

A Pilot Study of Service Coordinator and Family Experiences in Applying for Supplemental Security Income for Individuals with Intellectual and Developmental Disabilities:
Identifying Strengths, Obstacles and Recommendations for Improvement

Final Report

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The research reported herein was performed pursuant to a grant from Policy Research, Inc. as part of the U.S. Social Security Administration's (SSA's) Improving Disability Determination Process Small Grant Program. The opinions and conclusions expressed are solely those of the author(s) and do not represent the opinions or policy of Policy Research, Inc., SSA or any other agency of the Federal Government.

Abstract

In the United States, Social Security Administration provides financial benefits through Supplemental Security Income (SSI) to many individuals with intellectual and developmental disabilities (IDD). However, despite its many implications and significance, there remains a dearth of research investigating its impact and complexities. Through the use of focus groups and interviews with service coordinators (SCs) and family members, surveys were developed and piloted to understand their respective experiences with applying for SSI for individuals with IDD and to identify successful components and challenges, as well as recommendations for improvement. Survey participants included 122 SCs and 122 family members in the western region of New York State. Findings regarding experiences with the various steps of applying for SSI, including initial applications, interviews, and assessment processes, as well as quality of interactions with SSA personnel are presented. At times, significant differences were noted between SCs and family members, most notably in the quality of interactions with SSA personnel, general experiences and challenges, as well as in their recommendations for improvement between SSA and disability organizations. In addition, it was found that SCs provided integral support for families in obtaining SSI, often serving as a mediator with SSA; however, SCs expressed difficulty with SSA personnel understanding the SC role. Despite the limitations of the present study, numerous recommendations are offered and endorsed by those most critically involved in applying for SSI for individuals with IDD, namely, SCs and family members. Furthermore, the study provides a preliminary evaluation of an often difficult process to secure much needed financial support integral to the quality of life for individuals with IDD.

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Identifying Strengths, Obstacles and Recommendations for Improvement

Individuals with disabilities, especially those with intellectual and developmental disabilities (IDD) are highly marginalized in society. One-third of adults with IDD living below the poverty level (Reschly, Myers & Hartel, 2002) partly due to an inability to secure or maintain gainful employment. As such, many of these individuals are relegated to a life of poverty (Noblitt & Perskin Noblitt, 2010). Notably, the number of persons with IDD continues to increase as approximately 1 in 6 children are now diagnosed with some developmental disability – a 17.1% increase from 1997 to 2008 – with higher prevalence rates among families living below poverty (Boyle et al., 2011).

Supplemental Security Income (SSI), which operates under Title XVI of the Social Security Act, provides monthly income to individuals with disabilities and serves as a portal to other critical federal and state benefits such as Medicaid (Reschly et al., 2002). Based upon qualifying criteria (e.g. impairment and assets), SSI functions as a critical support in reducing the impact of poverty, enabling individuals to live in the community and providing access to a variety of supports and services including: vocational training, case management and family support services (Reschly et al., 2002; Noblitt & Perskin Noblitt, 2010). Of the nearly 12 million individuals with disabilities who received benefits through Social Security Administration (SSA) in 2010, nearly 3.3 million received SSI and another 1.4 million received a combination of Social Security and SSI. Of those who received SSI only, 19.8% had intellectual disabilities and another 2.3% had autism or other developmental disability (U.S. Social Security Administration, 2011).

Despite general guidelines and efforts made to facilitate the approval process (e.g. the integration of a quality review board; Barnhart, 2005/2006), the SSI application process is complicated by eligibility criteria as well as frequent exceptions (Council on Children with Disabilities, 2009). While the application process is limited to 60 days, the eligibility determination process can be quite lengthy “and mere application is no guarantee of a successful outcome” (Noblitt & Perskin Noblitt, p.275, 2010). As such, individuals with IDD “face an immediate barrier in the form of demonstrating eligibility, a barrier that may be insurmountable without an advocate to pursue access to benefits for them” (Reschly et al., p.43, 2002).

While many individuals have family members to assist with securing such benefits, a considerable number of individuals rely on the supports of service coordinators (SCs). Service coordinators employed by organizations serving the IDD population link and refer individuals to supports and services and maintain a working document of the individuals’ history, current status and services (NYSOPWDD, 2011). They often serve as a “single point of contact” for individuals and families while coordinating “services across agency lines” (Bruder et al., 2005, p.178).

The U.S. Social Security Administration (SSA) previously asked the National Research Council to assess its disability determination process for intellectual disability (Reschly, Myers, & Hartel, 2002). Within its report published in 2002, the Council recommended much needed research in disability-related issues (e.g. eligibility decisions, intellectual disability). More than 10 years later, there continues to be a dearth of relevant research; as such, understanding the many components and impact of a complex process to obtain critical financial resources for a vulnerable population becomes all the more salient.

Purpose

The present research was conducted to evaluate SC and family experiences in order to identify strengths and barriers with applying for SSI benefits for individuals with IDD in the Western New York (WNY) region, as well as to identify recommendations for improvement. The study sought to answer the following questions: a) What are SC and family experiences like in applying for SSI? b) Are there differences in their experiences? c) What recommendations do they see as helpful to improving the application process?

Methodology

Overview

Two surveys (i.e. one for SCs and the other for families; see Appendix A) were constructed from focus groups and interviews with SCs and family members of individuals with IDD. (Further detail regarding survey development is presented later in the manuscript.) Surveys were uploaded to SurveyMonkey with links broadly disseminated through electronic mail to organizations serving individuals with IDD throughout the eight western counties of New York State, as well as several affiliated networks and listservs in the same region. In addition, two organizations with which the researcher had prior affiliation sent hard copy letters with the survey link to families they identified as having recently gone through the process; one of the two organizations provided a second mailing with paper-and-pencil surveys. In order to ensure the privacy of families being served, organizations did not permit the researcher to have access to family contact information. Furthermore, families were able to request paper-and-pencil surveys from the researcher by phone if they did not have internet access. As such, it is unclear how many families received the information, subsequently limiting the interpretation and generalizability of findings. Yet, more than 60% of family respondents completed the survey online. All participants were eligible for an incentive (i.e. \$10 gift card) following survey completion. To ensure anonymity of survey responses, participants either sent an email or a postcard (in the case of the paper-and-pencil surveys) to the researcher requesting the incentive. Data collection lasted for three months.

Participants

Service Coordinators. Of the 122 SCs who participated in the survey, 93% were female and 98% were Caucasian, with 65% between 20 and 39 years old. While 31% were SCs for less than two years, 28% held the position for five to 10 years, and another 25% for more than 10 years. Twenty-six percent of SCs were currently assisting families with the application process while 52% indicated that they had done so within the past year.

