

Improving Knowledge Transfer to Families of People with Disabilities on the SSI Application
Process

Disability Determination Process Small Grant

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Abstract

The purpose of this project is to gain further understanding of the difficulties families of transition-aged youth with developmental disabilities and mental disorders experience in gaining the supports they need to maximize independence with relation to the Social Security Administration's Disability Determination Process and the receipt of SSI payments. This paper will address the following questions: 1) what options for employment and educational support are available for transition-aged youth with disabilities transitioning out of child SSI eligibility? 2) what information is needed for families to improve the accuracy with which they complete the adult SSI application? and 3) what information would help inform and prepare families for their transition-age youth's progression out of child SSI eligibility and facing adult SSI redetermination? Many youth with developmental and mental disorders receive child SSI prior to turning 18, but with the changed criteria for adult SSI, many families are left confused and provide incorrect or incomplete information in their application. Due to the high health care and social support needs of youth with developmental and mental disorders, the emphasis of this paper will be to understand what their experiences are in learning about and applying for SSI. First, this paper will review SSI and the decision process used to determine whether an applicant is eligible. Then it will review predictors of being found ineligible for SSI, why this population needs extra support in navigating this process, and then alternative options that the SSA has provided to support adults with disabilities who are found ineligible, specifically vocational rehabilitation programs. The methods for answering the above questions were three-fold: 1) conduct a detailed literature review on transition-aged youth's experiences with SSI and vocational rehabilitation programs, 2) administer an online survey asking families more specific questions about their experiences with the SSA, and 3) conduct in-depth interviews with survey participants. Results will be shared and used to generate suggestions for the SSA and families on how to facilitate families' clearer understanding of the adult disability determination process.

Background

Title XVI of the Social Security Act (1972) secures the availability of a federally-funded, monthly income for the aged, blind, and disabled under specific income thresholds, titled Supplemental Security Income (SSI). Within the disability group, the most common types of disability found by researchers to apply for SSI are intellectual disability (formerly known as mental retardation), mental and behavioral disorders (including autism spectrum disorders and mental health problems), and other disabilities (including physical or sensory disabilities) (Davis, Rupp, & Wittenburg, 2009). In 2010, 2,875,325 Americans applied for SSI, and there has been a steady increase in applications of over one million applicants since the early 2000s, mostly attributable to the recent recession in the United States economy. Of these applications, 2,263,670 were over age 18 years (SSA Disability Research File, 2011).

The annual SSI guarantee is designed so that it provides minimal income that does not lift the individual above the poverty threshold (Duggan & Kearney, 2007). This would theoretically encourage SSI recipients to take rehabilitative measures that would enable their ability to return to employment to increase their income. However, poverty is a major risk factor for disability (Emerson & Parish, 2010), and individuals with disabilities typically incur high health care costs associated with their diagnoses. As a result, individuals dependent on SSI are at a reduced likelihood of accessing rehabilitative supports to lift themselves out of a disability status once on SSI, though the guarantee of Medicaid eligibility that accompanies SSI eligibility in many states does allow the individual greater access to health care. Due to this complexity of needs and barriers, it is important that individuals with true eligibility are aware of the disability determination process (DDP) to ensure the appropriate identification of their health care needs and ensure they receive appropriate supports (Ozawa, 2002).

The primary goal of this project is to identify means for improving the experiences of transition-aged youth with disabilities in maneuvering the adult SSI application process. A literature review and qualitative data analyses will be performed to identify recommendations for a source of knowledge transfer, such as a website or fact sheet, to identify these means. For those who are unlikely to meet eligibility criteria for adult SSI, information is needed on alternative sources of support, such as vocational rehabilitation (VR) programs. The overall goal of these efforts is to help reduce the number of SSI appeals and increase the likelihood that eligible transition-aged youth are approved on first application for adult SSI. The current project seeks to answer the following questions:

1. What employment and educational support options are available for youth with disabilities transitioning out of child SSI eligibility?
2. What information is needed for families to improve the accuracy with which they complete the adult SSI eligibility forms?
3. What information would help inform and prepare families for their transition-aged youth's progression out of child SSI eligibility and facing adult SSI redetermination?

Steps to the DDP

The DDP is a complex evaluative process that is not widely understood. To apply for SSI and related Social Security benefits, the individual has to apply through the Social Security Administration (SSA), which passes the completed application to a state Disability Determination Services office (DDS). Currently it is estimated to take an average three to five months for the entire disability application process to be completed, despite numerous efforts made by the SSA to reduce wait times. One option the SSA has created to facilitate this process

is provide a confidential, toll-free line open 12 hours a day on weekdays for individuals or their families to ask specific questions regarding the application and benefits (The SSA, 2012). Another effort to reduce wait times for those with medical emergencies is to identify such cases as “Special Claims” that are processed more quickly by state DDSs. For those with a medical emergency or severe impairment, the claimant may request presumptive disability, at which level the SSA assumes disability and makes immediate payments for up to six months until the DDS has made a final decision. In the event that the application is denied, the claimant is not asked to repay presumptive disability payments, unless overpayment has occurred. The claimant can be granted presumptive disability with one of the following conditions:

- HIV infected
- Blindness
- Allegation of severe or total deafness
- Cerebral palsy
- Down Syndrome
- Muscular Dystrophy
- Severe intellectual disability by at least 7 years old
- Amputation of leg at the hip
- Allegation of total bed confinement or immobility without a wheelchair, walker, or crutches, due to longstanding condition
- Allegation of a stroke more than 3 months in the past and continued marked difficulty in walking or using a hand or arm
- Confirmation of the receipt of hospice services due to terminal cancer by a physician or knowledgeable hospice official
- Spinal cord injury producing inability to ambulate without the use of a walker or bilateral hand-held assistive devices for more than two weeks
- End stage renal disease with ongoing dialysis with complete medical evidence thereof in the applicant’s report

Current Child DDP

Under child criteria, disability is determined based on three steps. The first step is based on the earning record and resource eligibility of the child’s unit, typically referring to parents or legal guardians. This step is managed by SSA field offices. At this step it is determined whether the child is engaging in substantial gainful activity (SGA). Should either the child’s unit be earning above maximum income level or the child engaging in SGA, the claim is denied.

Should the child meet income, resource, and SGA criteria, the next step is a medical screen to determine severity of impairment. At this step, the impairment must be considered “severe” based on medical professional opinion and the impairment must last a given duration: should the impairment not be expected to result in death or has not lasted nor is expected to last over one year, the claim is denied.

