Developmental Disabilities Network Journal

Volume 3 | Issue 2 Article 12

July 2023

Factors impacting access to community services by people with intellectual disabilities

Caitlin Crabb
University of Illinois Chicago

Randall Owen
University of Nevada, Reno

Tamar Heller
University of Illinois Chicago

Recommended Citation
Crabb, Caitlin; Owen, Randall; and Heller, Tamar (2023) "Factors impacting access to community services by people with intellectual disabilities," *Developmental Disabilities Network Journal*: Vol. 3: Iss. 2, Article 12.
DOI: 10.59620/2694-1104.1075
Available at: https://digitalcommons.usu.edu/ddnj/vol3/iss2/12

Factors impacting access to community services by people with intellectual disabilities

Cover Page Footnote

Factors impacting access to community services by people with intellectual disabilities Caitlin Crabb, PhD, MPH1a, Randall Owen, PhD2b, & Tamar Heller, PhD1c 1Department of Disability and Human Development, University of Illinois at Chicago 1640 W. Roosevelt Rd. MC 626; Chicago, IL 60608; USA 2College of Education and Human Development, University of Nevada, Reno; 4090 William J. Raggio Building, Mail Stop 285; Reno, NV 89512; USA accrabb2@uic.edu, Visiting Research Assistant Professor brandallowen@unr.edu, Associate Professor ctheller@uic.edu, Distinguished Professor, Head Corresponding Author: Caitlin Crabb 1640 W. Roosevelt Rd. MC 626 Chicago, IL 60608; USA ccrabb2@uic.edu Phone Number: +1 (312) 413-1535 Disclosures: The authors have nothing to disclose.

Funding Details: Funding for this research was provided through the Institute on Disability and Human Development, University of Illinois at Chicago, which is funded through the Administration on Intellectual and Developmental Disabilities (AIDD) within the Administration for Community Living, US Department of Health and Human Services (Grant #90-DD-0010).

Factors Impacting Access to Community Services by People with Intellectual Disabilities

Caitlin Crabb,[1] Randall Owen,[2] and Tamar Heller[1]

[1]University of Illinois Chicago, Chicago, IL
[2]University of Nevada, Reno, NV

Plain Language Summary

Home- and community-based services (HCBS) are a type of long-term services and supports. HCBS are in the community, not in a nursing home or institution. HCBS are important for people with disabilities and chronic health conditions. HCBS allow people to stay in their homes in the community and get support. Our research looked at how different factors changed access to HCBS. Our research is only on people with intellectual and developmental disabilities (I/DD). Access to HCBS included the number of services received. It also included the number of extra services needed. We used a national survey of people with I/DD called the National Core Indicators. We also used some other datasets. We wanted to know how three groups of factors affected access to HCBS. These three groups are individual, community, and public policy factors. We found that variables in all three groups affected access to HCBS. Older people got more services and did not need as many. Black people got fewer services and needed more than White people. People with a higher problem behaviors score and those who used mobility devices got more services. They also needed more services. People who had better health did not need as many services. Age, race, problem behaviors score, use of mobility aids, and health are all individual variables. People who lived in group homes got more services than people living in their own or family homes. People who had jobs in the community got more services. Where people lived and if they had a community job were both community variables. People who lived in a state with a program called Balancing Incentive Program (BIP), got more services but also needed more services. BIP is one of five public policy factors. It is important to learn about this area to make sure people get the services they need. More work should be done in this area to add to what we know.

Abstract

Background: *People with intellectual disabilities increasingly live in smaller community settings rather than institutional settings. Home- and community-based services (HCBS)*

Funding for this research was provided through the Institute on Disability and Human Development, University of Illinois Chicago, which is funded through the Administration on Intellectual and Developmental Disabilities (AIDD) within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (Grant #90-DD-0010).

Correspondence concerning this article should be addressed to Caitlin Crabb, 1640 W. Roosevelt Rd., MC 626, Chicago, IL 60608; USA. Email: ccrabb2@uic.edu.

are a type of long-term care in which services and supports are provided in people's homes and communities. HCBS are essential for people with disabilities to remain in the community.

Method: *The 2015-2016 National Core Indicators survey data, along with other datasets, were used to determine how factors impacted service utilization and additional services needed for adults with intellectual and development disabilities (I/DD) in the US. Three groups of factors were used: individual, interpersonal, and public policy factors.*

Results: *Variables within each of the three groups of factors affected access to HCBS. Of significant note within individual factors, older adults received more services and had fewer additional services needed. Black respondents received fewer services and had more additional services needed. A higher problem behaviors score and use of mobility aids were associated with greater utilization and more additional services needed. Better health was associated with significantly fewer additional services needed. Within interpersonal factors, results indicated that people who lived in group homes received more services than people living in their own or family homes. Additionally, individuals with community jobs received more services. A notable public policy finding indicated people who lived in a state with a Balancing Incentive Program (BIP) got more services but also had additional services needed.*

Conclusion: *This study examined factors not studied previously and indicates that future research should look at different factors to better understand their impacts on access to HCBS for people with I/DD.*

Background

In recent years, the body of research exploring utilization and unmet need for medical care of people with intellectual and developmental disabilities (I/DD) has expanded, including identifying the social determinants that impact receipt of medical services (Chapman et al., 2018; Durbin et al., 2017; Patton et al., 2019). However, there is still much work to be done regarding factors that impact the use of long-term services and supports (LTSS), especially home- and community-based services (HCBS). Evidence-based policy demands an examination of HCBS and the factors that lead to enhanced outcomes for people in a range of community living settings (Kozma et al., 2009). During the 2021 Association of University Centers on Disability Technical Assistance Institute, Alison Barkhoff, Principal Deputy Administrator at the Administration for Community Living, noted this gap and issued a call for more research in the area (Barkhoff, 2021).

LTSS are long-term care to support people with disabilities and/or chronic health conditions in daily living, maintaining health, getting jobs, or participating in daytime activities, community participation, and relationships (Rizzolo et al., 2016). LTSS include both long-term care in segregated, congregate settings and HCBS. HCBS are beneficial for people with disabilities in that they promote independence, community living, and community participation and are delivered within a variety of community settings such as group homes and family homes (Kaye et al., 2010; Rizzolo et al., 2016). States may offer HCBS to people with I/DD through several Medicaid authorities including waivers (e.g., 1915(c) HCBS and 1115 Research and Demonstration waivers), state plan amendments (e.g., 1915(i) HCBS, 1915(j) Self-Directed

Personal Assistance Services, and 1915(k) Community First Choice state plan amendments), managed care, and state plan personal care (Rizzolo et al., 2016). HCBS waivers offer flexibility and tailoring, leading most states to use HCBS waivers in their provision of HCBS—95% of total HCBS expenditures for people with I/DD were from HCBS waivers (Eiken et al., 2018; Larson et al., 2017).

