

**SSI In Transition: Benefits Application and Transition Planning for Youth in Special  
Education**

Aдриanna Bagnall-Munson, PhD Student  
Department of Sociology, Columbia University  
*Final Draft*

**Disclaimer:** 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**

For families of children with developmental disabilities, preparing for life after high school is a monumental task. The transition process involves a wide selection of tasks from applying for public benefits like SSI and Medicaid, to finding employment and learning the skills for independent living. For each student, the individual tasks associated with transition are interdependent and embedded in the larger project of moving into adulthood. In this paper I argue that the application for SSI benefits should be considered as a part of the process of transition. To make this argument, I investigate the formal process of transition out of high school in order to better understand the ways in which families prepare for their child's post-secondary life. While I find that parents find the transition process to be unhelpful in understanding the specificities of SSI benefits and post-secondary options for their children, there are things that they like about their transition experiences. In particular, parents experience schools to be most supportive in the transition process in their role as an understanding and empathetic institution. I elaborate on the ways in which transition services are experienced as helpful by both parents and students in order to make suggestions for how we should understand the application process for SSI benefits for youth who are transitioning out of high school.

## **Introduction**

The transition out of high school is a critical time for all young adults as it puts into motion a plan that will likely direct long term outcomes for educational attainment, employment, and family life. It is a time of particular vulnerability for individuals with developmental disabilities as they transition out of a system where services are concentrated in the school to an adult system where services and public benefits are largely conditional and tenuous. Alongside training in the skills of daily living, school based transition services are aimed at providing extensive employment training for youth in special education. There is however evidence that transition services are not adequately preparing youth for independent living or employment (Certo et al. 2008; Friedman, Warfield, and Parish 2013; Hemmeter, Kauff, and Wittenburg 2009; Janus 2009; Newman et al. 2011; Osgood 2005; Wagner and Blackorby 1996). Given poor outcomes for many students in special education, public benefit programs like SSI, food stamps, or Medicaid are likely to play a big role in their adult lives. As such, navigation of these programs is a big topic of concern for families who have children transitioning out of high school. This study investigates parent and youth experiences of transition out of high school with the specific aim of identifying the place of SSI or other benefit programs in this process. I elaborate on what parents perceive as working well in the transition services they receive from their school and make suggestions for how transition services can better respond to parent and youth concerns and deliver transition services that contribute to success in adulthood.

## **Literature Review**

In general, students with disabilities have poor post transition outcomes across a number of domains (education, employment, housing, healthcare, social support, etc.) (Friedman et al. 2013; Osgood 2005; Wagner and Blackorby 1996). Relative to their peers, they have lower expectations for their educational attainment and higher expectations of the likelihood that they will experience an early pregnancy. Perhaps a self-fulfilling prophecy, these expectations closely match outcomes for students with disabilities (Shandra 2011). Students with Intellectual Disabilities are also more likely to have IEPs that reflect these low expectations. Compared to their neurotypical peers with IEPs, students with intellectual disabilities are more likely to have

supported (45% vs. 7%) or sheltered employment (33% vs. 8%) as an IEP transition goal and they are less likely to be recommended for vocational training or competitive employment (Grigal, Hart, and Migliore 2011). Post transition, students with intellectual disability achieve a lower level of education and are less likely to be employed than their peers. Grigal tested several potential drivers of these differences—contact with external programs and participation of professionals in transition planning—but they were unable to establish a significant relationship because they didn't have sufficient data. They did however find that increased access to post-secondary education increased young people's access to employment.

Compared to their nondisabled peers, people with intellectual and developmental disabilities are significantly less likely to have reached traditional markers of adulthood: post-secondary education, employment, and residential and financial independence. Only 28.7% of those with mental retardation and 43.9% of those with autism have enrolled in any post-secondary education compared to 67% of the general population. Rates of employment for people with intellectual and developmental disabilities are similarly low, around 38%. Only 36.3% of those with mental retardation and 17% of those with autism have lived independently since leaving high school and more than 90% made 25,000 or less in annual income. Twenty-nine of those with mental retardation and 45% of young adults with autism had a checking account (Newman et al. 2011).

Research on these markers of successful transition in the UK, where students have similar outcomes as in the US, successful transition tends to be attributed to parents rather than professionals or the school transition process (Hendey and Pascall 2002; Morris 2002). Some best practices have been identified for the school based transition process: specific service provision, development of skills of self-management and self-determination; supported psychosocial development; involvement of young people, peer involvement; support for changed relationships with parents and other career; the provision of choice and information; and a focus on a young person's strengths for future development (Forbes et al. 2002). In the United States, researchers have similarly found the self-determination, inclusion in the transition and choice are positively correlated to successful adult transition outcomes (Wehmeyer and Garner 2003; Wehmeyer and Palmer 2003)

Planning for adult life for people with developmental disabilities is a significant project undertaken by families almost as soon as they learn their child has a disability. From a sociological standpoint, it is useful to position transition in the context of the developmental life course, allowing us to imagine that transition planning is an important introduction into the moral careers of adults with developmental disabilities (Goffman 1959; Hogan 1980). Goffman defines the moral career through his research on patients in a mental institution. He uses the term to refer to “any social strand of a person’s course through life.” The focus on *moral* careers entails the ways in which an individual’s identity as disabled shapes the person’s sense of self and influences the ways in which they judge themselves and others (Goffman 1968:127–28). In the context of the student transitioning out of high school, I propose that the experience of negotiating disability status shapes the ways in which the individual comes to see themselves as an adult and thus shapes their dreams for the future and the ways in which they pursue the goals they have for their adulthood. The transition out of high school is particularly important because it likely has lasting consequences for both the youth’s perception of their adulthood and of their disability.

