

From High School to the Cliff: Disability policies experienced by transition work stakeholders in Chicago

Final Report: ARDRAW small grant proposal

Tonie Sadler, MSW

The University of Chicago School of Social Work

Project mentors: Harold Pollack, PhD and Michele Friedner, PhD

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) Analyzing Relationships Between Disability, Rehabilitation and Work. 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

Following high school, young adults with intellectual and/or developmental disabilities (IDD) experience a sudden drop in comprehensive day services provided through the U.S. education system and other types of cash assistance provided through children's Supplementary Security Income (SSI) (Neece, Kreamer, and Blacher 2009; Wilschke, 2016). During this transition period, transition work stakeholders help to facilitate access to state and federal disability policy programs for young adults with IDD and their families. This study seeks to better understand how transition work stakeholders experience state and federal disability policies and programs as they help facilitate the transition out of high school for young adults with IDD and their families. Using extended case study methodology, 19 transition work stakeholders who help facilitate the transition out of high school for young adults with IDD in the Chicago Metropolitan area participated in qualitative, semi-structured interviews. Also, field observations were conducted in two occupational learning facilities that specialize in education services for young adults with IDD, ages 18-22. Findings suggest that transition work stakeholders experience significant challenges when attempting to link individuals with IDD and their families to state and federal disability policies and services. More specifically access to these programs can be complicated, including barriers such as waitlists, administrative red tape, and a lack of centralized dissemination of information regarding available disability services.

Background

Statement of Problem

The transition to early adulthood can be particularly challenging for people with IDD and their families. Not only are they experiencing change developmentally, but they also experience a sudden drop in comprehensive day services and supports provided through the U.S. education system. “In the United States, after an individual with intellectual disability exits the school system, which can occur as late as age 22, services change from a system of entitlement to a system of eligibility” (Neece, Kreamer, and Blacher 2009, pg. 31). In addition to education services, families receiving Supplemental Security Income (SSI) for children with disabilities undergo a redetermination process after the child turns 18 years old using adult disability standards. The eligibility criteria shift from a focus on whether or not a child is disabled to whether or not an adult can participate in employment. During this time “About one-in-three such beneficiaries lose their SSI benefits” (Wilschke, 2016). Regarding service provision in Illinois and more specifically Chicago, fiscal effort toward IDD services is markedly less compared to other states resulting in large waitlists to access funding for disability services. (Braddock et. al., 2017).

In particular, the Prioritization for Urgency of Needs for Services (PUNS) list is of prominent focus as it determines if and when an adult with IDD will receive community-based services following high school. These services include job supports, vocational training, day and residential services, and respite services for families. The current average wait on the PUNS list is seven years, often making the transition out of high school more of a process of waiting than a transition (Fazio, 2019). The purpose of this study is to better understand the experiences of transition work stakeholders such as special educators, social workers, and other disability professionals as they help to facilitate access to disability services and policies after high school for young adults with IDD in Chicago.

IDD Services and Policies After High School

Services available to eligible young adults with IDD through state and federal policies after high school primarily include Supplementary Security Income (SSI), Medicaid health insurance, and Medicaid Home and Community-Based Services (HCBS). For purposes of this study, I focused specifically on SSI and Medicaid HCBS waivers as these two programs are the largest providers of Long Term Supports and Services (LTSS) and welfare cash assistance. Medicaid HCBS waivers generally include vocational and education supports, residential programs, day services, and LTSS such as home-based or institutional care for those with higher support needs. These services are limited and they are not considered entitlement programs where law requires services to those who meet the eligibility criteria. Rather, enrollment caps based on funding allocations to the waiver programs by state leave many who qualify without services. As a result, waitlists to receive services are common, creating significant barriers to access services. Anderson et. al. (2017) argue that “*Medicaid HCBS* supports would have to grow by 23% nationally to serve all of the people reported to be on a waiting list for that service” (Anderson et. al. 2017, pg. 20).

For Illinois and Chicago in particular, there is less fiscal effort toward IDD services compared to other states and the United States average (The State of the States in Developmental Disabilities Project, 2017). The total community and institutional spending for IDD services per \$1,000 of

personal income is \$2.72 compared to the national average of \$4.30. Moreover, across the U.S., “Illinois ranks 47th in federal-state waiver spending per capita” (Braddock, Hemp, and Rizollo, 2009). Given these national comparisons, it is no surprise that waitlists to receive HCBS waivers and community services are large and HCBS funding would need to increase 32% to serve all families in need (National Residential Information Systems Project, 2018).