Drawing on lessons learned from research on medical utilization and unmet needs, it stands to reason that multiple layers of factors may impact utilization of LTSS. For instance, Andersen's (1968) Behavioral Model seeks to understand differences in medical service utilization among families across predisposing, need, and enabling factors. That work was later adapted to shift focus from the family to the individual (Andersen, 1995). More recent work applies the Behavioral Model to HCBS utilization and unmet need (Joosten, 2015).

Andersen's Behavioral Model can be viewed as a precursor to contemporary social ecological models, which have been used in research and public/health policy and to identify factors impacting access to medical services and HCBS (Joosten, 2015). Many social ecological models consider five levels of factors regarding outcomes: (1) individual, (2) interpersonal, (3) organizational, (4) community, and (5) public policy (Savolainen et al., 2021). Other social ecological models consider four levels: (1) intra-personal, (2) interpersonal, (3) community, and (4) public policy. Regardless of which exact model is used, the same idea applies—utilization of and unmet need for medical care and LTSS radiate out from the intrinsic and demographic factors of an individual to include broader relational and societal components.

Individual Factors

Research on who utilizes and/or has unmet needs for LTSS has primarily focused on the role of individual characteristics and demographics. Common individual factors include gender, age, and race and ethnicity. Previous research found that men with I/DD had higher service expenditures than women with I/DD (Harrington & Kang, 2016). Studies have shown that younger individuals with I/DD have lower odds of receiving any LTSS and greater unmet LTSS needs as compared to older individuals with I/DD (Ellis et al., 2002; Harrington & Kang, 2016). Research has also shown that people with I/DD from minority backgrounds received fewer services and had more unmet needs than people with I/DD from non-minority backgrounds (Burke & Heller, 2017; Harrington & Kang, 2016; Magaña et al., 2002).

Individual factors can also include disability information, including diagnosis and functional limitations. For instance, intensive medical needs and limitations in gross motor functioning increased an individual's need for community resources and living supports (Almasri et al., 2014; Seo et al., 2017). Similarly, people with I/DD with higher levels of verbal communication and better health had fewer unmet needs for LTSS (Burke & Heller, 2017).

Interpersonal and Community Factors

For people with I/DD, interpersonal factors have typically focused on family characteristics and living situations. For example, previous research has associated greater family financial stability with fewer HCBS needs (Ellis et al., 2002). These might include what the person with I/DD did during the day or where in the community a person lives. Specifically, a person with an I/DD is found to spend less time participating in social activities than people with other types of disabilities and significantly less than people without disabilities (Verdonschot et al., 2009). However, family engagement and financial wealth are factors that have increased social involvement of people with I/DD (Ellis et al., 2002; Verdonschot et al., 2009).

Public Policy Factors

Another layer of important factors regarding utilization of and the unmet need for HCBS is public policy impacting individuals with I/DD. For instance, families of children with autism who received Medicaid or other public health insurance were more likely to receive case management services (Thomas et al., 2007). Another example of a public policy factor is the amount a state spends on community I/DD services. Previous research has suggested that lower fiscal efforts have been associated with greater unmet need for vocational, dental, social, and transportation supports and greater utilization of social work services (Pruchno & McMullen, 2004).

Research Contribution

The purpose of this study is to determine which factors significantly impact access to HCBS and unmet needs. This research is needed because without understanding how to better facilitate access to HCBS for people with I/DD, they may end up in more restrictive settings.

This research makes a significant contribution to existing literature by utilizing a modified social ecological framework to identify the factors that impact utilization of and unmet need for HCBS of people with I/DD. We use a well-established dataset, the National Core Indicators, to capture outcomes related to HCBS, as well as individual and interpersonal/community variables. We used a unique approach and merged additional public policy variables with the NCI data set, which included level of community spending on I/DD, presence of institutions in a state, state participation in the Balancing Incentive Program (BIP), percent of people with I/DD served by a state, and Medicaid HCBS waiver receipt. To the authors' knowledge, many of these variables (e.g., BIP) have not been studied before in their relationship to HCBS access.

This data set and methodological approach allowed us to explore the social ecological factors that impact HCBS and address the following research questions.

1. How do individual, interpersonal/community, and public policy factors impact utilization of HCBS?
2. How do individual, interpersonal/community, and public policy factors impact unmet need for HCBS?

Methods

Data Sources

This research relies on several data sources. The primary outcome measures come from the National Core Indicators (NCI) 2015-2016 Adult Consumer Survey (ACS). The 2015-2016 cycle of the NCI ACS included 35 states and Washington DC (Human Services Research Institute & National Association of State Directors of Developmental Disabilities Services, 2017). The NCI ACS survey data is collected through in-person interviews with 400 or more people with I/DD in each NCI-participating state who are at least 18 years old and receive at least one paid service from their state, in addition to case management (Human Services Research Institute & National Association of State Directors of Developmental Disabilities Services, 2018). The ACS includes five sections, but data for this study were only taken from two sections: Background Information (collected from administrative records and from service coordinators prior to the interview) and Section II (may be completed by the person receiving services or by a proxy if needed; Human Services Research Institute & National Association of State Directors of Developmental Disabilities Services, 2017). The Background Information section includes questions about demographics, living situation, services received, and employment status; while Section II includes questions about community inclusion, choice, rights, health, and additional services needed (Human Services Research Institute & National Association of State Directors of Developmental Disabilities Services, 2017).

The remaining three sections of the ACS not included in any study analyses include: (1) Pre-Survey Form, (2) Section I: Face-to-Face Survey With Person Receiving Services & Supports, and (3) the Surveyor Feedback Sheet. The Pre-Survey Form is intended to provide more information to surveyors in order to schedule and conduct the face-to-face interviews such as contact information, accommodation needs, and background information such as where the individual works or if they attend a community day service. Section I: Face-to-Face Survey With Person Receiving Services & Supports is intended only for the adult with I/DD and asks questions about experiences and satisfaction in the areas of home, employment, safety, friends & family, community participation & leisure, rights & privacy, and satisfaction with services/supports. The Surveyor Feedback Sheet is a reflective section to be completed by the surveyor such as when/ where the survey was conducted, the length of the survey, and any questions that were problematic. While important, these sections were excluded as they tended to be more subjective in nature and potential links between measures within these sections and outcomes of interest were unclear.

