Intellectual and Developmental Disabilities

Outcomes for Adults with Intellectual and Developmental Disabilities Receiving Long-Term Services and Supports

--Manuscript Draft--

Manuscript Number:	IDD-D-22-00066R2
Article Type:	Research
Keywords:	Long-Term Services and Supports; Outcomes; Systematic Literature Review; Intellectual & Developmental Disabilities
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Manuscript Region of Origin:	UNITED STATES
Abstract:	The impact of long-term services and supports on the quality of life of adults with intellectual and developmental disabilities (IDD) is not well understood given the highly complex nature of researching this topic. To support future research addressing this topic, we conducted a systematic literature review of studies addressing outcomes of adults with IDD receiving long-term services and supports. Results of this review describe current outcomes for adults with IDD who receive long-term services and supports and can be used to inform program evaluation, policy development, and future research.

OUTCOMES FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES RECEIVING LONG-TERM SERVICES AND SUPPORTS: A SYSTEMATIC REVIEW OF THE LITERATUIRE

Acknowledgments

We wish to acknowledge the death of Dr. James R. Thompson subsequent to the acceptance of this article for publication. We also wish to express our sincere gratitude for his mentorship and friendship.

Manuscript findings were presented as a part of an oral presentation during the American Association of Intellectual and Developmental Disabilities' 145th Annual Meeting.

Outcomes for Adults with Intellectual and Developmental Disabilities Receiving Long-Term Services and Supports: A Systematic Review of the Literature

Abstract

The impact of long-term services and supports on the quality of life of adults with intellectual and developmental disabilities (IDD) is not well understood given the highly complex nature of researching this topic. To support future research addressing this topic, we conducted a systematic literature review of studies addressing outcomes of adults with IDD receiving long-term services and supports. Results of this review describe current outcomes for adults with IDD who receive long-term services and supports and can be used to inform program evaluation, policy development, and future research.

Keywords: Long-Term Services and Supports, Outcomes, Intellectual & Developmental Disabilities, Systematic Literature Review

Outcomes for Adults with Intellectual and Developmental Disabilities Receiving Long-Term Services and Supports: A Systematic Review of the Literature

Adults with IDD deserve the opportunity to experience a good quality of life, one in which they have opportunities to live, learn, work, and socialize just like everyone else. Federal legislation makes it clear that a high-quality life should be within reach for people with disabilities. To achieve these ends, many people with IDD benefit from individualized supports, defined as resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning (Schalock et al., 2021).

To ensure access to the individualized supports needed to engage in culturally-valued life activities in integrated community settings, all levels of government across the United States offer adults with IDD access to long-term services and supports (Owen et al., 2015). Long-term services and supports encompass a variety of health-related and social services, such as assistance with activities of daily living (i.e., eating, bathing, and dressing) and instrumental activities of daily living (i.e., housekeeping and managing money) over an extended period (Collelo et al., 2013). The purpose of these services is to assist adults with IDD to maintain or improve their quality of life.

Long-term services and supports provided to adults with IDD are primarily funded through Medicaid (Rizzolo et al., 2013). To use Medicaid as a funding source for long-term services and supports, a provision in the federal Medicaid law allows states to waive some of the primary regulations of the Social Security Act to develop customized programs (i.e., Medicaid Waivers) tailored to underserved populations that would typically require institutional-based care (Friedman & Rizollo, 2017). There are several types of Medicaid Waivers used to fund long-term services and supports for adults with IDD, with the most frequently utilized waiver being the Home and Community-Based Services Waiver (HBCS; Braddock et al., 2013).

Given the potential impact of long-term services and supports on promoting a high quality of life, efforts have been made to evaluate the outcomes experienced by adults with IDD receiving long-term services and supports. These efforts have been undertaken by numerous government-funded research groups, independent research groups, committees, and individual researchers. Collectively, these efforts have led to a literature base establishing the positive impact of long-term services and supports on improving the quality of life of adults with IDD.

To advance research in this area, we conducted a systematic literature review of studies addressing outcomes of adults with IDD receiving long-term services and supports. The purpose of this study was to examine the literature base addressing adults with IDD receiving long-term services and supports and to characterize the variables influencing the outcomes they experience. Specifically, we addressed the following research question: What does the current literature base reveal about the outcomes of adults with IDD who receive long-term services and supports?

Methods

Literature Search

We applied a structured approach to systematically identify studies describing outcomes for adults with IDD who receive long-term services and supports. We conducted an extensive literature search utilizing numerous social science databases and sources of gray literature (i.e., information not published in conventional sources; Hammerstrøm et al., 2010). We performed electronic searches to identify relevant peer-reviewed articles using the following social science databases: (a) Academic Search Complete, (b) ERIC, (c) PsycInfo, and (d) Pub Med. Additionally, we reviewed the gray literature, a relevant source of information given this review’s focus on a topic with a limited literature base (Jewell et al., 2017) and the large number of independent research organizations and government agencies responsible for addressing this topic. Acceptable sources of gray literature included white papers, government reports, and dissertation/theses found in (a) electronic databases; (b) disability research organizations and measurement developer websites; and (c) government agency websites. Finally, we conducted an ancestral search of each included study (Petticrew & Roberts, 2005). We removed duplicate studies from the final pool of included articles. Any studies utilizing the same data sets were only used once, with preference given to peer-reviewed articles.

Inclusion/Exclusion Criteria

Each identified study was subjected to a title, abstract, and full article review using Covidence, a web-based software platform that streamlines systematic review production. Six criteria guided each level of review. First, we included studies published between 1981 (i.e., the first year of Home and Community-Based Services Waivers) and 2022. Second, given the country-specific nature of long-term services and supports, we included studies conducted in the United States. Third, we included studies focused on adult participants with IDD who receive long-term services and supports. Fourth, we included studies addressing outcomes, as defined by the review’s search terms. Fifth, only peer-reviewed articles and publications in the gray literature were considered for inclusion in this review. Finally, we included studies utilizing experimental or correlational research methodologies. Given the focus of this literature review, most relevant studies utilized correlational research methodologies, representing the best evidence in the field (Petticrew & Roberts, 2005).