Families. Of the 122 family members who participated, 83% were female and 92% were Caucasian. Nearly 61% of family members were between 40 and 59 years old. While 9% were currently going through the SSI application process, 41% indicated that they had done so within the past two years.

Measures

Family and Service Coordinator Surveys. Surveys were developed from focus groups and interviews with SCs and family members of individuals with IDD. After review and approval by the *Institutional Review Board*, brief presentations were provided by the researcher to the SC department at two IDD organizations with which the researcher had a prior relationship. Periodically, reminder emails regarding recruitment were sent by the researcher to designated points of contact in each organization for intradepartmental dissemination. Service coordinators were encouraged to share the information with their families. In addition, the researcher recruited families at a weekend training provided by a community resource

organization specific to parents of individuals with IDD. Participants were recruited over a 2-month period through the two organizations. After providing informed consent, participants were queried based upon their personal experiences regarding the strengths and barriers to applying for SSI, as well as recommendations for improvement. Two focus groups and five interviews were conducted in private meeting rooms with SCs and 11 family members were interviewed either at their homes or in another location that afforded privacy. All participants were provided a \$10 incentive and SCs were permitted to participate in the research on paid work time. Focus groups and interviews were audio-recorded and transcribed by a third party.

Interviews were analyzed using Atlas.ti 7 and open-coded for major themes. Open-coding, often associated with grounded theory, is the use of conceptual labels that are developed to identify information as it emerges from the data (Charmaz, 2007; Glaser, 1978). The codes and data were subsequently used to create two surveys which reflected the differences and similarities between SCs and families. Surveys were reviewed by two external researchers and expert panels comprised of SC supervisors and benefit/entitlement specialists. The family survey was also reviewed for cultural sensitivity (i.e. African Americans). Slight revisions were made and surveys were uploaded to SurveyMonkey. Online links were pilot tested among colleagues prior to dissemination.

In addition to demographic information, surveys queried experiences with initial applications, interviews and evaluations, redeterminations, appeals process, general experiences and challenges, and recommendations for improvement. Items elicited responses generally using likert-type scales (e.g. 1 “not at all” to 5 “very much so”) with SCs responding based on their overall experiences and families responding based on individual experiences. Sample items include “My experience with the initial interviews has generally been positive” and “The person doing the evaluation/assessment was sensitive to my child’s disability”.

Survey responses were collapsed across extreme categories resulting in the analysis of three response categories (e.g. “disagree”, “neutral”, “agree”). Chi-squares were used to analyze between-group differences on individual items. Items with significant chi-square values were further analyzed using post-hoc tests with significance levels adjusted using Bonferroni correction.

Results

Service Coordinators

Understanding Organizational Factors. Approximately 35% of SCs indicated that their agency had specific personnel contacts at SSA with whom they communicated. In addition, more than 59% of SCs noted that their agency had a benefits specialist and 57% noted that their agency provided families with benefits training.

Abilities and Communication. More than half of SCs (58.5%) indicated that they had considerably more challenges in assisting individuals living with their families with SSI than those residing in agency-operated disability-specific residences (in part due to agencies’ methodical record keeping and ability to readily transport individuals to appointments). Similarly, many SCs indicated that they were contacted by families when families had difficulties with SSI or with SSA personnel (61.5%) and when families needed help understanding respective paperwork (71.8%). Although more than half of SCs (58.3%) noted that prior experience with SSI was beneficial to providing subsequent support to families, 43.6% indicated that the steps/processes for obtaining SSI were unclear. In addition, 41% of SCs indicated that SSA personnel did not fully understand SCs role, 50% indicated that they had difficulty communicating with SSA personnel on behalf of individuals and 47.3% indicated that

they had received conflicting information from SSA personnel. However, a majority of SCs (84.2%) strongly endorsed having a specific contact at SSA as helpful.

Table 1

SC Abilities & Communication

Item	Not/Little (%)	Somewhat (%)	Quite a bit / Much (%)
Families contact SC due to problems with SSI or SSA personnel	9.4	29.1	61.5
Families contact SC for help understanding SSI paperwork	6.8	21.4	71.8
Prior experience with SSI has helped SCs to better inform families	18.5	23.1	58.3
SSA does not understand SC role	28.1	30.7	41.2
SC difficulty communicating with SSA on behalf of families	28.9	21.1	50.0
SC having specific SSA contact person is helpful	7.9	7.9	84.2
SC has received conflicting info from SSA personnel	30.9	21.8	47.3
SC difficulty providing dates to SSA	18.5	39.8	41.7
SC greater difficulty assisting individuals living with families/independently than those in agency-operated residences*	18.3	23.2	58.5

Note: SC (n=114). *35 indicated that this item was not applicable.

Families

Initial Applications. Family members first learned about SSI from a variety of sources. Although SCs accounted for 36.1%, other prevalent sources included: family and friends (13.4%), hospital social worker (11.8%), school system (10.9%), pediatrician (5.9%), employment (5%), and support groups/networks (5%). Many families (52.1%) completed the initial application independently while others received help from: SSA personnel (16%), SCs (15.1%), hospital social workers (8.4%) and other family members (5.9%). With regard to individuals’ primary qualifying diagnoses, intellectual disabilities accounted for 29.5% and autism spectrum disorders accounted for an additional 25%. Of 104 initial applications, 65.4% were approved, with 44.2% receiving notification within 2 months of the application. When considering denied applications by primary diagnosis, 23% were autism spectrum disorders, 23% were intellectual disability, 9% were developmental delay/learning disability, 9% were Down syndrome, 29% were classified as “other”, with cerebral palsy, epilepsy and traumatic brain injury each accounting for an additional 3%. As such, 71% of those classified as “other”, 50% of those with Down syndrome, 38% of those with developmental delay/learning disability, 34% of those with autism spectrum disorders, and 24% of those with intellectual disabilities were initially denied SSI. Reasons for denial were not elicited from participants.

Initial Interviews. Eighty-five family members indicated that they were required to do an initial interview. Of those, approximately 54% (n=46) of families indicated that they took time off from work and 35% indicated that they took their children out of school in order to attend the interview. Of the families who had their child present during the interview, 40.5% (n=15) indicated that it was difficult to do so (e.g. given the nature of their disabilities and behavior). Compared with families who went through the application more than two years ago, families who went through the application process within the past two years noted that fewer interviews required individuals with IDD to be present (14 compared to 23) and represented an increased use of either phone interviews (17 compared to 11) or no interview at all (6 compared to 3).