Additionally, four independent variables from three other datasets were matched to the NCI ACS dataset. These were state-level indicators related to state factors and public policy differences. Human Services Research Institute (HSRI) staff appended these variables to the NCI ACS in order to maintain the anonymity of the states. These additional data were derived from the following sources: (1) the State of the States in Intellectual and Developmental Disabilities report (Braddock et al., 2017); (2) the In-Home and Residential Long-Term Services for Persons with Intellectual or Developmental Disabilities report (Larson et al., 2018); and (3) Tipping the

Balance: The Balancing Incentive Program and State Progress on Rebalancing Their Long-Term Services and Supports (Sweetland-Lester et al., 2015). The specific variables are described below.

The State of the States in Intellectual and Developmental Disabilities is a longitudinal study of expenditures, revenue, demographics, and program trends in various settings for people with I/DD within the U.S., with data collected between fiscal year (FY) 1977 and FY2015 (Braddock et al., 2017). The Balancing Incentive Program report details BIP state progress towards increasing their share of LTSS expenditures spent within the community, explores BIP expenditures trends related to specific services, and describes successful initiatives that states have implemented within their BIP programs (Sweetland-Lester et al., 2015). The In-Home and Residential Long-Term Services for Persons with Intellectual or Developmental Disabilities report is a product of the Residential Information Systems Project (RISP), an Administration of Intellectual and Developmental Disabilities Project of National Significance, which has collected and compiled data on people with I/DD and LTSS since 1977 (Larson et al., 2018). The RISP report includes data on several components of LTSS, including state/non-state providers, living arrangement, size of living arrangement, age of person with I/DD, and funding authority (Larson et al., 2018). Data were taken from all three reports by the researcher and placed into a Microsoft Excel format to be merged with the NCI ACS master dataset by the HSRI/NASDDDS team. The variables taken from all three data sources are discussed in more detail below.

Sample

NCI ACS data included responses from 17,682 adults with I/DD across the 35 states and Washington, DC, for the 2015-2016 cycle. We excluded people who (1) did not identify as having an I/DD, (2) had missing values on the level of the intellectual disability (ID) variable, and/or (3) were not community respondents (e.g., lived in congregate settings). After these exclusions, 11,167 respondents were in the final sample. This study focused on people with I/DD and their access to services within the community; thus, people living in nursing facilities or institutional settings were not included as they were not considered to be community residents.

Measures

Unless otherwise noted, the measures came from the NCI ACS.

Outcomes

Services received was a count, ranging from 0 to 14, of the number of HCBS an individual received (“Which of the following services/supports funded by the state (or county) agency does this person receive?”). This information came from state records, such as service records, case management records, or Medicaid Management Information System databases and was typically recorded by service provider staff members. The individual services were listed as: (1) service coordination/case management; (2) respite/family support; (3) transportation; (4) assistance finding, maintaining, or changing jobs; (5) day services other than employment; (6) education, training, or skills development; (7) health care coordination; (8) dental care coordination; (9)

assistance finding, maintaining, or changing housing; (10) help with social/relationship issues, meeting people; (11) communication technology; (12) environmental adaptations/home modifications; (13) benefits/insurance information; and (14) residential support services.

Similarly, *unmet need* was a count of the same services, again ranging from 0 to 14, of HCBS that an individual (or proxy) indicated that they needed ("Do you need any of these additional services?").

Independent Variables

The independent variables are categorized around the three levels of the modified social ecological model.

Individual Factors included age, gender, and race. Age was continuous, measured in years. Gender was dichotomized as male or female. Race included categories of White only, Black only, and Other (people of multiple races or who identified as another race/ethnicity besides White only or Black only).

Individual variables also included data related to a person's disability and diagnosis. These included problem behaviors score, level of ID, use of spoken communication, use of mobility aids, and health. The problem behaviors score, calculated from the NCI ACS based on Scott and Havercamp (2014a), included self-injurious, disruptive, and destructive behaviors, and reflects the level of support needed to address these problem behaviors. The problem behaviors score ranges from 0, no support needed for any of the three problem behaviors, to 9, significant support needed for all three problem behaviors. Level of ID categories included mild, moderate, severe, and profound. Spoken communication was dichotomous (yes, used spoken language to communicate or no, used other methods to communicate, such as sign language). Mobility aid use was also dichotomous. Health was self-rated or completed by a proxy, if necessary, with categories of poor, fairly good, very good, and excellent.

Interpersonal and Community Factors included data about how a person relates to people and the community around them. One of the key variables at this level was residential setting. The NCI ACS includes a variable that categorizes the residential setting into a group home, family home, own home, or host/foster family home. Additionally, whether or not the person worked in a community job, either individually or in a group, was included as an interpersonal or community factor.

Public Policy Factors were derived from other reports and corresponded to the state where an individual lived. These included the level of community spending on I/DD, presence of institutions in the state, state participation in BIP, percent of estimated people with I/DD served by the state, and Medicaid HCBS waiver receipt. Level of community spending on I/DD categories included low, medium, and high, based on Table 6 in the State of the States in Intellectual and Developmental Disabilities report (Braddock et al., 2017). The presence of institutions in a state was dichotomous, taken from Figure 3 in the State of the States in Intellectual and Developmental Disabilities report (Braddock et al., 2017). BIP was a rebalancing initiative, ending in 2015, to encourage states to shift services away from congregate settings and to the community by providing a higher federal match for states spending less than 50% on HCBS (Sweetland-Lester et al., 2015). State participation in BIP included three categories: ineligible for BIP participation, participated in BIP, and eligible for BIP but did not participate. This variable was taken from the Tipping the Balance: The Balancing Incentive Program and State Progress on Rebalancing Their Long-Term Services and Supports report (Sweetland-Lester et al., 2015).

The percent of people with I/DD served by the state was categorized in 10% intervals starting at 31% up to 100%, taken from Table 1.2 in the In-Home and Residential Long-Term Services for Persons with Intellectual or Developmental Disabilities report (Larson et al., 2018). However, for easier interpretation, the percentage of people served by the state was treated as a continuous variable in the regression analyses. Finally, Medicaid HCBS waiver receipt was dichotomous.

Data Analysis

We used IBM SPSS Statistics version 24.0 for data organization and analyses. Descriptive statistics were computed for both the independent and outcome variables. Both outcome variables were counts ranging from 0 to 14 and were overdispersed (Rodriguez, 2013), so negative binomial regressions were performed to determine relationships with the independent variables. Cases with missing independent variable information were excluded from the analyses.

This research was reviewed by the lead authors' Institutional Review Board. Because the research relied on secondary datasets, it was exempt from further review.

Descriptive Statistics

Descriptive statistics are presented in Table 1 for the independent factors. The average age of the sample was 42 years and the majority (57.2%) identified as male. About a quarter of the sample was Black (18.9%) and over two-thirds were White (69.4%). The remaining 11.7% of the sample indicated another race/ethnicity apart from White or Black only and/or identified as multiple races. Respondents averaged a moderate problem behavior score of 4.1 out of a possible 9 (*SD* = 1.5). Most of the sample had a mild or moderate ID (76.6%), communicated using spoken language (79.7%), and did not use mobility aids (79.1%). Respondents indicated a high degree of health, with 68.8% reporting they were in excellent or very good health; only 2.8% of respondents indicated they were in poor health. The largest portion of respondents lived in family homes (39.0%), followed by group homes (33.5%), their own homes (20.1%), and foster/host family homes (7.5%). Most respondents did not have a job in the community (82.1%). The largest faction of respondents lived in states with low levels of community fiscal effort for I/DD services (44.8%) and in BIP-eligible but nonparticipating states (47.7%). Three-quarters of respondents lived in states with institutions. Most of the sample (58.1%) resided in states that served between 61 and 80% of the state's estimated I/DD population. Slightly over 80% of the sample received supports funded through their state's Medicaid HCBS waiver.

Table 1

Demographics and Descriptive Statistics (N = 11,167)

Variable	Mean ± *SD* or *n* (%)
Individual	
Age	42.3 ± 14.8
Gender	
Male	57.2 (6,388)
Female	42.8 (4,779)
Race	
White	69.4 (7,750)
Black	18.9 (2,108)
Other	11.7 (1,309)
Problem Behaviors Score	4.1 ± 1.5
Level of ID	
Mild	42.6 (4,761)
Moderate	34.0 (3,792)
Severe	14.3 (1,601)
Profound	9.1 (1,013)
Uses Spoken Language	
Yes	79.7 (8,902)
Uses Mobility Aids	
No	79.1 (8,833)
Yes	20.9 (2,334)
Health	
Poor	2.8 (310)
Fairly Good	28.5 (3,180)
Very Good	49.7 (5,547)
Excellent	19.1 (2,130)
Interpersonal and Community Factors	
Residential Setting	
Group Home	33.5 (3,739)
Family Home	39.0 (4,354)
Own Home	20.1 (2,241)
Foster or Host Home	7.5 (833)
Community Job	
No	82.1 (9,171)
Yes	17.9 (1,996)

(*table continues*)

Variable	Mean ± *SD* or *n* (%)
Public Policy Factors	
Level of Community Fiscal Effort for I/DD Services	
Low	44.8 (5,008)
Medium	25.5 (2,846)
High	29.7 (3,313)
Presence of Institutions in State	
No	25.0 (2,792)
Yes	75.0 (8,375)
State Participated in BIP	
Eligible, Participated	34.7 (3,876)
Eligible, Did Not Participate	47.7 (5,326)
Ineligible	17.6 (1,965)
Percent Served	
31 - 40%	2.7 (298)
41 - 50%	6.4 (716)
51 - 60%	13.9 (1,547)
61 - 70%	38.3 (4,275)
71 - 80%	19.8 (2,213)
81 - 90%	8.2 (911)
91 - 100%	10.8 (1,207)
Receives Medicaid HCBS Waiver	
No	18.7 (2,090)
Yes	81.3 (9,077)

Results

Services Received

Respondents received an average of about 6 services (*SD* = 3.2) out of a possible 14. Case management was the most frequently received service (96.2%), followed by transportation (65.8%). The least frequently reported services received were environmental adaptations/home modifications (15.7%) and communication technology (9.5%). See Table 2 for more details.

Table 3 shows the negative binomial regression results for both outcomes. For the individual factors, older age was associated with a slight, but significant, increase in the number of services received. While respondents of other or multiple races received more services than White respondents, Black respondents received significantly fewer services. A greater level of need in problem behaviors support and the use of mobility aids were associated with significantly more services received. No significant relationships were found between received services and gender, level of ID, spoken communication, or health.

Table 2

Descriptive Statistics of Received Services and Additional Services Needed

Service (*N* = 11,167)	Received Mean ± *SD* or *n* (%)	Additional services needed Mean ± *SD* or *n* (%)
Overall	6.3 ± 3.2	1.0 ± 1.9
Individual services and supports		
Case management	10,738 (96.2)	597 (5.3)
Respite/family support	2,854 (25.6)	832 (7.5)
Transportation	7,346 (65.8)	1,257 (11.3)
Job assistance	3,179 (28.5)	1,237 (11.1)
Day services	6,459 (57.8)	685 (6.1)
Education, training, or skills development	4,759 (42.6)	1,083 (9.7)
Health care coordination	5,851 (52.4)	600 (5.4)
Dental care coordination	5,480 (49.1)	879 (7.9)
Housing	3,939 (35.3)	682 (6.1)
Social/relationships	6,107 (54.7)	1,191 (10.7)
Communication technology	1,061 (9.5)	698 (6.3)
Environmental adaptations/home modifications	1,754 (15.7)	472 (4.2)
Benefits/insurance information	4,923 (44.1)	525 (4.7)
Residential support services	6,071 (54.4)	593 (5.3)

For the interpersonal and community factors, respondents who lived in their own homes and those living in family homes received significantly fewer services than those in group homes. Individuals with community jobs received significantly more services.

For the public policy factors, people in states with institutions received 7% fewer services than people in states without institutions. Compared to people in states that participated in BIP, those in states ineligible for BIP and people in states that were eligible but did not participate in BIP received significantly fewer services. People in states that served a higher percentage of their estimated I/DD population received slightly more services than those in states that served a lower percentage of their estimated I/DD population. Medicaid HCBS waiver recipients received significantly more services than non-waiver recipients. No significant relationships were found between services received and level of community fiscal effort.

Table 3

Received Services and Additional Services Needed Negative Binomial Regression Results

Variable	Received services adjusted IRR (95% CI)	Additional services needed adjusted IRR (95% CI)
Individual		
Age	1.00 (1.00 - 1.00)***	0.99 (0.99 - 0.99)***
Female[a]	1.01 (0.99 - 1.03)	1.00 (0.93 - 1.07)
Other Race[b]	1.09 (1.06 - 1.12)***	1.12 (1.00 - 1.26)
Black[b]	0.95 (0.93 - 0.98)***	1.18 (1.07 - 1.30)***
Problem Behaviors Score[c]	1.02 (1.01 - 1.03)***	1.05 (1.02 - 1.08)***
Profound ID[d]	0.98 (0.94 - 1.02)	0.73 (0.62 - 0.85)***
Severe ID[d]	0.99 (0.96 - 1.02)	0.76 (0.67 - 0.87)***
Moderate ID[d]	1.00 (0.98 - 1.03)	0.88 (0.80 - 0.96)**
Spoken Communication[e]	0.98 (0.95 - 1.01)	0.96 (0.86 - 1.07)
Mobility Aids[e]	1.04 (1.02 - 1.07)***	1.15 (1.05 - 1.27)**
Excellent Health[f]	1.05 (1.00 - 1.12)	0.64 (0.51 - 0.80)***
Good Health[f]	1.02 (0.97 - 1.08)	0.60 (0.48 - 0.74)***
Fairly Good Health[f]	1.03 (0.97 - 1.09)	0.71 (0.57 - 0.88)**
Interpersonal		
Host or Foster Home[g]	0.97 (0.94 - 1.01)	0.78 (0.67 - 0.92)**
Own Home[g]	0.85 (0.83 - 0.88)***	1.05 (0.94 - 1.17)
Family Home[g]	0.63 (0.61 - 0.64)***	1.00 (0.91 - 1.11)
Has a Community Job[e]	1.05 (1.03 - 1.08)***	0.95 (0.86 - 1.05)
Public Policy		
High Fiscal Effort[h]	0.98 (0.95 - 1.01)	0.89 (0.80 - 1.00)
Medium Fiscal Effort[h]	1.01 (0.99 - 1.03)	0.96 (0.87 - 1.05)
Has Institutions[e]	0.93 (0.90 - 0.97)***	0.89 (0.78 - 1.02)
Ineligible for BIP[i]	0.90 (0.87 - 0.92)***	0.88 (0.78 - 1.00)*
Eligible, did not participate in BIP[i]	0.95 (0.92 - 0.97)***	0.68 (0.62 - 0.75)***
% Served	1.01 (1.01 - 1.02)**	0.99 (0.95 - 1.02)
Medicaid HCBS Waiver[e]	1.03 (1.00 - 1.05)*	0.97 (0.88 - 1.07)

Note. BIP = Balancing Incentive Program; CI = confidence interval; HCBS = home- and community- based services; ID = intellectual disability; IRR = incidence rate ratio.

[a] Reference Group = Male.
[b] Reference Group = White.
[c] A higher problem behaviors score corresponds to more severe problem behaviors.
[d] Reference Group: Mild ID.
[e] Reference Group = No.
[f] Reference Group: Poor health.
[g] Reference Group = Group Home.
[h] Reference Group: Low Fiscal Effort.
[i] Reference Group = Participated in BIP.

*$p \leq .05$; **$p \leq .01$; ***$p \leq .001$.

Unmet Need

Respondents had an average of one unmet need (*SD* = 1.9) out of a potential 14. The most commonly reported unmet needs included transportation (11.3%) and job assistance (11.1%). The least frequent unmet needs were benefits/insurance information (4.7%) and environmental adaptations/home modifications (4.2%).

For the individual factors, older age was associated with slightly, but significantly, fewer unmet needs. Black respondents had 18% more unmet needs than White respondents. Greater problem behavior support need was associated with more unmet needs. However, a greater severity of ID, compared to mild ID, was associated with fewer unmet needs. Those who used mobility aids had about 15% more unmet needs than people who did not use mobility aids. Compared to poor health, better reported health was associated with fewer unmet needs. No significant relationships were found between unmet needs and gender and spoken communication.

For the interpersonal and community factors, compared to those living in group homes, those residing in host or foster homes had significantly fewer unmet needs. The relationship between community job and unmet needs was not statistically significant.

For the public policy factors, people in states ineligible for BIP and people in states eligible for BIP but not participating had significantly fewer unmet needs than people in states participating in BIP. No significant relationships were found between unmet needs and level of community fiscal effort, institutional presence in a state, the percent of the state's estimated population served, and receipt of Medicaid HCBS waiver services.

Discussion

Our results show evident disparities in HCBS access among different populations of people with I/DD and across the three modified social ecological factor levels.

Five of the eight *Individual Factors* were significantly related to services received while six of the eight were related to unmet needs. Age was the only independent variable that was associated with better outcomes for both utilization and unmet needs: older adults received more services and had fewer unmet needs, which is consistent with previous findings (Caldwell, 2008; Ellis et al., 2002; Harrington & Kang, 2010, 2016; Pruchno & McMullen, 2004; Thomas et al., 2007). The service system seems to recognize the support needs of older adults, a population that is projected to significantly increase in the coming decades.

Furthermore, it is possible that older adults report having fewer unmet needs because they expect less from the service system than younger adults (Burke & Heller, 2017; Hayden & Heller, 1997), which may help explain our findings. Future qualitative inquiry is an ideal mechanism to dig deeper into this difference, specifically to gauge if older adults truly expect less from the service system.

Conversely, Black respondents had worse outcomes for *both* services received and unmet needs. Interestingly, people of other or multiple races received *more* services than White respondents. Previous literature has found that minorities experience worse outcomes in accessing community services (Burke & Heller, 2017; Harrington & Kang, 2016; Magaña et al., 2002; Pruchno & McMullen, 2004; Thomas et al., 2007) and health care (Bershadsky et al., 2014; Parish et al., 2013; Scott & Havercamp, 2014b), although how race/minority status is categorized differs among the studies. Research on personal care services has found an association between minority status and a higher likelihood of receiving these services, but with concurrent unmet needs or fewer personal care hours (Harrington & Kang, 2010; Magaña et al., 2002). We did not have access to the amount of services received (in terms of hours, days, or other applicable units), but it is plausible that respondents who received more of the 14 listed services received fewer hours or units of those services, while other respondents may have received a larger number of hours or units dedicated to fewer service types. Further research should delve into the *extent* of unmet need in terms of service units (e.g., hours) and how more nuanced unmet need differs between minority and non-minority respondents. Black respondents and other minorities may experience barriers in accessing the service system, including their discomfort navigating the system, asking questions, and challenging professionals, as well as not fully understanding their right to services (Harrington & Kang, 2016). Across respondents (i.e., not just minority respondents), further research that dives into access to information about HCBS and knowledge about what may be available to support community living would be helpful in an effort for Medicaid waiver operators to tailor outreach efforts. It is important to target minorities using culturally competent approaches, especially for Black consumers and families, in interventions that work to improve access to HCBS. Particularly, providers should prioritize culturally competent approaches in interacting with people with disabilities and families from minority backgrounds and in providing education and information.

Both behavioral and mobility support needs were associated with more services received as well as reports of more unmet needs, in line with previous research (Almasri et al., 2014; Chan & Sigafoos, 2000; Hartley & Schultz, 2015; Palisano et al., 2010; Seo et al., 2017). These results suggest that these populations of people with I/DD need specific kinds of services. For example, a person who uses mobility aids may need home modifications more frequently than someone who does not use mobility aids. While these results show a commitment of resources to people with I/DD who have specialized needs, the supports are still not enough to meet all the varying needs of the diverse I/DD community. Intuitively, this result may not seem consistent with the finding that people with more severe levels of ID had fewer unmet needs, but the latter is at least partially substantiated by existing research that found less unmet need for job supports, a type of HCBS, among people with more severe ID (Anderson et al., 2011). While access to broader HCBS is important to understand, it is also important to understand disparities for specific HCBS, such as the need for specific services for particular subgroups of people with I/DD. Future research should look at the receipt and unmet need of each of the 14 types of HCBS (and beyond) and disparities individually.

Better health (compared to poor health) was associated with fewer unmet needs. These results make sense. People in better health probably do not need as many services or are getting the services they need, which in turn promotes their health. Extant literature has linked better health with fewer unmet needs (Bershadsky et al., 2012; Burke & Heller, 2017; Freedman et al., 1999; Seo et al., 2017).

Our study did not find significant relationships between either service use or unmet need outcomes and gender. However, previous research has found significant gender disparities within personal care utilization (Harrington & Kang, 2010). Furthermore, our study did not find a significant relationship between spoken communication and either outcome despite previous links of spoken communication with fewer unmet needs (Burke & Heller, 2017), lower utilization of personal care (Harrington & Kang, 2010), and higher utilization of respite (Chan & Sigafoos, 2000). With the exception of the Burke and Heller study, the other two studies focused on specific services, which may explain the difference in findings.

Type of residence and having a community job were both *Interpersonal and Community Factors* that were associated with services received; only type of residence was associated with more unmet needs. People living in their own homes or family homes received fewer services than those living in group homes, which is in line with literature tying group homes and other larger settings with greater dental utilization (Bershadsky & Kane, 2010; Bershadsky et al., 2012). Group homes are typically operated by provider agencies, which report to state and federal agencies in order to receive their funding to provide services. Group homes and other larger settings that are subject to federal and state regulations may have more robust systems to manage medical and community services for those that they support. Additionally, staff in group homes are likely more familiar with the service system and can act as advocates for the people they support. There are also *more* individuals familiar with the service system involved in their supports (i.e., case managers, day program staff, and residential staff). On the contrary, family members may be less familiar with the service system. For instance, one study found that less than 50% of families were familiar with services such as day programs, in-home care, personal assistance, and employment (Samuel et al., 2012). While some people with I/DD who live with their families or in their own homes can still receive services, the majority of those with LTSS needs, including people with I/DD, rely on unpaid care from family and friends (Hado & Komisar, 2019), which is an advantage for state budgets. Our study also found that people living in host/foster family homes had fewer unmet needs as opposed to those in group homes. Again, these families may not be as aware of service options and may not know that they are eligible for a particular service, leading to fewer perceived needs. Having a community job was associated with significantly more services received. This finding may be due to those with community jobs being more able to advocate for themselves and for the services they receive.

Four of the five *Public Policy Factors* were significantly linked to services received, but only one was linked to unmet needs. People in states with institutions received significantly fewer services. These states may be more committed to providing services in institutional settings rather than within the community. BIP-participating states received more services than states that did not participate in BIP but also had more unmet needs than states not participating in BIP. It is logical that people in BIP-participating states received more services, as the intention of BIP was to increase spending on community services. States that opted not to participate in BIP, but were eligible, may have felt confident in the other mechanisms in place to fulfill need or were experimenting with other novel approaches, and therefore, had fewer additional needs, despite their spending on HCBS being below 50%. Because this is the first study, to the authors' knowledge, that included BIP as an independent variable in predicting service utilization and need, future research should include BIP and other rebalancing programs to better understand their impacts on HCBS utilization and unmet need both overall and for specific services related to I/DD (Williamson & Perkins, 2014).

A greater percentage of the estimated I/DD population served was associated with more services received. The greater utilization among higher numbers of people with I/DD served within a state is promising, though research should continue to examine the comprehensiveness and quality of the services received. Waiver receipt was also associated with more services received, as expected, since Medicaid HCBS waivers are the primary funder and provider of community services for people with I/DD. It was not significantly related to unmet needs.

Policy Recommendations

While the individual factors that were significant in this research may be difficult to change, they help to identify areas for local, state, and federal governments to provide redress for disparities that populations are facing. On the other hand, policy-level factors are easier to change. Governments should pay attention to those factors that are significant and adopt policies that promote access to HCBS services for people with I/DD. An overarching policy recommendation is for states to adopt greater flexibility in rate-setting structures to support all individuals with I/DD, but particularly those with specific support needs (in this instance, people who using mobility aids and those with more problem behavior support needs). Anecdotally, there appears to be a perception that those with mild intellectual disability have fewer support needs, yet our results show that those with a mild intellectual disability had *more* unmet needs. This is yet another example calling for policies to allow greater flexibility in rate structures that are tailored to each individual's needs and calls for better integration of person-centeredness in service planning and delivery. Most glaringly, Black adults with I/DD need greater access to HCBS. Policies that promote culturally competent education around HCBS that specifically target Black families are desperately needed. Last, younger adults need greater access to HCBS. With an increased focus on future planning in the field, perhaps this could be an avenue to educate young adults with I/DD about services they may receive now and in the future.

Furthermore, policies that work to bolster the direct support workforce are particularly important in the provision of HCBS. Policy recommendations to increase and support the direct support workforce include continued advocacy related to the provision of livable wages, guaranteed benefits including health insurance and paid time off, continued professionalization and opportunities for advancement in the field, high-quality training, and flexibility.

Limitations

Most of the data within this study comes from a section of the survey instrument that was completed by a service coordinator and/or using administrative records. It is possible that these sources have inaccuracies or biases. Conversely, some data came from another section of the survey instrument that allowed proxies to respond, rather than using records or the perception of the person with I/DD, though most of those who completed those questions were the person with I/DD or a family member/friend. Furthermore, there is no data to determine whether the person is eligible for a service or that an assessment of need for a particular service has been completed (i.e., need is perceived). Survey respondents only included people who received at least one state service in addition to case management; this limits the generalizability of the results in that it does not portray the needs of people who do not receive any state services but may need them. Furthermore, some states have better access to ID diagnosis information, so it is possible that bias exists in the sample when excluding respondents who were missing a level of ID or did not have an ID diagnosis. The wording of the question in the survey instrument that is used for the unmet needs outcome is general ("Do you need any of these additional services?") in that it is unknown if the person needs more of a particular service or if they are not receiving it at all. HCBS for people with I/DD are primarily funded by Medicaid HCBS waivers (Braddock et al., 2017; Eiken et al., 2018) and most of the respondents in this study received these waiver services. Medicaid is funded by both the federal government and states. States tailor each Medicaid program to their specific populations, which limits generalizability of the results. Other state policies and programs were not controlled by those in this research, so other differences may exist among states that contribute to variability in service access. Questions in the survey instrument are all closed-ended, so more detailed information or follow-up could not be collected from respondents. This information would have been useful for some of the variables, such as the outcome of unmet needs. Both outcomes are aggregated into count variables, which may blur associations between the independent factors and the specific services that make up the outcomes (Pruchno & McMullen, 2004). The lists of services received and unmet needs are not exhaustive, and some states do not provide each specific service. Additionally, there are a number of other reasons that are not discussed here for why a person may not receive a service that they perceive is needed. The data used here is cross-sectional and cannot be used to examine change in utilization or need, unlike longitudinal data.

Conclusion

To live and actively engage in the community, people with disabilities require access to supports. Unfortunately, some individuals with I/DD experience disparities in this access, which can put them at risk for institutionalization, less independence, reduced community engagement, and a lower quality of life. This research highlights disparities for Black people with I/DD, people with mobility impairments, people with behavioral support needs, those residing outside group homes, those in states with institutions, and those in states that did not participate in BIP. This research, and even further research, is crucial to better understand disparities—the first step in addressing and reducing such disparities. The results are a call to action, to improve the outcomes of people with I/DD in their communities.

References

Almasri, N. A., O'Neil, M., & Palisano, R. J. (2014). Predictors of needs for families of children with cerebral palsy. *Disability and Rehabilitation, 36*(3), 210-219. https://doi.org/10.3109/09638288.2013.783123

Andersen, R. M. (1968). *Families' use of health services: A behavioral model of predisposing, enabling, and need components* (Publication Number 6902884) [Doctoral dissertation, Purdue University]. ProQuest Dissertations & Theses A&I.

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior, 36*(1), 1-10. https://doi.org/10.2307/2137284

Anderson, L. L., Larson, S. A., & Wuorio, A. (2011). *2010 FINDS national survey technical report part 1: Family caregiver survey*. https://www.thearc.org/document.doc?id=3673

Barkhoff, A. (2021, March 23-April 1). *Transition to new administration* [Keynote presentation]. AUCD Technical Assistance Institute, Washington, DC, United States.

Bershadsky, J., Hiersteiner, D., Fay, M. L., & Bradley, V. (2014). Race/ethnicity and the use of preventive health care among adults with intellectual and developmental disabilities. *Medical Care, 52*(10), S25-S31. https://doi.org/10.1097/MLR.0000000000000130

Bershadsky, J., & Kane, R. L. (2010). Place of residence affects routine dental care in the intellectually and developmentally disabled adult population on Medicaid. *Health Services Research, 45*(5p1), 1376-1389. https://doi.org/10.1111/j.1475-6773.2010.01131.x

Bershadsky, J., Taub, S., Engler, J., Moseley, C. R., Lakin, K., Charlie, Stancliffe, R. J., Larson, S., Ticha, R., Bailey, C., & 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

Braddock, D., Hemp, R. E., Tanis, E. S., Wu, J., & Haffer, L. (2017). *The state of the states in developmental disabilities* (11th ed.). American Association on Intellectual and Developmental Disabilities.

Burke, M. M., & Heller, T. (2017). Disparities in unmet service needs among adults with intellectual and other developmental disabilities. *Journal of Applied Research in Intellectual Disabilities, 30*(5), 898-910. https://doi.org/10.1111/jar.12282

Caldwell, J. (2008). Health and access to health care of female family caregivers of adults with developmental disabilities. *Journal of Disability Policy Studies, 19*(2), 68-79. https://doi.org/10.1177/1044207308316093

Chan, J. B., & Sigafoos, J. (2000). A review of child and family characteristics related to the use of respite care in developmental disability services. *Child and Youth Care Forum, 29*(1), 27-37. https://doi.org/10.1023/A:1009420206722

Chapman, H. M., Lovell, A., & Bramwell, R. (2018). Do health consultations for people with learning disabilities meet expectations? A narrative literature review. *British Journal of Learning Disabilities, 46*(2), 118-135. https://doi.org/10.1111/bld.12222

Durbin, A., Sirotich, F., Lunsky, Y., & Durbin, J. (2017). Unmet needs of adults in community mental health care with and without intellectual and developmental disabilities: A cross-sectional study. *Community Mental Health Journal, 53*(1), 15-26. https://doi.org/10.1007/s10597-015-9961-6

Eiken, S., Sredl, K., Burwell, B., & Amos, A. (2018). *Medicaid expenditures for long-term services and supports in FY 2016*. https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpenditures2016.pdf

Ellis, J. T., Luiselli, J. K., Amirault, D., Byrne, S., O'Malley-Cannon, B., Taras, M., Wolongevicz, J., & Sisson, R. W. (2002). Families of children with developmental disabilities: Assessment and comparison of self-reported needs in relation to situational variables. *Journal of Developmental and Physical Disabilities, 14*(2), 191-202. https://doi.org/10.1023/A:1015223615529

Freedman, R. I., Griffiths, D., Wyngaarden Krauss, M., & Mailick Seltzer, M. (1999). Patterns of respite use by aging mothers of adults with mental retardation. *Mental Retardation, 37*(2), 93-103.