Search Terms

The literature search was guided by three sets of search terms addressing: (a) age (i.e., *adults*), (b) population (i.e., *intellectual disabilit*, developmental disabilit*, intellectual and developmental disabilit*),* and (c) outcomes (i.e., *personal outcomes, family/community outcomes, societal outcomes*). Search terms addressing outcomes were informed by previous publications addressing HCBS quality measurement (i.e., National Quality Forum, 2016) and outcomes for adults with intellectual disability (i.e., Shogren et al., 2009). The literature search was carried out across four social science databases. We developed customized search strategies for each social science database in conjunction with a librarian (Hammerstrøm et al., 2010). Search terms addressing long-term services and supports were not used when conducting the initial literature searches. These terms are often not well described in titles/abstracts or well-indexed using controlled vocabulary terms. Thus, they did not lend themselves to being effectively used as search terms during literature searches (Kugley et al., 2016). Instead, these terms were addressed during the inclusion/exclusion screening processes.

Screening Results

A total of 19,945 studies were identified. Seventy-two studies were identified by searching the gray literature, while 19,873 studies were located using social sciences databases. All 19,945 studies were uploaded into Covidence, where a total of 11,295 duplicate studies were removed. The titles and abstracts of the remaining 8,650 studies were reviewed using the study's inclusion/exclusion criteria. A total of 7,682 studies were excluded for the following reasons: (a) wrong country, (b) wrong disability, (c) wrong population, (d) wrong methodology, (e) study not focused on outcomes, (f) participants not recipients of long-term services and supports. In Covidence, studies considered during the title and abstract stage are only screened for relevance, as specific exclusion criteria are not applied. As a result, information addressing the application of specific exclusion criteria was not available at this stage. The full text of 968 studies was reviewed. A total of 933 were excluded for the following reasons: (a) wrong country (*n*=181), (b) wrong disability (*n*=21), (c) wrong population (*n*=95), (d) wrong methodology (*n*=149), (e) study not focused on outcomes (*n*=66), (f) participants not recipients of long-term services and supports (*n*=421). A total of 35 studies were identified using social sciences databases. An ancestral search was conducted, leading to the identification of nine additional studies. The literature search process is documented in Figure 1.

Coding Categories

After conducting the literature search, we content analyzed each study to systematically identify and record information addressing the review's research questions. During content analysis, we coded according to the following categories: (a) search (i.e., search type, gray literature type, gray literature source), (b) research (i.e., research questions, research design, analysis type, sampling procedures, respondent type), (c) outcome domains (i.e., the National Quality Forum [NQF] Quality in Home and Community-Based Services to Support Community Living Framework, and Shogren et al.'s [2009] Public Policy Outcome Domains), (d) participants (i.e., number, disability, age, gender, race, location, funding source), and (e) results (i.e., measures, independent variables, dependent variables, control variables, and outcomes).

Interrater Agreement Protocols

Interrater agreement was calculated for study inclusion at the title/abstract level and full article level. The first author trained the interrater reviewer on inclusion/exclusion criteria, providing examples from studies not included in the sample of studies identified for interrater agreement activities. When conducting interrater agreement at the title/abstract level, the interrater reviewer reviewed a randomly selected sample of 25% of articles (*n* = 2163).

Agreements and disagreements were recorded and used to calculate interrater agreement. Interrater agreement at the title/abstract level was 86.81%. When conducting interrater agreement at the full article review level, the interrater reviewer reviewed a randomly selected sample of 25% of studies (*n*=968). Agreements and disagreements were recorded and used to calculate interrater agreement. Interrater agreement at the full article level was 98.76%. Interrater agreement was also calculated for the application of coding criteria. The first author trained the interrater reviewer on coding categories. When conducting interrater agreement for the application of coding criteria, the interrater reviewer coded a randomly selected sample of 25% of articles (*n*=12). Agreements and disagreements were recorded and used to calculate interrater agreement. The mean interrater agreement was 88.7% (range: 78.7% to 95.1%).

Results

A total of 44 studies were included in this systematic literature review. Articles were published across 20 journals between 1997 and 2022. The majority of articles (*n*=33) were identified using social science databases. Two articles were identified during the gray literature search. A total of nine articles were identified during the ancestral search. Coding applications for each study can be found in Table 1.

Included Participants

To fully understand findings, it is essential to describe the participants used to establish these results. It should be noted that descriptions are only of participants with IDD. Despite the fact that 43 of the 44 studies included in this review utilized proxies as a part of data collection procedures, only three studies reported on the demographics of proxy participants. A total of 602,151 people with IDD were participants in the studies included in this systematic literature review. Thirty-six of the 44 studies reported on participants' gender. Fifty-nine-point-five percent (*n*=330,550) of participants whose gender was identified were male, while 40.5% (*n*=225,292) were female. Four studies included both children and adult participants, while the remaining 27 studies included only adult participants. Thirty-one studies reported on participants' age, but they were reported differently across studies. Twenty studies offered a mean age (i.e., 40.75), while 11 studies reported age ranges (i.e., age 2 to age 95) and nine studies reported frequencies of specific age ranges. Twenty-nine studies reported on participants' race. Sixteen of the 29 studies reported on all categories of race. Thirteen studies reported on specific combinations of race categories, including black and white (*n*=2); white and other (*n*=5); black, white, and other (*n*=5); and black, Hispanic, and white (*n*=1). Of the 536,247 participants whose race was identified, 5.9% (*n*=32,104) were Asian, 16.1% (*n*=86,146) were black, 22.7% (*n*=121,719) were Hispanic, 0.1% (*n*=419) were Native American, 48.5% (*n*=259,958) were white, and 6.6% (*n*=35,568) were another race. A total of 40 states were represented.

Focus of Long-Term Supports and Services

Nine studies considered long-term services and supports as a whole, not focusing on a specific type of long-term service or support. The remaining 35 studies focused on the provision of a specific type of long-term service or support. The majority of these 35 studies (*n*=28) focused on one type of long-term service and support. Only a few studies (*n*=7) focused on multiple types of long-term services and supports. All seven of these studies focused on only two types of long-term services and supports. Studies considered the following long-term services and supports: (a) residence type or residence supports (*n*=21), (b) employment (*n*=6), (c) healthcare (*n*=6), (d) consumer-directed services (*n*=4), (e) direct support or personal assistance (*n*=3), (f) day programs (*n*=2), and (g) agency support (*n*=1). The seven studies focusing on multiple long-term services and included a focus on residential type or residential services in conjunction with another type of long-term service or support.

Focus of Outcomes

To accurately capture the focus of the outcomes described in the studies included in this systematic literature review, we utilized two frameworks.

Public Policy Outcome Domains

In 2009, the Terminology and Classification Committee of the *American Association on IDD* (AAIDD) put forth a framework outlining desired public policy outcomes for people with IDD. According to this framework, policies, practices, and outcomes can be organized as: (a) person-referenced, (b) family/community-related, (c) systems-referenced, or (d) global influences, such as living in a particular region or state (Shogren et al., 2009). Shogren et al.'s (2009) *Public Policy Outcome Domains* are organized according to (a) personal outcomes, (b) family and community outcomes, and (c) societal outcomes. Forty-one of the 44 studies included in this review addressed personal outcomes, including societal inclusion (*n*=29), participation (*n*=23), self-determination (*n*=16), physical well-being (*n*=13), emotional well-being (*n*=10), rights (*n*=4), material well-being (*n*=4), and personal development (*n*=0). Four of the 44 studies addressed family and community outcomes, including disability-related supports (*n*=3), physical well-being (*n*=2), parenting (*n*=2), family interactions (*n*=1), emotional well-being (*n*=1), personal development (*n*=1), financial well-being (*n*=1), and community involvement (*n*=0). Twenty-seven of the studies addressed societal outcomes, including health (*n*=11), subjective well-being (*n*=11), and socioeconomic position (*n*=7).

Quality in Home and Community-Based Services to Support Community Living Framework

In 2016, a national committee representing advocacy organizations, state Medicaid agencies, academic research centers, consumers, direct support providers, and caregivers developed an operational definition of Home and Community-Based Services. One result of this committee's work was the development of a conceptual framework, the *Quality in Home and Community-Based Services to Support Community Living Framework*. This conceptual framework outlines different domains and sub-domains of quality measurement in Home and Community-Based Services. The NQF (2016) *Quality in Home and Community-Based Services to Support Community Living Framework* is made up of eleven domains. Included studies addressed community inclusion (*n*=29), holistic health and functioning (*n*=18), choice and control (*n*=13), service delivery and effectiveness (*n*=12), system performance and accountability (*n*=11), workforce (*n*=8), person-centered planning (*n*=5), human and legal rights (*n*=5), equity (*n*=5), caregiver support (*n*=3), and consumer leadership (*n*=0).

Description of Outcomes

Quality of Life Outcomes

Numerous studies investigated outcomes associated with various quality of life indicators, including choice, community integration, and relationships. Two studies focused generally on quality of life. Neely-Barnes and colleagues (2008) found that improved quality of life was associated with more opportunities for choice-making. Campo and colleagues (1997) found that quality of life for people with severe or profound intellectual disability was related to engaging in day-to-day activities that were highly individualized, incorporated universal human experiences, and balanced independence and interdependence.

Two studies focused on relationship outcomes. Stancliffe and colleagues (2009) found that people with IDD who lived in larger residential settings were significantly lonelier. When researching the frequency and stability of family contact based on residential setting, Stancliffe et al. (2006) reported that people in contact with their immediate family tended to sustain contact over time, and those without such contact continued to be isolated. Additionally, these researchers found that a significantly higher proportion of people who left institutions had contact with their family once living in the community than they while living at the institution.

Three studies addressed community integration outcomes. Heller et al. (2002) found that higher levels of community integration were associated with greater opportunities to make choices. Additionally, these researchers found that higher levels of community integration were also associated with greater family involvement. Campbell and colleagues (1998) found that people funded with state funds lived more independently than people funded with HCBS waiver funds, who in turn lived more independently than people livings in ICF/MRs. Dinora and colleagues (2020) reported that people with IDD living in sponsored residential settings were more likely to engage in inclusive activities in the community than those living in larger congregate settings or those living in a family home.

Four studies addressed outcomes associated with choice. Neely-Barnes and colleagues (2008) found that adults with mild intellectual or developmental disabilities experienced greater choice than did those with severe intellectual or developmental disabilities. Results from Heller et al. (1999) indicated that having greater adaptive behavior led to more choice-making opportunities. Lakin and colleagues (2008) found that choice was more strongly associated with living in a congregate setting than whether the setting was an ICF/MR or financed by an HCBS Waiver. Tichá et al. (2012) found that people in residential settings with 16 or more people had fewer choice opportunities than people in other residential settings. In most instances, people with IDD had more opportunities for everyday choices when living in their own homes.

However, people with extensive and pervasive support needs had more opportunities for choice when living in agency homes of three or fewer residents.

Outcomes Associated with Residential Settings

Two studies addressed the influence of community-based residential settings. Stancliffe and Lakin (1997) found that adults with IDD who lived in community-based residential settings experienced uniformly better outcomes than those living in institutions. Heller and colleagues (2002) found that adults with IDD who moved into community settings displayed higher levels of adaptive behavior and experienced increased community integration than those who remained in nursing homes.

Numerous studies investigated outcomes associated with different aspects of residential settings. Four studies considered the impact of residential setting size. All four studies indicated that smaller living arrangements were associated with improved outcomes, including greater choice (Neely-Barnes et al., 2008; Ticha et al., 2012); increased personal control (Stancliffe et al., 2000); and greater adaptive behavior (Heller et al., 1999). Two studies researched the influence of funding type. Stancliffe et al. (2000) found that adults with IDD living in semi-independent residential settings experienced greater personal control than those living in ICF/MRs and HCBS Waiver-funded sites. Conversely, Friedman (2019) found that people with IDD who lived in provider-owned settings did not experience significantly better quality of life when compared to people living in ICF/MRs. Finally, one study, conducted by Howe et al. (1998), investigated the influence of living supports on outcomes, finding that adults with IDD receiving supported living services experienced significantly more community activities more often and with a greater variety of people. One study addressed satisfaction with living arrangements. Stancliffe et al. (2009) found that adults who lived in smaller residential settings liked their living arrangement significantly more.

Four studies considered trends in residential settings by type of disability diagnosis. Stancliffe and colleagues (2011) found that few adults with severe or profound intellectual disability chose where or with whom to live. Neely-Barnes and colleagues (2008) reported that people with mild intellectual disability lived in smaller residential settings more often than those with more significant intellectual or developmental disabilities. Lakin et al. (2007) found that people with intellectual disability and psychiatric disorders were more likely to live in ICF/MRs and agency-operated congregate care settings. Hewitt and colleagues (2017) found that a higher number of adults with intellectual disability and Autism lived with family members than in other residential settings, such as agency apartments or in their own homes.

Employment Outcomes

Six studies considered employment outcomes. One study, conducted by Nord et al. (2018), investigated the relationship between employment goals and employment outcomes. Results indicated that adults with IDD who had employment goals were significantly more likely to participate in community employment. Results also demonstrated that people with guardians, as well as people with more extensive support needs, communication challenges, and/or mobility challenges were significantly less likely to have employment goals, and thus to participate in community employment.

Two studies addressed employment rates for adults with IDD. Nord et al. (2016) found that adults with co-occurring intellectual disability and Autism were significantly less likely to participate in community employment when compared to adults with intellectual disability. Butterworth and colleagues (2015) investigated the relationship between employment rates and residential settings, finding that adults with IDD living independently in a home or apartment were more likely to participate in community employment than adults with IDD living with relatives or in other community-based residences.

Two studies examined the impact of community employment on outcomes. Blick and colleagues (2016) found that adults with IDD who participated in community employment experienced increased community integration and financial autonomy when compared to people with IDD who participated in adult day programs and sheltered workshops. Stephens et al. (2005) found community employment was associated with improved adaptive behavior.

One study, conducted by Morgan-McInnes and colleagues (2010), researched the influence of employment supports on employment outcomes. Results indicated that people with IDD who received supported employment services were more likely to be and stay employed. Results also demonstrated that supported employment services were more often provided to men, people with higher IQs, people with lower incidences of emotional/behavioral problems, and to those living in areas with lower unemployment rates.

Healthcare Outcomes

Ten studies addressed healthcare outcomes, two of which focused generally on healthcare outcomes. Freedman and Chassler (2004) found that overall health status of adults with IDD was significantly related to the presence of additional disabilities and specific support needs. Stancliffe and colleagues (2011) found a relationship between obesity and level of intellectual disability, with people with mild or moderate intellectual disability having the highest prevalence of obesity. Results also revealed that people with IDD living in congregate or supervised settings, such as institutions, had the lowest rates of obesity.

Six studies addressed preventative healthcare. One study, conducted by Hall and colleagues (2007), considered preventative health care access in general. Results indicated that nearly 40% of adults with IDD receiving Medicaid Waivers in Florida did not see a primary care provider between 1999 and 2003. Another study, conducted by Wood et al. (2007), found that high continuity of both primary care and specialty care were associated with a significant reduction in the likelihood of emergency room visits. Bershadsky and colleagues (2014) considered the influence of race and ethnicity on preventative health care access, finding that race and ethnicity did not have a significant influence on the receipt of preventative healthcare when accounting for other personal-level factors.

Three studies addressed the influence of residence type on the preventative health care access, with all three studies finding a significant relationship between the two variables. Freedman and Chassler (2004) found that access to physicals, dental examinations, and ob/gyn examinations varied significantly by residential setting. Bershadsky and colleagues (2012) found that people with IDD living with parents or relatives were less likely to receive preventive health exams and procedures than people living in other types of residences. Bershadsky and Kane (2010) found that people with IDD living in their own home or in a family home were less likely to receive routine dental procedures than those living in ICF/MRs or in a group home.

Three studies addressed medication usage. Spreat and Conroy (1998) found that adults with IDD who scored higher on measures of challenging behavior were more likely to receive antipsychotic medications. Lakin and colleagues (2007) found that adults with IDD who also had psychiatric disorders were much more likely to receive medications for mood, anxiety, and/or behavioral disorders when compared to adults with IDD without psychiatric disorders. Esler and colleagues (2019) found that people with intellectual disability and Autism had higher percentages of psychotropic medication use, even when controlling for co-occurring conditions, age, gender, and level of intellectual disability.

Behavioral Outcomes

Two studies addressed behavioral outcomes, considering the behavioral outcomes of adults with IDD who had been deinstitutionalized. Stancliffe and colleagues (2002a) found that the adaptive behavior of adults with IDD was influenced by the type of community residence to which they moved upon deinstitutionalization. Adults with IDD who moved to community residences funded by HCBS Waivers saw significant improvements to their adaptive behavior when compared to those who moved to ICF/MRs. Stancliffe et al. (2002b) found that higher adaptive behavior scores were associated with shorter periods of institutionalization, living in smaller community residences, and participating in the community.

Service Receipt, Service Use, and Expenditure Outcomes

Three studies considered service receipt, service use, and expenditure outcomes. Two studies found that Californians with IDD from racial and ethnic minority groups were less likely to receive supports and out-of-home services when compared to white counterparts (Harrington & Kang, 2016; Kang & Harrington, 2008). Harrington and Kang (2016) found that Californians with IDD who were younger, female, and from racial and ethnic minority groups received significantly lower expenditures. Kang and Harrington (2008) determined that Californians with IDD who had more significant support needs were more likely to receive services. Findings from Dinora and colleagues (2020) suggested that people with IDD who also had high behavioral needs or high medicals needs received significantly higher expenditures than others.

Outcomes Associated with Using Consumer-Directed Supports

Four studies considered the influence of consumer-directed supports on outcomes experienced by adults with IDD. Two studies (Benjamin et al., 2000; Heller et al., 1999) compared the outcomes achieved by people with IDD receiving consumer-directed supports to those receiving agency-delivered supports. Benjamin and colleagues (2000) determined that people with IDD receiving consumer-directed supports experienced improved outcomes in the areas of safety, unmet service needs, and service satisfaction. Similarly, Heller et al. (1999) found that people with IDD participating in a consumer-directed family support program reported greater satisfaction with services, had fewer unmet service needs, and had improved community functioning. Another study, conducted by Caldwell and Heller (2007), investigated the influence of consumer-directed supports over time. Results indicated that people with IDD receiving consumer-directed supports and their families experienced decreased unmet service needs, higher service satisfaction, and increased community participation over time.

One study, conducted by Heller and colleagues (2012), examined the influence of the type of person providing consumer-directed supports. Researchers found that physical health outcomes and daily choice-making of adults with IDD receiving consumer-directed supports differed significantly by type of personal support worker hired. Physical health outcomes were best when parents were providing consumer-directed supports, while daily choice-making was improved when agency staff were providing consumer-directed supports.

Outcomes Associated with Support Staff

Three studies considered the influence of staff on outcomes for adults with intellectual and developmental disability. Two studies (Friedman, 2020; 2021) considered the influence of training staff who provide long-term services and supports on the outcomes of adults with IDD. Both studies determined that staff training led to improved outcomes for adults with IDD.

Friedman (2020) found that training support staff to recognize each person as a unique individual and to promote dignity and respect led to a significant reduction in the number of challenging behaviors exhibited by people with IDD. Friedman (2021) found that providing ongoing staff development led to a significant reduction in instances of abuse and neglect. One study, conducted by Campo and colleagues (1997), found that staff have an important role in influencing the community involvement and social relations of adults with IDD.

Discussion

Limitations

It is important to identify certain design, search, and analysis decisions and describe how they might have impacted results. First, this review included studies from a three-decade timespan. Consequently, the results of this review were likely influenced by inconsistencies in understandings of IDD, advancements in research design standards, and modifications to the policies governing long-term services and supports and their funding sources. Second, search terms addressing long-term services and supports were only applied during the full article screening process. This decision, made in conjunction with a librarian well-versed in indexing and social science databases, is believed to have led to the identification of more articles than would have been identified had these terms been used in the initial social science database search. However, because these terms were not considered until the full article inclusion/exclusion screening process, it is possible that some relevant articles may have been missed. Finally, this review focused specifically on characterizing the current literature base addressing the outcomes of adults with IDD who receive long-term services and supports. This review did not evaluate research design quality or consider the magnitude of effects, thus limiting the strength of conclusions.

Focus of Long-Term Services and Supports

In relation to long-term services and supports, the studies included in this review most often provided general descriptions of the types of long-term services and supports addressed by the research. There were very few studies that provided specific descriptions of the types of services or supports addressed by the research. In certain instances, such as those studies addressing consumer-directed supports, this level of detail was not necessary for understanding the purpose or the results of the research. In other instances, such as those studies carried out across multiple states, this level of detail would have been difficult to provide. When studies provided descriptions of long-term services and supports, the majority of studies focused on a single type of long-term service or support. However, those studies addressing multiple types of long-term services and supports suggested the importance of the interplay of multiple types of long-term services and supports on the outcomes experienced by adults with IDD. For example, Campo and colleagues (1997) found that quality of life for adults with extensive and pervasive support needs appeared to be defined by the interrelations among variables that describe their day-to-day living experiences as (a) being highly individualized, (b) incorporating universal and basic types of human experience (e.g., grocery shopping in the community), and (c) balancing independence and interdependence.

Focus of Outcomes

As it relates to the focus of outcomes, results of this review indicated that certain outcomes have a more comprehensive literature base than others. In relationship to Shogren et al.’s (2009) *Public Policy Outcome Domains*, the societal inclusion, participation, and self-determination domains were investigated most frequently. Very few studies addressed the material well-being domain, and there were no articles that explicitly focused on the personal development domain. In relationship to the NQF's *Quality in Home and Community-Based Services to Support Community Living Framework*, the areas of community inclusion, holistic health and functioning, and choice and control were most frequently investigated. Person-centered planning, rights, and equity were topics not frequently addressed by studies included in this review, and the topic of consumer leadership was never addressed.

Given the inclusion criteria guiding this literature review, it is understandable that certain topics were not well represented. For example, this literature review's focus on adults with IDD naturally excluded many studies addressing caregiver supports, one of the domains in the NQF's *Quality in Home and Community-Based Services to Support Community Living Framework*. Additionally, it is likely that there are certain domains that are better investigated using qualitative research methodologies, and qualitative studies were excluded from this literature review. Regardless, results still highlight areas where further research is needed.

Descriptions of Outcomes

Results of this literature review identified a number of variables that consistently impact outcomes experienced by adults with IDD who receive long-term services and supports. First, results demonstrated that type of residential setting matters. In most circumstances, smaller residential settings were associated with improved outcomes. For example, smaller living arrangements were associated with increased choice opportunities (Neely-Barnes et al., 2008); increased access to the community (Neely-Barnes et al., 2008); and increased levels of integrated employment (Butterworth et al., 2015). However, there were certain circumstances, such as gaining access to preventative healthcare and maintaining a healthy weight, when improved outcomes were associated with larger residential settings (Bershadsky et al., 2012). Despite the influence of residential settings on outcomes, findings from this review indicated that adults with IDD rarely have a choice regarding where and with whom they live (Stancliffe et al., 2011).

Second, findings from this review highlighted the influence of disability diagnosis and specific support needs on outcomes. The influence of disability diagnosis was evident in residential outcomes. For example, Hewitt and colleagues (2017) found that a higher number of adults with co-occurring intellectual disability and Autism Spectrum Disorder lived in family members' homes in comparison to adults with IDD. Disability diagnosis and support needs also influence choice outcomes. For instance, Stancliffe et al. (2011) found that adults with IDD with a greater number of support needs have less choice when it comes to their living arrangements than those people with fewer support needs. Employment outcomes were also influenced by disability diagnosis and support needs. Nord and colleagues (2018) found that people with more significant intellectual disability, those with communication and mobility support needs, and those with a guardian were much less likely to have an employment goal, a predictor of actual employment.

Third, this literature review established the influence of staff providing long-term services and supports on outcomes. Findings indicated that staff providing long-term services and supports influence quality of life outcomes for adults with IDD. For example, Campo and colleagues (1997) found that improved quality of life was associated with having a large number of supportive staff members, as they play an important role in influencing community involvement and social relations. Friedman (2021) described the influence of staff training on instances of abuse and neglect among adults with IDD. Staff members also influenced the behavior of adults with IDD. For instance, Friedman (2020) found that training support staff to promote dignity and respect and to recognize each person as a unique individual led to a significant reduction in the number of challenging behaviors exhibited by people with IDD.

Fourth, this review’s findings indicated that the type of funding impacted outcomes. This influence was seen in residential outcomes. For example, Campbell and colleagues (1998) found that the type of funding used to cover the cost of long-term services and supports influenced living arrangements, and that in turn the type of living arrangement influenced level of independence and community integration. This influence was also apparent when traditional long-term services and supports were compared to consumer-directed supports. For instance, Heller and colleagues (1999) found that people with IDD who participated in consumer-directed support programs experienced greater satisfaction with services, had fewer unmet service needs, and experienced improved community functioning.

Finally, results demonstrated ways in which disparities in service receipt and use are tied to demographic variables. Disparities are evident in the provision of employment services and supports. For example, Morgan-McInnes and colleagues (2010) found that people with IDD who receive supported employment services are more likely to be men, have higher IQ scores, and have lower incidences of emotional and behavioral problems. Disparities were also evident when considering the types of services received. Harrington and Kang (2016) found that all racial and ethnic minority groups were less likely to receive services compared to white populations. Disparities were also evident in regard to expenditure amounts. Harrington and Kang (2016) found that females, younger people, and all racial and ethnic minority groups had significantly lower expenditures.

Implications for Future Research

Over the past decade, the field has called for an integrated approach to outcome evaluation, wherein research considers: (a) disability policy goals, (b) personal outcome domains, (c) factors influencing personal outcome domains, (d) support strategies to enhance the outcome domain, and (e) outcome domain indicators (Shogren et al., 2017). The results of this review underscore the importance and feasibility of an integrated approach when evaluating the outcomes of adults with IDD receiving long-term services and supports. Moreover, findings from this literature review can inform future research in this area. Specifically, the results of this review can inform the type of future research that should be conducted. Researchers studying this topic should consider using the results of this review to identify specific types of long-term services and supports and outcomes areas that are in need of additional research. Results also reveal the need for future research to consider the interplay of multiple types of long-term services and supports. Furthermore, the results of this review can inform how research in this area can be conducted in the future. For example, researchers can use the findings of this review to inform their knowledge of datasets that can be used to study this topic and their understanding of how these data sets can be combined to carry out more targeted research. Outcome research guided by an integrated approach, such as that carried out by Dinora and colleagues (2023), can promote the effective use of resources, inform the provision long-term services and supports, and lead to systemic changes that enhance the personal outcomes of adults with IDD.

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Figure 1

Literature Search Summary

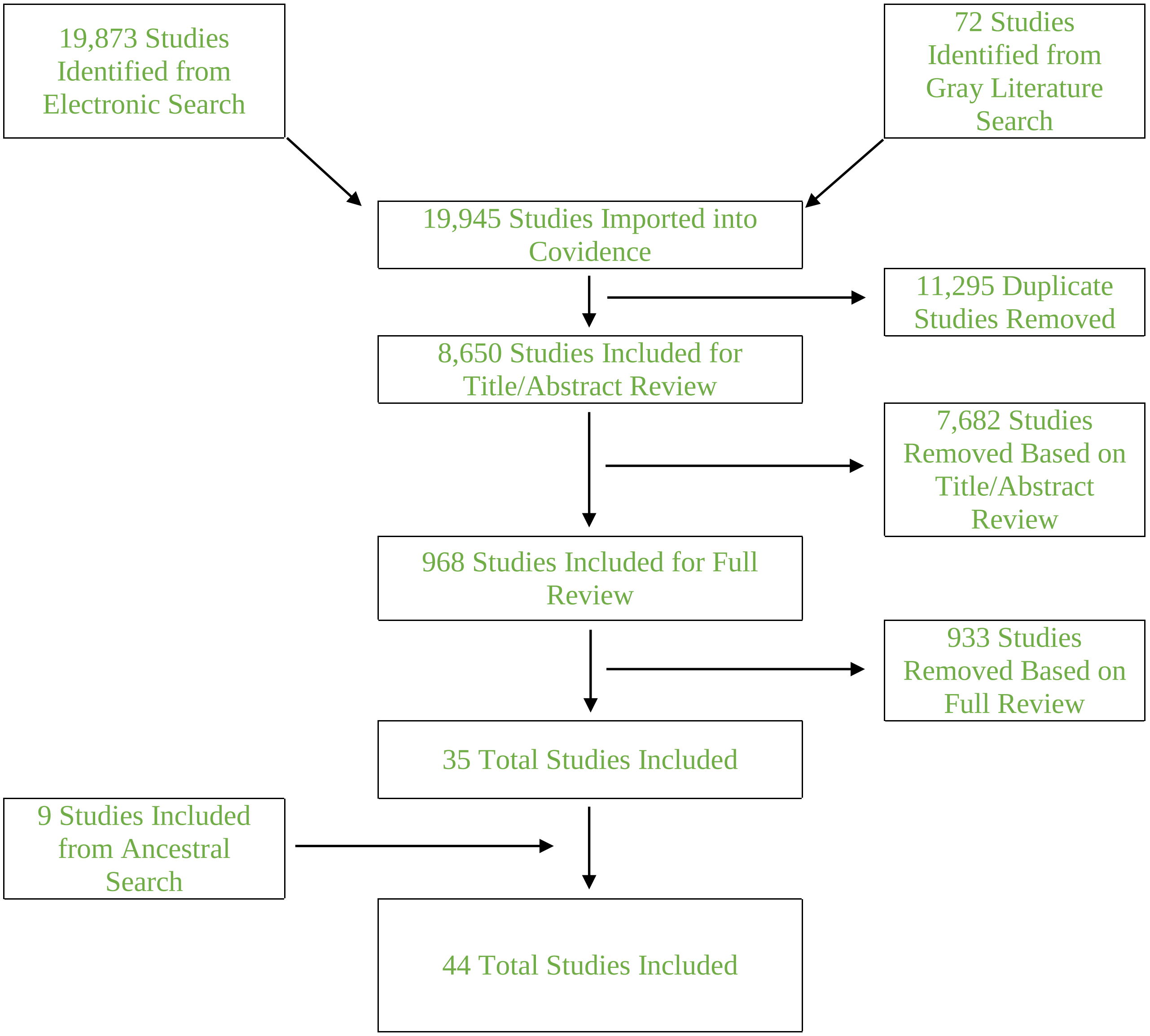

Table 1

Coding Summary

Citation	Long Term Service or Support	Study Type		Analysis Type		Location		Measure(s)	IV(s)	DV(s)	CV(s)
		Cross Sectional	Longitudinal	Primary	Secondary	Single	Multiple				
Blick et al. (2016)	Day Programs / Employment	X		X		X		Essential Data Elements	Daily Activities / Community Integration	Quality of Life	None
Benjamin et al. (2000)	Consumer Directed Services	X		X		X		Interview / California Management & Payrolling System	Support Model	Safety / Unmet Need / Service Satisfaction	Age / Gender / Ethnicity / Education / Work Status / Marital Status / Case Mix

Bershadsky & Kane (2010)	Health Care / Residence Type or Supports	X		X		X		Medicaid Analytic Extract Data / Minnesota's Medicaid Management Information System Database	Place of Residence	Access to Routine Dental Care Procedures	Age / Gender / Race / Length of Observation Period
Bershadsky et al. (2012)	Health Care / Residence Type or Supports	X			X		20	National Core Indicators	Place of Residence	Receipt of Preventative Health Care Services	Age / Gender / Race / Length of Observation Period

Bershadsky et al. (2014)	Health Care	X			X		19	National Core Indicators	Race / Ethnicity	Receipt of Preventative Health Care Services	State / Age / Sex / Language / Level of ID / Mobility / Other Diagnoses / Health / Residence Type / Behavioral Support Needs
Butterworth et al. (2015)	Employment	X			X		26	National Core Indicators	Living Arrangement / State	Daytime Activities / Community-Based Paid Jobs	None
Caldwell & Heller (2007)	Consumer Directed Services		X	X		X		Family Support Index / Service Satisfaction / Community Integration Scale	Enrollment in Consumer-Directed Support Program	Unmet Service Needs / Service Satisfaction / Community Participation / Caregiving Burden	None

Campbell et al. (1998)	General	X		X			2	Inventory for Client and Agency Planning	Funding Type	Integration / Residential Independence / Daytime Independence	State / City Size / Unemployment Rate / Personal Income / Competency / Behavior / Seizure Frequency / Medical Needs / Age / Agency Ownership / Agency Size / Staff Client Ratio / Reimbursement Rates

Campo et al. (1997)	Residence Type or Supports	X		X		X		Quality of Life Index / Group Home Management Schedule / Residential Staff Performance Rating / Staff Training / Residence Supervisor Performance Rating / Community Integration Activities / Domestic Integration Checklist / Social Network Analysis	Residence Type	Program Characteristics / Quality of Life / Lifestyle Characteristics	None
Dinora et al. (2020)	General	X			X	X		National Core Indicators / Supports Intensity Scale / Medicaid Claims	Demographic Characteristics / Residence Type / Support Needs / Medicaid Expenditures	Personal Outcomes	None

Esler et al. (2019)	Health Care	X			X		25	National Core Indicators	co-diagnosis of ASD for adults with IDD	Number of Psychotropic Medications	Co-Occurring Conditions / Age / Gender / Level of ID
Freedman & Chassler (2004)	Health Care / Residence Type or Supports	X		X		X		DMR Consumer Survey / CRS Database	Residential Settings	Health Problems / Behavior Problems	None
Friedman (2019)	Residence Type or Supports	X			X			Personal Outcomes Measure	Residence Type / Impairment Severity	Quality of Life	None
Friedman (2020)	LTSS Agencies or Staff	X			X	X		Basic Assurances	Training	Number of Challenging Behavior Events	Agency Size / Agency Geographic Location
Friedman (2021)	LTSS Agencies or Staff	X			X	X		Basic Assurances	Ongoing Staff Development / Agency Geographic Location / Agency Size	Health & Safety of People w/IDD	None

Hall et al. (2007)	General		X		X	X		Medicaid Eligibility Database / Health-Related Services Database	Service Type	Primary Health Care Visits / Overall Physician Visits	Age / Gender, Race / IQ Level / Qualifying Disability / Disability District / Resident Type
Harrington & Kang (2016)	General		X		X	X		Client Master File / IDD Client Developmental Evaluation Report File / IDD Purchase of Service File	Allowable Factors of Client Need / Non-Allowable Factors of Client Need	Service Use / Service Expenditures	Client Needs
Heller, Miller, & Factor (1999)	General		X	X		X		ICAP / Community Integration Scale / Opportunities for Choice-Making Scale / Multiphasic Environmental Assessment Procedure	Opportunities for Choice-Making / Level of Involvement in Policymaking	Adaptive Behavior / Community Integration	None

Heller, Miller, & Hsieh (1999)	Consumer Directed Services	X		X		X		Community Integration Scale / Bandura's Self-Efficacy Scale / Family Support Index	Enrollment in Consumer-Directed Family Support Program	Service Need / Service Use / Caregiver Satisfaction / Caregiver Appraisal / Need for Out of Home Placement	Age / Minority Status
Heller et al. (2002)	Residence Type or Supports		X		X	X		ICAP / Community Integration Scale / Physical Health Scale / Environmental Measure / Physical Attractiveness Scale / Choice Scale	Residence Type / Size / Choice-Making / Physical Attractiveness / Family Involvement	Adaptive Behavior / Community Integration / Health	Age / Level of Mental Retardation / Adaptive Behavior / Health
Heller et al. (2012)	Consumer Directed Services / LTSS Agencies or Staff	X		X		X		Demographics / Satisfaction with Personal Support Worker / Family Caregiver Appraisal and Outcomes / Outcomes for the Person with IDD	Type of Support Worker Hired	Differences in Experiences / Differences in Outcomes	None

