

The Application Process for Supplemental Security Income for Individuals with Intellectual and Developmental Disabilities: A National Survey of Service Coordinator and Family Experiences

Final Report

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Abstract

Supplemental Security Income (SSI) began in 1974 as a critical source of financial support for many individuals with intellectual and developmental disabilities (IDD), enabling them to live in the community while reducing the impact of poverty and providing access to various supports and services. Although anecdotal evidence highlights the challenging nature of the application process for SSI, there is a dearth of research regarding the experiential component of the process. The present research sought to understand the experiences of service coordinators (SCs) and family members with the application process for SSI benefits for individuals with IDD. The study focused on the parts of the application process that facilitated success, barriers that hindered the procurement of benefits, and elicited suggestions for improvement of the process. Respondents to the online survey included 96 SCs and 483 family members from across the United States. Analyses considered respondent role, time (i.e. length of time as an SC, when families applied for SSI) and region of the US. Findings highlight systemic deficiencies (e.g. Social Security Administration's (SSA) understanding of SC role, privacy and sensitivity to IDD); positive and negative emergent trends (e.g. increased use of phone interviews and decreased training attendance); and, recommendations for improvement (e.g. simplification of application process and increased transparency). This study provides preliminary insight into a difficult process to secure a much needed resource, however, additional research remains warranted.

Supplemental Security Income (SSI) began operation in the United States in 1974 following the Social Security Amendments of 1972. Administered under the Social Security Administration, SSI is part of the nation's welfare programs that provides monthly financial support to eligible individuals who are aged, blind or disabled (SSA, 2013), the latter of which includes intellectual/developmental disabilities (IDD).

Individuals with IDD are often economically and socially marginalized in society (Noblitt & Perskin Noblitt, 2010) with approximately one-third of adults with IDD living below the poverty level in the US (Reschly, Myers & Hartel, 2002), in part due to an inability to secure or maintain gainful employment. With an increasing prevalence of individuals diagnosed with IDD (i.e. 12.84% in 1997 to 15.04% in 2008), and, higher rates among families living below poverty (Boyle et al., 2011), the need for access to financial resources is intensified. SSI functions as a critical source of support, enabling individuals with IDD to live in the community while reducing the impact of poverty and providing access to various supports and services, including: vocational training, case management, family support services and access to other essential benefits like Medicaid¹ (Reschly et al., 2002; Noblitt & Perskin Noblitt, 2010). The present research focuses on the disability procedures under the SSI program from the perspective of service coordinators and family members who often assist with the application process on the behalf of individuals with IDD.

Application Process and Eligibility for SSI

A stepwise application process is used for SSI to determine the presence of a qualifying disability based upon a claimant's medical and vocational information, with an emphasis on educational information for children. When such information is insufficient, disability determination service agencies can arrange and pay for a consultative examination to be completed by a treating or independent physician (American Academy of Pediatrics, 2009). Eligibility for SSI requires a disability to be a physical or mental impairment that is medically determinable and "expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months." For those under the age of 18, the disability must result "in marked and severe functional limitations", and, for those 18 and older, it must result "in the inability to do any substantial gainful activity" (SSA, 2014).

The application process can be complicated by numerous factors, including: objective and subjective indicators based upon different conceptualizations of adaptive behavior; less easily quantified deficits in adaptive behavior among individuals functioning in the mild range of intellectual disability; differences in assessment tools (e.g. content, standardization, floor/ceiling effects); and, the process of combining data from different sources to identify deficits in functioning used by trained lay examiners. Although applications are required to meet criteria with supporting evidence, such considerations can result in a delayed determination, inconsistent decision-making and errors (Reschly et al., 2002).

Those who have been denied during the initial application process can petition the decision through a four-level appeal process² which includes: 1) reconsideration of the application by a new adjudicator; 2) a hearing before an administrative law judge; 3) a review by the Appeals Council; and, 4) a review by the Federal Court. In addition, SSI recipients can be subsequently subjected to redeterminations. A child recipient must complete a redetermination upon reaching age 18 due to differences in criteria for the definition of a disability during adulthood. Furthermore, adult recipients receive planned medical reviews every seven years, with the exception of when medical improvement might be expected in which case reviews can

be done every three years. Redeterminations among adult recipients may also be triggered by changes in an individual's work status or financial earnings (SSA, 2013b).

Service Coordination and SSI

Individuals with IDD and their families frequently experience challenges with the application and disability determination process “that may be insurmountable without an advocate to pursue access to benefits for them” (Reschly et al., 2002, p.43). Although family members often apply on behalf of, or assist, individuals with the process, service coordination may be an additional source of support for many. Service coordination is accessible to individuals with IDD through two different mechanisms. While it is a mandated service for early intervention programs under the Individuals with Disabilities Education Act (IDEA; 34 CFR 303.22) (US GPO, 2012), it is also afforded under Section 1905(a)(19) of the Social Security Act that authorizes State Medicaid agencies to provide case management services to Medicaid beneficiaries (SSA, n.d.). Service coordinators (SCs) often serve as a “single point of contact” for individuals and families and coordinate “services across agency lines” (Bruder et al., 2005, p.178).

Purpose

Although anecdotal evidence highlights the challenging nature of the application process for SSI, there is a dearth of research regarding the experiential component of the process. Policy is often insufficient in explaining the experiences of those seeking services and their interactions with personnel under the auspices of the policy (i.e. SSA field office personnel) given the influence of numerous factors such as personal characteristics (Hupe & Hill, 2007). Yet, “(b)y examining how policy is delivered at the ‘front lines’... it brings into view...practices that systematically shape the policy experience” (Brodkin, 2008, p.327). Thus, a front line or street-level perspective can be used to illuminate the informal “practices that otherwise can escape analytic scrutiny and even recognition...(and) opens up a broad set of important questions at the intersection of policy, management and organizational studies” (Brodkin, 2011, p.i199-i200).

Given the participation of SCs and families in the SSI application process for many individuals with IDD, it is integral to understand both perspectives in order to capture the collective experiences associated with SSI. The inclusion of SSA field office personnel is also warranted, however, it is beyond the scope of the present study. The current research sought to understand the experiences of the application process for SSI for individuals with IDD by surveying families and SCs. The study focused on the parts of the application process that facilitated success, barriers that hindered the procurement of benefits, and elicited suggestions for improvement of the process. As such, the aims of this study are: to describe experiences in the application process for SSI that are unique to SCs and families; to describe and compare experiences shared among SCs and families; and, to identify and compare recommendations that SCs and families perceive as helpful to improving the application process.

Methodology

Overview

In the fall 2013, an online survey was disseminated through social media and email to national organizations serving individuals with IDD and their families throughout the United States. Purposive sampling targeted SCs and families who were solicited to complete the survey that asked about their experiences applying for SSI for individuals with IDD. Respondents were eligible for incentive by lottery with contact information submitted through a separate survey link. Data collection lasted for approximately six months.

Measure

Family and Service Coordinator Survey. The survey was based upon two surveys previously constructed by the researcher from focus groups and interviews conducted with SCs and families of individuals with IDD. The two surveys were comprised of items unique to the respective groups, as well as items common to both, and were structured in either multiple choice format or Likert scaled responses (e.g. 1 “strongly disagree” to 5 “strongly agree”). The wording of items reflected the respective roles and experiences (i.e. the collective experiences of SCs; the individual experiences of families). Items specific to SCs queried aspects of their agencies (e.g. The agency I work for has a benefits specialist to help with paperwork associated with SSI benefits.) and their professional role (e.g. I have had difficulty communicating on behalf of an individual/family with SSA field office personnel.). Items specific to families included individual-specific items (e.g. After completing the initial application, how long did it take to hear whether you were approved or denied?). Items common to both groups encompassed: experiences with initial applications, interviews and evaluations, redeterminations, appeals process; general experiences and challenges; and, recommendations for improvement. Sample items include “My experience with the initial interview(s) was/has generally been positive” and “The person(s) doing the evaluation/assessment was/have been sensitive to the individual’s disability”. Surveys were pilot tested among SCs ($n=122$) and family members ($n=122$) in the same community. Following data analysis and minor revisions (e.g. addition of several items to increase clarity of experiences), the surveys were combined into a single measure utilizing skip-logic on SurveyMonkey.

Procedures

The survey link and brief overview were disseminated to organizations through social media (i.e. Facebook) or email during a 6-month period beginning in September, 2013. The primary sources of sampling were through the National Arc and Center for Parent Information and Resources. The National Arc is the largest national community-based organization with approximately 700 state and local chapters serving individuals with IDD and their families. The National Arc disseminated survey information via electronic newsletter and posted the link on their Facebook page several times. The researcher subsequently contacted individual chapters that had active Facebook pages and/or provided service coordination/case management as determined by chapters’ webpages. The Center for Parent Information and Resources (CPIR) has approximately 90 centers serving families of children with disabilities throughout the United States. Centers with active Facebook pages were contacted by the researcher. Approximately 15% of organizations contacted by the researcher agreed to disseminate the survey information. Sampling was supplemented by an additional 10 national disability-specific organizations (e.g. Easter Seals, TASH, National Down Syndrome Society) the agreed to disseminate the survey overview and link. In nearly all circumstances, the organizations or chapters that agreed to disseminate the study overview and survey link did so only once.

Data Analysis

Survey responses to 5-point Likert scaled items were dichotomized to contrast scores 4 and 5 (e.g. *agree/strongly agree*) with all other response options (i.e. 1, 2 and 3). Chi-squares were used to analyze differences on individual items between families and SCs, and, where appropriate, by U.S. Census region and time (i.e. when SSI application was filed). Significant p -values are reported; where applicable, corrections for family-wise error rate are noted.

Findings

Respondents

Survey respondents were 94 SCs and 479 family members, predominantly (>80%) Caucasian and female, with more than half between the ages of 40-59 years old. Eighty-two percent of SCs had either a bachelor's or graduate degree and 54% of family members had some college education or a bachelor's degree. SCs represented 28 of 50 States and families represented 43 of 50 states. Five of the seven states not represented among families were in the Western region. Six states were not represented by either SCs or families (DE, HI, MT, NV, SD, UT). Twenty-three percent of SCs and 10% of families were from New York State. Implications are later discussed.

Table 1
SC and Family Demographics¹

Characteristics	SCs	Families
Gender ²	(n=96)	(n=483)
Male	16%	8%
Female	84%	92%
Race/Ethnicity	(n=96)	(n=479)
Caucasian	84%	87%
African American	9%	4%
Hispanic	4%	3%
Biracial/Mixed races		3%
Native American/Asian/Other	2%	4%
Age	(n=96)	(n=469)
<20 years		1%
20-29 years	17%	7%
30-39	19%	18%
40-49	32%	26%
50-59	22%	36%
60 & older	10%	13%
Education ³	(n=95)	(n=457)
< High school		3%
High school/GED	3%	11%
Some College	7%	27%
Associate's	7%	13%
Bachelor's	51%	26%
Graduate (Master's/PhD)	29%	20%
Region of United States ⁴	(n=89)	(n=467)
Northeast	34%	33%
Midwest	17%	19%
South	33%	27%
West	17%	21%

Note. ¹The sum of percentages in each demographic category may not equal 100% due to rounding error. ²Two SCs indicated that they were transgendered. ³Two SCs indicated "other". ⁴States were collapsed into regions defined by the United States Census Bureau: Northeast (CT, ME, MA, NH, NJ, NY, PA, RI, VT); Midwest (IL, IN, IA, KS, MI, MN, MO, NE, ND, OH, SD, WI); South (Al, AR, DE, FL, GA, KY, LA, MD, MS, NC, OK, SC, TN, TX, VA, WV); and, West (AK, AZ, CA, CO, HI, ID, MT, NV, NM, OR, UT, WA, WY).

Service Coordinators

Agency and skills. Of 94 SCs, 14% were in the role for less than two years and 18% were in the role for two to five years. Forty-three percent indicated that they were in the role for 10 years or more, accounting for the largest proportion (37%-53%) of SCs in each of the 4 US Census regions. A majority (81%) of SCs were either currently assisting a family with the application process or had done so within the past year. About one-quarter of SCs indicated that they worked for an agency that had specific contacts or “go-to persons” at their local SSA office (27%), that their agency had a benefits specialist to help with SSI paperwork (25%), or that their agency offered benefit/entitlement trainings to families (26%). No differences were noted by region.

Approximately two-thirds of SCs indicated that they understood the steps/process in applying for SSI (60%) and stated that prior experiences with SSI aided in their ability to better inform families (67%). Nearly half (47%) of SCs reported that they were confident in their ability to assist families with the application process with no differences by length of time as an SC. Those who expressed limited confidence were more likely than confident SCs to indicate the need for additional training (64% vs. 20%) and increased support from their supervisors (11% vs. 2%). However, regardless of confidence level, 64% of SCs indicated that their confidence would be improved by simplifying the application process (e.g. reduction in amount of paperwork, simplification of terminology). In addition, a majority of SCs indicated that their confidence would be fostered by increased communication with SSA, with the higher endorsement among confident SCs (76% vs. 66%). The percentage of SCs who were confident with assisting families with the application process differed by region [$\chi^2(3, N=87)=8.09, p<.05$]. The percentage of SCs who were confident was highest in the Northeast (64%) and lowest in the West (20%).

Relationships with families and SSA field office personnel. A majority of SCs indicated that they had been contacted by families subsequent to problems with applying for and/or receiving SSI benefits (77%) and that they had been contacted by families for help to understand SSI paperwork (90%). No significant differences by time in role or by region.

More than a third of SCs indicated that they had difficulty with SSA either understanding the SC role (37%) or being able to communicate with SSA on behalf of families or individuals (40%)³. More than half of SCs (53%) indicated that they received conflicting information from SSA personnel. A majority of SCs (85%) indicated that specific contacts at SSA was more helpful than utilizing the general hotline with a significant difference for time in role [$\chi^2(3, N=65)=12.50, p<.01$]. Approximately half of SCs (53.8%) who had been in the role for two to five years indicated that having a specific contact at SSA is more helpful than calling the 1-800 number. No differences were noted by region.

Interviews. Sixty-six SCs indicated that they had participated in the initial interview process with SSA office personnel either in-person, over the phone or both. Overall, about half of the SCs agreed that interviews were positive experiences (53%), reasonable in duration (56%) and allowed for privacy when discussing personal information (53%). Although standardized questions are used during the interview to ensure equity and thoroughness, about half of SCs (46%) indicated that interview questions were sensitive to individuals’ disabilities and 70% of SCs indicated that questions were appropriate to individuals’ needs/circumstances. However, there were significant differences by length of time as an SC [$\chi^2(3, N=63)=9.82, p<.05$] such that those who were SCs for less than two years consistently (100%) agreed that the interview

questions were appropriate and only 50% of those who had been in the position for 10 or more years had agreed. No differences were noted by region.

Evaluations. Of the 30 SCs who indicated that they had attended an evaluation for SSI, a little more than half (53%) were permitted in the assessment room with the individual. Half of those permitted in the room indicated that the evaluations were appropriate given individuals' abilities. Although a majority (85%) indicated that the evaluators were knowledgeable regarding IDD, only about half of the SCs indicated that the evaluators were sensitive to individuals' disabilities (57%) and culturally/racially sensitive (54%). No differences were noted by length of time as an SC or by region.

General aspects of SSA. General aspects of the SSI application process were also considered in the survey. Of the 75 SCs who responded, 45% indicated that appointments at SSA offices were reasonable when considering such factors as dates, times and locations. Less than one-quarter (22%) of SCs felt that the amount of paperwork was reasonable. Twenty-four percent of SCs indicated that phone calls were reasonable considering such factors as duration of a phone call, being put on hold and transferred, with significant differences for time in SC role [$\chi^2(3, N=75)=11.57, p<.01$] such that those who were SCs for two to five years consistently (100%) indicated that phone calls were not reasonable and 50% of those who were in the role for five to ten years indicated that phone calls were reasonable. No differences were noted by region.

Challenges. More than half (55%) of SCs indicated that they found it challenging to provide specific dates for various factors on an individual's application for SSI. While one-third of SCs were challenged in understanding SSI paperwork, approximately 60% indicated that they were challenged by redundancy in the application process (e.g. questions, information requested). No significant differences by region or time in role.

Table 2

Percentage of SCs Endorsing Items As Challenging

Item	SCs
Providing specific dates (e.g. date of diagnosis, history)	55.4
Understanding SSI paperwork	35.2
Redundancy in questions/paperwork	59.4
Having to start application over due to missed appointment/paperwork deadline ¹	60.4
Obtaining approval from managed care/doctor's prescription for an evaluation required by SSA ¹	42.6

Note. (n =70). ¹One-third of SCs indicated that the item was not applicable based upon their experiences.

Families

Initial sources. Overall, families first learned about SSI from a variety of sources, most often (28%) from other family members or a service coordinator. There is a trend toward significance for when families applied for SSI and from whom they first learned about SSI [$\chi^2(8, N=459)=15.41, p=.052$]. When comparing those who applied for SSI in the past five years with those who applied more than five years ago, there may be emergent trends for increases in medical/psychiatric providers and other therapists (66% vs. 34%), family (64% vs. 37%), SCs (67% vs. 33%) and online/other medium (68% vs. 32%) as primary sources of SSI information. Additionally, initial source of information about SSI differed by region [$\chi^2(24, N=467)=42.01, p<.05$]. In the South, medical/psychiatric/therapists (20%) and family (20%) were most often the initial source for learning about SSI. In the West, SCs (18%) and agency training/groups (21%)

were most often the initial source for learning about SSI. In the Midwest, family (21%) was most often the initial source, while in the Northeast sources were fairly evenly distributed.

Table 3

Percentage of Families by Initial Source for SSI Information

Source	Families
Family member	13.8
Service coordinator/case manager	13.8
IDD agency/group ¹	12.8
Medical/psychiatric/therapist ²	12.8
Hospital social worker	11.7
School teacher/social worker	10.9
Friends/other families	10.2
Online/other ³	9.1
Work/Employer	4.9

Note. (N=470). ¹This includes support and advocacy groups, as well as trainings provided by IDD agencies. ²This includes occupational, physical and speech therapists as well as mental health counselors. ³“Other” includes State agencies, attorneys, as well as individuals who noted “self”.

Applications. Although most (68%) families completed the application for SSI without help, 16% received assistance from SSA field office personnel. Other sources of assistance included SCs (5%), family/friends (4%), hospital social worker (4%), and advocate/other (4%). Most families first applied for SSI when their child was between birth and five years old (40%) or between 16-20 years of age (34%); 18% applied when their child was between 6-15 years old. About one-third (31%) of applications were filed within the past two years, 26% were filed in the past two to five years, and 43% were filed more than five years ago. Approximately 26% ($n=110$) of families indicated that they had more than one person with a disability living in their household. Of these families, 15% noted that the asset assessment was fair considering the demands of multiple persons with disabilities.

Benefit/entitlement trainings. Twenty-eight percent ($n=130$) of families indicated that they participated in benefit/entitlement trainings provided by schools or organizations for individuals with IDD (52%), parent support groups (24%), and local state benefits/disability offices (16%). Sources of training did not differ by region or when they applied for SSI. The percentage of families attending trainings differed by time [$\chi^2(2, N=436)=6.09, p<.05$]. Thirty-five percent of those who applied for SSI more than five years ago attended trainings while 22% of those who applied within the past two years did so, a decline from the 28% who applied two to five years ago. Half (49%) of families who attended the training indicated that it was very helpful with understanding SSI and/or the application process, regardless of when they attended, region, or training provider.

Whether or not families attended trainings was associated with applications being awarded SSI [$\chi^2(1, N=398)=6.40, p<.05$]. Families who had attended trainings had a higher percentage (79%) of being awarded SSI than those who did not attend trainings (67%). Similarly, training attendance was associated with a trend toward significance for increased awareness of the online disability report [$\chi^2(1, N=386)=3.19, p=.07$]; a significant increase in awareness of the online benefit screening tool [$\chi^2(1, N=386)=7.25, p<.01$]; and, an increased awareness of what to do after an application has been denied [$\chi^2(1, N=118)=4.03, p<.05$].

Interviews. Of 393 families who responded, 58% were required to do an in-person interview with SSA (35% with child present; 23% without the child present) and 32% were required to do a phone interview. Only 10% of families noted that an interview was not required as part of the application process. Families frequently indicated that the interview was a positive experience (58%) of reasonable duration (60%) and conducted in an area that allowed for privacy while sharing personal information (49%). Similarly, 50% of families perceived the interview questions as being sensitive to the individual's disability while two-thirds (63%) perceived the questions as relevant to the individual's circumstances. No differences were noted by when the application for SSI was filed or by region.

Half (54%) of the families who were required to do an interview with SSA indicated that they had to take time off from work for the interview. When the child was required to be present for the interview, it was necessary for 32% of families to take their child out of school. In addition, nearly half (46%) of the families indicated that it was difficult to have the child present during the interview because of his/her disability. However, the percentage of families who expressed difficulty with having their child present at the interview differed by region [$\chi^2(3, N=237)=15.88, p<.01$]. In the Midwest, a majority (79%) of families did not find it difficult to have their child present, compared with the other regions that were about equally divided regarding whether or not having the child present was difficult. Reasons for this difference warrant further research.

Whether or not an initial interview was required by SSA did not differ by the diagnostic category for the claim, however, the percentage of interviews in which the child was required to be present differed by diagnostic category [$\chi^2(10, N=349)=30.22, p<.01$]. Sixty-eight percent of children with genetic/chromosomal disorders were required to be present during the interview, however, 85% of those with "other" diagnoses, 77% of those with autism spectrum disorders, and 67% of those with traumatic brain injury were *not* required to be present during the interview. All other diagnostic categories were about equally divided with whether or not the child was required to be present.

Changes in the interview process were noted between applications filed within the past two years and those filed more than five years ago. For example, the percentage of applications that were required by SSA to have an interview *with* the child present differed by time [$\chi^2(2, N=348)=11.19, p<.01$], such that having the child present decreased from 49% of those filed more than five years ago to 29% of those filed within the past two years. Similarly, the modality for interviews differed by time [$\chi^2(2, N=352)=13.73, p<.01$] such that phone interviews have increased, from 25% of applications filed more than five years ago to 47% of applications filed within the past two years. No differences were noted for initial interviews by region.

Evaluations. Of 433 families, 48% indicated that their child was required by SSA to have a medical or psychological evaluation. A majority (71%) of these families indicated that they were permitted in the examining room for all or part of the evaluation. About half of the families who were present in the room during the evaluation perceived the evaluation to be appropriate given their child's needs (52%) and the evaluator to be sensitive to the child's disability (58%) as well as culturally/racially sensitive (55%). No differences were noted by when applications were filed or by region.

Determinations. Of 432 applications, 67% received a determination from SSA within 6 months of being filed, of which nearly three-quarters (72%) were approved for SSI. Although claims were more likely to be approved than denied when determinations occurred within six months of the application being filed, when the time it took to receive a determination exceeded

six months the likelihood of the application being denied was slightly more than half (54%) [$\chi^2(4, N=325)=18.71, p<.001$]. No differences were noted for length of time to determination and outcome (i.e. approval/denial) by when the application was filed or by region.

The percentage of applications approved differed by primary diagnosis [$\chi^2(10, N=410)=22.21, p<.05$]. Applications for seizure disorder, traumatic brain injury, psychiatric disorders, autism spectrum disorders, neurological/cephalic disorders and “other” were about equally divided. Applications for all other diagnoses were more likely to be approved than denied benefits, with the highest percentage of approvals among developmental delays (93%), Down syndrome (81%) and genetic/chromosomal disorders (81%).

Of families that were approved for SSI, 35% indicated that they knew what to do next. Of families that were denied for SSI, 21% indicated that they knew what to do next. Of the 125 families who were denied SSI, reasons for denial included: excessive income and/or assets (66%), medical reasons (27%) and insufficient/incomplete documentation and “other” reasons (7%). However, one-third of families indicated that they did not know the reason for the denial.

Table 4

Percentage of Applications by Diagnosis and Approval

Diagnosis	Initial Applications	Approved
Autism spectrum disorder	31.8	62.4
Intellectual disability	19.2	76.2
Down syndrome	11.4	81.2
Cerebral palsy	11.1	77.1
Genetic/chromosomal disorder	5.6	81.0
Traumatic brain injury	3.8	53.8
Epilepsy/seizure disorder	3.6	57.1
Developmental delay	3.1	92.9
Neurologic/cephalic disorders	2.7	63.6
Psychiatric disorder	2.2	55.6
Other/unspecified	5.6	47.4

Note. (N=449).

Appeals. Of the 125 families who were initially denied SSI, 59% indicated that they had received information regarding the appeals process. Forty-four families indicated that they proceeded with the appeals process, 65% of whom found the process overwhelming. Of 44 families who appealed the initial determination, 42% received a subsequent determination within one to three months, 17% received a subsequent determination within four to six months and 19% waited more than one year. Following the appeals process, 60% of families were awarded SSI.

Among those who were initially denied and did not appeal (n=81), 46% indicated that they did not do so because they thought it would not matter and another 27% indicated that they did not know what to do or that the appeals process was an option. The percentage of those who chose not to appeal differed by receipt of information about the appeals process [$\chi^2(3, N=53)=16.66, p<.01$]. Families who indicated that they had not received information about the appeals process subsequent to being denied SSI were three times as likely to not appeal because they did not know what to do. Of the families who were denied SSI benefits and chose not to appeal, or who were denied subsequent to the appeals process, 53% (n=51) applied again for SSI at a later date, of whom 51% were approved for SSI.

General aspects of applying for SSI. Of 390 families, approximately one-half indicated that the following aspects of applying for SSI were reasonable: the dates, times, and locations of appointments with SSA field office personnel (52%); the time allocated to submit any requested paperwork (51%); and, the length of time to receive first SSI payment (48%). Approximately one-third of families indicated that telephone calls (e.g. duration, being put on hold/transferred) (33%) and the amount of paperwork for SSI (30%) were reasonable.

The percentage of families that indicated that the time spent in SSA offices was reasonable differed by region, with a trend toward significance [$\chi^2(3, N=357)=7.33, p=.06$]; and, by time [$\chi^2(2, N=380)=6.76, p<.05$]. Families in the West indicated least often (29%), and families in the Midwest most often (49%), that the time spent in SSA offices was reasonable. Families who applied more than five years ago least often (47%) endorsed appointments as reasonable, while those who applied within the past two years did so most frequently (63%).

Challenges. Of 390 families, about one-third (34%) of families were challenged by knowing what to do throughout the application process. Additional challenges included: understanding the paperwork (29%), obtaining paperwork from other sources (e.g. doctors, schools) (23%), and redundancy in questions and paperwork (49%). The percentage of families who found the redundancy in questions/paperwork differed by region [$\chi^2(3, N=381)=7.86, p<.05$] with families in the South least frequently (41%) and those in the West most frequently (58%) endorsing redundancy as challenging.

Approximately one-third of families indicated items regarding transportation and eligibility were not applicable to their circumstances. However, one-fifth (19%) of families indicated that transportation to SSI appointments was challenging. The percentage of families who found transportation to SSI appointments to be challenging differed by time [$\chi^2(2, N=268)=6.40, p<.05$]. Those who applied two to five years ago most often (28%) indicated that transportation was a challenge in contrast to those who applied within the past two years (14%). Approximately one-third (37%) of families were confused by their child being eligible for developmental disability services but not SSI and nearly half (46%) were challenged by disruptions in SSI checks despite no known changes in diagnosis or family resources. In addition, although 46 families indicated that it was not applicable, 32% experienced difficulty understanding the differences between Social Security Disability Insurance (SSDI) and SSI.

SCs and Families

SSA field office personnel skills. The survey solicited responses from SCs and families regarding ratings of SSA field office personnel's skill set. The percentage of respondents endorsing SSA personnel skills differed by role for: returning phone calls [$\chi^2(1, N=394)=10.46, p<.001$]³; and, timely processing of paperwork [$\chi^2(1, N=432)=14.86, p<.001$]. Families were twice as likely as SCs to agree that SSA personnel returned their phone calls (45% vs. 24%) and that they processed paperwork in a timely fashion (50% vs. 25%). The percentage of respondents endorsing that SSA personnel used easily understood words differed by role [$\chi^2(1, N=432)=3.84, p<.05$]. Families indicated more often than SCs that personnel used easily understood word (70% vs. 58%). After Bonferroni adjustment, the difference was no longer significant.⁴

The percentage of respondents endorsing SSA field office personnel skills differed by region for: cultural/racial sensitivity [$\chi^2(3, N=332)=8.14, p<.05$]; understanding personal schedules [$\chi^2(3, N=382)=8.24, p<.05$]; and, timely processing of paperwork [$\chi^2(3, N=428)=9.37, p<.05$]. Respondents from the Midwest consistently endorsed the respective skills most often (56%, 54%, 60%) and those in the West least often (33%, 36%, 39%). In addition, the

percentage of respondents endorsing SSA personnel as having good communication skills differed by region [$\chi^2(3, N=433)=8.31, p<.05$] with highest percentage in the Midwest (67%) and the lowest (48%) in the South. After Bonferroni adjustment, differences were not significant. Similarly, there were trends toward significance for perceiving SSA personnel as demonstrating a pleasant attitude [$\chi^2(1, N=436)=7.58, p=.056$] and good social skills [$\chi^2(1, N=436)=7.45, p=.059$] with highest percentages in the Midwest (64%, 62%) and lowest percentages in the West (45%, 41%).

Table 5

Percentages of SCs and Families Endorsing SSA Field Office Personnel Skills

Item	SCs	Families
Provided helpful answers to questions	60.0	54.6
Provided helpful resolutions to problems	47.1	46.2
Sensitive to personal situation	33.8	45.7
Returned phone calls ¹	23.9	45.3***
Pleasant attitude	44.3	51.9
Culturally/racially sensitive ²	44.6	47.1
Sensitive to intellectual/developmental disabilities	36.8	44.4
Spoke using easily understood words	58.0	70.0*
Good communication skills	48.6	56.7
Timely in processing paperwork	24.6	49.9***

Note. (N=432). ¹This item was not applicable to 49 respondents, 47 of which were families. ²This item was not applicable to 108 respondents, 94 of which were families. * $p<.05$, *** $p<.001$

Online resources. SSA operates a webpage with online resources, such as a benefit eligibility screening tool and a disability report, to assist in the application process. Although more than three-quarters of SCs and families have accessed the SSA webpage, the percentage of respondents who have used the online benefit eligibility screening tool and the online disability report was less, with the latter differing by region [$\chi^2(3, N=261)=8.26, p<.05$]. Among those who were aware of the online report, those in the Midwest most frequently (65%) endorsed using it, while those in the West did so least often (39%). After Bonferroni adjustment, the difference was not significant. Among families, the percentage that endorsed awareness of the online disability report differed by time [$\chi^2(4, N=398)=23.07, p<.001$]. Awareness *and* subsequent use of the report consistently increased among families, from those who applied more than five years ago (45%, 37%) to those who applied within the past two years (61%, 69%).

Table 6

Percentages of SCs and Families Endorsing SSA Online Resources

Item	SCs	Families
Ever accessed SSA webpage ¹	95.9	76.8***
Aware of online benefit eligibility screening tool ¹	81.9	64.8**
Used the screening tool ²	57.6	48.8
Aware of online disability report ¹	72.2	52.4**
Used the disability report ³	58.5	51.9
Easy to use	59.4	60.4
Too long	43.8	42.9
Helpful (i.e. can stop, save, return later)	77.4	80.8

Can save time at the interview	68.8	70.9
Provides an idea of questions asked at interview	74.2	71.4

Note. ¹(SCs, n=73; Families, n=400). ²(SCs, n=59; Families, n=260). ³(SCs, n=53; Families, n=210). **p<.01, ***p<.001

Recommendations. The five recommendations most frequently (>80%) endorsed by families as likely to create significant systemic improvements were among the 10 recommendations most frequently endorsed by SCs. SCs more often than families endorsed recommendations that would likely facilitate their collective workload, such as having a consistent person at SSA work on a given claim [$\chi^2(1, N=464)=11.65, p<.001$]; revising the application to indicate receipt of SC services [$\chi^2(1, N=460)=17.06, p<.001$], and SC receiving duplicates of paperwork sent to families [$\chi^2(1, N=462)=22.91, p<.001$]. The percentage of combined respondents recommending increased accessibility to appointments/communication with SSA differed by region [$\chi^2(3, N=459)=8.67, p<.05$] with greatest frequency among respondents from the South (82%) and least often from those in the West (67%). This difference was no longer significant after Bonferroni adjustment.

Table 7

Percentages of SCs and Families Endorsing Recommendations

Item	SCs	Families
Communication		
Have consistent SSA personnel on a given claim	94.4	76.8***
Increase accessibility to appointments/communication (e.g. increased hours of operation, local telephone numbers, transportation assistance)	84.7	71.9*
Improve online services (e.g. electronic paperwork, online chat)	73.6	81.4
Assets and Supports		
Increasing asset limit	72.2	79.2
Removing retirement accounts from asset assessment	70.4	73.1
Include individuals' level of supports in assessment	72.9	73.6
Office and Staff		
Improve office environment (e.g. more welcoming, privacy)	52.9	51.8
Improve personnel skills (e.g. increased sensitivity, customer service)	67.1	62.4
Use standardized checklist for paperwork (e.g. received/needed)	72.9	78.2
Have some personnel specialize in IDD	84.3	83.4
Agencies and SC		
Increase communication between SSA and IDD agencies	88.7	75.5*
Revise application to note receipt of SC services	82.9	56.7***
Have SC receive duplicates of paperwork sent to families	87.0	56.5***
Application and Paperwork		
Streamline application for families with >1 child seeking benefits	71.0	62.8
Simplify process for severe/lifelong disabilities (e.g. IDD)	88.4	86.4
Increase transparency/clarity of application/process	85.7	82.8
Increase clarity of paperwork sent by SSA	85.3	82.0
Keep records for those denied to simplify process for any re-applicants	88.2	78.4

Note. *p<.05 (no longer significant after Bonferroni adjustment). ***p<.001

Discussion

This study provides a preliminary assessment of experiences the unique and shared experiences among SCs and families in applying for SSI on behalf of individuals with IDD. Consideration is extended to the implications of time (i.e. length of time as an SC; length of time since families filed claims) and the US Census region from where the respondent was located. Although SSI is statutorily mandated by the US Congress, understanding the experiences of SCs and families illuminates the implementation of policy at the street level. While it is critical to understand and interpret the results within the context of the respondents' respective roles and study limitations, overall, the study highlights potential areas for improvement.

SCs generally perceived themselves as integral supports for families while applying for SSI benefits. Although families were not queried regarding the nature of any relationship with SCs, it is evident from the SC perspective that families had contacted them for support when challenges arose with SSI. SCs might serve as a more direct source of information and support given their ongoing relationship with families as well as their access to agency supports such as a benefits specialist. Yet, regardless of SCs' level of confidence in their ability to help families with SSI, many SCs advocated for a simplification of the application process and for increased communication with SSA. Although the survey did not elicit explanations, it is plausible that despite SCs' self-perceived ability to navigate the application process, it remains cumbersome. Similarly, despite SCs' abilities, families are often challenged by the process and frequently rely on SCs for support. Simplifying the process and increasing communication could facilitate the process for families and subsequently lighten the burden for SCs.

It is important to note that SCs expressed difficulties with SSA field office personnel regarding SCs role. Given that SCs perceived SSA personnel as not understanding SCs role, it is not surprising that SCs had difficulty communicating on behalf of families. Although SSA affords the opportunity for claimants to appointment a representative through form SSA-1696, this research did not solicit SCs for information regarding the use of the respective form. Notably, at least one-third of SCs had difficulty communicating with SSA personnel. While interpretation is limited, it is plausible that there is a need for increased awareness of the respective form among SCs, and/or that regardless of the form, communication remains hindered between the respective groups.

In addition to support from SCs, benefit/entitlement trainings can also be a critical source of information regarding SSI for families. A little more than a quarter of families in the study attended trainings, with half of them indicating that the training was helpful. Notably, those who attended trainings were associated with a higher percentage of being awarded SSI benefits than those who did not attend trainings. Similarly, those who attended trainings were more aware of online resources and how to proceed if their application was denied. However, there appears to be a downward trend in families attending such trainings. Given the implications of training attendance, reasons for this trend warrant further elucidation.

Amid the determination process, slightly more than half of the families indicated the requirement to attend in-person interviews, frequently having to have their child with a disability present. Many families were required to take off from work and/or take their child out of school. Having the child present during the interview was challenging for a number of families. Although the reasons for this were not elicited, it is plausible that challenges arose at least in part due to behavioral concerns associated with the children's disabilities. While an interview may be feasible for someone with a physical disability, children with diagnoses like autism or severe intellectual disability may have greater difficulty given such concerns as stereotypy and attention deficits. With many families already challenged by pre-existing factors such as low socio-

economic status, the additional concerns such as having to take off from work and having to take the child out of school may present additional stress and thus warrant alternative options. Findings do suggest a downward trend in the requirement for children to attend the interviews and for increased use of phone interviews, however, in contrast, having the child present may facilitate the substantiation of a claim for disability through direct observation of the child. Additional consideration is also warranted given the prevalence of families with more than one individual with a disability. Notably, these families may experience increased strain and financial hardship that might not be adequately captured in such parts of the application process as the assessment of income and assets.

Families and SCs were relatively consistent in their endorsement of items on the survey, despite their respective individual and collective experiences. For example, about half of all SCs and families agreed that SSA workers were helpful, pleasant and demonstrated good communication skills. Likewise, SCs and families were consistent in their rating of the online disability report as well as recommendations for improving different aspects of the application process (e.g. assets, offices and paperwork). Yet some differences emerged, in particular, with SCs more aware of online resources for SSI benefits and with families rating characteristics of SSA workers more favorably. Such differences may be attributable to the training and nature of employment as an SC, and their collective experiences. Similarly, SCs may have additional time constraints and sensitivity to systemic efficiency, which is perhaps exemplified in their particular endorsement of agency-related recommendations such as increased communication and collaboration. Nonetheless, the most frequently endorsed recommendations by families were also among those most frequently endorsed by SCs, calling for the simplification of that application process for individuals with IDD such as reduced paperwork, increased transparency and clarity in the application process, improved online services and having SSA workers specialize in IDD.

As noted earlier, the application process for SSI, including the interviews, relies upon standardized questions and procedures, regardless of the type of disability. However, families and SCs have noted the need for increased sensitivity to IDD which can be, in many ways, qualitatively different from other types of disabilities, particularly physical disabilities. Although standardization might be necessary to ensure equity and thoroughness, some questions might be perceived as irrelevant and inappropriate when considering particular diagnoses, such as severe and profound intellectual disability. In addition, some of the challenges perceived by SCs might be related to a fundamental difference in focus between the IDD system and the SSA system. Notably, within the IDD system, policies and staff training focus on the abilities of individuals with IDD, in contrast to the criteria for SSI which emphasize individuals' deficiencies.

This study provides some preliminary insight into potential differences across the United States. The West emerged most frequently as different from the other three regions with such concerns as families most often indicating that too much time was spent in SSA offices, the redundancy of paperwork and questions most challenging, SSA workers needing enhanced skill sets, families least often using online services and SCs demonstrating the lowest level of confidence in their abilities to help families with the application process for SSI. While the sample size for SCs is small and the 4 regions of the US are fairly expansive, interpretation of such findings is limited. However, given their preliminary nature, they suggest the need for more focused research regarding the implications of regional differences.

Despite the potential implications of findings, this study presents limitations. The sample is predominantly Caucasian and female. While this is perhaps related to the predominance of females in helping professions such as SCs and as the primary caregiver in families, findings may not be generalizable to other populations such as African Americans or Latinos, or to those whose primary language is not English, as they may experience additional hardships and barriers. Similarly, while the use of an online survey facilitates dissemination, it restricts sampling to those who are literate and have internet access. Given that many families receiving SSI have low SES, both literacy rates and internet access may be compromised. Likewise, the many facets of the application process were reflected in a lengthy survey which may have resulted in respondent fatigue. Additionally, the survey asked families and SCs to consider prior experiences which, in some cases, were years prior. As such, recall bias is a potential concern.

The sample size for SCs is small given the intended national representation of this study and despite wide-spread dissemination of survey information. While more than half of the United States are represented by SCs, many are not. In addition, the use of the four regions according to the US Census Bureau provides some context, however, limited sample sizes do not permit the subdivision of the regions into more tangible areas. Data analysis is limited by sample size and the predominance of categorical data. While associations are possible, causality is not. In addition, the over-representation of SCs and families from New York State is difficult to interpret given the broad dissemination of the online survey and the solicitation of organizations across the US. However, one possible explanation is the researcher's affiliation in NY which was identified in the dissemination process as well as on the information page of the survey. In conclusion, it is unclear if the sample is representative of the population and caution is warranted in the interpretation of findings.

In conclusion, the study utilized a street-level lens to understand the SSI application process from the experiences of SCs and families who applied or assisted with the application on behalf of individuals with IDD. Although preliminary, the findings provide insight into areas warranting improvement and further attention. Given the challenges of families with children with disabilities, SCs with potentially large caseloads, and a government that seeks to become more cost-efficient, the improvement and facilitation of the application process for SSI is duly noted.

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Footnotes

¹ The application for SSI is also an application for Medicaid in many States (SSA, 2014).

² The reconsideration level was eliminated in 10 states for applications filed October 1, 1999 or later due to the piloting of a prototype process (SSA, 2013).

³ The survey did not elicit information regarding the use of Form SSA-1696 for the appointment of a representative. It is unclear what percentage of SCs had completed this form which would potentially facilitate communication between SCs and SSA office personnel.

⁴ Bonferroni adjustment is the division of the desired level of significance (e.g. $p=.05$) by the number of comparisons used within a given set of data. It is used to minimize the likelihood of type I error (i.e. concluding that there is a statistically significant difference when in fact there is not) due to multiple statistical analyses within the same data. When differences are no longer significant following Bonferroni adjustment, it is possible that the difference was significant due to chance (Munro, 2005).