Having met impairment severity and duration criteria, the claim moves to the third step. In Step 3 Part A the child’s impairment is explored as to whether it is considered a “medically determinable impairment” based on the SSA’s DI 34001.005 Listing of Impairments, aka the “Blue Book of Listings” (The SSA, 2008a), a list that covers the major body systems and includes descriptions of the most common physical and mental impairments that are considered eligible, along with specific medical severity criteria that accompany these impairments. Information provided by the applicant’s primary care physician and any available medical and

related health records is used at this step. Accepted sources of records are licensed physicians, podiatrists, speech language pathologists, psychologists, school psychologist, optometrists in the event that the applicant has vision impairment, the applicant's school, public or private health agencies, audiologists, parents, and caregivers. Information specifically requested for a claim includes the following:

- Dates of treatment
- Diagnosis and capability statement
- Testing and imagery results
- Operative and pathology reports
- Office notes
- In-patient and emergency room records
- Psychological testing records
- Description of functional limitations due to symptoms of diagnosis

In the case that insufficient medical information is provided to the SSA for the DDP, the SSA may pay for additional consultative examinations. These examinations are scheduled by a DDS with medical professionals contracted by the SSA to complete disability evaluations. If the child demonstrates one or more impairments or medically equals the severity criteria required of a "Listing" and meets the duration requirement, the child is considered disabled and the DDP is complete.

In the event that the child has one or more impairments that are severe but does not have a DI 34001.005 Listing impairment nor meets medical severity criteria of a DI 34001.005 Listing, the claim continues to Step 3 Part B. In this step the DDS will determine whether the impairment is "functionally equal" to a DI 34001.005 Listing, based on its effects and whether the child is able to function in the home, school, and community. Some questions asked to determine functional equality are: "what activities is the child able to or not able to perform?", "What activities are limited in comparison with children of the same age without the impairment?" and "What type and amount of help does the child need to complete age-appropriate activities?" The DDS then evaluates the extent of the child's limitations in each of six domains of functioning: acquiring and using information, attending and completing tasks, interacting and relating with others, moving about and manipulating objects, caring for him or herself, and maintaining health and physical well-being. If the child demonstrates "marked" limitations in at least two domains of functioning, or has a limitation in only one domain but that is of an "extreme" nature, then the child is found to functionally equal the DI 34001.005 Listings. "Marked" limitation is defined as one that interferes seriously with his or her ability to independently start, sustain, or complete activities. "Extreme" limitation is defined as one that interferes very seriously with those abilities. Further examples of what is meant by "seriously" or "very seriously" are not provided, which presents the risk for DDS to determine these criteria subjectively rather than objectively (The SSA, 2013d). For child SSI claims in 2010, 526,100 claims were filed, of which 187,693 allowances and 263,492 denials were made (outstanding applicants were pending a decision at the time of this report) (The SSA, 2013c).

Current Adult DDP

In 1996, the Federal Government implemented the Personal Responsibility and Work Opportunity Reconciliation Act, which requires child SSI recipients to have their SSI eligibility determined under adult criteria at 18 years (Hemmeter, Kauff, & Wittenburg, 2009). The Adult

DDP follows the same initial 3 steps followed under the Child DDP, with the addition of a fourth and fifth step, the entire process referred to as the Five Steps to Sequential Evaluation. The difference between the adult and child DDP in the first three steps is that SGA, income, and asset count for the adult applicant are based solely on the adult applicant, rather than the applicant's parents or guardians as is the case with the child DDP. For 2013, the monthly maximum earning is \$1040. The applicant is also to have less than \$2,000 in liquid assets, or \$3000 in the event that the applicant is married.

The fourth step of the adult DDP determines whether the impairment has prevented work in the last 15 years, and in employment positions previously held, whether the applicant's "residual functional capacity" met the skill and task requirements of those positions. The claim is denied at this step if the applicant is found to have been able to complete the tasks of previous jobs.

At the fifth step it is considered whether the applicant, though unable to perform work required of previously held jobs, is able to meet task requirements of other jobs, taking residual functional capacity and vocational factors (such as age, education, and work experience) into account. The DDS uses the "medical-vocational guidelines", a set of tables to make final decisions of allowance or denial at this step (The SSA, 2013d).

In 2010, a total of 110,664 individuals aged 18 and over applied for adult SSI and Social Security benefits. Of these, 42,127 were denied based on medical criteria, 114 were denied for nonmedical reasons, and 57,057 (55.50%) were awarded benefit. 10,827 allowances for Social Security and SSI benefits were made based on medical criteria (The SSA, 2011). About one third of SSI beneficiaries lose eligibility as they turn 18 years old. It is unclear whether this loss is due to the change ineligibility requirements or due to difficulties with the application process.

DDP Appeals Process

For both child and adult DDP, the applicant has the option to appeal the DDS decision to deny their case. There are four levels through which an appeal process can occur: reconsideration, hearing, review by Appeals Council, and Federal Court review. At each level, reviewers who were not previously involved in the case consider the evidence presented when the original decision was made as well as any newly presented evidence. At the reconsideration level, the individual may meet with an SSA representative to explain their case. At the hearing level, the claimant may attend the hearing along with a representative and other witnesses, such as medical professionals, to present the case to an adjudicative law judge (ALJ). The ALJ then reviews information presented, along with the original and any subsequent evidence submitted, to make a decision. At the Appeals Council level, all requests for review are explored, and in the event that the Appeals Council decides to review a case, it may return the case to an ALJ or come to a determination itself. At the Federal Court level, a lawsuit is filed by the claimant in a federal district court. During the appeals process, the claimant may request continued receipt of SSI payments, but may have to pay back these payments in full if ultimately found ineligible (The SSA, 2008b). At the reconsideration level in 2010, 731 of 13,091 appeals for SSI benefits were approved at the medical decision level (The SSA, 2011).

Risks Associated with Losing SSI Eligibility

Having SSI eligibility reassessed at 18 years is a difficult time for transition-aged youth with developmental and mental disorders, a particularly vulnerable group for negative mental, physical, and social outcomes. The current differences in SSI eligibility criteria between children

and adults add to an already-existent base of stressors for families. It is well-recognized that disability can have an immensely negative impact on the family. As already mentioned, disability is associated with poverty, which in turn is associated with fewer life opportunities and poorer health (Emerson & Parish, 2010). Most youth with mental impairments remain in segregated settings for academic and work experiences at school (Fraker & Rangarajan, 2009). The special education and direct support fields have high rates of turn-over, which makes it difficult for youth with disabilities to find long-term, quality providers they can trust (Fraker & Rangarajan, 2009). Beyond impairments associated with disability, young adults with disabilities have fewer opportunities for independent living and employment due to their limitations in self-advocacy, mobility, healthcare, health insurance, finances, and transportation (American Pediatric Committee on Children with Disabilities, 2002; Blomquist, 2006). These risk factors often take the priority for caregivers, at the expense of appropriately planning to build the child's human capital in the event that she or he is not reappraised for SSI at 18, and may even negatively impact the family's ability to complete SSI paperwork (Hemmeter et al., 2009). Youth are also less likely to come from well-educated families, as greater than one third of parents of youth on SSI have less than a high school education (Hemmeter et al., 2009), further reducing the likelihood of positive experiences maneuvering the adult transition process. Youth with disabilities and their families are also less likely to receive support completing the application and related activities to provide needed documentation for determination.

Concerning health, most adult health care providers possess insufficient expertise in pediatric-onset conditions, and it is rare to find interdisciplinary health care teams that provide adult-focused care for youth who age into the adult health care system. Meeting SSI eligibility criteria also implicates eligibility for other benefit programs in many, but not all, states, such as Medicaid and VR programs (Berry & Caplan, 2010). The prospect of losing Medicaid eligibility contributes to negative health outcomes for child and in turn the family, specifically due to the stressors associated with caring for their child. There may be a lack of appropriate referrals for developmental disability or mental health services, due to service providers' lack of expertise or a general lack of funding for such programs. Compared to other age groups and non-disabled youth, transition-aged youth with disabilities are least likely to obtain regular healthcare. They are also more likely need pharmaceutical treatment and lack health insurance, including Medicaid. This population is at higher risk for negative health behaviors such as substance abuse, unsafe sexual activities, violence, and obesity (Blomquist, 2006). When from lower-income backgrounds and in some cases more rural residences, families are more likely to experience long wait times for appointments in large health care systems (Bohman et al., 2011). The transition-aged child may consequently feel abandoned by his former health providers and unprepared to negotiate the adult health care system.

These health care disparities further impair the ability of transition-aged youth and their families to maneuver the adult SSI application process, especially if they do not have a case workers for knowledgeable in the DDP process for assistance. These barriers pose substantial barriers to youth trying to build human capital through gaining employment experiences.

Predictors of SSI Eligibility

To date, estimating applicant motivation and behavior has been difficult as the SSA does not have administrative data about those who choose not to apply and collects limited socioeconomic information on those who do. Efforts have been made to credibly estimate the rates of applicants found eligible under SSA disability criteria through national surveys, such as

the 2004 Survey of Income and Program Participation (US Census Bureau, 2006) and the National Survey of Children and Families on SSI (NSCF; The SSA, 2013a), but little data is available on child applicants who are re-determined as eligible at age 18.

Disability type appears to predict the likelihood of meeting criteria for SSI. Children with mental and behavioral disorders constitute the majority of child SSI recipients (75%), with more than 40% of these children having intellectual disability (Wittenburg & Loprest, 2007). Of the three disability categories, youth with mental and behavioral disorders are least likely to be approved for adult SSI (Hemmeter et al., 2009). Although likely to be denied adult SSI, approximately 60% of young adults with mental disorders reported having functional limitations that interfered with their ability to develop and maintain vocational skills (Nageswaran, Parish, Rose, & Grady, 2011). This raises the question of whether Disability Determination teams are receiving a full report of the applicant's disability status based on medical and physician documentation, and if so, what is the remaining disconnect? More than 90% children with developmental disabilities and 60% children with mental disorders have functional limitations, which is one important criteria considered in the Five Steps of Sequential Determination used by the SSA (Nageswaran et al., 2011).

Other factors that influence a transition-aged youth's eligibility for adult SSI include age of entry into the child SSI program, residential setting, and gender. Entering the program between the ages of 10 to 13 years significantly reduces the likelihood of receiving adult SSI compared to youth who entered during early childhood. It can be assumed that a child's disability may be less severe if it is not apparent in early childhood. Living in an institution and being female increases a child's likelihood of meeting adult SSI eligibility (Wittenburg & Loprest, 2007).

Growth in SSI Applications

The last 20 years have witnessed a significant growth in the number of applicants and enrollees in SSI. Several hypotheses exist to explain program growth, including expansion of eligibility criteria, factors affecting the administration of programs, and incentives to apply for benefits (possibilities for additional welfare benefits, such as Medicaid and food stamps) (Autor & Duggan, 2003). Demographic factors contributing to higher enrollment include increased longevity and a therefore larger aging population, and it is known that aging is associated with increased rates of disability, which translates into higher societal health costs. From an economic perspective, the loss of blue collar jobs and high unemployment related to the recent recession, higher competition for available jobs, and potential loss of health insurance coverage for workers has motivated unemployed Americans to argue a disability case to secure government income, which has also led to higher application rates. This has in turn created more work for DDSs and created longer wait times for individuals with more severe disabilities. Other population groups, such as immigrants and refugees, have also contributed to the increased workload of the SSA. Aged or disabled immigrants who enter the United States as refugees, under active warrant for deportation, or active warrant for removal are also eligible to apply for SSI (The SSA, 2013a).

Ozawa (2002), emphasizing the role of the economy in rates of SSI application, looked at the relationship between the unemployment rate and adult SSI participation. Ozawa proposed two means by which applicants seek out SSI: after having lost employment, the individual is motivated to apply for SSI to primarily maintain health insurance, or to re-establish and income. It is likely that these two reasons contribute to the ever increasing rates of SSI applicants, as well as the decreased rate of recovery for recipients. Once on SSI, few recipients leave the program,

suggesting that, despite the implementation of the continuing review process, few are recovering, which reflects the permanence of many disabilities. The estimated mean duration of preretirement-age SSI receipt by adults was 10.5 years, suggesting that once transition-aged youth enter the program, quick recovery is uncommon (Rupp, Davies, & Strand, 2008; Ozawa, 2002).

The increased workload of the SSA and local DDSs to process applications has also occurred through high rates of appeals. DDSs and ALJs have been in disagreement about decisions on appeal cases, and applicants have often been encouraged to reapply for SSA benefits, as either the addition of new information to the application or it being reviewed at the next level may increase the application's likelihood of allowance. Over the last 30 years, attempts have been made by the SSA to increase the congruity between decisions made by the DDS and ALJs. In 2010, ALJs on SSI appeal cases judges deciding that 48% of test cases should result in SSI awards, while DDS offices decided only 13% of these same cases should result in award. Of medical decisions made at the hearing level or above, 732 allowances out of 1,487 total case reviews were made (The SSA, 2011). One investigation into the DDP process by the National Public Radio podcast, *This American Life*, found that often ALJs experience difficulties with such cases because, while the applicant presents to defend their case and often with legal representation, there is no one present at the hearing to represent the SSA, which makes it more challenging to review cases objectively (*This American Life*, 2013). Such inconsistencies may provide greater motivation for applicants to have their case appealed.

Vocational Rehabilitation Programs

Disability advocates have called on policy makers to create opportunities for transition-aged youth with disabilities and their families to increase their capital and protect themselves from additional health risks to promote their independence as adults. One response has been to develop VR demonstration projects. For youth who start receiving SSI during childhood and are successfully re-determined at age 18, the average duration of their SSI receipt is 27 years (Fraker & Rangarajan, 2009).

Paid-work experience in community settings (compared to all other work-based experiences) are the strongest predictor of post-school employment success (Grigal & Neubert, 2004), therefore the SSA has made efforts to provide transition-aged youth with opportunities to engage in paid-work experience and to avoid pitfalls that prevent them from seeking employment. So far, research has suggested that the lack of coordinated transition services is a major barrier preventing the successful transition of age 18 youth with disabilities (Maximus, 2002). To address this, child SSI recipients are entitled to continue receiving SSA benefits such as SSI and Medicaid until age 22 years as long as they continue attending school or are enrolled in a training course to prepare for employment for 12 hours per week and have an earned monthly income below \$1,730 based on the SSA's Student Earned Income Exclusion (The SSA, 2013a). Since 1990, government and human service organizations have met these employment support needs through VR programs, such as the SSA's Ticket to Work Program (TTW; The SSA, 2013). These programs focus on providing vocational training and placements for transition-aged youth with disabilities in order to encourage their financial independence. Additional supports, such as the previously mentioned prolonged insurance coverage, as well as facilitated health care access, are also provided. In doing so it is hoped to help the participant maintain health and in turn his or her ability to work. Further incentives exist for SSI recipients, including trial work periods during which eligibility is maintained, and an extended, 36-month

period of eligibility after gaining employment during which they are able to immediately resume cash benefits should their earned income fall below a certain minimum (Grigal & Neubert, 2004). More recently, youth transition demonstration projects have implemented a case management approach in addition to vocational supports, to ensure that continued social and health supports are available to recipients (Grigal & Neubert, 2004).

One example of a recent three-year long demonstration project was the Working Well – Texas Demonstration to Maintain Independence and Employment (Bohman et al., 2011). This study explored whether a coordinated set of health benefits, comprehensive case management services, and employment supports could help low income, employed adults maintain employment and exist independent of publicly funded disability assistance in Houston, Texas. The sample consisted of individuals at risk of becoming disabled due to chronic physical and/or behavioral symptoms. This was a randomized controlled trial that provided the intervention group with health navigation, employment supports, expedited health care appointments, free medications, and no co-pays for medical visits. Results showed greater access to health care and reduced reliance on disability assistance such as SSI, and provided evidence that such a program could be successfully administered by a public health care system. Being allocated increased case manager hours was related to higher overall health care needs and increased employment needs, but also predicted fewer ER visits. Intervention participants were more likely to access prescription and medical supply needs. The intervention group was significantly less likely to apply for SSI or SSDI than the control group (4.8% versus 6.9%, respectively).

Other demonstration projects have also shown some success. The US Department of Labor's Structured Training and Employment Transitional Services (STETS) demonstration project provided job training for 18 to 24 year olds with mild to moderate intellectual disability using a randomized, controlled design. Results included 31% of the intervention group had achieved employment, compared to only 19% of the control group, with those employed in the intervention group making an income 74% higher than those in the control group (Fraker & Rangarajan, 2009). The SSA's Transitional Employment Training Demonstration Project (TETD) targeted 18 to 24 year olds with intellectual disability with specific job training, showing an increased rate of employment in the intervention group by 9% and an increase in annual earnings of those employed by 72%. Project Network, also implementing a randomized, controlled trial design, provided case management services to SSI and SSDI claimants, showing a small increase in rates of employment by the 6th year of the demonstration project (Fraker & Rangarajan, 2009).

Despite preliminary success of transition demonstration projects, transition-aged SSI recipients and their families are often discouraged from seeking out work experiences and opportunities (Fraker & Rangarajan, 2009). Attempts have been made to further characterize child SSI recipients during their transition periods (eg.: Schuster, Timmons, & Moloney, 2003; Wittenburg & Loprest, 2007; Hemmeter et al., 2009; Berry & Caplan, 2010; Berry, 2000; Davis, et al., 2009; Fraker & Rangarajan, 2009; Loughlin, 2004). While preexisting national survey data on these populations exist (eg.: NSCF), they often lack sufficient sample sizes and or data content to characterize the decision process child SSI recipients follow in their attempt to secure adult SSI. In their assessment of the experiences of transition-aged youth with the SSI process, Wittenburg and Loprest (2007) suggested identifying reasons participants failed to meet eligibility criteria and exploring how predictive factors, such as disability type, may relate to the child's subsequent attempts to secure income and independence. Many families remain confused

as the complex nature of the DDP, and for transition-aged youth and their families considering applying for adult SSI, up-to-date and easily accessible sources of information are required.

Methods

Procedure

Three different approaches were taken to gather information on current barriers families are experiencing in the adult SSI DDP: 1) a review of the existent literature published on this topic, 2) an online survey designed to identify key difficulties families experienced in applying for adult SSI, and 3) in-depth phone interviews with participants to gather follow-up information on their experiences with the application process.

Literature Review: An advanced search of peer-reviewed scientific journal articles was performed through The Ohio State University's online library search engine, WorldCat@OSU. Articles published between 2000-2013 using key terms "transition-aged," "youth" or "young adults," "SSI" or "supplemental security income," and "application" were used. Emphasis in the literature review was placed on youth with disabilities who are most likely to lose SSI eligibility but continue to need community supports and youth with developmental disabilities. Since there was minimal literature on this topic specific to the developmental disabilities field, articles looking at transition-aged youth with general "disabilities" were also included.

Online Survey: Based on results from the literature review, an online survey was designed and administered via surveymonkey.com. The survey was administered through a secure encrypted webpage to ensure participant confidentiality, and geared towards parents or families of transition-aged youth with disabilities who applied for SSI in the last eight years. Questions inquired as to the nature of the youth's disability, year of application, information reported by the family on the application, and any perceived difficulties experienced by the family at each stage of the application process. Feedback on the initial draft of the survey was solicited from a Disability Determination case reviewer at a local DDS and the Policy Research Associates, Inc. DDP Small Grant program, who funded this project. An incentive of a \$10.00 grocery store gift card was offered to individuals in exchange for survey completion. Institutional review board approval was granted through The Ohio State University for the administration of this survey and to conduct qualitative interviews with participants.

Qualitative Interviews: Qualitative interviews were held with families, typically parents, of SSI recipients who endorsed interest in further participation in the study. A specific question at the end of the online survey probed participants as to whether they were interested in further participation. These participants were contacted via email or phone to ask more in-depth questions regarding their experiences in supporting their youth's transition from child to adulthood, and experiences in applying for adult SSI. Topics covered were the nature of their youth's disability, whether they applied for and received child SSI, whether they applied for and received adult SSI, positive and negative experiences with the adult SSI application process, information they wish they had had during this process, whether any information provided or individuals such as case workers were helpful in the process, and the youth's current or previous access to vocational training. For parents who endorsed their youth having vocational training, information was asked about the setting, whether it was through their school or the SSA, and their perceptions of the benefits of these programs. Participants who completed both the survey and the interview were provided with an incentive of a \$40 grocery store gift card. Beyond

parents, professionals and parent advocates were also contacted to gain further perspectives on their difficulties with the application process.

Survey Recruitment

A study flyer was created to inform the public of opportunities to participate in this study through both an online survey and focus group participation. This flyer was posted in public waiting areas at a university-based center specializing in research and service provision to children and adults with developmental disabilities at The Ohio State University. Organizations within this center known to provide services directly to adults and transition-aged youth with developmental disabilities were also contacted and asked to distribute flyers to its participants. Additionally, the flyer and information about the study was distributed to 101 organizations found to provide human services directly to adults with developmental disabilities and their families. Study information was also distributed at the Ohio Department of Developmental Disabilities headquarters, and through case managers and service providers at the board for developmental disabilities in Franklin County, Ohio.

Results

Literature Review

To characterize the experiences of transition-aged youth and their families in maneuvering the adult SSI application system and securing alternative incomes such as through employment, the multitude of barriers that were found through a literature review are divided into levels of barriers to help identify areas where future interventions would be most beneficial. Barriers can be found at the level of the child and family, the child's school, the SSA, and VR programs.

Barriers at the Child and Family Level

From the perspectives of the child and family, one of the primary motivators in the decision process related to applying for adult SSI is parent expectations of negative outcomes for their child should they lose SSI and gain employment experiences. The fear of losing SSI, which could translate into the loss of Medicaid and other benefits, discourages their pursuit of vocational experiences because they understand that vocational aptitude could render them ineligible for SSI, and that any job they would be able to attain would not provide health insurance. Consequently, transition-aged SSI beneficiaries with disabilities are more likely to experience long-term dependence on SSI benefits if they are not appropriately educated and connected with transition-focused services. This may explain why only 41% of youth between 16 and 17 years of age receiving SSI have had any form of income (Hemmeter et al., 2009). Children who apply and are approved for child SSI at a later age, specifically between 10 and 13 years, are much less likely to be approved for adult SSI (53% vs. 64% total), especially compared to children who began receiving SSI benefits prior to age 10 years (71% of this subgroup met re-determination criteria vs. 64% total child SSI applicants) (Hemmeter et al., 2009). It is assumed that children approved at a later age may have less severe disabilities for which SSI eligibility may be more questionable since they are not apparent during early childhood.

Through parent and teacher interviews on the transitions process, Grigal and Neubert (2004) explored the value that parents of students with disabilities place on specific secondary

school instructional domains, transition planning areas, and post-school outcomes, comparing parents of high incidence (specific learning disability, mild to moderate intellectual disability, emotional disability, and speech/language disability; 69% of sample) to low incidence disabilities (autism spectrum disorders, multiple or severe disabilities, severe orthopedic disabilities, severe to profound intellectual disability, visual or hearing impairment, and traumatic brain injury; 31% of sample). Results showed that parents of students with low incidence disabilities were significantly more likely to prioritize their child receiving life-skill instruction and placed lower importance on receiving community-based instruction, as may be experienced in an employment setting. Parents of students with high incidence disabilities prioritized academic instruction while parents of low incidence disabilities ranked academic instruction last. This is significant considering academic skill instruction, such as in reading, writing, and math, is an important predictor of a child's ability to accumulate vocational skills and post-secondary education. Additionally, despite several low incidence disability students pursuing educational certificates rather than high school diplomas, parents of low incidence disability students prioritized self-determination as a goal outcome for their child. This is concerning considering that IDEA legislation specifically mandates that students with disabilities have access to general education, and separation of these low incidence students into certificate programs is likely to reduce career options as well as their opportunities for self-determination. These findings appear consistent with the literature on this topic, that parents of students with severe disabilities had lower expectations for their child to have employment, whether full- or part-time, following school exit, and rather had greater confidence that their child would be employed in a day activity or sheltered workshop that provides below minimum wage income, and therefore continue to rely on SSI. Parents of students with milder disabilities reported slightly higher hopes for their child's employment opportunities, expecting them to gain entry-level or low paying jobs that may lessen their dependence on SSI (Grigal & Neubert, 2004; Kraemer & Blacher, 2001).

As mentioned in the introduction, demographic features, such as race, ethnicity, and place of residence also affect the probability of applying and being approved. The higher the percentage of African Americans and Hispanics in a given county, the lower the rate of individuals receiving SSI, which is most likely because fewer African Americans and Hispanics apply for SSI than Caucasians. African Americans and Hispanics are also least likely to be approved for SSI. Additionally, counties with higher rates of unemployment have higher rates of SSI participation (Ozawa, 2002). While an obvious answer to this may be to increase opportunities for VR in lower-income, more disparate counties, African Americans have been shown to experience poor outcomes in public VR programs (Alston, 2004). This supports the notion that increased interventions are needed in these counties to improve vocational outcomes and reduce SSI reliance.

In exploring the challenges faced by students between 14 and 17 years of age prior to transitioning into the adult healthcare system, Wittenburg and Loprest (2007) found that beliefs about the DDP were strong predictors of the applicant's subsequent behavior. Child SSI recipients who had little confidence that they would maintain benefits at redetermination were more likely to seek out other human capital, such as work experience and education. Those who were unsure of their likelihood of continuing with benefits upon redetermination were wary of gaining further human capital, believing that this would lower the likelihood of them meeting eligibility requirements. In families in which an SSI check is one of the primary sources of income, the family may additionally dissuade the child from gaining work-related experiences.

Even minimal earnings may lead the family to have to “spend down” earnings, which could further limit their ability to accumulate assets. Additionally, many adults have previously reported being uninterested in human capital advancement through participating in vocational rehabilitation or employment programs, as their high degree of medical needs or financial needs make them unable to envision a life without SSI (Berry & Caplan, 2010). For children with developmental disabilities who have been receiving Medicaid and SSI supports since infancy or early childhood, parents are particularly skeptical regarding their child’s preparation for life without SSI and Medicaid, as their high health needs, high costs incurred by their disability, and low earning potential dissuade their pursuit of alternative support options (Berry & Caplan, 2010; DeCesaro & Hemmeter, 2009).

Hemmeter et al. (2009), looking at experiences of child SSI recipients after turning 18, found that despite 82% of the sample had received special education services at some point, 30% of these children ended up dropping out of school, and 43% were suspended, expelled, or arrested. Negative school enrollment history additionally predicts a reduced likelihood of meeting adult SSI redetermination criteria. Negative social experiences during childhood also predicted reduced likelihood of adult SSI, which suggests increased risks for transition-aged youth with developmental and mental disorders who are higher functioning, such as those with autism spectrum disorders and behavioral disorders. It can be anticipated, however, that children who have negative social experiences are likely to struggle with the social demands of employment, and therefore will need extra supports as they transition into the adult health care and work system. Youth with mental and behavioral disorders are much less likely to meet adult SSI re-determination criteria and are more likely to have a high arrest and delinquency history prior to age 18 years, which may prevent them from qualifying for VR or transition-support programs and reduce their opportunities for employment, resulting in these individuals having a higher chance of unmet needs (Hemmeter et al., 2009). Indeed, authors found that this population of youth had a particularly difficult time adjusting to adulthood, and that this is a population of youth who would benefit from additional supports.

