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Association of state-level and individual-level factors with choice making of individuals with intellectual and developmental disabilities

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ABSTRACT

Background: State-level factors have not been examined in research on choice, despite findings of between-state differences.

Aims: To examine both individual and state-level factors associated with choice.

Methods and procedures: We used multilevel modeling to explore two choice scales, support-related and everyday choice, based on the National Core Indicators (NCI) data from 2013–14.

Outcomes and Results: At the individual level, milder ID, greater mobility, fewer problem behaviors, answering questions independently, communicating verbally, and living in a non-agency setting, particularly independent settings, were associated with more choice for both scales. State-level factors overall explained variance for both scales, but were more strongly associated with support-related choice. A higher proportion of people with IDD living independently within the state predicted more support-related choice. High cost of living within a state predicted less everyday choice. Higher proportion of people living with family and lower proportion being served within a state predicted more everyday choice.

Conclusions and implications: These findings suggest further study of choice in relation to policies that: (1) increase independent living for individuals with IDD, and (2) assist individuals/families living in high cost states. State differences on important QOL outcomes are likely to be associated with economic and system-based factors beyond individual differences.

What this paper adds?

Comparisons among US states have the potential to begin to identify how state policy, funding and contextual factors are related to outcomes for people with IDD, thereby providing evidence on how these factors might be changed to achieve better outcomes. This paper is an important addition as it examines the relationship between state-level factors and choice by people with IDD. These factors include features of the state IDD service-system, such as the proportion of IDD service users within a state living independently. Such factors are within the control of state IDD administrators and so are potentially modifiable. This paper uses a new statistical approach in this field, multilevel modeling, to explore these state-level contextual factors on the outcome of choice for individuals with IDD. Compared to previous studies that found living in different states significantly affected both an everyday and support-related choice for people with IDD receiving services, this paper was able to identify specific state-level factors that contribute

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to these differences over and above individual-level factors. Specifically, the higher the proportion of people with IDD living independently, the more likely they were to make support-related choices. In contrast, when fewer people are served in a state, experience a lower cost of living, and when there is higher proportion of people with IDD living with family, people with IDD are more likely to make everyday choices. These findings are important as they provide guidance to state agencies about making system-level changes in order to increase choice making opportunities for people with disabilities.

1. Introduction

To explain how US state-level factors may be related to the choices adults with intellectual and developmental disabilities (IDD) make, and why this issue is important, this introduction is organized into five sections. First, we discuss state differences in IDD funding and outcomes, and make the case as to why choice is an important outcome. Second, we examine specific findings of state differences in choice-making among individuals with IDD. Third, we explore state-level factors associated with quality of life more broadly. Fourth, we explain how previous research has consistently identified two types of choice, support-related and everyday choice, and propose their potential relationship to state-level variables. Finally, we describe the study and set out the research questions.

1.1. State context

In the United States (US), there is a long history of large and persistent between-state differences in the funding, nature and extent of intellectual and developmental disabilities (IDD) services and the outcomes experienced by service users. For example, [Braddock, Hemp, Parish, and Rizzolo, 2000](#) documented that in 1997 there was a 295% difference between the highest and lowest states in fiscal effort on disability services (disability service expenditure per \$1000 of overall state personal income), with states ranging from 23% to 97% in the percentage of total disability funding expended in that state allocated to community-based services. Similarly, 2014 Residential Information Systems Project (RISP) data ([Larson et al., 2016](#)) revealed large between-state differences in living arrangements, with the number of IDD service users per 100,000 of the overall state population living in their own home varying from 0 (West Virginia) to 168 (North Dakota). Likewise, outcomes experienced by users of IDD services vary considerably by state. Since the advent of the National Core Indicators (NCI) program in 1997 ([Bradley & Moseley, 2007](#)), these differences among participating states have been publicly documented. For example, using 2011–12 [National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute \(2012\)](#) reported that among 19 participating states, the percentage of adults with IDD in integrated (community) jobs varied from 0.9% in Alabama to 38.1% in Connecticut.

Despite these stark differences in expenditure and service outputs, there has been relatively little examination of the effect of between-state differences on the outcomes experienced by service users with IDD. Comparisons among states have the potential to begin to identify how state policy, funding and contextual factors are related to outcomes, thereby providing evidence on how these factors might be changed to achieve better outcomes.

We opted to examine the outcome of choice in this study because of its importance. First, individuals with IDD have reported having less choice than individuals without IDD ([Sheppard-Jones, Prout, & Kleinert, 2005](#)). Further, people with IDD have stated clearly and repeatedly that choice is very important to them ([Miller, Cooper, Cook, & Petch, 2008](#)). Choice is a fundamental component of quality of life ([Schalock & Verdugo, 2012](#)) and is an indicator of self-determination ([Abery & Stancliffe, 2003a, 2003b](#)). In fact, choice is a key right enshrined in state, federal and international regulations and legislation, such as the Developmental Disabilities Assistance and Bill of Rights Act of 2000, as well as in the UN Convention on the Rights of Persons with Disabilities (CRDP: UN, 2006). Finally, previous research has shown robust between-state differences in choices exercised by people with IDD, differences that are evident even after personal characteristics (e.g., level of intellectual disability) and key environmental variables (e.g., living arrangements) have been controlled statistically ([Lakin et al., 2008](#); [Tichá et al., 2012](#)).

1.2. Between-state differences in choice

Using step-wise linear regression to analyze National Core Indicators Adult Consumer Survey (NCI-ACS) choice data from six states, [Lakin et al. \(2008\)](#), found that state differences independently accounted for 10% and 9% respectively of variance in support-related choice and everyday choice, more than any other factor except for level of intellectual disability (ID). In the step-wise approach employed by [Lakin et al. \(2008\)](#), independent variables were entered sequentially in blocks. The addition of each new block of variables was assessed to see if it explained significant additional variation in the outcome. By entering state last, the researchers were able to control for other factors - such as individual characteristics, residential settings, and funding program - and demonstrated that differences between states were independently associated with a significant amount of variation in choice. Using a similar analytic approach, [Tichá et al. \(2012\)](#) examined NCI-ACS data from 19 states and found state significantly accounted for 12% and 3% variance in the NCI-ACS support-related and everyday choice scales respectively.

1.3. Relationship between state context variables and individual outcomes

Some researchers have begun to conceptualize environmental factors, such as (state) disability policies, as inputs, with individual outcomes as outputs. [Shogren, Luckasson, and Schalock, \(2015\)](#) 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

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