Existing research on transition services points to the fact that aid in this process is largely inadequate and families are typically left on their own to navigate the confusing system of adult services (Certo et al. 2008; Freed and Hudson 2006; Williams 2009)—all this in spite of the fact that transition services are mandated as a part of the special education curriculum under IDEA. At least part of the parental frustration with this transition process could be attributed to the discontinuity between services for adolescents and adults, described by some as a transition from entitlement to eligibility.

SSI is a means tested program (based on financial need) and requires that individuals meet specific definitions of disability, which define specific qualifying impairments and methods for defining disability. For the purposes of SSI and its role in transition, it is important to point out that the definition of disability for children and adults differ. For children (applicants under age 18), disability status is determined based on developmental delay relative to peers. For adults, disability status is based on the individual’s ability to perform *substantial gainful activity* (SGA) in the US workforce. Youth who have received SSI benefits as children must have their eligibility re-determined at age 18 according to this new definition of disability.

Supplemental Security Income (SSI) plays an important role in the adult lives of people with disabilities in the United States as it is linked to other benefits (Medicaid, education benefits, job training). It is also often relied on as one source of stability in an otherwise tenuous array of supports (Bilder and Mechanic 2003; Estroff 1981). Research on the employment and income status of adults with developmental disabilities finds that a majority are unemployed and living near the poverty level, even when accounting for income from SSI and other benefits programs (Yamaki and Fujiura 2002). Prior research on the SSI redetermination process at age 18 has shown that a significant number of individuals fail to retain benefits in the transition from child to adult benefits (Fishman 2001; Hemmeter et al. 2009). Hemmeter's study found that 32.5 percent of children with a diagnosis of Mental Retardation diagnosis at age 17 were denied adult benefits despite the fact that many had insufficient work and independent living skills to support themselves. Beside the differences in adjudication criteria for child and adult benefits, it is unclear what drives this dropout rate from child to adult SSI benefits. Further research is needed which addresses the connection between employment, income, and receipt of public benefits. This study will focus on the work of preparing youth for post-secondary employment and independent living.

In a prior research project about the SSI determination process for adult applicants with developmental disabilities (Bagnall 2015), I found that the process is largely opaque to families. They are often unaware of their rights as applicants or beneficiaries of SSI benefits. They also tend to be unaware of special programs that would allow their children to work part-time, pursue post-secondary education, or engage in other productive activities, while retaining benefits. This project has also revealed that families and service providers alike understand SSI benefits in the context of a broad array of adult services. Families describe SSI as a gateway to other supports while service providers discuss the ways in which SSI often hinders the pursuit of productive activity for a family's fear of losing benefits. These findings point to the fact that SSI is properly understood in the context of a wide array of services for people with developmental disabilities. A decision to apply for SSI benefits may open up new opportunities for an individual while perhaps limiting opportunities for employment or other activities. Again, more research is needed to explore this process of decision-making. The present study provides further investigation into the role that SSI plays in future planning.

This current project is aimed at learning more about the role of SSI application in the process of transition out of high school for youth with developmental disabilities. I address the following questions:

- How do families understand SSI benefits within the context of adult services for their developmentally disabled child?
- What are the difficulties families experience with their school-based transition services?
- What do families identify as helpful in the transition services their child receives in school?
- How can education about SSI programs be more fully incorporated into the school-based transition process?

## **Methods**

The following analysis presents the results of four focus groups conducted with both parents and youth who are receiving school based transition services. Focus groups were held near the beginning of the school year in September 2017 in New York City with residents of various boroughs. There were two focus groups for parents (totaling 17 parents) and two for their high school students (totaling 13 youth) who were receiving transition planning services as a part of their special education curriculum. Focus groups were held simultaneously in the evening following a dinner with families. Discussions were audio recorded and later transcribed for analysis.

I received four redacted transcripts of these focus groups. I analyzed the transcripts one at a time, reading them closely and taking notes on the responses participants gave. After reading, I rewrote my line-by-line notes into a narrative for each focus group. I then re-read the narratives side by side, making note of differences, similarities and themes that arose. While efforts were made in the administration of the focus groups to distinguish between the responses of particular participants, the focus group transcriptions often represented a group discussion and participant responses were not attributed to specific participants. In addition, I have no way to link responses from parents to the responses given by youth. While I was initially worried that this would analysis of responses difficult or impossible, what emerged from the transcripts was a surprising

amount of consensus (evidenced by large portions of the transcripts where the moderator goes around the circle and asks, “you too?” to a chorus of yesses).