Cash assistance provided by SSI is a means-tested program and eligible recipients must not have assets that exceed \$2,000. SSDI is considered an insurance program where the person receiving the benefits must contribute a certain amount of “work credits” to receive benefits. Both programs emphasize facilitating a path to self-sufficiency and independence through incentives to become a part of the U.S. workforce through gainful employment (Livermore, Bardos, and Katz, 2017). For this study, I will focus on the SSI program as young adults with IDD typically have not accumulated enough work credits to qualify for SSDI. While prevalence of intellectual disability in the U.S. ranges between 8.7 to 36.8 per 1,000 children depending on the diagnostic criteria, about 14% of all working-age SSI and SSDI beneficiaries are people with intellectual disabilities (Livermore, Bardos, and Katz, 2017). It is important to note that “[w]hile SSA does not collect data on “developmental disabilities,” the agency classifies SSI recipients into several diagnostic groups that may be associated with developmental disabilities (such as “developmental disorders”)” (Anderson & Hewitt, 2018). Therefore, an exact estimate of those with IDD receiving SSA benefits is unknown but surely surpasses 14%.

While the cash assistance that SSI provides is invaluable, access to these benefits proves to be challenging. Families receiving SSI for children with disabilities undergo a redetermination process after the child turns 18 years old using adult disability standards. While child criteria focus on developmental delays, the focus of adult criteria is an individual’s ability or inability to work. At this time “[a]bout one-in-three such beneficiaries lose their SSI benefits” (Wilschke, 2016). Additional barriers include low approval rates that often require decision appeals, significant processing wait times, and a need for professional and legal advocates to assist with the long process.

Research Questions

This study seeks to better understand the experiences of transition work stakeholders as they help facilitate access to disability policies and services following high school. Transition work stakeholders in this study include school social workers, disability agency professionals, medical professionals, and legal/policy disability professionals. Using qualitative case study methodology, the following specific research questions were addressed:

1. How do transition work stakeholders experience disability policies as they assist young adults with IDD and their families in accessing these programs following high school?
2. What are the challenges and successes experienced by transition work stakeholders as they assist families in this transition?
3. What barriers do transition work stakeholder face when they are facilitating the transition out of high school for young adults with IDD and their families?

Literature Review

Many publications cite the transition to early adulthood for people with disabilities from the medical perspective as a “transition of care” rather than a developmental transition to adulthood (Stewart et. al. 2010). While research examining adult transitions for populations with disabilities have primarily been embedded in medical model theory, many studies have emerged in the transition literature that focus more on the social model of disability (Osgood et al. 2005 as cited by Stewart et. al. 2010). The social model views “disability as socially constructed and a consequence of society’s lack of awareness and concern about those who may require some modifications to live full, productive lives” (Smeltzer 2007).

In shifting away from the medical model perspective, literature in the field of disability has focused on important traditional or normative adulthood markers such as employment, post-secondary education, residential independence, and social/community life (Stewart et. al. 2010). Many of these studies have used quantitative methods running associational analysis to understand predictors of adult success or challenges based on these measures. (Newman et. al. 2011; Sulewski et. al. 2012; Lindsay et. al. 2015; Sima et. al. 2014; Stewart et. al. 2010; Wehman et. al. 2014; Wittenburg & Maag 2002; Murray et. al. 2015; Mazzotti et. al. 2015).

Research specifically examining the transition to early adulthood for people with IDD and their families similarly focuses on measuring traditional adulthood markers such as employment, post-secondary education, residential independence, and social/community independence as indexes for “success” (Stewart et. al. 2010). While inquiry into these specific outcomes are crucial to the research field of early adulthood transition, favoring these research questions and policy goals can be problematic for people with more intensive support needs especially with the high prevalence of waitlists across the U.S. to access services that facilitate these outcomes. A smooth connection to appropriate services including employment, education, residential, and day services are typical markers to consider when understanding what a “successful” transition looks like from a policy perspective. Policies in place at the federal, state, and local levels lean toward these more traditional markers in measuring a “successful” transition.

As noted, on average, young adults with disabilities experience much lower rates of employment and post-secondary education up to eight years following high school as compared to the general population (Newman et. al. 2011). For young adults with IDD, these rates are much lower than many other disability categories included in the National Longitudinal Transition Study-2 (NLTS2)¹. Up to eight years following high school only 29% of students with IDD had ever been enrolled in postsecondary education program (Newman et. al. 2011). Also, Nord et al. (2013), citing the NLTS2, found that only 26% of youth and young adults were reported to be employed two years after high school.

Supportive employment and post-secondary programs have been implemented across the U.S. to address these disparities and to provide opportunities for those who have educational and vocational goals (Wehman et. al., 2014). However, Luecking and Wittenburg (2009) emphasize

¹ The National Longitudinal Transition Study-2 (NLTS2), commissioned to begin in 2001 by the U.S. Department of Education, Office of Special Education Programs (OSEP 2001-2011) and Institute of Education Sciences (IES 2000-2011), is a follow-up of the original National Longitudinal Transition Study. The original NLTS was designed and conducted by SRI International for OSEP from 1985 through 1993. NLTS2 includes 11,270 youth nationwide who were ages 13 through 16 at the start of the study (2000). Information was collected over 10 years from parents, youth, and schools and provided a national picture of the experiences and achievements of young people as they transition into early adulthood. <https://nlts2.sri.com/index.html>

that “[an] important policy concern is whether youth who receive disability cash benefits from the Social Security Administration (SSA) are obtaining the necessary supports to make a successful transition to adult life” including access to employment and education (Pg. 241). Further research and policy efforts could identify SSI recipients that may benefit from supportive employment and post-secondary education programs.

While traditional post-high school goals like employment and post-secondary education are attainable for some, they may be more difficult to access for individuals with higher support needs or families with little resources. Additionally, waitlists to access education and employment services following high school significantly slow this transition process. Much of the research and policies examining transition to early-adulthood for individuals with IDD have focused on these traditional markers especially following “The No Child Left Behind Act (2001) and the Individuals with Disabilities Education Act (2004) [which] mandated the use of evidence-based practices so that all students with disabilities graduate high school ready for employment, post-secondary education, and independent living” (Mazzotti, Test, & Mustian, 2014 as cited by Rosetti et. al., 2016, pg. 260). Again, these early adult achievements are important, but it is also important to examine how waiting to obtain access to these achievements impact the transition to adulthood.

Research Design, Methods and Data Analysis –

Using extended case study methodology, 19 transition work stakeholders who help facilitate the transition out of high school for young adults with IDD in the Chicago Metropolitan area participated in open-ended, semi-structured interviews. These stakeholders included school social workers, medical professionals, disability agency professionals, and legal/policy disability professionals (Table 1). In addition to interviews, observations were conducted at two occupational learning facilities in Chicago that specialize in providing education services to young adults with IDD from ages 18 to 22 years old. The case study approach in social science research is a bounded approach to investigating social phenomena as it looks in-depth at a specific case or set of cases (Creswell and Poth 2018; Yin 2014). For this study I conducted a case study that aims to better understand the phenomena of transitioning out of high school for people with IDD within the Chicago metropolitan area. This method is not seeking associations through closed variables; rather, it is seeking contextual and structural understanding within a bounded case or set of cases. Samuels (2009) explains that qualitative methods combined with policy analysis are foregrounded in extended case method. She explains that, “through in-depth interviews, participant observation, archival research, and political analyses, [extended case method] researchers demonstrate how theory can be expanded and improved with data from the field” (p. 1607).

Table 1: Transition Work Stakeholders

School social workers (SW)					
	Age	Race	Gender	# practice years	Chicago area
SW1	32	White	f	8	West town
SW2	32	White	f	4	Elmwood park
SW2	32	White	f	10	8 Chicago districts
SW4	23	White	f	2	Skokie
SW5	44	Black	f	21	West Englewood
Medical professionals (MP)					
	Age	Race	Gender	# Practice years	Chicago area
MP1	***	Arab American	f	30+	South/west loop
MP2	63	White	f	30+	South/west loop
MP3	***	Latino	f	10	Hyde Park
Disability agency professional (DP)					
	Age	Race	Gender	# Practice years	Chicago area
DP1	37	White	f	13	West Town
DP2	29	White	f	8	West Town
DP3	29	White	f	6	West Town
DP4	47	White	f	30	Niles
DP5	***	White	f	15	Auburn Gresham
DP6	***	White		30+	West Town
DP7	***	White		30+	West Town
Legal/policy disability professionals					
	Age	Race	Gender	# Practice years	Chicago area
LP1	23	Arab Latino	F	4	Englewood
LP2	63	White	F	30+	Loop
LP3	***	Asian American	F	30+	Loop
LP4	***	White	F	10	Austin

