Bronfenbrenner, 1977). Shogren et al. (2015) particularly mentioned macro and meso-level factors related to housing independence and supports from state and federal funding, factors we examined in the current study. Previous studies have explored state variation by dummy coding state, thus establishing there are variations in choice between the states. However, there are no previous studies of choice by adults with IDD that model state-level environmental factors. This study explored factors that may be related to choices made by persons with intellectual and developmental disabilities (IDD) in the United States (US). Our analyses encompassed two important innovations in measuring choice for individuals with IDD: (a) a focus on both individual and state-level factors and (b) the use of multilevel modelling to most appropriately analyze state-level factors. We examined the constructs of support-related and everyday choice by developing scales based on items from the National Core Indicators Adult Consumer Survey (NCI-ACS) (Bradley & Moseley, 2007). In this research, we also pay attention to the impact of living with family on choice making for people with IDD as an important individual and state contextual factor.

Method: We analyzed data from the 2013-2014 National Core Indicators Adult Consumer Survey (NCI-ACS), developed by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) (Smith & Ashbaugh, 2001). The NCI-ACS is used to collect data on service users with IDD across the United States (the current study examined data from 29 states). We employed hierarchical linear modeling (HLM) because it incorporates higher level predictors into a model, by taking into account the contribution of each level of analysis (Raudenbush & Bryk, 2002). This process allowed us to consider both individual level factors (such as level of ID, mobility, etc.) and state factors (cost of living, proportion living independently within a state, etc.) and how they relate to the degree to which individuals with IDD make two kinds of choices on their own: support-related (e.g. choosing one’s staff) and everyday (e.g. choosing what to do with one’s free time).

Results: At the individual level, milder intellectual disability, mobility, few if any problematic behaviors, ability to answer survey questions independently, speaking verbally, and living in a non-agency setting, particularly in an independent setting, were all associated with more choice for both scales. Controlling for the individual level factors, state factors predicted choice. Higher proportions of people with IDD living independently within the state was associated with more support-related choice. High cost of living within a state was associated with less everyday choice. Finally, higher proportion of people living with family related to more everyday choice.

Discussion: This study suggests we can better explore how particular contexts support choice and gain a deeper understanding of factors that could be addressed by policymakers and advocates. One method to support such endeavors is multilevel modeling. IDD services are funded and regulated largely at a state level, so differences between states in IDD service policy likely will be important.

There were three findings of relevance to consider in regards to families and individuals with IDD. First, individuals with IDD who live in states with particularly high costs of living may be more at risk of less choice, particularly everyday choices. In addition, in states with higher cost of living, there tend to be less people living independently, which again most likely limits choice of residential settings and autonomy. Adults with IDD and their families each have unique economic difficulties compared to the general population. Therefore, states with higher costs of living, other things being equal, very well could limit everyday choices. One policy implication of the current study, supported by Stancliffe et al. (2000), is to enable consumers to earn more by helping them to work in supported employment.
Next, living with family, regardless of state context, was associated with more support-related choices, but was not associated with more or less everyday choices. This suggests families may be helping an individual navigate their support service system while having less of an impact on autonomous everyday activities.

Finally, states with more independent-living opportunities provided more support-related choices overall, regardless of an individual’s personal living situation. We believe this finding may reflect a shift in state culture. More people living independently likely makes more stakeholders in that state aware of the higher level of support-related choice exercised by individuals living independently, potentially increasing expectations of what choices are possible. As expectations rise, individuals are better encouraged, allowed, and assisted in making support-related choices. Policies that increase independent living for individuals with IDD within a state should be evaluated in relation to personal choice.

References/Citations: