

# **Policy implications, eligibility and demographic characteristics of people with intellectual disability who access self-directed funding in the United States**

## **Abstract**

This study identifies factors (state of residence, personal characteristics and living situation) associated with access to self-directed funding (SDF) for adults with intellectual disability in the U.S. Data from 10,033 participants from 26 states in the 2012-13 National Core Indicators Adult Consumer Survey were analyzed. We examined state, age group, residence type, disability diagnoses, mental health status and type of disability support funding used. Availability of SDF for people with ID varied by state, which aligned mostly with state-by-state policy data on SDF eligibility and availability. The results of a logistic regression analysis demonstrated that access to SDF was lower in older adults and higher for people who lived in their parents' or relatives' home, an independent home, and with certain personal characteristics. Potential influences from policy and practice and approaches to increase access to SDF are discussed.

**Key Words:** *Intellectual Disability, Individualized Funding, Self-Directed Funding, National Core Indicators, Disability Policy.*

Self-directed disability support funding is an individualized alternative to agency-delivered block-funded models. Self-directed funding (SDF) has been introduced in a number of countries including the United States (U.S.), United Kingdom (U.K.) and Australia, with increased numbers of people using SDF (Glendinning et al., 2008; Moseley, 2005). User control/self-direction can be demonstrated when people with disability and their families can choose how to spend their individualized funding by purchasing services and supports they value most (Leadbeater, 2004). One objective of this funding is to view the person with a disability and/or their family as a customer, rather than a passive recipient of services (Friedman, 2018).

According to the National Disability Insurance Scheme Act 2013 (2013) in Australia, the purposes of SDF are to enhance choice, independence and self-determination, to break down traditional service barriers and to increase social inclusion and participation. Moseley (2001) suggested that the effective use of SDF requires the utilization of person-centered planning, such as setting goals and decision-making about how the person wants to use their funding. This type of user control creates a culture where the individual is asked first about what they want in their life (Buntinx & Schalock, 2010; Fisher et al., 2010; Robertson et al., 2006).

As is discussed in greater detail below, in many high-income countries, including the U.S., SDF is available to only some service users, not all. Therefore, one important issue concerns who uses this form of funding and under what circumstances. This issue involves a range of policy, eligibility, funding and uptake factors, which can influence the degree to which policy intentions are realized in practice. While policies may specify eligibility criteria, implementation practices can vary. Policy actors across federal, state and local public administration often embed processes which may differ from the initial policy, resulting in variable implementation and delivery (Carey & Friel, 2015). Currently, there is little specific research addressing the particular characteristics and circumstances of people with

intellectual disability who access self-directed disability funding, without which it is hard to identify possible barriers to obtaining SDF or who needs further support or policy action to access this funding. The current study is designed to examine access to SDF for adults with intellectual disability in the U.S. Before detailed examination of issues related to the availability of SDF, we will first briefly consider the benefits of SDF to help make the case that access to SDF is important.

### **Benefits of Self-Directed Funding**

In 1995, the Robert Wood Johnson Foundation launched a U.S. self-direction program for people with intellectual and developmental disabilities to assist with the empowerment of decision-making and choice. This program promoted individualized, self-directed supports as a valuable strategy for people with disability to live more fulfilling lives and enhance the choice and control they have in their community (National Council on Disability, 2013).

One important issue concerns evidence about quality of life outcomes and level of satisfaction for people on SDF (Moseley, 2005). There are many reasons why SDF is considered beneficial, including the model's fundamental basis of enhanced levels of consumer choice and control (David & West, 2017). In the U.K., Glendinning et al.'s (2008) randomized control trial (RCT) found that people with ID indicated they had more control over their lives when using SDF. However, many people with ID do not live self-determined lives and do not currently self-direct their funds (Friedman., 2018; Robertson et al., 2001; Stancliffe, Abery, & Smith, 2000), suggesting that greater access to SDF could enhance choice and control.

A closely related issue is the processes involved in using SDF and the supports that are purchased with this funding. SDF can be used to pay for supports and services chosen by the person and their family. Glendinning et al. (2008) found that most people with physical

disabilities on SDF were happy with the services purchased for support and the quality of support was perceived to be higher than for people who did not access this type of funding.

Crozier, Muenchberger, Colley and Ehrlich (2013) described a program called Cash and Counseling in the U.S., developed for SDF, which found that the most common funding areas were for staff supporting personal care, housework, health care needs and transport. More research is required to determine what services SDF purchases, and how well it supports choice making.

Harry, Mahoney, Mahoney, and Shen (2017) undertook a secondary analysis of an RCT focused on young adults aged 18-30 from 3 U.S. states with long-term disability support needs, some of whom had developmental disabilities. Compared to usual care controls, and controlling for numerous confounding factors, the SDF group had higher satisfaction with life, daily support arrangements, transport, home and community supports, personal care and rapport with staff. This group was also more likely to have their transport, home-based healthcare and medication needs met than controls receiving agency-based care.

Overall, the available evidence shows SDF to be associated with a range of benefits.

Therefore, any inequities in access to SDF need to be identified, so appropriate policy reform can be enacted to make these benefits more widely and equitably available.

### **Availability of Self-Directed Funding**

In many countries, including U.K., Australia and the U.S., the availability of SDF is limited and uneven. Access varies from one jurisdiction to another (e.g., from state to state), with the result that some participants access such funding, while others do not.

*U.K.* In England in 2012-2013, 16.8% of those using social care were using SDF, an increase from 13.7% in 2011-2012 (NHS Digital, 2013). This percentage involves people with various types of disabilities, including intellectual disability.

*Australia.* In Australia, the recently implemented National Disability Insurance Scheme (NDIS) allows all eligible individuals with a significant, permanent disability to access individualized funding. Participants can choose their funding to be managed by the National Disability Insurance Agency, plan-managed through alternate services, or self-managed by the customer. In June 2017, 16% of NDIS participants, with various types of disability, including intellectual disability, had fully (7%) or partially (9%) self-managed funding packages. There was variation between Australian states, with the Australian Capital Territory (ACT) having the highest prevalence of self-management at 38% (National Disability Insurance Agency, 2017). The percentage of people self-managing in Australia is increasing, with 24% of participants choosing self-managed funding in 2018 (National Disability Insurance Agency, 2018).

*U.S.* In the U.S., intellectual and developmental disability (IDD) funding, including SDF availability, is administered by each state. States have differed markedly in the past regarding availability of SDF (Moseley, 2005; Walker, Bogenschutz, & Hall-Lande, 2009). There is evidence that over time, SDF has become available to more people in more states (DeCarlo, Hall-Lande, Bogenschutz, & Hewitt, 2017; Friedman, 2018).

### **U.S. Self-Directed Funding Policy**

Medicaid Home and Community Based Services (HCBS) funding (also referred to as “Medicaid waivers”) is the primary funding source for U.S. IDD services and can include an SDF option (Friedman, 2018; Walker et al., 2009). The other source of Medicaid funding – intermediate care facilities for individuals with intellectual disability (ICF/ID) – does not have an SDF option, so by definition, SDF is not available to people receiving ICF/ID services.

Within HCBS funding, SDF is optional, meaning that individual states are encouraged but not mandated to offer SDF (Friedman, 2018). Moreover, most waivers with an SDF option do not require participants to self-direct their funding. The widely-used 1915(c) U.S. waiver was amended to identify acceptable variation of state provision of SDF. Accordingly, states can offer self-direction in the entire state or in specific areas/regions; allow services to be directed by a consumer's representative; offer participants employer authority (staff hiring) and/or budget authority (budget management, purchasing goods/services) (Crisp, Doty, Smith, & Flanagan, 2010). There is a widespread expectation among state IDD administrators that SDF should cost less than similar agency-delivered services (Bogenschutz, DeCarlo, Hall-Lande, & Hewitt, 2019). In addition, individual state waivers may have SDF caps, hourly wage rate caps, or constraints on the number of participants (Walker et al., 2009). These factors likely limit access to SDF, and may also affect the willingness of individual service users to choose the SDF option over agency-delivered services. For all these reasons, it is important to document and analyse the actual state-by-state availability and uptake of SDF in the U.S.

Two recent studies have provided more detail, by state, on SDF policy and availability in the U.S. DeCarlo et al. (2017) collated and summarized the details of *all* IDD HCBS waivers offering SDF, whereas Friedman (2018) reported state estimates of the numbers of people expected to use SDF only under a 1915(c) waiver. Neither study directly examined the personal characteristics or living situations of individuals with ID actually using SDF. Both studies concluded that there has been growth in SDF opportunities in recent years.

DeCarlo et al. (2017) reported 2015 policy data regarding state-by-state availability of all IDD waivers with SDF options. They found that many states, but not all, provided the possibility of SDF under one or more HCBS waivers. Because of missing data from many states on the number of participants using SDF, it was not possible for DeCarlo et al. (2017)

to report what percentage of IDD service users self-directed. These authors provided state-by-state details about each waiver, including year of SDF onset and participant characteristics required for eligibility to access each waiver (e.g., living situation, disability diagnosis, and age). The eligibility restrictions identified by DeCarlo et al. (2017) often involved personal characteristics and/or living arrangements, which supports our approach of examining such variables when analyzing who has access to SDF. Our variable for living arrangements (see Analyses section for more detail) was tailored to align with the specific restrictions on residential status for SDF eligibility reported by DeCarlo et al. (2017). This approach allowed us to determine how these policy restrictions actually operated in practice.

Friedman (2018) examined self-directed 1915(c) waivers for people with IDD in the 2015 fiscal year, in 46 states and the District of Columbia. Friedman reported the percentage of participants in each state who were predicted by state IDD administrators to self-direct and found that nationally, only 12.1% of participants were predicted to be directing their services. Friedman (2018) also reported that 20.9% of Medicaid HCBS 1915(c) waiver funding was predicted to be used in services that enabled the choice of self-direction for people IDD in the 2015 fiscal year, an increase of 2.2% from FY 2013.

While DeCarlo et al. (2017) reported waivers with SDF options and their eligibility requirements and Friedman (2018) reported predictions on the percentage of people expected to use SDF, neither study was able to identify the number of people who actually used SDF, their individual characteristics and living arrangements. These issues are important for researchers to explore because, while policies (such as waivers) may specify access criteria, actual practices can vary. Policymaking is a complex non-linear process where the governments' own 'sense of capacity' may also be a barrier to change or their ability to embed specific processes in service delivery (Carey & Crammond, 2015). In addition,

policies and practices of federal, state and sub-state entities interact (Turnbull & Stowe, 2014).

### **Individual Characteristics**

In addition to eligibility issues specified by state policy, personal characteristics of service users may also be related to access to SDF. It is well established that characteristics including milder level of intellectual disability are strongly related to service options such as living in one's own home (Stancliffe et al., 2011). Therefore, one aim of the current study is to determine whether there are differences in selected demographic characteristics between adults with ID who do and do not receive SDF. This issue is important, because equity requires the option to access SDF and its benefits to be available to all, not a select few. However, as noted above, eligibility requirements specified in state-by-state policy (DeCarlo et al., 2017) may limit access to certain groups.

Available research does show that people with certain characteristics have differential access to SDF. Leece and Leece (2006) in the U.K. highlighted inequities in SDF allocation, with older people less likely to access SDF. SDF has been a relatively recent development and was not available to older participants when they entered the service system in the 1970s and 1980s. This situation raises questions, such as whether older participants can transition to SDF and if so, whether they do so.

The research evidence about the characteristics of people who receive SDF is not consistent. For example, in the U.K. people with mental health diagnoses, older individuals, those with milder disability and people with ID are under-represented in SDF options (Leece & Leece, 2006). In Australia however, according to Fisher et al. (2010), at that time, the people who were most likely to use individualized funding were of working age, had low support needs, and had one disability. As noted, in the US, the major multi-state studies of SDF for people

with ID (DeCarlo et al., 2017; Friedman, 2018; Moseley, 2005; Walker et al., 2009) have not directly addressed the issue of SDF user characteristics or policy versus practice differences.

This apparent lack of consistency regarding characteristics of SDF users suggests that there may be some differences in funding, policy and service delivery for SDF between countries, which likely indicates that different priorities and policies operate in different international jurisdictions.

In the face of somewhat inconsistent evidence, we based our selection of personal characteristics for inclusion in our analyses on several factors. First, we chose personal characteristics (e.g., disability diagnosis, and age) identified by DeCarlo et al. (2017) as eligibility criteria in U.S. state policy. Second, we included characteristics that had been identified in previous research as related to SDF, such as age, severity of disability, and the presence of mental health diagnoses (Fisher et al., 2010; Leece & Leece, 2006). The core concept of self-direction - choice and control over services and supports – was captured by the variable *support-related choice* examined by Tichá et al. (2012), who found that verbal individuals exercised more such choice, so we included a binary variable on use of verbal communication. Our final criterion for personal characteristic selection was based on prevalence. Because of the substantial numbers of adult service users with autism (Hewitt, Stancliffe et al., 2012), we included autism diagnosis in our analyses, but did not include Prader-Willi syndrome for example, because very few individuals have this diagnosis. We concede that other individual characteristic may also be worth investigating but were constrained by pragmatic limitations (e.g., data availability) and statistical power considerations arising from the number of independent variables given the available sample size.

### **National Core Indicators**

This paper involves secondary analysis of U.S. National Core Indicators Adult Consumer Survey (NCI-ACS) data to examine the relationship between access to SDF, various participant characteristics, and their living situation. The National Core Indicators program is a voluntary method for state IDD agencies to track and evaluate their performance (Bradley & Moseley, 2007).

## **Research Questions**

Using 2012-13 NCI-ACS data, this paper will explore the following research questions:

1. How pronounced are the state differences in the availability and utilization of SDF in the United States?
2. Are there significant differences in the personal characteristics and/or living situation of adults with intellectual disability who do and do not receive self-directed disability funding?

## **Method**

### **Measures**

The data source for this study was the 2012-13 NCI-ACS ([www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)). This survey is one critical component of the annual National Core Indicators (NCI) program. The NCI is co-sponsored by the National Association of State Directors of Developmental Disability Services (NASDDDS) and the Human Services Research Institute (HSRI) (Bradley & Moseley, 2007).

The NCI-ACS survey questions were developed for people who have intellectual and developmental disability. The survey addresses core areas, such as work, community, self-determination, choice, decision-making, relationships, participation, access, safety, health and family support (Bradley & Moseley, 2007).

The NCI-ACS has three sections, the first being *Background Information*, which has questions about the characteristics of and service use by the person with disability including each participant's gender, age, residence type, level of ID, verbal capacity, autism diagnosis, mental health diagnoses, use of extensive behavior support, and other supports and services including the type of funding people access and whether this is SDF. Typically, the Background Information Section is completed from administrative records, with additional information provided by a service coordinator or case manager. The current study focused solely on data from the Background Information section.

NCI-ACS Sections One and Two are administered by in-person interview. *Section One* is self-report only by the person with disability and deals with more subjective issues such as friendship and loneliness. In *Section Two*, self-report or proxy responses are allowed. The NCI-ACS protocol is the same across all participating states. Cross-state consistency is further facilitated by an interviewer training program with standardized training resources (manuals, presentation slides, videos, scripts etc.) and the train-the-trainer sessions.

The National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute (2012) sets out the psychometric characteristics of the NCI-ACS, but these data relate to Section One, not the Background Section used in the current study.

### **Use of self-directed funding**

The primary question from the NCI-ACS on SDF is: "Is this person currently using a self-directed supports option?" The response options are yes or no. In the NCI-ACS, the following information is provided about SDF to help respondents answer this question. "Self-directed" or "participant-directed" supports options offer individuals (and their representatives, including family members) the opportunity to manage some or all of their services. They may hire and fire their own support workers and/or control how their budget is spent." (National Association

of State Directors of Developmental Disabilities Services & Human Services Research Institute, 2012, p. 20).

### **Sampling**

The goal of the NCI-ACS is to sample at least 400 adults from each participating state. Most states recruit a random or stratified random sample of adult IDD service users, but some states decide to oversample users of certain programs in some survey years. The inclusion criteria are that participants are 18 years or older and receive at least one IDD service other than case management. Table 1 shows U.S. participating states and their abbreviation.

Insert Table 1 here.

### **Participants**

A total of 13,157 participants responded to the 2012-13 NCI-ACS. We omitted those with missing data about disability funding ( $n= 526$ ), as well as individuals living in non-community settings (e.g., institutions, nursing homes) and recipients of ICF-DD funding ( $n = 1,905$ ). This form of funding is for congregate services and does not allow for individualized funding or SDF. From the remaining sample of 10,726, we selected participants with a diagnosis of ID, yielding a sample of 10,033, hereafter referred to as the *full sample*. The characteristics of these participants are set out in Table 2. Participants had an average age of 42 years ( $SD = 14.6$ , range = 18 to 93). Participants excluded solely because they did not have an ID diagnosis ( $n=693$ ) represented 5.3% of all 2012-13 NCI participants. Compared to the full sample, this excluded subgroup without ID had a higher proportion of people with autism, cerebral palsy or brain injury. The full sample used in our analyses contained large numbers of people from each of these diagnostic groups, all of whom also had an ID diagnosis.

Insert Table 2 here.

## Analyses

First, data from all participants with ID from all 26 states (*full sample*) were analyzed to determine the overall percentage of participants in this sample in receipt of SDF and to describe between-state variation in receipt of SDF to answer research question one.

Second, to answer research question two we explored the association between socio-demographic factors and receipt of SDF. We included the following demographic, diagnostic and residential variables in our analysis because they have in the past frequently shown an association with funding or outcomes: (a) gender, (b) age group, (c) level of intellectual disability, (e) verbal capacity, (f) autism diagnosis, (h) mental health diagnoses (i) extensive behavior support, (j) residence type, and (k) state (Hewitt, Stancliffe, & Emerson, 2013; Stancliffe et al., 2011; Stancliffe, Lakin, Taub, Chiri, & Byun, 2009; Tichá, Hewitt, Nord, & Larson, 2013). DeCarlo et al.'s (2017) state-by-state analysis of SDF policy guided our selection regarding the levels of the residence type variable (i.e., independent home, family member or relative's home, group home with less than 4 residents, and other residence type).

We were concerned that state differences in policy and practice could confound our analyses of the association of socio-demographic factors and receipt of SDF. In order to address this possibility, we restricted the analyses to data from 11 states, selected because they each had a minimum of 40 participants who received SDF (*restricted sample*). This cut-off of 40 represents 10.0% of the recommended state NCI random sample size of 400 (Bradley & Moseley, 2007). This strategy was intended to enable us to analyze data from states where there was reasonable availability of SDF, so that we could be more confident that the associations identified reflected factors related to SDF access, not merely service-system differences between states with little or no SDF and states with greater SDF availability. The 15 omitted states only had 0 to 24 people on SDF and therefore did not meet the 10%

requirement. These 11 states in the restricted sample included in the analyses (CT, FL, HI, IL, KY, NH, PA, TX, UT, VA and WI) had a total of 4,532 participants.

Further potential complication arose regarding the Wisconsin sample. The level of ID variable was missing for all 308 participants from Wisconsin, meaning that they were all omitted from any analysis involving the level of ID variable. In addition, the sampling technique used during the 2012-2013 NCI-ACS data collection in Wisconsin appears to have resulted in an oversampling of people who used funding programs with an SDF option.

Lastly, the entire New Hampshire sample had missing data on mental health diagnoses. This meant that all 360 participants from that state were excluded from analyses involving mental health diagnoses.

All analyses were performed using SPSS version 24. We used descriptive statistics to estimate the prevalence of SDF. The full sample was used to identify the total number of participants with ID in the 2012-13 NCI-ACS data who received SDF. We performed univariate analysis using Chi-square to identify the association between SDF and socio-demographic characteristics. Some of these factors, such as type of residence and age group, were associated with each other. Therefore, multivariate analysis using logistic regression was then performed to look at which variables remained associated with receiving SDF when potential confounding factors in univariate analysis were accounted for. These analyses were carried out with SDF as the dependent variable, and the following independent categorical variables: age group, level of ID, mental health diagnoses, verbal communication, autism diagnosis, residence type and state.

As a further check of the reliability of our findings, multiple imputation was then used because some variables, such as mental health diagnoses and level of ID, had large amounts of missing data. The missing data for age group, level of ID, mental health diagnoses, verbal

communication, autism diagnosis and residence type were imputed by sorting cases by state, splitting file into separate states and then using the SPSS multiple imputation procedure to impute missing data values where possible. The imputed data were then used with separate logistic regression analyses for each state. We wanted to see if similar patterns were evident for significance level and odds ratio per state for each independent variable used as compared to the overall multivariate analysis findings for the restricted sample as a whole, that was analyzed without missing data imputation. Complete results are reported for the *restricted sample* and only important differences using other analysis techniques are reported in this paper.

## Results

### State variation in NCI-ACS Data

There were marked differences between states as to the percentage of participants who used SDF. These differences are shown in Table 3.

Insert Table 3 here.

As Table 3 shows, there was a wide range between states of access to SDF, ranging from 0.0% in Alabama and Indiana to 71.1% in Wisconsin. We compared the 26 states in the full sample using chi-square analysis and found that states varied significantly  $\chi^2(25) = 1836.56, p < .001, N = 10,033$ . Findings without WI were similar ( $\chi^2(24) = 714.81, p < .001, N = 9725$ ).

Wisconsin was clearly an outlier within these 26 states and this may be due to the NCI sampling technique used in 2012-13 in WI, which may have oversampled people who had access to SDF. The total for all states was 10,033 participants of whom 1,055 received SDF, which was 10.5% of the full sample (8.6% without WI). The 11-state restricted sample had 20.0% of participants on SDF (16.2% without WI). The 15-state omitted sample had 2.5% of participants on SDF.

### State Policy and National Core Indicators Data Comparisons

### **State comparisons (*Full Sample*)**

All states in our NCI-ACS sample were also represented in the DeCarlo et al. (2017) policy survey, thereby enabling us to cross check the SDF policy situation for each state. This information supported the integrity of the NCI-ACS data analyzed by confirming availability of SDF at a waiver (policy) level and helped to determine which independent variables would be used for our analyses, such as the specific types of residence examined.

Our between-state comparisons (see Table 3) showed that SDF participation rates were consistent with DeCarlo et al.'s policy results. Some states had few or no participants with SDF, while other states had much larger numbers with such funding. For example, the "Year State Started Self-Direction" according to the DeCarlo et al.'s (2017) policy data for Alabama and North Carolina was 2013, with 0.0% participants from NCI data using SDF in Alabama and 1.0% in North Carolina. These results appear to be reflective of the later onset of this type of funding and the year of NCI data being used for our analyses (2012-2013). Indiana was also reported as not having SDF in DeCarlo et al.'s (2017), consistent with 0.0% of Indiana participants we found using SDF in NCI-ACS data.

### **State comparisons (*Restricted Sample*).**

All 11 states that had 40+ people using SDF in our restricted sample were also shown to have SDF in 2012-13 in the policy data (DeCarlo et al., 2017). The median year of SDF onset for these 11 states was 2001.

### **Personal Characteristics, Living Situation and Self-Directed Funding**

DeCarlo et al.'s (2017) state policy data provided valuable guidance for selecting independent variables, particularly aspects of living situation, for our analyses of factors associated with access to SDF. Because there are multiple waiver funding provisions in states, some states have been listed in multiple categories below (e.g., Connecticut has multiple waivers pertaining to

the criterion for “Own home or family members” or “Own home or family members’ or group home < 4”).

DeCarlo et al. (2017) reported that SDF eligibility stipulations ranged from more stringent to less stringent. Among the 11-state restricted sample, living in “Own home or family members” was an eligibility criterion in 6 states (Connecticut, Hawaii, Illinois, Pennsylvania, Texas and Wisconsin), “Own home or family members’ or group home < 4” in 3 states (Connecticut, Kentucky and Utah), “Own home, family members or group home” in 1 state (Virginia), “All individuals with the exception of congregate service or services incompatible with self-directed funding” in 1 State (New Hampshire), all participants in 2 states (Kentucky and Wisconsin) and no SDF residency restrictions were stated or no data on this issue was available for 3 states (Florida, New Hampshire and Texas) in DeCarlo et al. (2017).

*Univariate analyses – restricted sample.* Chi-square tests were used to examine univariate associations between SDF and the variables listed in the first column of Table 4. Table 4 shows univariate analyses of SDF for the restricted sample.

Insert Table 4 here.

Table 4 shows significant associations between SDF access and the following variables: age group, level of ID, mental health diagnoses, verbal communication, autism diagnosis, and residence type.

*Multivariate analysis – restricted sample.* Table 5 shows the results for logistic regression (multivariate analysis) of SDF using the restricted sample. Because of the systematically missing data on level of ID (WI) and mental health diagnoses (NH), this analysis only involved 9 of the 11 states from the restricted sample.

Insert Table 5 here.

Table 5 shows that the likelihood of a person receiving SDF was significantly related to various characteristics of the sample  $\chi^2(21) = 623.00, p < .001$ . Nagelkerke *R* Square value = .288.

People from older age groups were less likely to have access to SDF (even after factoring in living situation). Individuals who live in a parent or relative's home or in an independent home were more likely to have SDF, with the size of the odds ratio (OR) in both cases indicating that these were strong effects. Participants who are non-verbal or have an autism diagnoses were more likely to access SDF. Individuals living in five states (CT, HI, IL, UT, VA) were significantly more likely to access SDF than those living in the reference state (PA). Mental health diagnoses and level of ID were not significant predictors when other variables were accounted for using multivariate analysis.

Logistic regression was repeated using multiple imputation to impute missing data and the findings were no different. These results are not presented here but can be requested from the first author.

Some factors that were significant in multivariate analysis of aggregated data did not show up as significant in state-by-state multivariate analyses within individual states. For example, Residence Type (living with family or relative) remained significant for all states except Texas. Texas has multiple waiver programs including community living assistance, consumer-managed personal attendant services and HCBS services. More information is needed to understand why Texas differed from other states. The individual state regression findings were generally consistent with the overall results from the aggregated analysis of the restricted sample. We interpret this consistency to show that the overall results were due to similar patterns of association across multiple states, and not to a small number of numerically dominant states overshadowing smaller states.

## **Discussion**

We analyzed an NCI-ACS random sample of 10,033 adults with ID who used disability services in 26 U.S. states in 2012-13. Of these, 10.5% received SDF. The restricted sample (*N*

= 4,532, 11 states) had 20.0% of participants on SDF. The two most important factors that predicted use of SDF were the state the person lives in and residence type (especially living in a parent or relative's home or living independently). Our findings align with Friedman's (2018) result of 12.1% of participants of all ages having a goal for SDF across 46 states and Washington DC in 2015. As Lakhani et al. (2018) suggested, enhanced policy, for greater choice and control, and specific adjustments to supports provided are important issues for engagement in SDF. Our findings suggest that such reforms need to start at the fundamental stage of who currently has access to SDF.

### **Self-directed Funding Policy**

Our overall findings were mostly consistent with the results of a recent state-by-state analysis of SDF policy (DeCarlo et al., 2017), which reported that many states restrict eligibility for SDF by living situation, with only those living with family, in their own home, or in very small group homes having access to SDF. The frequent use of these eligibility restrictions effectively limits SDF access to those who already live in more individualized settings.

Our findings were also consistent with published data on the availability of SDF in each state, with substantial agreement with findings from both DeCarlo et al. (2017) and Friedman (2018), thus providing independent evidence of the validity of our findings. For example, according to DeCarlo et al. (2017), Alabama did not have SDF until 2013, which accounts for the lack of access to SDF in that state in our findings for 2012-13 (see Table 3). Friedman (2018) indicated no goals for self-direction in Indiana (i.e., projected number of waiver participants who elected self-direction), which aligns with our finding of no Indiana participants using SDF and accords with DeCarlo's et al.'s (2017) data. However, agreement was not perfect, in that our research found low levels of SDF in Mississippi (4.4%) and Arkansas (7.8%) whereas DeCarlo et.al. (2017) and Friedman (2018) reported no waivers with SDF options in these states. Given that

Table 2 shows that 9.2% of participants used non-HCBS funding, it is possible that these two states used non-HCBS state funding for SDF, but the specific reasons for this modest discrepancy are currently unknown.

All 26 of the states we analyzed were represented in DeCarlo et al. (2017) and 24 of these states were included in Friedman's (2018) publication. Minor variations in findings arose from methodological differences. For example, Florida had SDF in our study (15.7%, see Table 3) and in DeCarlo et al. (2017) due to a 1915(j) waiver, but was not reported to have SDF by Friedman (2018) because she only considered the 1915(c) waiver.

### **State Variation**

Using the 26-state *full sample* to answer research question 1, between-state comparisons showed that the state of residence was a clear determinant of access to SDF (range 0.0% - 71.1%, Table 3). As noted, states that had zero participants on SDF using NCI data also had no self-direction policies or had not taken up this funding by the year of NCI-ACS analysis (2012-2013) as shown in the state-by-state policy data (DeCarlo et al., 2017). These states were also reported by Friedman (2018) as having zero or below 1% of waiver participants with goals for SDF. By contrast, states with well-developed SDF policies and long-established self-direction, had a much higher level of SDF in our NCI data. As Moseley (2005) suggested, there have been state-by-state differences in the past regarding availability of SDF and according to the current research study, this variability remains.

### **Variables Associated with Access to Self-Directed Funding**

To address research question 2 personal characteristics, living situation and access to SDF, we analyzed a *restricted sample* of 11 states that each had reasonable numbers (40+) of SDF recipients. Chi square statistics (univariate analysis) and logistic regression (multivariate analysis) were used to determine factors associated with access to SDF. There were clear

differences, especially in relation to living situation and age group. People living with family, in an independent home and younger people were more likely to be using SDF. Individuals with an autism diagnosis or who were non-verbal were also significantly more likely to receive SDF.

### **Living Situation**

Even when people live in states with SDF, there are still access limitations evident due to funding limits, caps on participant numbers (Walker et al., 2009), or where state waiver funding policy stipulates eligibility prerequisites, such as the requirement to live in a particular type of setting (DeCarlo et al., 2017). We found that people living in an independent home ( $OR = 10.23$ ) or with family ( $OR = 17.85$ ) were significantly more likely to access SDF. According to DeCarlo et al. (2017), living in a group home with less than four people was a criterion for access to SDF in some state waivers, but our research showed that people living in group homes with fewer than four people ( $OR = 1.50$ ) was *not* significantly associated with access to SDF. This finding underlines the importance of empirical evaluation of policy implementation, rather than simply assuming that the SDF reality will always match the policy intention. However, it is also important to note that DeCarlo et al. (2017) reported that only 5 of these 11 states in our restricted sample explicitly allowed SDF in waivers for recipients living in small group homes. Furthermore, we did not look at people in institutions accessing SDF because HCBS waiver funding is only available for community living. Therefore, people who are in the least individualized settings, institutions, are locked out of access to SDF.

### **Age**

As service provisions change and the expectations of people with intellectual disability increase, the number of people living independently or with family is growing (Larson et al., 2018). Younger adults were more likely to live with family, and both younger age group and

living with family were significant factors in increased access to SDF. Because SDF has only been available in recent years (DeCarlo et al., 2017), older individuals who entered the service system prior to SDF availability would not have had this option available to choose from at that time. It is probable that many older people continued to use the congregate service and funding they first joined and have not been given the option to transfer to an SDF alternative.

### **Disability**

Several personal characteristics were found to be significantly related to SDF under multivariate analysis. However, the effect size in each case was relatively small compared to residence type, and the reasons for the directions of some effects were unclear. These results are examined below.

**Autism diagnosis.** According to Hewitt et al. (2012), there is a disproportionate number of younger adult IDD service users with autism compared to older service users with this diagnosis. The current study found people who have an autism diagnosis were more likely to access SDF, even after age had been controlled in our multivariate analysis. Looking at results from DeCarlo et al. (2017), seven out of eleven states in our study's restricted sample had waivers which allowed people to access SDF due to autism diagnoses, although some participants may also have had a co-occurring ID diagnosis which allowed them to access waiver funding. The relatively recent development of autism-specific waivers (Hall-Lande, Hewitt, & Moseley, 2011) could mean that these waivers are also more likely to include and emphasize SDF.

**Verbal capacity.** People who were non-verbal were more likely to obtain SDF. The reasons for this finding are unclear. One possible factor is their greater need for advocacy and support from family members to request and access SDF.

More research is needed to understand why these demographic impacts were found, together with further investigation into self-direction policy and practice to highlight how access and supports impact SDF allocation.

### **State**

State was included in the multiple regression analysis partly as a control variable, to demonstrate that other factors remained significantly associated with SDF even when state differences were controlled statistically. However, the clear pattern of significant difference between states showed that, even among the restricted sample of states selected for their relatively high prevalence of SDF, important between-state differences in SDF access remained.

### **Strengths and limitations**

Strengths of our study include its large sample size and capacity for state-by-state comparisons. A further strength is that our data reported *actual* usage of SDF by individual IDD service users, thereby complementing the SDF policy analysis reported by DeCarlo et al. (2017) and the *projected* number of SDF recipients identified by Friedman (2018). Because our major analyses were completed using the restricted sample of 11 states that each had 40 or more SDF recipients, caution is needed relating these findings to states that have few or no people using SDF.

We found that participants living with family were clearly more likely to access SDF. Because all NCI-ACS participants were 18 years or older, our study reported no data on the proportion of individuals who already had SDF before age 18, when presumably the vast majority were still living with family (Larson et al., 2018).

Only limited information was available about state-by-state variations in NCI-ACS sampling, so it is possible that the data for some states, notably Wisconsin, may not have been fully representative of the state's overall IDD adult service system.

In the current study, being identified as an SDF recipient could mean that the participant had the opportunity to do one or more of the following: manage all or part of their funding, hire and fire their own staff (employer authority), and control their own budget (budget authority). We reported no data on these issues, so the degree of such control exercised by participants is unknown.

Crisp et al. (2010) identified that the 1915(c) waiver was amended to represent acceptable variations in SDF including allocation in the entire state or specific areas or regions. No information was available to identify these within-state differences. We had no data on the actual dollar amount of SDF compared to other waiver funding. Such expenditure data may assist in identification of further inequities of allocation, especially given the emphasis by state administrators on cost savings with SDF (Bogenschutz et al., 2019).

### **Implications for Policy and Practice**

SDF was nonexistent in some states and its very limited availability in several other states effectively prevented service users in those states from accessing SDF. Whereas SDF is currently optional for states (Friedman, 2018), one policy response to increase access to SDF could be a federal mandate requiring *all* states to offer SDF.

We found that people who live with family or live in independent settings were more likely to access SDF. SDF can be managed by an individual, a family member or representative, and these living situations may involve people (i.e., service users or family members) perceived as more able to self-manage funding. In addition, these living arrangements are highly individualized, a situation that is administratively more convenient for individualized funding

such as SDF. Furthermore, this finding is consistent with policies in many states (DeCarlo et al., 2017), which restrict eligibility for SDF to those who already live in individualized settings. In short, this aspect of SDF policy appears to be operating as intended by policy makers, with SDF being far more readily available to those living with family or in independent settings. The question arises, is this an appropriate policy? These living arrangements are associated with positive outcomes, such as greater wellbeing and better choice of living companions (Stancliffe et al. 2009; 2011). However, living with family and independent living are both much lower cost than options like group homes (Larson et al., 2018). Given the emphasis on cost savings with SDF by state administrators (Bogenschutz et al., 2019), the SDF policy rationale is complex. Perhaps these considerations could form a virtuous circle involving better outcomes and lower cost, if people in congregate settings could access SDF and use it to transition to a more individualized living situation (discussed further below).

However, it is evident from our findings that living situations such as group homes have a very low percentage of people using SDF, with barriers in both policy and practice that prevent individuals from accessing such funding. The likely effect is that people are locked into congregate living arrangements and excluded from SDF options. Targeted approaches to address these barriers are required, such as giving SDF access to people currently living in congregate settings. Policy change must be accompanied appropriate support to enable individuals to navigate complex administrative processes and to use SDF to move to more individualized living arrangements if desired. Such arrangements may already be (partly) in place in certain states and could be replicated or adapted in other states. For example, DeCarlo et al. (2017) found that waivers in some states had no SDF-access restrictions based on living situations and SDF was open to *all* participants who chose it. It was notable that states such as Wisconsin, which had very high SDF participation rates in our study, had multiple waivers with no restrictions on living situation (DeCarlo et al., 2017).

According to Priestley et al. (2007), in Australia disability staff were more likely to support SDF if they were informed about, understood and had previous involvement with such funding. Therefore, further education regarding funding, availability and benefits is recommended.

### **Further Research**

Future research should focus on whether recipients of SDF experience better quality of life outcomes. The findings from this study can help identify appropriate variables to control when analyzing quality of life outcomes for individuals with ID who do and do not have access to SDF, such as age, living situation and the state the person resides in.

The number of people accessing SDF in the U.S., UK and Australia is increasing and the demand for access to this funding is growing. Because different priorities, policies and practices operate in different state, federal and international jurisdictions, further investigation of the similarities and differences between each country's approach and each jurisdiction's strategy will assist in understanding how policies such as Australia's country-wide individualization of funding for people with permanent disabilities compare to differing availability in the U.S. and U.K. in regard to SDF.

As shown by DeCarlo et al. (2017), there are differences in what SDF means in different states. For example, waivers in some state jurisdictions include budget authority, employer authority or the option to employ family members, whereas other waivers do not. To better understand the nature and extent of self-direction, it would be valuable for future research to include specific details regarding if individuals are hiring their own staff, planning their own supports, accessing case management, plan management, support coordination, advocacy, and fiscal intermediary supports. It is also important to examine whether the participant's family member is assisting with self-direction as a paid or unpaid support. Furthermore, looking at the impact

of each of these variables on the quality of life outcomes experienced by individuals who use SDF would assist in understanding best-practice funding supports.

Finally, a key issue is distinguishing between the effects of targeted provision of SDF and inequities in access among people within the targeted groups. For example, factors such as family education and income levels, race and ethnicity, and urban versus rural location could be investigated to determine whether these variables are related to access to SDF.

## **Conclusion**

The limited available research suggests that self-direction enhances control for individuals with ID (Glendinning et al., 2008), which arguably assists people to obtain desired quality of life outcomes by designing the life they choose, with the supports they want and need. Our findings were mostly consistent with state SDF policy (DeCarlo et al., 2017), with the important exception that, contrary to SDF eligibility policy in a number of states, living in a small group home was not significantly related to accessing SDF. Going beyond state policy on whether SDF is available, we quantified the availability of SDF in the U.S. to adults with ID and showed it is limited (only 10.5% accessed SDF), uneven, with state-by-state differences in allocation, and access restrictions, which largely limit this funding to younger adults, already in individual or family settings. U.S. SDF policies and practices need to be reformed to enhance equity of opportunity so all people with ID can choose to access SDF.

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