Denial, Appeals and Redeterminations. Of the 36 families who were initially denied, 26 chose not to appeal the decision. While thinking “it would not matter” was the primary reason cited for not appealing, 23% stated that they “did not know what to do”. Other reasons included that the appeal process would be too much work and that household income was too high. Of the 10 who went through the appeals process, more than half indicated that: the experience was overwhelming (n=8), going before the judge was intimidating (n=7), the support of Neighborhood Legal Services was needed (n=6), and the support of an SC was helpful (n=6). In addition, 40% indicated that hiring an attorney was a financial burden. Thirty percent of those who appealed received a final decision within 6 months, while 40% indicated that it took more than 1 year. In addition, most (n=26) of the 29 families who had gone through the re-determination process were re-approved and two were awaiting a decision.

Challenges. Nearly 28% of families indicated that they had more than one individual with a disability living in their household. Of these families, 42% indicated that they felt that the asset assessment was unfairly conducted given the demands of multiple persons with disabilities in their household. With regard to knowing what to do throughout the SSI application process, 40% of families indicated that it was a considerable challenge and more than half (62.1%) indicated that they were unsure of what to do following the initial determination. Similarly, of the 17% of families who indicated that they had previously participated in an SSI/benefits training, 42% indicated that knowing what to do throughout the process was a considerable challenge. Regarding transportation to appointments, although 42 participants indicated that it was not applicable to their circumstances, nearly 26% of families indicated that transportation was a challenge. Furthermore, almost half of families (49.5%) noted that it was difficult to understand the differences between Social Security Disability (SSD) and SSI, and 60% were confused that their children were eligible for developmental disability services but not SSI. In addition, although 45 families had not experienced disruptions in SSI checks, 46% of the remaining families indicated that disruptions in SSI checks presented a considerable challenge.

Common Items among Service Coordinators and Families

Interview Experience. A majority of all participants indicated that the interview experience was generally positive, involved relevant questions, and was reasonable in duration. In contrast, nearly one-fifth of families (19.8%) indicated that interviews were generally too long and lacked sensitivity to individuals’ disabilities. Likewise, 28% of SCs indicated that interview questions lacked sensitivity to the nature and impact/limitations of the individuals’ disabilities. Furthermore, more than 45% of SCs and 23% of families indicated that the interviews were not conducted in areas that allowed for privacy, with a significant between-group difference [$\chi^2(2, N=146)=11.00, p<.01$], such that families were more likely than SCs to indicate a neutral response [$\chi^2(1, N=21)=8.05, p<.01$].

Table 2

Comparing Interview Experiences

Item	Group	Disagree (%)	Neutral (%)	Agree (%)	Sig.
Positive experience	SC	12.9	19.4	67.7	---
	Family	14.1	20.7	65.2	---
Relevant questions	SC	6.2	18.5	75.4	---
	Family	14.1	19.6	66.3	---
Reasonable length of time	SC	9.2	21.5	69.2	---

Afforded privacy	Family	19.8	14.3	65.9	.004
	SC	45.3	6.2 ^a	48.4	
Questions were sensitive to individuals' disabilities	Family	23.2	20.7 ^a	56.1	---
	SC	28.1	32.8	39.1	
	Family	19.8	23.1	57.1	

Note: Same superscript =difference. SC (n=64); Family (n=91)

Experiences with Evaluations. While half of SCs and a little more than half of family members (55.3%) found evaluations to be sensitive to individuals' disabilities, 50% of SCs and more than 43% of families indicated that questions during the evaluation were directed *only* to the individual with IDD rather than the caregiver or SC. Similarly, more than 44% of SCs and 34% of families indicated that the evaluations were *not* appropriate given the individuals' abilities. Implications are explored further in the discussion section.

Table 3

Comparing Experiences with Evaluations

Item	Group	Disagree (%)	Neutral (%)	Agree (%)
Sensitive to the individuals' disability	SC	33.3	16.7	50.0
	Family	21.1	23.7	55.3
Evaluation questions directed only to individual with IDD	SC	38.9	11.1	50.0
	Family	45.9	10.8	43.2
Appropriate to individual's abilities	SC	44.4	16.7	38.9
	Family	34.2	10.5	55.3
Culturally/racially sensitive*	SC	23.5	29.4	47.1
	Family	6.7	30.0	63.3

Note: No significant differences. SCs (n=18); Family (n=38). *Interpretation of item is limited given the predominance of Caucasian participants.

Quality of Contacts with SSA Personnel. On average, 53% of SCs and families (range 32.4% to 68%) agreed that SSA personnel demonstrated positive characteristics. Yet, in contrast, nearly one-fifth of SCs (18.8%) and families (19.6%) indicated that the SSA personnel did not provide helpful answers to questions, and further, 25% of SCs and 28.3% of families indicated that SSA personnel did not provide helpful resolutions to problems. Approximately one in four SCs and family members indicated that SSA personnel lacked sensitivity to personal situations and schedules. In addition, significant between-group differences were noted for items querying the following worker characteristics: sensitivity to personal situations [$\chi^2(2, N=209)=9.97, p<.01$], personal attitude [$\chi^2(2, N=209)=8.64, p<.05$], social skills [$\chi^2(2, N=207)=8.61, p<.05$], and communication skills [$\chi^2(2, N=210)=7.52, p<.05$]. As such, SCs were more likely than families to indicate a neutral response regarding personnel's sensitivity toward personal situations [$\chi^2(1, N=47)=9.38, p<.01$], having a pleasant attitude [$\chi^2(1, N=67)=9.33, p<.01$], demonstrating good social skills [$\chi^2(1, N=66)=8.73, p<.01$] and good communication skills [$\chi^2(1, N=61)=8.67, p<.01$]. Additionally, significant between-group differences were noted for items regarding phone calls [$\chi^2(2, N=191)=16.16, p<.01$] and the processing of paperwork [$\chi^2(2, N=206)=14.84, p<.01$] with SCs more likely than families to disagree, indicating that SSA personnel did not return calls [$\chi^2(1, N=63)=13.35, p<.001$] nor did they process paperwork in a timely fashion [$\chi^2(1, N=52)=9.31, p<.01$].

Table 4

Comparing Experiences with SSA Personnel

Item	Group	Disagree (%)	Neutral (%)	Agree (%)	Sig.
Provided helpful answers to questions	SC	18.8	21.4	59.8	---
	Family	19.6	12.4	68.0	
Provided helpful resolutions to problems	SC	25.0	23.2	51.8	---
	Family	28.3	21.7	50.0	
Sensitive to personal situations	SC	28.6	30.4 ^a	41.1	.007
	Family	27.8	13.4 ^a	58.8	
Returned phone calls	SC	43.8 ^b	23.8	32.4	.000
	Family	19.8 ^b	20.9	59.3	
Had a pleasant attitude	SC	18.6	40.7 ^c	40.7	.013
	Family	21.9	21.9 ^c	56.2	
Had good social skills	SC	19.6	40.2 ^d	40.2	.014
	Family	20.0	22.1 ^d	57.9	
Was culturally/racially sensitive	SC	7.3	47.9	44.8	---
	Family	5.4	33.8	60.8	
Was sensitive to disabilities	SC	20.5	29.5	50.0	---
	Family	16.8	24.2	58.9	
Spoke using easy to understand words	SC	12.3	23.7	64.0	---
	Family	9.5	12.6	77.9	
Was understanding of personal schedules	SC	24.5	34.3	41.2	---
	Family	24.1	26.4	49.4	
Demonstrated good communication skills	SC	13.2	36.8 ^e	50.0	.023
	Family	14.6	19.8 ^e	65.6	
Was timely in processing paperwork	SC	33.3 ^f	31.5	35.1	.001
	Family	15.8 ^f	23.2	61.1	

Note: Same superscript =difference. SC (n=112); Family (n=95).

Comparing General Experiences. While more than half of all participants indicated that appointments with SSA and the time allocated for the submission of requested paperwork were reasonable, nearly one out of two SCs (45.7%) and families (44.9%) found the amount of paperwork to be unreasonable. Significant between-group differences were noted for reasonability of phone calls [$\chi^2(2, N=219)=9.05, p<.05$], amount of time spent in SSA offices [$\chi^2(2, N=209)=11.25, p<.01$] and the length of time to receive initial SSI payments [$\chi^2(2, N=198)=14.67, p<.01$]. Post hoc tests were conducted; however, after adjusting the alpha level using Bonferroni correction, these differences were no longer significant.

Table 5

Comparing General Experiences

Item	Group	Unreasonable (%)	Neutral (%)	Reasonable (%)	Sig.
Appointments	SC	21.9	23.7	54.4	---
	Family	22.5	17.6	59.8	
Telephone calls	SC	62.7	9.3	28.0	.011
	Family	44.6	7.9	47.5	

Time spent in Social Security office	SC	44.0	21.1	34.9	.004
	Family	28.0	14.0	58.0	
Time to submit paperwork	SC	28.7	16.5	54.8	---
	Family	18.4	14.6	67.0	
Time to receive first check	SC	32.1	32.1	36.7	.001
	Family	18.0	18.0	64.0	
Amount of paperwork	SC	45.7	24.1	30.2	---
	Family	44.9	17.8	37.4	

Note: SC (n=114); Family (n=100)

Identifying Challenges. At least one in four of all survey participants noted considerable challenges with various aspects of the SSI application. A significant between-group difference was noted for getting approval from managed care or obtaining scripts for assessments/evaluations [$\chi^2(2,N=178)=21.26, p<.001$] such that families were more likely than SCs to indicate that it was not a challenge [$\chi^2(1,N=76)=17.05, p<.001$]. Furthermore, a significant between-group difference was noted regarding redundancy in questions/paperwork [$\chi^2(2,N=216)=10.98, p<.01$] such that SCs were more likely than families to indicate that redundancy was “quite a bit” or “very much” a challenge [$\chi^2(1,N=105)=8.01, p<.01$]. In addition, although many SCs (n=34) and families (n=76) indicated that having to start the application process over was not applicable, a significant between-group difference was noted [$\chi^2(2,N=115)=15.13, p<.01$] such that SCs were more likely than families to find this “somewhat” [$\chi^2(1,N=29)=15.21, p<.01$] or “very much” [$\chi^2(1,N=46)=19.57, p<.01$] a challenge.

Table 6

Identifying Challenges

Item	Group	Not at all / Little (%)	Somewhat (%)	Quite a bit / Very much (%)	Sig.
Having to get approval from managed care or script from doctor for evaluations*	SC	26.7 ^a	48.0	25.3	.000
	Family	56.5 ^a	15.2	28.3	
Understanding paperwork	SC	34.5	37.1	28.4	---
	Family	34.9	34.0	31.1	
Redundancy in questions and paperwork	SC	14.7	27.6	57.8 ^b	.004
	Family	31.0	31.0	38.0 ^b	
Having to start an application over after missing paperwork/appointments**	SC	24.1	30.1 ^c	45.8 ^d	.001
	Family	62.5	12.5 ^c	25.0 ^d	

Note: Same superscript = difference. Service coordinator (n=116); Family (n=103) *43 service coordinators indicated that this item was not applicable; **34 service coordinators indicated this item was not applicable. 76 families indicated that this item was not applicable.

Evaluating the Online Disability Report. Eighty-nine SCs and 65 families indicated that they were aware of the ability to provide preliminary information online to begin the application process for SSI. However, while this report is completed online and is not an actual application, families and SCs referred to it as the “online application”. As such, the surveys were constructed using the language represented in the field; however, there are potentially significant limitations in doing so. Nonetheless, 36% of SCs and 60% of families indicated that they had completed or attempted to complete the disability report (i.e. “online application”).

Although a majority of respondents agreed that it was beneficial, more than 53% noted it was too long.

Table 7

Evaluating the Online Disability Report

Item	Group	Disagree (%)	Neutral (%)	Agree (%)
Easy	SC	12.5	21.9	65.6
	Family	22.5	30.0	47.5
Too long	SC	12.5	34.4	53.1
	Family	12.8	33.3	53.8
Helpful	SC	3.1	18.8	78.1
	Family	7.5	17.5	75.0
Saves time	SC	12.5	21.9	65.6
	Family	13.5	16.2	70.3
Helps with the interview	SC	6.2	31.2	62.5
	Family	10.5	28.9	60.5

Note: SC (n=32); Family (n=40).

Recommendations for Improvements. On average, more than 50% of all participants strongly endorsed recommendations for improvement in communication, assets and supports, office and staff, collaboration between SSA and IDD organizations, and the application process and paperwork. However, significant between-group differences were noted on items regarding: online/internet services [$\chi^2(2, N=223)=7.43, p<.05$]; individual's current level of supports [$\chi^2(2, N=220)=6.35, p<.05$]; worker skill-level [$\chi^2(2, N=226)=9.11, p<.01$]; communication between SSA and IDD organizations [$\chi^2(2, N=225)=9.95, p<.01$]; application revisions to indicate individual receives SC services [$\chi^2(2, N=225)=12.09, p<.01$]; having SCs receive duplicate paperwork provided to families [$\chi^2(2, N=225)=11.62, p<.01$]; and, keeping denied applications on file [$\chi^2(2, N=223)=6.99, p<.05$]. Post hoc tests were computed; however, after adjusting the alpha level using Bonferroni correction, the results were no longer significant.

Table 8

Comparing Recommendations for Improvement

Item	Group	Not at all / Little (%)	Somewhat (%)	Quite a bit / very much (%)	Sig.
Communication					
Having a consistent person for an individual case	SC	2.5	10.2	87.3	---
	Family	5.5	15.6	78.9	---
Increasing accessibility to appointments (i.e. hours of operations)	SC	5.1	11.9	83.1	---
	Family	7.5	15.9	76.5	---
Improving online/internet services	SC	5.2	12.1	82.8	.024
	Family	12.1	20.6	67.3	---
Assets & Supports					
Raising Asset Limit	SC	16.1	29.7	54.2	---
	Family	12.4	21.0	66.7	---
Removing retirement accounts from asset assessment	SC	18.6	30.5	50.8	---
	Family	15.2	21.9	62.9	---

Consider individual's current supports in addition to disability/family income	SC	7.0	21.7	71.3	.042
	Family	18.1	20.0	61.9	
Office & Staff					
Improving office environment	SC	22.9	29.7	47.5	---
	Family	25.9	23.1	50.9	
Improving worker skill-level	SC	10.2	13.6	76.3	.010
	Family	18.5	24.1	57.4	
Have personnel utilize standardized checklist for paperwork	SC	5.1	13.6	81.4	---
	Family	12.0	13.9	74.1	
Having personnel specialize in IDD	SC	4.2	9.3	86.4	---
	Family	5.6	18.7	75.7	
Agencies & Service Coordination					
Increased communication between Social Security & IDD agencies	SC	4.2	9.3	86.4	.007
	Family	11.2	19.6	69.2	
Revising SSI application to indicate individual receives SC services	SC	4.2	15.3	80.5	.002
	Family	12.1	28.0	59.8	
Having SCs receive duplicates of paperwork families receive	SC	5.9	12.7	81.4	.003
	Family	18.7	18.7	62.6	
Application/Paperwork					
Having an initial brief screening prior to applying	SC	11.1	29.1	59.8	---
	Family	20.8	22.6	56.6	
Streamlining application for families seeking benefits for >1 child	SC	4.3	25.9	69.8	---
	Family	13.3	24.8	61.9	
Simplify application process for individuals with severe/lifelong disabilities	SC	0.9	8.5	90.6	---
	Family	3.8	14.3	81.9	
Increasing transparency of application process	SC	4.3	9.4	86.3	---
	Family	7.7	10.6	81.7	
Ensuring clarity of paperwork	SC	4.3	8.5	87.2	---
	Family	11.4	11.4	77.1	
Keep records on file for those denied to simplify future applications	SC	2.6	15.4	82.1	.030
	Family	11.3	16.0	72.6	
Simplify re-determination for IDD	SC	2.6	9.4	88.0	---
	Family	10.5	7.6	81.9	

Note: MSC (n=118), Family (n=106)

Discussion

The present research surveyed the experiences of SCs and families in applying for SSI benefits for individuals with IDD. In general, SCs and families were fairly consistent in their appraisal of the experience. However, at times, significant differences were noted which may be attributable to differences in factors such as general education level (i.e. at minimum, SCs are required to have an associate's degree, however, several agencies require a baccalaureate degree), the influence of organizational requirements and employment responsibilities.

Although many families first learned about SSI from sources other than SCs and often completed the application without the assistance of SCs, from the SCs' perspective families frequently relied on them for information and guidance regarding issues with applying for SSI. As one-third of SCs indicated that their agency had specific contacts at SSA and still more noted that their agency had a benefits specialist, it is plausible that relevant and necessary information may be more readily accessible to families through SCs. Similarly, given the nature of the role of SCs, they are likely to have established relationships with their respective families thereby facilitating communication. Furthermore, SCs are likely to be more informed of the requirements of SSI through the cumulative and additive impact of trainings and prior

experience. However, despite the apparent integral and dynamic role of SCs, there appears to be a need for improvement in the relationship between SCs and SSA, with an emphasis on facilitating communication and increasing understanding by SSA of the role of the SC. Through increased awareness of the SC role and other mechanisms of improvement (e.g. revising SSI forms to indicate whether or not an individual receives SC services, SCs proactively receiving duplicate copies of paperwork sent to families), the gap between SCs, SSA and families can be narrowed and the application process potentially facilitated.

The application process for SSI remains a challenge amid a system that is difficult to navigate, yet, there may be emerging some beneficial trends. While few families indicated that they had actually participated in SSI/benefit trainings, there appears to be an increasing tendency toward doing so when comparing those who went through the application process over the past two years with those who went through the process more than 2 years ago (13 out of 57 vs. 6 out of 56). Another trend may be developing as well with an increasing number of families initially learning about SSI from sources other than SCs, such as family members, friends, employment, and support groups. In addition, there appear to be fewer interviews requiring individuals with IDD to be present, with an increasing use of either phone interviews or no interviews. Given the additional demands and challenges that families may experience because of interviews, this may prove beneficial.

From both the perspectives of SCs and family members, it is evident that the process of applying for SSI could be enhanced through various systemic and environmental improvements that are sensitive to the needs of individuals with IDD as well as their caregivers and service providers. Both families and SCs noted considerable challenges in their interactions with SSA personnel whether in person or over the telephone. Given that contact with personnel is often an integral part of the application process, increased attention to various personnel characteristics (e.g. customer service skills, problem-solving strategies, sensitivity training) is perhaps warranted. In addition, the application process could be facilitated for families who are often stressed by meeting the complex needs of individuals with IDD and managing gainful employment by: improved communication through a consistent contact person at SSA, increased online services (e.g. on-line chat person, secure website for email correspondence and to check approval status, and the ability to receive paperwork electronically) and increased accessibility to appointments through increased hours of operation for SSA (e.g. evening hours). Similarly, families and SCs have advocated for decreased redundancy in paperwork and the use of simplified language in forms and correspondences. While SSA may have standard terminology understood among its employees and perhaps among other professionals, families and even SCs struggle to fully comprehend what is being requested or communicated. In addition, discrepancies may exist between SSA and practices in the field as previously exemplified between the disability report and the “online application”. Given the relationship between disabilities and other hardships including diminished resources (e.g. poverty, lack of education), this challenge is not surprising yet suggests the need for greater use of “lay terms” in SSA documentation.

Similarly, while the nature and impact of an individual’s disability and his/her family’s assets are criteria integral to the determination of eligibility for SSI, it has been recommended that the individual’s level of supports also be considered. For example, one family noted that the cost of their child’s required specialized diet exceeded \$15,000 a year, however, this was never considered in his eligibility determination. Individuals with IDD frequently present with unique needs (e.g. dietary, behavioral supports) that increase the financial burden for caregivers. As

services in the IDD field are increasingly moving toward individuals residing with their families, there is greater need to consider surrounding circumstances that have significant implications for caregiving.

Furthermore, families and SCs noted that, at times, interviews and evaluations lacked sensitivity to the nature of individuals' disabilities and that evaluations were inappropriate to the individuals' abilities, with questions often directed solely to the individuals with IDD. As such, the need for increased training and specialization in IDD was strongly endorsed by both SCs and families. While there may be similarities among types of disabilities, the scope of IDD presents with considerable heterogeneity and numerous implications (e.g. stereotypy, impulsivity). Thus, it becomes important to have a knowledge of and sensitivity toward individuals' particular cognitive and behavioral capacities. For example, for someone with more profound intellectual deficits, while it is important to consider the individual's input, it also becomes appropriate and necessary to solicit information from family members and perhaps service providers (e.g. SCs), above and beyond the target individual. Likewise for an individual with significant maladaptive behavior related to a diagnosis of autism, it may be contraindicated to require him/her to be present for a lengthy interview.

Several challenges were experienced while conducting this research. Initially, prior to survey development recruitment of SCs for focus groups was complicated by the diversity of their work schedules; therefore, it became necessary to utilize individual interviews. Although there are limitations to both methods, allowing individual interviews increased the number of participants. Similarly, recruitment of families was difficult despite their direct link through SCs and organizations' support of this initiative. In part, it was determined that families' lack of understanding (e.g. confusing the role of the researchers as a contact person for problems with benefits, not understanding the differences between SSD and SSI) contributed as a barrier. In an effort to facilitate recruitment, the language used in the recruitment flyer was revised to reflect a more common understanding among families (e.g. from "disability determination process" to "experiences with getting SSI for your child").

Despite the benefits of this research, there are inherent limitations. The most salient limitation is perhaps the lack of gender and racial diversity in the sample. While human services and caregiving remain predominantly female, the 2010/2011 United States Census Bureau suggests far greater racial diversity than the 3% represented in this study (i.e. Buffalo: 50.4% Caucasian and 38.6% African American; Erie County: 81.1% Caucasian and 13.9% African American). Although specific data regarding location (e.g. address or zip code) was not elicited from participants, and, despite the dissemination of survey links throughout WNY, a notable percentage of the sample is likely from Buffalo or Erie County given the location of organizations, population density, etc. Furthermore, although SSI is federally funded with many common procedures across the nation, it is possible that participant experiences in WNY are not representative of the nation as a whole. Therefore, any conclusions should be interpreted cautiously.

In addition, while the use of online surveys facilitates broad distribution and administration, it inherently limits the pool of possible participants. Given that families with disabilities and minority status are more likely to come from lower socio-economic status, it is possible that they are less likely to have access to internet and online services. However, this was considered in the study design and methodology (e.g. mailing of recruitment flyers that indicated availability of paper-and-pencil surveys). Although one organization endeavored to distribute paper-and-pencil surveys to their families through their SC department, various factors

such as increasing work demands and family illiteracy were identified barriers. It should be noted that, at the time of this research considerable changes were underway in SC practices, as well as organizational strains of Medicaid changes (i.e. the primary funder of SC) and state-proposed financial cutbacks.

Survey design presented additional limitations. The complexity of the SSI application process was reflected in the structure and length of the survey which may have been intimidating to potential participants. Similarly, at times, despite the integration of logic in the online survey, SurveyMonkey does not afford the complexity necessary to minimize errant responses. Therefore some participants either responded to items which they should not have done so or responded in a way that did not follow preceding items. This concern was addressed through data management and statistical analyses. In addition, the structure and content of several survey items did not afford the ability to differentiate participant responses in terms of difficulty with SSA personnel or difficulty with SSI paperwork. Separating concerns regarding the federal agency (i.e. SSA) from the benefit (i.e. SSI) may prove beneficial and provide greater clarity of specific issues. Similarly, the surveys did not elicit additional open-ended responses from participants. Furthermore, as was previously noted, it is impossible to determine the representativeness of the current findings given the use of multiple recruitment modalities, especially with the inability to track dissemination of flyers and paper-and-pencil surveys as organizations ensured family confidentiality. However, efforts were made to ensure general representation of both SCs and family members through broad dissemination of surveys via online access, ongoing communication with organizations through electronically delivered survey reminders and access to hardcopy surveys.

Social Security Administration has endeavored to make improvements in the application process for SSI overtime, yet in addition to the immediate challenges of navigating the system (e.g. completing the application) there are subsequent obstacles with interviews, evaluations, and ongoing communication with SSA. Despite its limitations, this pilot study presents a preliminary evaluation of the various components of the application process as well as recommendations for systemic improvements and provides a foundation for future research at the national level. However, given the unstable economic environment, the redefining of SC in New York State and the integral role of SCs in the lives of individuals with IDD, the adoption and integration of recommendations might facilitate access to an invaluable resource while increasing positive experiences and systemic efficiency.

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Appendix A

Family Survey

Is a **service coordinator helping you** to complete this survey?

Yes No

What is your **gender**?

Male Female Other I choose not to disclose this information.

What is your **race/ethnicity**?

Caucasian African American Asian Native American Other
 I choose not to disclose this information.

What is your **age**?

Less than 20 years old
 Between 20 - 29 years old
 Between 30 - 39 years old
 Between 40 - 49 years old
 Between 50 - 59 years old
 Between 60 - 69 years old
 70 years old or older
 I choose to not disclose this information

PLEASE NOTE

Some families may have more than one individual for whom they have sought Supplemental Security Income (SSI). If this is true for you, answer the following questions based upon your most recent child/experience.

Certain sections of this survey **may not apply** to you based upon your experience. As such, some sections have **directions** on whether or not you should SKIP them.

How **long ago** did you go through any part of the application process (e.g. initial application, appeals, re-determination) to get Supplemental Security Income (SSI) benefits for your child?

I am currently going through the process More than 1 year ago
 Within the past 6 months More than 2 years but less than 5 years ago
 More than 6 months ago but less than 1 year More than 5 years ago

How did you **first** learn about Supplemental Security Income (SSI)?

Hospital Social Worker Service Coordinator
 Pediatrician Agency training
 School Teachers/Social Worker Work/Employer
 Occupational/Speech/Physical therapist Other, specify: _____
 Spouse/Family member

Have you ever participated in a **training** related to benefits & entitlements such as SSI?

Yes No I do not remember

2. I had to take my child out of school so he/she could be at the interview.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. It was difficult to have my child at the interview because of his/her disability.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION: Evaluation/Assessment

Did Social Security Administration **ever** require your child to be evaluated by a medical provider/psychologist designated by Social Security Administration?

Yes No I do not remember

If **yes**, were you permitted in the examining/assessment room with the child?

Yes, I was there for the full time Yes, I was allowed in for part of it No I do not remember

If you answered **yes** to the 2 previous items, please indicate your level of agreement/disagreement with the items in the following box by filling in the corresponding circle; **otherwise**, SKIP this box.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
1. The person doing the evaluation/assessment was sensitive to my child's disability.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. The person doing the evaluation/assessment only directed questions to my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. The evaluation/assessment was appropriate.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. The person doing the evaluation/assessment was culturally or racially sensitive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

After completing the **initial** application, how long did it take to hear whether you were approved or denied?

- less than 1 month
- 1-2 months
- 3-4 months
- 5-6 months
- more than 6 months

After my initial application, I was _____ for Supplemental Security Income.

Approved Denied Pending (I am still waiting to hear back)

If you were **either approved or denied**, did you know what to do next?

Yes, I clearly knew what to do I had some ideas but I wasn't really sure No, not at all

If at any point your child was **denied** Supplemental Security Income (SSI), did Social Security Administration provide you with information regarding the appeals process /fair hearing?

Yes No I cannot remember

If you were **denied** after applying for Supplemental Security Income, did you go through the appeals process/fair hearing?

Yes No

If you chose **not** to go through the appeals process/fair hearing, **why not?**

I thought it would be too much work.

I didn't know what to do.

I thought it wouldn't matter.

Other; specify: _____

If you **chose to go through the appeals process/fair hearing**, how long did it take before you received the **final decision** regarding whether you were approved or denied?

1-3 months

10-12 months

4-6 months

more than 1 year

7-9 months

I am in the middle of the appeals process now

SECTION: Re-determination

The re-determination process is a re-evaluation of your child to determine if he/she remains eligible for Supplemental Security Income (SSI) benefits at some point after he/she originally began receiving SSI.

Have you ever gone through the **re-determination process**?

Yes No I do not know/remember

If **yes**, were you subsequently approved or denied?

Approved Denied Pending (I am still waiting to hear back)

Answer the following items **only** if you were **DENIED** at **re-determination**; otherwise skip this box.

If your **re-determination** resulted in being **denied** Supplemental Security Income, did you go through the appeals process?

Yes No

If **yes**, how long did it take from starting the appeals process to when you received a **final decision** for approval/denial?

1-3 months

10-12 months

4-6 months

more than 1 year

7-9 months

I am in the middle of the appeals process now.

If you chose **not** to go through the appeals process/fair hearing, **why not?**

I thought it would be too much work.

I didn't know what to do.

___ It would not matter because our income is too high.
 ___ Other; specify: _____

SECTION: Appeals Process/Fair Hearing

After a child is denied Supplemental Security Income, he/she can go through the appeals process in an effort to fight the initial decision with the hopes of being found eligible for Supplemental Security Income benefits.

Directions: If you have **EVER** gone through the appeals process complete the next box; **otherwise**, SKIP.

Indicate your **level of agreement** by filling in the corresponding circle for each item.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
1. The appeals experience was overwhelming.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Having to go before a judge was intimidating.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Having to secure a lawyer was a financial burden.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I needed the help of Neighborhood Legal Services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Having a service coordinator was very helpful with the appeals process (e.g. understanding what I needed to do, getting legal help)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you have **more than 1** person in your household with disabilities?

___ Yes ___ No

If **yes**, do you believe the assessment of assets fairly considered the demands of multiple persons with disabilities in your household?

___ Yes ___ Somewhat ___ No, not at all ___ I do not know ___ I do not understand this question

Has there **ever** been a delay in receiving Supplemental Security Income for your child?

___ Yes ___ No ___ I do not remember

If **yes**, were you provided with back payment?

___ Yes ___ No ___ I do not remember

SECTION: Your Experience with Social Security Administration Workers

Directions: If you have **EVER** had contact **in-person** or **on the phone** with a worker, please complete the next box; **otherwise**, SKIP the next box.

Indicate your **level of agreement** with the following items regarding **worker qualities/characteristics**.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable

SECTION: Challenges

People have had different challenges along the way in getting or maintaining Supplemental Security Income benefits for their child.

Directions: Please **indicate how much of a challenge** each of the following items has been for you.

How MUCH of a CHALLENGE has each of these been for you?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much so	Not Applicable
1. Understanding paperwork from Social Security Administration.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Redundancy in questions and paperwork from Social Security Administration (e.g. requests for things I already submitted or mail I already received).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Knowing what to do throughout the process of applying for Supplemental Security Income.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Getting benefits for my older child (e.g. 18 th birthday).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Transportation to appointments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Having to start the application process over because of missed appointments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How MUCH of a CHALLENGE has each of these been for you?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much so	Not Applicable
7. Obtaining paperwork (from doctors, school, estranged mother/father, etc.) for my child's application.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Obtaining assessments/evaluations was complicated by having to either obtain prior approval from a managed care company or to obtain a script from my child's doctor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. When at the Social Security Administration Office, having been told to reschedule because of missing paperwork.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Confused by differences between <u>Social Security Disability</u> and <u>Supplemental Security Income</u> .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Confused because your child is eligible for intellectual/developmental disabilities services but <u>not</u> for Supplemental Security Income.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Having disruptions (e.g. increases/decreases in dollar amount, cut-offs) with your child's Supplemental Security Income checks, despite there being <u>no changes</u> in your child's diagnosis or your family's assets/income.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION: On-line Application Process

Are you aware that there is an on-line application process for SSI?

___Yes ___No

Do you have access to a computer to do the application on-line?

___Yes ___No

Have you have ever tried or completed the on-line application?

___Yes ___No

If you have **completed/tried** the **on-line application**, rate the following items based upon your experience by filling in the corresponding circle; **otherwise**, SKIP this box.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
1. The on-line application is easy to complete.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. The on-line application is too long.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. The online process is helpful because you can stop, save and come back to it later.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Completing the application online can save time in the interview.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. The online process is helpful because it gives you an idea of what questions might be asked in the interview.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION: Recommendations for Improvement

Directions: Please indicate how much the application process would be **improved** if Social Security implemented each of the following items.

AREA: Communication

How much would each of the following IMPROVE the application process?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much
1. Having a consistent person at Social Security Administration to handle an individual’s paperwork.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Increasing accessibility to appointments & communication with offices (e.g. having evening or weekend hours, offering transportation to required appointments for low-income families, providing local telephone numbers).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Improving on-line/internet services through Social Security Administration (e.g. on-line chat person, secure website for email correspondence & to check approval status, ability to receive electronic paperwork).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

AREA: Assets & Supports

How much would each of the following IMPROVE the application process?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much
1. Raising the asset limit for Supplemental Security Income.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Removing 401(k)'s & other retirement accounts from asset assessment for Supplemental Security Income.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Considering an individual/child's current level of supports in addition to his/her disability and/or family income when determining his/her eligibility.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

AREA: Office & Staff

How much would each of the following IMPROVE the application process?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much
1. Improving the environment of Social Security Administration offices (e.g. to be more welcoming, to allow for greater privacy).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Improve the skill-level of workers at Social Security Administration Offices (e.g. increased sensitivity to type of disabilities, customer-service skills, communication).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Have workers utilize a standardized checklist to indicate what & when paperwork has been received.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Having some workers specialize in intellectual/developmental disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

AREA: Agencies & Service Coordination

How much would each of the following IMPROVE the application process?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much
1. Facilitating communication between Social Security Administration & agencies for intellectual/developmental disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Revising applications to include option for individuals to specify if they receive service coordination.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Having service coordinators receive duplicates of paperwork individuals & families receive from Social Security Administration.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

AREA: Application/Paperwork

How much would each of the following IMPROVE the application process?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much
1. Having an initial brief screening process for individuals prior to completing the lengthy application.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Streamlining the application for families with more than 1 child seeking Supplemental Security Income.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Simplifying the initial application and/or redetermination process for individuals with more severe and lifelong disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Questions asked during interviews have generally been relevant and appropriate.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. The length of time spent in initial interviews is generally reasonable.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Interviews are conducted in areas that allow for privacy when sharing personal information.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Interview questions are generally sensitive to individuals' disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section: On-Line Application

Are you aware that there is an on-line application process for SSI?

Yes No

Do you have access to a computer to do the application on-line?

Yes No

Have you have ever completed the on-line application?

Yes No

If you have **completed the on-line application process**, please rate the items in the following box based upon your experience by filling in the corresponding circle. Otherwise, **SKIP** this box.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
1. The on-line application is easy to complete.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. The on-line application is too long.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. The online process is helpful because you can stop, save and come back to it later.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Completing the online process can save time in the interview.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. The online process is helpful because it gives you a "head's up" for some of the questions asked in the interview.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section: Evaluations/Assessments

Have you ever assisted an individual with attending an evaluation or assessment completed by a medical provider/psychologist designated by Social Security Administration?

Yes No I do not remember

If **yes**, were you permitted in the examining/assessment room with the individual?

7. I have found that having a specific person to contact at the Social Security Administration office is helpful compared to calling the 1-800 number.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I have received conflicting information from Workers at Social Security Administration Offices.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I have had greater difficulty assisting individuals who reside with families or independently in the community <u>than</u> those who reside in agency-operated residences.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section: Paperwork & Challenges

Directions: Please indicate **how much of a challenge** each of the following items has been for you based on your experience by filling in the corresponding circle.

How much of a CHALLENGE has each of these been for you?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much	Not Applicable
1. Having to get approval from a managed care company or having to obtain a script from individual’s doctor BEFORE going to an assessment/evaluation required for benefits.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Providing actual dates (<i>e.g. date of diagnosis, previous work history</i>) to Social Security Administration.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much of a CHALLENGE has each of these been for you?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much	Not Applicable
3. Understanding paperwork from Social Security Administration.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Redundancy in questions and paperwork from Social Security Administration (<i>e.g. requests for things already submitted or mail you already received</i>).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Having to start an individual’s application process over after missing appointments/paperwork deadlines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION: Recommendations for Improvement

Directions: Please indicate how much the application process would be improved if Social Security implemented each of the following items by filling in the corresponding circle.

AREA: Communication

How much would each item IMPROVE the application process?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much
1. Having a consistent person at Social Security Administration to handle an individual’s paperwork.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Increasing accessibility to appointments & communication with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

offices (e.g. having evening or weekend hours, offering transportation to required appointments for low-income families, providing local telephone numbers).					
3. Improving on-line/internet services through Social Security Administration (e.g. on-line chat person, secure website for email correspondence & to check approval status, ability to receive electronic paperwork).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

AREA: Assets & Supports

How much would each item IMPROVE the application process?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much
1. Raising the asset limit for Supplemental Security Income.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Removing 401(k)'s & other retirement accounts from asset assessment for Supplemental Security Income.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Considering an individual/child's current level of supports in addition to his/her disability and/or family income when determining his/her eligibility.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

AREA: Office & Staff

How much would each item IMPROVE the application process?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much
1. Improving the environment of Social Security Administration offices (e.g. to be more welcoming, to allow for greater privacy).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Improve the skill-level of workers at Social Security Administration Offices (e.g. increased sensitivity to intellectual/developmental disabilities, customer-service skills, communication).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Have workers utilize a standardized checklist to indicate what & when paperwork has been received.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Having some workers specialize in intellectual/developmental disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

AREA: Agencies & Service Coordination

How much would each item IMPROVE the application process?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much
1. Facilitating communication between Social Security Administration & agencies for intellectual/developmental disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Revising applications to include option for individuals to specify if they receive service coordination.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Having service coordinators receive duplicates of paperwork	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

individuals & families receive from Social Security Administration.

AREA: Application/Paperwork

How much would each item IMPROVE the application process?	Not at All	A Little Bit	Somewhat	Quite a bit	Very much
1. Having an initial brief screening process for individuals prior to completing the lengthy application.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Streamlining the application for families with more than 1 child seeking Supplemental Security Income.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Simplifying the initial application and/or redetermination process for individuals with more severe and lifelong disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Increasing transparency/clarity of the application/approval process (e.g. providing clear outline of steps/requirements, proactively educating families/service coordinators about what to do/expect)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Ensuring clarity of paperwork distributed by Social Security Administration (e.g. simplify language, clear explanations of why someone was denied, clear requests for specific documents)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Keeping records on file at Social Security Administration for individuals who have been denied in order to simplify the process should that individual apply again in the future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Simplifying the re-determination process for individuals with intellectual/developmental disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>