Barriers at the School Level

School-aged SSI beneficiaries receive services that are centralized within the school system and are mandated by the IDEA Amendments of 1997 (IDEA, 1997). Upon entering early adulthood, youth with disabilities are transferred onto the adult health care system that lacks centralization, with services being provided across several independent organizations. While IDEA called for student IEP plans to include statements of transition needs to link the student to interagency services by age 16 years (Grigal & Neubert, 2004), there continues to exist a deficit of coordinated services within school systems that assist students’ transition from a school to workplace setting. Students’ difficulties in accessing job skill development in school was related to disconnect between their needs and the school system, as well as disconnect between the students’ reported job interests, the job skills taught, and the opportunities provided. One disconnect was limited ability of teachers with large class sizes to make accommodations for students when they missed school due to health concerns or appointments related to the students’ disability—it can be anticipated that students with disabilities will miss more days than average and therefore risk falling behind in their curriculum, putting them at an even greater learning disadvantage.

Schuster, Timmons, and Moloney (2003) explored barriers to successful transitions to adulthood for students on child SSI and their families by interviewing 12 transition-aged students

and their parents on the transitions process at the school level. Parents reported barriers to successful transitions related to SSI, including managing the continued receipt of payments, limited understanding of the connection between employment and SSI, and a lack of awareness of the supports available through the SSA to seek employment and independence. Further barriers unrelated to SSI included the students' jobs not being matched with their interests, lack of partnership between families and schools, limitations posed by the child's disability to their ability to maintain employment, social supports, and continued education opportunities. A major barrier also reported was the family reporting being in a constant state of crisis, making future planning difficult and feeding into continued financial constraints (i.e.: difficulties planning and saving income). These findings suggest that the multitude of difficulties families face in accessing support for their child with a disability throughout the lifespan render making long-term transition and job planning more challenging.

Barriers at the SSA Level

Schuster et al. (2003) found that an inability to save in some families was associated with the family's requirement to spend down excess money earned by the youth to maintain Medicaid eligible, resulting in fewer opportunities to save for the future. Concerning work, parents viewed the receipt of SSI and employment as mutually exclusive opportunities – the youth could either receive SSI or work, but not both. None of the interviewed families were aware of work incentive programs and demonstration projects run through SSA. Associated with the low income of these families, many families report their SSI paycheck being used for things other than to support the transition-aged youth, such as family housing and bills (Hernandez et al., 2007; Duggan & Kearney, 2007), and that many youth are unaware of the purpose of their SSI check, other than their parents using it to “pay for bills”, further suggesting it may not be used to the advancement of the youth's health and independence (Schuster et al., 2003). When the youth's personal assets are taken into account to determine SSI eligibility, larger assets such as a vehicle or home would count against them, but for individuals with disabilities, having such assets is associated with greater health access and stability and should therefore be encouraged (Hemmeter et al., 2009).

Barriers at the Vocational Rehabilitation Program Level

Recognizing many of the above challenges that transition-aged youth with disabilities experience, one of the primary difficulties reported in accessing transition programs was that most parents and transition-aged youth are unaware of existing SSA work incentive programs (Dreilinger & Timmons, 2001; Schuster et al., 2003). Only 5% of 17-year-olds on SSI from the 2002 NSCF sample had ever been referred to VR services by a service provider. Additionally, only 22% of child SSI beneficiaries reported that a SSA representative had ever discussed available work incentives with them (Ozawa, 2002; Wittenburg & Loprest, 2007). Interviewing youth and their families on experiences with SSA work incentives, Schuster et al. (2003) found that only 22% of their sample had been informed of work incentives by an SSA representative. Only 5% had been referred for VR services, and 2% said they had been accepted for supports by a VR program. Individuals who have participated in VR programs have repeatedly claimed that these services were not helpful to the transition-aged youth, and that they were no more likely to be employed than SSI recipients who did not participate in VR services (Ozawa, 2002; Berry & Caplan, 2010). To address this issue, the SSA in some instances has only provided payment to VR agencies for their services when they are able to successfully get recipients to work.

Of Hernandez et al.'s (2007) sample ($n = 74$) in a qualitative study on the experiences of disabled adults with TTW, only half of those on SSI had general awareness of TTW, and of those, most were confused about the nature of the program, specifically because of the complex language of the informative materials they received on TTW. The sample overall dismissed TTW and other VR programs because they did not see benefits in program participation. Disincentives towards seeking employment that were most commonly reported were that employers showed negative attitudes towards workers with disabilities (~30%), transportation was insufficient (~30%), and that participants did not have enough education for the positions (~25%). Further disincentives were that jobs that are attained through VR programs are typically low-paying, temporary, and menial.

Schuster et al. (2003) additionally found that post high school young adults with disabilities had high school attrition rates over 30%, low enrollment in postsecondary education programs, higher unemployment rates, continued residency in parents' homes, and low self-determination. Of 12 students interviewed in their qualitative study, Schuster and colleagues documented that only 4 had held paid employment positions prior to graduating high school, but that their wages ranged less than minimum wage, between five and six dollars. Three additional students had been employed through school programs involving manual labor that was non-paid. Despite few of these students having employment opportunities, eight reported strong interest in using perceived skills for work, but that their employment experiences were incongruent with their work interests and skills. This suggests that VR programs should place greatest emphasis on tailoring skill training to tasks in which the individual feels more confident, to in turn promote interest and motivation for work to increase independence and self-determination.

Berry and Caplan (2010) explored the success of transition-aged SSI participants in securing employment and earnings beyond their benefits check after participating in a short-term VR program. Analyses of employment and earning trends showed that former child SSI recipients with intellectual disability had the highest probability of gaining employment after completing a VR program than those with mental or physical disorders. They found that individuals with mental illness were least likely to be employed 2 years after completing a VR program. The participant having any college or university training surprisingly decreased the odds of gaining employment, which is consistent with previous studies (Rogers et al., 2005), while having engaged in supported employment increased the odds; however, for those with any college or university education who did secure employment, they were more likely to experience earnings growth over time. African Americans were found to show higher earnings compared to other racial minority groups. Participants who participated in VR for longer periods and applied for VR enrollment at older ages were less likely to find employment after program participation, and if employed, were earning less on average. For those transition-aged youth who left the SSI program, they were more likely to experience poverty and school attrition. Only 2% those who left SSI received follow up VR services, compared to 10% those who remained on SSI. These findings suggest that short-term vocational supports are not sufficient in maintaining employment for former and current SSI recipients, and that a more long-term, involved network of services is needed. Especially for youth with high needs such as mental disorders and developmental disabilities, VR programs across the board need to extend services into the long-term and provide a multitude of supports to increase the likelihood that the individual will continue employment.

Alston (2004) explored African Americans' experiences with SSA work incentives to explore whether racial and cultural factors pose additional barriers to program participation.

Results showed that participants experienced a degree of cultural mistrust which limited African Americans' confidence and interest in work incentives. They did not trust benefits included by TTW, such as that the program would pay entirely for services from a private provider and feared that hidden fees would be involved that would drain on their funding. Other mistrust listed was that the policy of extended SSDI coverage during the 7.5 years following TTW enrollment may be changed at the federal level since 7.5 years is likely to see multiple changes in presidency and policies. Therefore, despite the extensive support and incentives offered by work incentives such as TTW, additional supports revolving around cultural barriers and perceptions are needed to support equal access across all demographic groups to these services.

Hernandez et al. (2007), exploring transition-aged youths' experiences with TTW, found that difficulties also lie at the end of the employer. Employers at job sites identified for youth with disabilities, despite them being chosen as a partner in TTW, were reported to have prejudiced beliefs against the capabilities of employees with disabilities. Additional barriers included limited transportation options to and from job sites, limiting youths' abilities to participate in the program, and inadequate levels of formal education needed to successfully meet all of the demands of their employment position. TTW participants that belonged to racial and ethnic minority groups experienced additional discrimination from employers based on these characteristics, further limiting their employment and learning opportunities at their job sites. Caucasian participants were found to use VR services the most, followed by African Americans and Latino participants. Concerning educational attainment, less than 3% of program participants had a bachelor's degree, and 19% had some college education, limiting participants' opportunities to advance in their employment which may in turn limit their motivation to work hard and demonstrate good work ethic. Another barrier was limited awareness of TTW. Of a sample of social security benefits sampled, only 50% reported knowing of TTW, and even those aware of TTW lacked accurate knowledge of the nature of the program. Many reported that the complex language of the informational materials presented about TTW and other VR programs dissuade them from following up. Spanish recipients also reported difficulties understanding the nature of the program as they only received informational materials in English. One significant misconception regarding TTW that families reported was that medical benefits, such as Medicaid, would be automatically terminated after enrolling in the program, and that they would have to redo the lengthy SSI/SSDI application process should they become unemployed after TTW participation. Participants who were interviewed by Hernandez et al. generally dismissed it as they doubted its efficacy and were unmotivated to learn more. Only 3 individuals in the sample reported enrolling in TTW, and that they did not experience success in finding employment even after completing TTW. Of other families who had previously pursued VR programs, their experiences were that the employment positions found through such VR programs were non-competitive, that they experienced limited career advancement and development opportunities, and that they had difficult interactions with their VR counselor. Difficulties experienced with VR counselors include a high turnover, counselors being non-responsive and non-collaborative, failing to return calls, or were culturally-insensitive.

Survey Results

Despite multiple outreach attempts, the sample of survey responses collected was relatively small ($n = 12$), nine of which were complete that could be used. Of parents who completed the survey, five reported their child had a severe disability that limited his or her ability to work. These five also endorsed that a medical professional or teacher had informed

them that their child would most likely qualify for SSI based on the child's level of difficulties. Concerning type of impairment, five indicated that their child had difficulties learning, four indicated having difficulties moving or manipulating objects, four indicated having difficulties completing activities of daily living, and eight reported as having difficulties socially.

Of the participants, three reported that they were denied for adult SSI at adult determination and six reported being approved. One participant reported having to apply for SSI twice before being approved. Two participants reported not understanding why their first application was denied; one participant reported denial because not enough information was provided in the application, and three participants were denied because their child's diagnosis did not qualify. No other reasons for denial, such as not meeting income criteria, were reported.

Concerning the application's organization, six reported that instructions were easy to understand, while three did not. Satisfaction with wait-time for application review was relatively high, with five thinking it was fast or very fast. Regarding help, eight did not receive help completing the application process, for the participant who did receive help, it was from an employee at a DDS, and this person was reported to have been very helpful in facilitating understanding of the process. While completing the application, participants were unaware and therefore did not refer to websites that would have provided further information as to their child's eligibility, such as the Five Steps to Sequential Evaluation or the Blue Book of Listings.

As the previous literature review suggests, one difficulty that families of youth with disabilities have is ensuring that the relevant medical records are available to the primary care physician and, in turn, the SSA. Of the sample, six reported that their child's primary care physician had access to their child's full medical records so that they may be provided to the SSA at the time of application. An additional communication barrier can be seen at the level of the family after SSI has been approved. During the continuing review process, if SSA is unable to reestablish communication with the family, benefits may be terminated. In this sample, four reported not informing the SSA of their new address when they moved.

A majority of the sample reported having had access to VR or job training services for their child. Formal VR programs had been accessed by six and one had accessed informal vocational programs, while remaining participants endorsed interest in these services for their child, ideally at the child's school, likely because this is an environment the child already knows. At the time of application, six did not have a paid employment position.

Interview Results

Interviews were held with survey participants to gain additional information about the nature of positive or negative experiences they had with the SSI application process. One parent reported having no difficulties with the application process, primarily because he called SSA before hand and the Disability Determination representative was very helpful in directing them to the correct forms and made recommendations on how to maximize benefits for their child.

Concerns that were raised by parents revolved around minimal information transfer to families about SSI. One family reported that it was "serendipitous that we figured it out" as they had never been informed of the possibility of SSI for their child as they aged into adulthood, despite this family having a case worker through their local board of developmental disabilities. Others reported that the information provided on the SSA websites and in pamphlets sent to the homes of SSI beneficiaries by the SSA were not adequate for families to fully understand the application process and how to appropriately report their child's disability status. Because of this, one family reported making a mistake in the application process that delayed their approval

for benefits. Using the online application system, this participant could not tell based on the information if it was for working or non-working individuals, and they were not informed until several weeks later about their mistake. Additional technicalities were the immense difficulties families had calculating their child's expenses to determine if they met income requirements.

Discussion

The aims of this project were to explore families' experiences in applying for adult SSI as their child ages into adulthood, to determine areas in which families are continuing to experience difficulties with the DDP and to identify suggestions for knowledge transfer that could help facilitate this process for families. Several areas of limitations and difficulties were highlighted through the completion of a literature review, data collection, and interviews on family experiences with the DDP. I proposed to conceptualize these barriers at the level of the child and family, the school, the SSA, and those VR programs that are intended to provide alternative income supports.

The ever increasing application rate for adult SSI is reflective of several societal problems: increases in unemployment, competition for jobs, and limited available services to support adults with disabilities in acquiring vocational skills, whether it is related to resources availability, personnel shortages, or attitudes and discrimination. Due to the multitude of barriers, it may be fortuitous to identify small-scale changes that can be implemented at each barrier level to facilitate overall change. Based on the above results, the following recommendations are made to increase knowledge transfer to families of transition-aged youth with disabilities aging out of child SSI:

Recommendations for Knowledge Transfer to Families:

1. Encourage families to contact a SSA representative should questions arise during the application process. Many families reported having completed the application process without help from professionals, such as a doctor's office or service coordinator. As a consequence, families reported making mistakes in the process, or having limited awareness of the stipulations involved in receiving SSI and seeking employment or further education. While current educational pamphlets sent to families receiving SSA benefits includes information on the SSA website and toll-free number, greater emphasis should be placed on the importance of families contacting a SSA representative prior to deciding to apply for adult SSI, to ensure that they receive the best possible recommendations on adult application criteria, how to calculate expenses, and what mistakes to avoid in the application process.
2. Simplify language used in the application and in informational materials sent to beneficiaries. Results from the literature review, survey, and interviews suggest that families found information available on the DDP difficult to understand and were more likely to make mistakes when they did not receive help from a professional. Along with encouraging families who are finding it difficult to maneuver the process to contact a DDS representative, methods for providing increased information on SSI eligibility criteria and how to complete the application should be explored. Since individuals with disabilities are more likely to come from families with lower educational attainments, the language used in informational materials should be adjusted to facilitate families' understanding.

3. Greater emphasis should be placed on submitting the “Adult Disability Report” electronically. While low-income families may not have access to a computer, their case workers or school service providers should work with them to complete the disability reporting process online. This may help facilitate screening and reduce wait time to schedule an appointment with the SSA. This reduces mailing costs, eliminates the need for DDS representatives to make follow-up calls due to the mail transit wait time, and makes it easier to connect the application to its appropriate medical documentation, which doctor’s offices typically provide electronically as well.
4. Increase knowledge of case managers and school-based transitions programs on SSA benefits. A transition-aged youth’s direct service providers, such as case managers and schools, should be used to help facilitate families’ understanding of the application process and work in partnership with the SSA in connecting eligible families to these services. Public schools and community service agencies would benefit from being sent the same information material by the SSA that is sent to families, as they are more likely to recommend a family apply for SSI than the family is to discover this supports option independently. Designing standardized tutorials or workshops that include a learning assessment component for transition program instructors and coordinators at the school level and case managers at the community level to educate them on SSA benefits would also improve their ability to connect families to relevant services. Such workshops or learning modules could even count towards continuing education credits for professionals or could be included as a mandatory professional development training to increase educators’ and service providers’ motivation to learn about SSA benefits.
5. The SSA may wish to consider more evidence-based methods of assessing functional limitations. For example, the Supports Intensity Scale (Thompson et al., 2004) is a tool developed for use with individuals with developmental disabilities to quantify their level of support needs to help them live as independently as possible within the community. Use of this tool may also help increase the congruity between DDS representatives and ALJs decisions on disability determination should a family appeal their decision. This documentation is also becoming increasingly used by direct service providers and healthcare professionals, making this documentation more amenable to be a permanent part of the applicant’s medical records. Since this scale is being used across different organizations outside of the SSA, families may also be able to use this information to gain a better sense of whether they would be found eligible based on the “functional limitation” criteria.
6. Increase information and encouragement for families to contact a TTW representative prior to dismissing VR options for their child. For families who become overwhelmed by the language used in pamphlets sent to their homes by the SSA on benefits and VR programs, it may be beneficial to include some basic information under the “You may be able to get other help” section of the SSA’s current Supplemental Security Income pamphlet posted on its website at <http://ssa.gov/pubs/EN-05-11000.pdf>. Information to include under this section should express that to increase the applicant’s future independence and opportunities, VR programs are available in some regions, and that the SSA extends certain benefits to beneficiaries while participating in such programs. It is recommended that a TTW representative should be contacted for further information on such programs to answer families’ specific questions.
7. Target information on SSI and VR programs to individuals from ethnic or racial minority groups. Research reviewed the literature review showed that African Americans showed greater mistrust of benefits associated with VR enrollment, such as continued SSI and Medicaid receipt. Additionally, it was found that of all groups, Caucasians had highest enrollment in VR programs, and Hispanics and African Americans had the lowest. Promoting ethnic diversity to increase

cross-cultural trust of the government's efforts to support Americans with disabilities should be explored. Ways in which this may be done is through offering opportunities for callers to speak with representatives from their same ethnic background or Spanish-speaking representatives. Informational materials may include pictures of individuals from all ethnic backgrounds.

8. Encourage families to advocate for their child's learning in schools. Research showed that youth with disabilities, when taught independent living and vocational skills, were inconsistent in being taught skills in which they perceived themselves to be adept or more interested. Encouraging youth to learn skills they are interested in will in turn promote their self-confidence and independence. For those who do not qualify for adult SSI, encouraging early skill building while still in school is crucial to positive future outcomes.
9. Encourage families and schools to push for youth with disabilities to be identified early and connected with appropriate resources. Research found that those who are identified as having a disability at a later age and applied for SSI at a later age were less likely to be approved for benefits. As a result these individuals are at greater risk for negative outcomes.
10. Encourage families to continue to ensure their child receives social and mental health supports either through their VR program or from an outside source while enrolled in SSI and VR supports. For individuals with disabilities, poor mental health and experiences of social difficulties, such as involvement in the judicial system, was predictive of fewer support needs being met and a greater likelihood of losing adult SSI eligibility when aging out of the child program. To maximize the youth's independence, and maintain needed supports throughout the lifespan is important, whether or not he or she is eligible for SSA benefits.

Conclusion

Individuals with disabilities present with complex needs throughout the lifespan, and advocating for their needs to an entity such as the SSA proves difficult for their families and service providers. Attempts were made in this paper to review barriers that individuals with disabilities, specifically more complex disabilities such as developmental and mental disorders, have in applying for SSI. SSI, along with other benefits such as Medicaid, presents as a huge source of support for many individuals with disabilities, making it important that they can appropriately identify and advocate for their needs. The SSA strives to facilitate the DDP and to promote opportunities for individuals to increase their independence, such as through VR programs. Societal factors, such as minority status, lack of information on the DDP by health and service providers, and limited resources at the school level, present barriers to families, making it necessary for families themselves to access as much information on the DDP as possible to promote best outcomes for their youth. While this study of barriers in the DDP was limited by the small sample size attained for the survey and interviews, it still presented a number of key issues families continue to face. Future research on this topic should continue to focus on reaching out to families to identify methods for facilitating knowledge transfer and promoting the independence of youth with disabilities as they age into adulthood. Trials of methods for knowledge transfer, such as piloting communication flyers to families and facilitating feedback on them, and adding further websites on the DDP to increase accessibility to families, should continue to be pursued to decrease the knowledge gap between families and the SSA on the DDP.

List of Acronyms

Acronym	Full Term
SSI	Supplemental Security Income
DDP	Disability Determination Process
VR	Vocational rehabilitation
SSA	Social Security Administration
DDS	Disability Determination Services office
SGA	Substantial Gainful Activity
ALJ	Adjudicative Law Judge
TTW	The Ticket to Work Program
SSDI	Social Security Disability Insurance
NSCF	National Survey of Children and Families on SSI
STETS	Structured Training and Employment Transitional Services demonstration project
TETD	Transitional Employment Training Demonstration project

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