For the most part, this paper draws on the topics around which there was near consensus among parents. Where there was only one response to a question, I do not report the response in my analysis. The exception to this rule is for the student focus groups. Because of the nature of the respondent’s disabilities it is clear from the transcripts that this type of question and answer dialog is difficult for many of the students. As a result, many questions asked of students were only answered by one or a few students. I report here on all of the responses from students regardless of the frequency. While the findings here are not necessarily generalizable to a wider population, I include these single responses because student and young adult perspectives are usually left out of research on the transition process. Given that student involvement, self-perception, and self-determination are all associated with better transition outcomes, this should be alarming. Thus, I include here all of the student responses as a first step toward including students with disabilities in research about themselves.

While I do not have detailed demographic information on the participants in the study, all were attending schools in the New York City public school system and all were receiving special education services as a result of their intellectual and learning disabilities. All of the youth represented, either by themselves or by their parents, were in high school and all were receiving transition services in compliance with the Individuals with Disabilities Education Act which requires that transition services be written into an IEP beginning at age 14 or 16 and continuing until the student leaves high school by age 22.

Participants were recruited through their participation in the New York State PROMISE project, a research project for 14-16 year old students currently receiving SSI benefits. The goal of the program is to better help SSI recipients successfully navigate the transition to adulthood, focusing on preparation for post-secondary education and employment. One parent and one youth focus group represented an “intervention” group who was receiving additional transition services through the PROMISE project. Because the project is ongoing, I cannot elaborate on specific differences between the control and intervention groups. Rather, this project will investigate generally the experience of transition for all of the families, identifying attitudes and frustrations with the project of transition. Because this data has been collected in one city, the

sample is not representative of the larger US population and therefore the findings are not generalizable. That the focus groups were conducted at the beginning of the school year further limits the generalizability of this study as parents are likely to be confused and disoriented at the beginning of the school year. However, as a qualitative research project, the goal here is to probe deeply into the experiences of students who are currently transitioning. The depth of this type of inquiry is particularly well positioned to make suggestions for future research, something I will do at the end of my analysis.

The families in this study are receiving different levels of transition services based on the quality of service available to them and in the stage of transition they are in based on the youth's age. While I can't elaborate on the specific level of service that families are receiving, there are clear distinctions that can be drawn between those who perceive their transition services to be comprehensive and those who do not. Questions asked in focus groups spanned a wide array of topics related to school based transition services including benefits application, future planning, and advocacy skills. Only a few questions focused specifically on SSI benefits, however, SSI benefits application is one part of a larger project of transition which is focused on the goal of establishing the individual in a stable adult life. With this in view, we can also analyze questions about work readiness and preparation for independent living as related to SSI benefits as they will undoubtedly influence the individual's reliance on SSI benefits in the future. Put more clearly, we can reasonably expect that a student who is well equipped for workforce participation and confident in their independent living skills will need a lower level of support through SSI and other benefits in their adult life. Therefore, we should be especially concerned about the efficacy of school based transition services for their role in preparing students for adulthood and in preparing their parents to support them in this transition.

Based on the responses to focus group questions, which focused on the efficacy of transition services to prepare the youth for life after high school and employment, I investigate what types of transition services are perceived to be most helpful by parents. I also probe perceived gaps in transition services to investigate where parents need increased support in transitioning their child from school to adulthood. I also analyze the alternative sources of support that families utilize in their transition in order to make recommendations about additional services that could be provided in schools.

## **Findings**

### *General Experience of Transition*

When asked about their child's transition services, parents describe a general frustration with the lack of services available to them. Parents have difficulty naming specific programs and services that have been helpful to them in planning their child's transition and feel that they do not have enough information about the process of transition, their child's benefits, or opportunities available to them when they leave high school. When asked to describe additional things that they would like that they are not currently receiving, parents nearly unanimously report that they would like more "services" which is offered as a blanket request for more intervention to help their child in their transition. Parents who expanded on the need for more "services" reported that they wanted the security of post high school services for their child. They wanted to know that there was a day program, employment opportunity, or further training available to their child when they completed high school. In this context, "services" were meant as a request for the security of knowing that their child would have something in the future, not necessarily as a request for more intervention in their child's current life. When parents do identify a service that has been helpful, they usually describe in vague terms something that has increased their understanding of a general process, for example, how to apply for state services. It is not clear from the data I have how helpful these services and programs are in assisting them with personal transition planning, for example helping them to actually submit the application.

In place of naming programs or services that have been helpful to them, parents talk at length about specific staff and teachers that have supported their child. According to parents, teachers and other school professionals are most helpful when they are "involved" in their child's life. By involved, parents seem to mean that they understand their child's needs and take an interest in their success beyond their own classroom and they take initiative to teach students how to cope with their behavioral challenges. As an example, one parent offered that one of her daughter's teachers helped her to cope with anxiety attacks by leaving the classroom to calm down by herself in the hallway. Other parents shared that understanding teachers would open up their classroom to a student when they needed to "calm down" and communicated with other

teachers to allow the student to leave their classroom to seek out help from the understanding teacher. Supportive teachers also acted as advocates for students by communicating with other teachers about the student's coping strategies and encouraging them to also be understanding of the student's needs. Importantly, this advocacy work and the understanding that the teacher exhibited, kept disciplinary action to a minimum. While this doesn't on the surface seem like a service related to transition, parents interpreted this as critical for their child's future success as disciplinary action could accumulate on a child's record and even erupt into a legal issue if the police were called for a behavioral issue.

In addition to knowing children well and advocating for them within the school environment, supportive teachers and professionals maintain an open line of communication with parents. For example, several parents in focus groups mentioned that the most helpful thing staff at school did for their child was to call parents rather than police when there was a behavioral conflict involving their child. This was important to parents, again because it allowed them to intervene, avoiding a record with law enforcement. One parent aptly described the fact that arrangements like this were the result of a cultivated relationship with staff who understand when and how parents are available to their child throughout the school day. Again, while not readily associated with transition services, parents viewed interventions like these as essential to their child's transition because they allowed the child to remain engaged in school throughout the day and prevented their removal through suspension, as a disciplinary measure: "They know that they have student, that has, you know, behavior problems, autistic, whatever, and they don't understand when they do have temper tantrums and you know, attitude and stuff, they'll tell them to get out of [the] classroom, they'll fail them, they, and not allowed back in the classroom. They're missing days and it's like..." The need to keep students engaged in school as crucial to transition was reiterated by another parent whose child had significant medical issues requiring their hospitalization. School personnel worked with the student to provide tutors and curriculum to enable them to remain engaged in their schoolwork even in their physical absence from school.

While staff was named in place of specific services as the most helpful thing in their child's education, parents also named staff as the source of greatest frustration in the transition process. Specifically, they were frustrated by what they perceive as a general lack of

communication between school and parents. Parents report that school officials “don’t tell you anything,” and that when they try to get in contact with transition coordinators at their child’s school, they have difficulties. When asked to suggest what could make their transition experience easier, parents suggested that there should be an increased investment in staff in order to keep parents better informed. They also suggested that staff should take more of an initiative to reach out to them, as they are busy caring for a special needs child. Parents who experienced their transition services to be particularly helpful attribute the success to dependable transition coordinators who are “on the ball.” Parents desired increased communication with their school because it would enable them to play a more active role in their child’s transition, “we could be a wrap-around service and be able to guide our children as, as a united school and parent, ‘cause it takes a village to raise a child, not just the parent.” While they didn’t feel informed by their schools, parents reported that they get much of the information about their child and potential programs and services from the internet or from other parents. Some in the focus group suggested that schools could invest specifically in parent liaisons who may be more equipped at communicating effectively with other parents.

As parents described barriers to preparing their child for the transition out of high school, their descriptions pointed to a larger problem that can be characterized as a barrier between school and home. Given that their children spend such a significant amount of time at school, parents experienced the lack of communication and information they received from school professionals as detrimental to their child’s success both at school and at home. This was particularly difficult when stress at school produced behavior problems at home which parents were ill equipped to address because they were kept in the dark about school requirements. This observation is particularly poignant given that the expressed purpose in school based transition services is to create continuity between school and life in adulthood. If there is to be adequate continuity it may be important to start creating a smooth flow of information between school and home during the school years.

### *What is Transition Good for?*

Section 1401 of the Individuals with Disabilities Education Act (IDEA) defines transition services as a "coordinated set of activities" designed to "improve the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-

school activities." These post-school activities include "post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation." In short, transition services should be designed to fully equip the student to leave high school and take on their adult life in all its facets. While the project of transition involves many of the same components as it would for anyone regardless of disability status, for students with an Individualized Education Plan (IEP), the transition process is made explicit. The tasks of taking on adult life—finding something meaningful to do when you leave school, determining your living situation, taking responsibility for the self and learning the activities of daily living—are to be written into the student's education plan beginning at age 16, sometimes age 14, and the school is legally mandated to manage the process<sup>1</sup>.

While the process for transitioning the student to take on the facets of adult life after high school are outlined in detail in the IDEA, the precise content of what the individual will do when they leave high school is left open. It is to be determined in accordance with the student's "strengths, preferences, and interests" and in collaboration with the student, their caregivers, and relevant professionals involved in the student's life. Like the student without an IEP, the student with a disability should be helped in finding something to do after high school (attending college, finding employment, living independently, etc. Unlike the typical student, the adult life of a student with an intellectual and developmental disabilities is likely to also include the negotiation of public benefits, understanding of special healthcare needs, and management of stigma related to their disability. As essential components of their own lives, information about public benefits and medical care should be integrated into the transition process for students with disabilities. [add some references here for special healthcare needs]

While management of public benefits and special health care needs is likely to be a large part of the adult life of a person with disabilities, parents in this sample reported that the transition services they were receiving were not helpful to them in understanding their child's SSI benefits. Parents reported not having received any helpful guidance on applying for SSI benefits. They also felt that their participation in transition services had not helped them learn

---

<sup>1</sup> <http://www.wrightslaw.com/idea/idea.2004.all.pdf>  
<https://www.law.cornell.edu/uscode/text/20/1401>

anything new about the benefits their child was receiving or might receive after they transition out of high school. Parents who felt comfortable navigating the process of applying for SSI benefits had learned to do so by applying for SSI benefits with other family members or from other parents and neighbors. Not only did parents feel like school based transition services failed to help them understand their child's SSI benefits, some parents reported that school personnel were ill informed about SSI benefits in general. For example, one parent shared the following: "They actually look at your child, like they look at my daughter and be like, she gets SSI? For why? And I'm like ah, just because somebody receive SSI, doesn't mean that you can see what their problem is. Some of their issues is not visible... and they really don't discuss it in school." This interaction suggests that school personnel are not fully understanding of the ways in which SSI would be useful to families and thus not equipped to educate families. Parents also report that school based transition services fail to help them secure employment and other post-secondary programming like college and day habilitation programs.

The role of schools in helping parents and students navigate public benefits programs and post-secondary activities like education and employment is a complicated matter. On the one hand, the mission of the school is to prepare the student to be as independent as possible, improving their ability to perform the activities of daily living and preparing them for continuing education, employment, or day habilitation programs. On the other hand, a majority of students are likely to depend on SSI, among other public benefits programs throughout their adult lives regardless of their capacity for independence. We know that employment for people with developmental disabilities is tenuous. People with developmental disabilities tend to work in low wage jobs that have high rates of turnover. What is more, finding a job and keeping it is likely to be dependent on benevolent employers who are understanding of social difficulties people with disabilities have in the workplace, even if they can physically perform the work they are expected to do (Greenspan and Shoultz 1981). Because of these documented difficulties people with developmental disabilities are likely to have in getting and keeping jobs, SSI is likely to continue being an important safety net for adults if and when they find themselves to be unemployed or underemployed.

While it may not be realistic to expect school personnel to be experts on everything I am framing here as a part of transition, this should not be an excuse for incomprehensive transition

planning. If teachers are not going to become experts on the full range of concerns transitioning families have, they should make information available, inviting speakers, or providing referrals to families who need to know more about public benefits. None of the parents in this sample reported having received such information or referrals from a school professional. Because SSI is often a gateway to other services and supports for the young adult, school personnel should be developing an expertise in negotiating SSI. Without this expertise, school-based transition services are likely to continue being perceived as inadequate by parents who cannot disentangle SSI from other things like post-secondary programming, employment, or medical care. From the reports of parents and their children in this sample, schools served two distinct functions related to transition: they were understanding of students' specific situation, and they had potential to prepare students for life after high school. I elaborate on the *understanding* and *preparing* functions of the school below and elaborate on the ways these can be harnessed to better shape the transition process.

### *Understanding*

As I have already talked about at length, parents identified understanding teachers and school professionals as their favorite things about their child's school experience. While understanding is readily conceived as an interpersonal trait, not immediately related to transition, parents viewed it as crucial to their child's success. Understanding teachers were "on the ball" and organized. They often reached out the parents directly and had an open line of communication with parents. They were aware of life issues like medical conditions that might affect a student's academics. Most importantly, understanding teachers were "involved" in the student's life, meaning that they took an interest in the student's success beyond the classroom, took initiative to help the student cope with behavioral challenges, and advocated to other teachers in the school on behalf of the student. Understanding from teachers and school professionals was important for keeping students engaged in school and out of trouble with law enforcement. Both of these goals were perceived by parents as critical to their child's future success in school and employment.

Understanding was also important for its role in helping student learn self-advocacy skills. Parents recognized that their children needed to learn appropriate ways to communicate but some had trouble indicating where their children were currently learning concrete self-

advocacy skills. They were however able to identify behavior from teachers and school professionals that aided their aided students in appropriate behavior. Specifically, parents saw that the approach and demeanor teachers exercised toward students influence their communication styles in return. According to these parents, teachers who influenced appropriate behavior in their children were aware of their tone of voice and body language while they interacted with students, especially in times when the student was anxious or having a behavioral episode. In this way, a teacher's understanding was immediately relevant to interactions with the student, not just in influencing protocol within the school to give the student space to deal with anxiety.

Students also relied on understanding teachers as critical for their self-concept. Students with interested others (teachers, mentors, other professionals) felt more confident in their future generally and specifically as it relates to work, "I know my future is gonna be great because is that the more people that know me very well, and I want to tell everybody what I feel to have a good future." A few students in the focus groups had dedicated mentors with whom they were able to talk about future plans. Students especially liked that these dedicated mentors gave them someone to talk with besides their parents. A primary criticism from students about their school based transition services was that they did not provide adequate instruction in their personal interests and desires for the future. Students with personal mentors had an outlet for their need for personalized attention to their future plans.

### *Preparing*

In addition to understanding teachers, who fostered a deep care and interest in the student's overall well-being, parents were also concerned about the role of the school as a *preparing* institution. Preparing schools focused on developing a student's skills for adult living. Specifically, parents and students expected that preparing schools would provide instruction in "hard skills" like communication, job readiness and interviewing, college preparation, and instruction in credit and finances. Parents also saw a properly preparing school to be one that provided a seamless transition to post high school programs. In order to consider a school to be fully preparing students for their transition from high school, parents wanted the security of knowing that there is an opportunity available to their student when they left school.

While parent's experience of their child's school as understanding was perceived as important to their child's post-secondary success, parents did not experience their schools as directly helping their child prepare for life after high school when it came to more concrete things like finding employment, securing benefits, etc. In short, schools were perceived to be understanding but not preparing institutions. According to parents, a school that did a good job preparing students for life after high school would concentrate on the areas of communication, job readiness and interviews, college preparation, and instruction in credit and finances. What is more, in anticipation of the death or incapacity of parents, schools would equip students to continue growing in these areas independently of their parents. Because they didn't see their children learning these skills in school, parents anticipated that they would need to learn them in a day habilitation program or group home after they left high school. While parents didn't generally consider their schools to be providing adequate preparation, I outline some areas where parents saw success in order to highlight where transition services can focus in the future to better prepare students for adult life after high school: work, financial planning, and future plans.

Transition services aimed at helping students prepare for employment primarily provided students with work experiences through school based internships or summer internship programs. These were perceived as able to help students gain skills for their future employment. It is unclear however, from talking with parents and youth, what help students receive to prepare for work beyond the work experience gained through internships. Parents desired transition services that would provide instruction in interviewing, resume writing, and job search techniques in addition to the work experience they were already getting. Students too identified work experience as a primary benefit they received from their transition services. More than anything else, students name a job and work experience as the thing they liked best about their transition services. Echoing their parents' concern that they are receiving work experience but no ancillary skills related to employment more generally, students seem unable to name skills they have learned to help them manage employment or find jobs in the future. Rather, students can name specific jobs and tasks they have been trained to do. The few students in this sample who were able to name more general employability skill—like how to cope when you are upset with a coworker, schedule management, job searching, and resume skills—were more confident and optimistic about their future employment outcomes. That students with more specific skills *seemed* more confident in their future employment prospects is no small finding as it has been

well documented by Wehmeyer in a number of studies that self-determination, a feeling of control over one's own life, is correlated with better outcomes across a number of domains including employment, access to health care, and financial and general independence (Wehmeyer and Palmer 2003). More research is needed to investigate the techniques of instruction that would allow students to learn these skills.

When it comes to financial planning, it is not clear that parents or students are being adequately prepared. Some parents reported having attended financial planning sessions sponsored by their child's school or another supporting organization. However, it is not clear how helpful this information was to parents. Students also reported little in the way of preparation related to financial planning. Students primarily reported having learned about SSI benefits and money from their parents. A few remembered having received dedicated training about financial aid for college, credit cards and banking however, none of the students reported having a checking account of their own. While students are unlikely to have a bank account of their own, without their parent's cosigning, based on the confidence that students gained when they had more concentrated experience with writing resumes and practicing interview skills, it is likely that students would benefit from a similar hands on experience learning about money management. Their discussion of money was largely abstract and dependent on their knowledge of their parents' finances.

While all parents expressed frustration with communication, the amount of direct support they received from schools, and a general lack of information, there was a clear distinction between families who experienced the process of transition as opaque and confusing and those who were more hopeful about their child's transition. Families who were hopeful about their child's transition were unique in that they felt that they had something to work toward in the future. These parents describe a shift that happened in their thinking, attributable to their transition services, from being passive consumers of services that "move through" a system and then leave it, to being active in the process of transition. These families saw their children as working toward being a productive member of society. In contrast, families without a vision for the future tended to be preoccupied with their immediate frustrations with the transition process. This attitudinal disposition is reiterated in student responses. For students, the promise of future employment as something concrete to work toward during their transition was also associated

with a more positive outlook on their adult life. In summary, while all families experienced some frustration with transition planning, those with a clearer vision about employment prospects and other post-secondary programs were empowered in the process of transition and more likely to be encouraged about their child's future, even if there was continued uncertainty and "nothing in place yet." While it is unclear whether a clear vision for the future makes the transition process less opaque and confusing for families or whether a clear transition process clears the way for imagining the future, what can be concluded from this finding is perhaps that it would be good to provide more of both to families. A clear and transparent transition process means that parents are less frustrated by the small details of transition and they feel more empowered in the process, an important thing when we consider that parents are likely to be involved in their child's care long into the future.

When asked about what they expect to get from their transition services, students are primarily focused on the prospect of having a job when they leave high school. While students expect that they will have a job when they leave high school, they would like to have more guidance in the "how" of working and finding a job. Specifically, they wanted help searching for a job and in preparing for one. Overall, students identified having a job as the ultimate marker of a successful transition and reported that the most important thing their school based transition service provided to them was confidence in their ability to learn about work, "One thing I did expect [is a] boost in confidence... cause you know, if you're, if you've never had a job before the idea of it sounds scary because all our lives we're trained to be students. And so, now we have to shift gears from being a student to you know, being a responsible adult." Students who reported the most confidence in finding a job after high school were students who had been guided step by step through the process of finding a job, "Everyone gets it [anxiety], but [transition services have] helped relieve some of that anxiety in a way, but through taking me step by step through the processes of getting a job and things like that. So, I have a clear, much more concise agenda on how to get a job. And so, you know, it makes it a little easier on my mind. Like, I can do this. I can do it again and its okay if I don't get a job, because I can just try again." While it is the case that all students would likely benefit from concentrated training on job applications and resume writing, students in special education are required to receive these things by law. What is more, these students are significantly less likely to receive post-secondary

education than their peers meaning that they are unlikely to learn these skills anywhere other than high school.

## **Discussion and Conclusion**

The present study is a preliminary attempt to investigate the effectiveness of school-based transition services in preparing youth for employment and independent living. Three main findings emerge from this analysis. The first is that the school, as an institution involved in transition, serves two distinct functions for parents and youth, understanding and preparing. The second concerns the components of the transition process: families identify that schools provide both experience and skills to youth who are transitioning out of high school. Finally, parents and youth talked at length about the types of individuals that are most helpful to them in the work of transition.

Schools were perceived by parents as both understanding and preparing institutions. While these are distinct functions of the school, both were named by parents as particularly important for their child's successful transition from high school. As understanding institutions, schools were attentive to the individual needs of students and accommodated special needs the students had, especially for managing anxiety and behavioral problems. The work of understanding students was important for helping them learn coping and advocacy skills, assets that will follow them after school increasing their ability to advocate in social situations and possibly helping them to maintain employment in the future. It should be noted that perceptions of the school as an understanding institution were primarily dependent on the presence of an individual teacher or school administrator who took an interest in the student and advocated on their behalf to other teachers in the school. As preparing institutions, schools provided students with concrete skills they would need to access employment and public benefits in the future. In particular, parents felt that schools that provided adequate preparation for youth's adult life would equip them to continue learning and pursuing adulthood independently of their parents' intervention. Schools were also viewed as successful preparing institutions when they helped parents to develop a clear post-secondary plan for their child. In particular, both parents and youth identified the prospect of employment as the primary marker of successful transition.

Both parents and youth described the transition services they received in school in terms of the experience and the skills they gained. Most students represented in this study had received some sort of work experience as a part of their transition services. For all students and parents, work experience was seen as a benefit to their child. The only complaint directed toward work experience was that both parents and youth wanted more work opportunities and training in specific work-related skills. Training in employment related skills involved learning about resume writing, job search techniques, and interpersonal skills training to help them interact with employers and coworkers. Students with these skills seemed more confident in their ability to find a job and to keep one and seemed more proactive in their approach to finding employment even if they didn't have a specific plan in place for after high school. This persistence and optimism is likely to be particularly important for this population as they are more likely to experience unemployment (Yamaki and Fujiura 2002) and more likely to be in service related jobs which have high turnover (Hemmeter 2009). Considering this, it may be that schools should invest more resources into employment related skills in addition to providing work experience as skills are more important for the long term employability of youth.

Finally, both youth and parents identified specific supportive individuals as the most helpful thing for their child's transition planning. Supportive teachers, school professionals, and personal contacts were named above any specific service or program as particularly important for both the understanding and preparing work that families identified as important. While a good deal of effort goes into designing programs and curriculum to help parents and students understand employment and benefits, it is clear from this study that those efforts might not be effective if they are not accompanied by an individualized, empathetic consideration of the young adult's life. While it is difficult to say how to identify and train these supportive individuals in benefits and post-secondary programs, this research suggests that designated mentors or service coordinators would be important to help students and parents navigate the transition process. Considering that parents in this study most frequently reported that they heard about SSI benefits from friends and family, a priority of the Social Security Administration should be in distributing information about SSI/SSDI to families in a way that makes it easy to pass along specific information about SSI and employment opportunities. The Social Security Administration might also consider training teachers and school professionals in SSI benefits in order to equip them to educate parents about the relationship between employment and income

benefits. Schools could also consider inviting professionals trained in public benefits to schools to talk with parents about how benefits will change when their child leaves high school and how to plan for this as a part of transition.

The project of transition is a project which involves the whole life of the individual student. Quite obviously, it means leaving school and moving into another program, job, or post-secondary education setting. This is the focus of many transition services and the first thing many people think of when they think about transition. This study shows that this is an apt understanding of transition in many ways as both parents and students are primarily worried about employment after high school. What lies underneath these concerns with finding a concrete post-secondary activity however, is a larger project of equipping the parent and student to *feel secure* in what comes after high school. What we know about post-school outcomes for people with developmental disabilities is that they are likely to experience a high degree of job, income, health, and relationship insecurity relative to their non-disabled peers (Newman et al. 2011). Parents and students in this sample who had a clear vision of the future were more optimistic about their post school outcomes and more confident in their ability to overcome setbacks like the loss of a job. Returning to the topic of the “moral career” of youth with developmental disabilities, it is also of note that equipping students with a generally positive disposition toward their adult life is likely to have lasting consequences for the way in which they navigate future decisions about employment, public benefits, and independent living. Research on self-determination confirms that this kind of confidence is associated with better transition and independent living outcomes (Wehmeyer and Garner 2003; Wehmeyer and Palmer 2003). Future research should continue investigating the long term effects of this positive disposition on outcomes like employment and independent living.

As a final note to this study of the transition experiences of parents and youth with developmental disabilities, I would like to turn to the topic of SSI benefits. I have already made the case that understanding public benefit programs and medical information is an essential component of transition for students with disabilities. As a probable part of their adult experience, education about these programs into the school-based transition process should be more seamlessly incorporated into the education of parents and students. Further, SSI is a means tested program with unique disability definitions dependent on participation in the workforce. If

a primary focus of school-based transition services is post-secondary education and employment, SSI benefits also deserve a space in the formal transition process because of their close ties to income and workforce participation. From this research on parents and transition aged youth, it is not clear that families are gaining information about SSI from their schools. I would assert that this leaves them with an incomplete knowledge of the ways in which the benefits program is connected to other areas of transition, although further research is needed in this area.

## **Bibliography**

Bagnall, Adrianna. 2015. *Don't Step in the Cracks: Individuals with Autism and Their Parents in the Disability Determination Process.*

Bilder, Scott and David Mechanic. 2003. "Navigating the Disability Process : Persons with Mental Disorders Applying for and Receiving Disability Benefits." *The Milbank Quarterly* 81(1):75–106.

Certo, Nicholas J. et al. 2008. "Seamless Transition and Long-Term Support for Individuals with Severe Intellectual Disabilities." *Research and practice for Persons with Severe Disabilities* 33(3):85–95.

Estroff, Sue E. 1981. *Making It Crazy: An Ethnography of Psychiatric Clients in an American Community.* Los Angeles, CA: University of California Press.

Fishman, Eliot. 2001. "Aging out of Coverage: Young Adults with Special Health Needs." *Health Affairs* 20(6):254–66.

Forbes, Angus et al. 2002. *A Multi-Method Review to Identify Components of Practice Which May Promote Continuity in the Transition from Child to Adult Care for Young People with Chronic Illness or Disability.* London.

Freed, Gary L. and Ericka J. Hudson. 2006. "Transitioning Children with Chronic Diseases to Adult Care: Current Knowledge, Practices, and Directions." *The Journal of Pediatrics*

148(6):824–27.

- Friedman, Nora Db, Marji Erickson Warfield, and Susan L. Parish. 2013. “Transition to Adulthood for Individuals with Autism Spectrum Disorder: Current Issues and Future Perspectives.” *Neuropsychiatry* 3(2):181–92.
- Goffman, Erving. 1959. “The Moral Career of the Mental Patient.” *Psychiatry* 22(2):123–42.
- Goffman, Erving. 1968. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Aldine Transaction.
- Greenspan, Stephen and Bonnie Shoultz. 1981. “Why Mentally Retarded Adults Lose Their Jobs: Social Competence as a Factor in Work Adjustment.” *Applied Research in Mental Retardation* 2(1):23–38.
- Grigal, Meg, Debra Hart, and Alberto Migliore. 2011. “Comparing Transition Planning, Postsecondary Education, and Employment Outcomes of Students with Intellectual and Other Disabilities.” *Career Development for Exceptional Individuals* 34(1):4–17.
- Hemmeter. 2009. “Occupations of SSI Recipients Who Work.” *Social Security Bulletin* 69(3).
- Hemmeter, Jeffrey, Jacqueline Kauff, and David Wittenburg. 2009. “Changing Circumstances: Experiences of Child SSI Recipients before and after Their Age-18 Redetermination for Adult Benefits.” *Journal of Vocational Rehabilitation* 30(3):201–21.
- Hendey, Nicola and Gillian Pascall. 2002. *Disability and Transition to Adulthood: Achieving Independent Living*. York, UK: Joseph Rowntree Foundation.
- Hogan, Dennis P. 1980. “The Transition to Adulthood as a Career Contingency.” *American Sociological Review* 45(2):261–76.
- Janus, Alexander L. 2009. “Disability and the Transition to Adulthood.” *Social forces* 88(1):99–120.
- Morris, Jenny. 2002. *Moving into Adulthood: Young Disabled People Moving into Adulthood*. York, UK: The Joseph Rowntree Foundation.

- Newman, Lynn et al. 2011. "The Post-High School Outcomes of Young Adults with Disabilities up to 8 Years after High School: A Report from the National Longitudinal Transition Study-2 (NLTS2). NCSER 2011-3005." *National Center for Special Education Research*.
- Osgood, D.Wayne. 2005. *On Your Own without a Net: The Transition to Adulthood for Vulnerable Populations*. University of Chicago Press.
- Shandra, Carrie L. 2011. "Life-Course Transitions among Adolescents with and without Disabilities: A Longitudinal Examination of Expectations and Outcomes." *International Journal of Sociology* 41(1):67–86.
- Wagner, Mary M. and Jose Blackorby. 1996. "Transition from High School to Work or College: How Special Education Students Fare." *The Future of Children* 6(1):103–20.
- Wehmeyer, Michael L. and Nancy W. Garner. 2003. "The Impact of Personal Characteristics of People with Intellectual and Developmental Disability on Self-Determination and Autonomous Functioning." *Journal of Applied Research in Intellectual Disabilities* 2 16(255–265).
- Wehmeyer, Michael L. and Susan B. Palmer. 2003. "Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination." *Education and Training in Developmental Disabilities* 38(2):131–44.
- Williams, Roberta G. 2009. "Fumbling the Handoff: Managing the Transition to Adult Care for Adolescents with Chronic Conditions." *The Journal of adolescent health : official publication of the Society for Adolescent Medicine* 44(4):307–8.
- Yamaki, Kiyoshi and Glenn T. Fujiura. 2002. "Employment and Income Status of Adults With Developmental Disabilities Living in the Community." *Mental Retardation* 40(2):132–41.