Hado, E., & Komisar, H. (2019). *Long-term services and supports*. https://doi.org/10.26419/ppi.00079.001

Harrington, C., & Kang, T. (2010). Personal care services utilization by individuals with developmental disabilities. *Family Relations, 59*(2), 136-151. https://doi.org/10.1111/j.1741-3729.2010.00591.x

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

Hartley, S. L., & Schultz, H. M. (2015). Support needs of fathers and mothers of children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*(6), 1636-1648. https://doi.org/10.1007/s10803-014-2318-0

Hayden, M. F., & Heller, T. (1997). Support, problem-solving/coping ability, and personal burden of younger and older caregivers of adults with mental retardation. *Mental Retardation, 35*(5), 364-372.

Human Services Research Institute, & National Association of State Directors of Developmental Disabilities Services. (2017). *Adult Consumer Survey 2015-16 final report*. https://www.nationalcoreindicators.org/upload/core-indicators/2015-16_ACS_Report_Part_I_0623.pdf

Human Services Research Institute, & National Association of State Directors of Developmental Disabilities Services. (2018). *About National Core Indicators*. https://www.nationalcoreindicators.org/about/

Joosten, M. D. (2015). Social work decision-making: Need factors of older adults that affect outcomes of home-and community-based services. *Health & Social Work, 40*(1), 34-42. https://doi.org/10.1093/hsw/hlu043

Kaye, H. S., Harrington, C., & LaPlante, M. P. (2010). Long-term care: Who gets it, who provides it, who pays, and how much? *Health Affairs, 29*(1), 11-21. https://doi.org/10.1377/hlthaff.2009.0535

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: A systematic review. *American Journal on Intellectual and Developmental Disabilities, 114*(3), 193-222. https://doi.org/10.1352/1944-7558-114.3.193

Larson, S. A., Eschenbacher, H. J., Anderson, L. L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M. L. (2018). *In-home & residential supports for persons with intellectual or developmental disabilities: Status and trends through 2016*. https://risp.umn.edu/sites/risp.umn.edu/files/2018-07/RISP2016_WEB.pdf

Larson, S. A., Eschenbacher, H. J., Anderson, L. L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M. L. (2017). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2014*. https://ici-s.umn.edu/files/My9n-gPj6a/2014_risp_web

Magaña, S., Seltzer, M. M., & Krauss, M. W. (2002). Service utilization patterns of adults with intellectual disabilities: A comparison of Puerto Rican and non-Latino White families. *Journal of Gerontological Social Work, 37*(3/4), 65-86. https://doi.org/10.1300/J083v37n03_06

Palisano, R., Almarsi, N., Chiarello, L., Orlin, M., Bagley, A., & Maggs, J. (2010). Family needs of parents of children and youth with cerebral palsy. *Child: Care, Health and Development, 36*(1), 85-92. https://doi.org/10.1111/j.1365-2214.2009.01030.x

Parish, S. L., Swaine, J. G., Son, E., & Luken, K. (2013). Receipt of mammography among women with intellectual disabilities: Medical record data indicate substantial disparities for African American women. *Disability and Health Journal, 6*(1), 36-42. https://doi.org/10.1016/j.dhjo.2012.08.004

Patton, D. A., Liu, Q., Adelson, J. D., & Lucenko, B. A. (2019). Assessing the social determinants of health care costs for Medicaid-enrolled adolescents in Washington State using administrative data. *Health Services Research, 54*(1), 52-63. https://doi.org/10.1111/1475-6773.13052

Pruchno, R. A., & McMullen, W. F. (2004). Patterns of service utilization by adults with a developmental disability: Type of service makes a difference. *American Journal of Mental Retardation, 109*(5), 362-378.

Rizzolo, M. K., Larson, S. A., & Hewitt, A. S. (2016). Long-term supports and services for people with IDD: Research, practice, and policy implications. In *Critical Issues in Intellectual and Developmental Disabilities: Contemporary Research, Practice, and Policy* (pp. 89-107). American Association on Intellectual and Developmental Disabilities.

Rodriguez, G. (2013). *Models for count data with overdispersion*. https://data.princeton.edu/wws509/notes/c4a.pdf

Samuel, P. S., Hobden, K. L., LeRoy, B. W., & Lacey, K. K. (2012). Analysing family service needs of typically underserved families in the USA. *Journal of Intellectual Disability Research, 56*(1), 111-128. https://doi.org/10.1111/j.1365-2788.2011.01481.x

Savolainen, O., Sormunen, M., & Turunen, H. (2021). Public health nurses' perceptions on promotive and risk factors for children's mental health: A qualitative interview study. *Journal of Advanced Nursing, 77*(12), 4815-4826. https://doi.org/10.1111/jan.14987

Scott, H. M., & Havercamp, S. M. (2014a). Mental health for people with intellectual disability: The impact of stress and social support. *American Journal on Intellectual and Developmental Disabilities, 119*(6), 552-564. https://doi.org/10.1352/1944-7558-119.6.552

Scott, H. M., & Havercamp, S. M. (2014b). Race and health disparities in adults with intellectual and developmental disabilities living in the United States. *Intellectual and Developmental Disabilities, 52*(6), 409-418. https://doi.org/10.1352/1934-9556-52.6.409

Seo, H., Shogren, K. A., Wehmeyer, M. L., Little, T. D., & Palmer, S. B. (2017). The impact of medical/ behavioral support needs on the supports needed by adolescents with intellectual disability to participate in community life. *American Journal on Intellectual and Developmental Disabilities, 122*(2), 173-191. https://doi.org/10.1352/1944-7558-122.2.173

Sweetland-Lester, R., Irvin, C. V., Mosca, A., & Bradnan, C. (2015). *Tipping the balance: The Balancing Incentive Program and state progress on rebalancing their long-term services and supports*. https://www.disabilitypolicyresearch.org/our-publications-and-findings/publications/tipping-the-balance-the-balancing-incentive-program-and-state-progress-on-rebalancing-their-longterm

Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to care for autism-related services. *Journal of Autism and Developmental Disorders, 37*(10), 1902-1912. https://doi.org/10.1007/s10803-006-0323-7

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

Williamson, H. J., & Perkins, E. A. (2014). Family caregivers of adults with intellectual and developmental disabilities: Outcomes associated with U.S. services and supports. *Intellectual and Developmental Disabilities, 52*(2), 147-159. https://doi.org/10.1352/1934-9556-52.2.147