Hewitt et al. (2017)	Residence Type or Supports	X			X		25	National Core Indicators	Diagnosis of Autism	Living Arrangement	Age / Gender / Level of ID / Level of Challenging Behavior
Howe et al. (1998)	Residence Type or Supports	X		X		X		Supported Living Interview / Community Based Activities Interview / Social Relationships Interview	Types of Residential Services Received	Levels of Community Activity / Community Activity Variety / Community Activities Rating Scale / Number of Friends / Number of Activities Done with Friends	None
Kang & Harrington (2008)	General	X			X	X		Client Master File / Client Development Evaluation Report File / DD Purchase of Service File	Client Need Characteristics / Client Predisposing and Enabling Characteristics / Provider Supply / Population Characteristics	Service Type Expenditures	None

Lakin et al. (2007)	General	X			X		6	National Core Indicators	Service Type	Dual Diagnosis / Self-Determination / Community Inclusion	Level of ID
Lakin et al. (2008)	Residence Type or Supports	X			X		6	National Core Indicators	Service Type	Choice in Everyday decisions / Choice in Support Related Decisions	Level of ID / Medical Care Needs/ Mobility / Behavioral Conditions / Psychiatric Conditions / Self-Reporting
Morgan McInnes et al. (2010)	Supported Employment		X		X	X		DDSN Records	Supported Employment Services	Employment Outcomes / Participation in Supported Employment	Constant and Individual Demographic Characteristics

Neely-Barnes et al. (2008a)	Residence Type or Supports	X			X	X		National Core Indicators	Choice / Living Arrangement	Community Inclusion / Quality of Life / Rights, Relationships	None
Neely-Barnes et al. (2008b)	General	X			X	X		National Core Indicators	Choice / Living Arrangement	Community Inclusion	Respondent Type
Nord et al. (2016)	Employment	X			X		19	National Core Indicators	Diagnosis of Autism / Diagnosis of IDD	Employment Outcomes / Community-Based Employment	Age / Health / Mobility / Gender / Level of ID/ Challenging Behavior
Nord et al. (2018)	Employment / Residence Type or Supports	X			X		26	National Core Indicators	Disability / Guardianship Status / Employment Goal	Employment Goal Attainment / Employment Setting	Demographics/ Housing Supports / Disability

Spreat & Conroy (1998)	Health Care / Residence Type or Supports		X		X	X		Developmental Disabilities Quality Assurance Questionnaire	Adaptive Behavior / Age, Length of Nursing Home Residence / Sex / Presence of Mental Health Problems / Physical Violence / Property Damage / Rebellious Behavior / Disruptive Behavior / Profane Language / Self Injurious behavior / Hyperactive Tendencies	Receipt of an Antipsychotic Medication	None

Stancliffe & Lakin (1997a)	Residence Type or Supports	X		X		X		ICAP / Minnesota Longitudinal Study Residential Service Provider Interview / Social Activities in the Last 30 Days / Community Integration Inventory / Contacts w/Family / Consumer Choice Scale / Staffing Levels / Service Costs / Age of Community Residence	Residential Setting	Expenditures / Staff / Community Access / Social Activities / Community Inclusion / Family Relationships / Choice	Demographics / Residential Setting / Adaptive Behavior / Challenging Behavior
Stancliffe & Lakin (1997b)											
Stancliffe & Lakin (1999)	Day Programs / Residence Type or Supports	X		X		X		ICAP / Minnesota Longitudinal Study Service Provider Interview	Deinstitutionalization	Types of Services Received / Types of Outcomes Achieved	Challenging Behavior / Level of ID

Stancliffe & Lakin (2006)	Residence Type or Supports		X	X		X		Minnesota Longitudinal Study Residential Service Provider Interview	Institutionalization Status	Contact with Immediate Family Members / Frequency of Contact / Longitudinal Stability of Contact	None

Stancliffe et al. (2000)	Residence Type or Supports	X		X		X		Minnesota Opportunities and Exercise of Self-Determination Scale / Minnesota Self-Determination Skills / Attitudes, and Knowledge Evaluation Scale / ICAP / Community Oriented Programs Environment Scale / Group Home Management Schedule / Responsibility for Household Decision-Making Scale / Residence Supervisor Performance Rating /Community Living Attitudes Scale / Social	Living Environment Factors / Living Size Unit	Personal Control / Self-Determination	Adaptive Behavior / Challenging Behavior / Self-Determination

								Network Analysis			
Stancliffe et al. (2002)	Residence Type or Supports		X	X		X		ICAP / Residential Services & Support Survey	Duration of Community Living	Adaptive Behavior / Challenging Behavior	None
Stancliffe et al. (2009)	Residence Type or Supports	X			X		6	National Core Indicators	Features of Living Environments	Satisfaction / Well-Being	Level of ID / Challenging Behavior / Age / Gender / Autism Diagnosis / Psychiatric Diagnosis / Seizure / Medical Support Needs
Stancliffe et al. (2011)	General / Health Care	X			X		20	National Core Indicators	Different Syndromes / Level of Intellectual Disability / Living Arrangement / Demographic Variables	BMI Status / Obesity	None

Stancliffe et al. (2011)	Residence Type or Supports	X			X		26	National Core Indicators	Personal Characteristics / Residence Types	Choice of Where to Live / Choice of with Whom to Live	Individual Differences / Data Sources
Stephens et al. (2005)	Employment		X		X	X		Developmental Disability Quality Assurance Research Project Interview	Employment / Level of Integration	Adaptive Behavior / Challenging Behavior	None
Tichá et al. (2012)	Residence Type or Supports	X			X		19	NCI	Residence Type / Residence Size	Everyday Choice / Support Related Choice	Physical Impairments / Sensory Impairments / Age / Behavioral Support / Communication / State

Wood et al. (2007)	Health Care	X			X	X		Administrative Dataset / Medicaid Claims Dataset	Primary Care / Specialty Care / Disability Type	Emergency Room Visits	Sociodemographic characteristics / Clinical Characteristics