Recruitment and sampling –

Transition work stakeholders in the Chicago Metropolitan area over the age of 18 were recruited to participate in this study. Using non-probability purposive sampling, participants were selected from occupational learning facilities, the University of Chicago school social work email listserv, Independent Service Coordinator Agencies (ISC's), developmental pediatric departments, as well as Chicago disability legal firms. In addition to direct recruitment, Facebook ads were published targeted at disability professionals in the Chicago metropolitan area. In total, 19 transition work stakeholders were recruited for the study to participate in interviews and observations.

Interviews and Observation -

The instrument used for this study was an interview guide which asked open-ended questions and probes about the variables embedded in the research questions and how the participant experiences or has experienced each topic. The topics included: experiences supporting young adults with IDD and their families as they access disability services after high school; experiences with disability policy and service access and utility including Supplemental Security Income (SSI) and Medicaid Home and Community Based Services (HCBS); and experiences with managing and preparing for the drop in services provided by the U.S. education system. Interview participants received a \$25 Amazon gift card as a “thank you” for their participation in the study. Some participants requested that they not receive the payment. These gift cards were donated to a local disability advocacy agency in Chicago. In addition to the qualitative interviews, observations were conducted at two occupational learning facilities in Chicago that specialize in providing education services to young adults with IDD from ages 18 to 22 years. Observations included attending a “transition fair” for families as well as observing some of the interview participants as they worked at their job site.

Data Analysis –

Once interview data and observational data were collected, a comprehensive review of the interview and observations notes was conducted to begin the data analysis process. The purpose of the initial review of notes was to invoke a process of orienting to the data allowing time for reflection as the data was viewed as a whole. Once oriented to the data, analytic memos which were written following each interview and observation were reviewed. Analytic memos serve the purpose of helping the analyst move away from actively working with data to conceptualizing the data (Strauss & Corbin 2008).

The next step in the data analysis process was the examination of professionally transcribed interview transcriptions. Analysis was then conducted using Excel spreadsheet software. The analysis of the interview data involved a layered and iterative process of coding. Initial codes were created that directly reflected the interview prompt including topics of individual and agency background, experiences providing disability services, experiences providing transition services, and experiences navigating state and federal disability policies. As interviews were coded, more themes emerged such as specific challenges and/or successes with providing transition services. Additional codes were added to reflect emerging themes in the data. Finally, analysis of interview and observational data were contextualized using thematic and narrative summaries. These summaries provided descriptive synopses of the initial findings within the

interviews. Cases were analyzed separately, and case summaries were developed as a process of direct interpretation.

Findings

Findings suggest that transition work stakeholders experience significant challenges when attempting to link individuals with IDD and their families to state and federal disability policies and services. Both Medicaid HCBS waivers and SSI are difficult to access. Medicaid HCBS Waivers are limited in funding and budget cuts to the SSA have led to stricter eligibility criteria to reduce rolls. These factors result in long waits to *potentially* access these programs. The pathway to apply for and eventually receive SSI involves layers of “passing the buck” between transition work stakeholders. Experts, such as lawyers who specialize in disability policies express that legal assistance, time, and persistence are necessary. For Medicaid HCBS waivers, the average wait for services is seven years in Illinois. Therefore, access to these services including residential, vocational, and day programs may extend well beyond high school graduation. As a result, transition care stakeholders struggle to help secure a patchwork of services and supports for individuals with IDD and their families following high school.

Access to federal and state disability policies and services

Medicaid HCBS Waivers – “Waiting to get on the waitlist”

The following section focuses on transition work stakeholders experience with connecting families to adult disability services following high school. Education and state disability professionals work diligently to assist families with this process as families scramble to figure out what their child will do after high school. The first step in accessing comprehensive disability services after high school without significant financial burden is to apply for a Medicaid HCBS waiver to receive funding to pay for disability services including day supports, respite care, residential habilitation, and employment training. Barriers such as waitlists to receive service funding and strict criteria for prioritization of allocation of waivers are exposed as families attend a transition fair on the south side of Chicago.

“Waiting to get on the waitlist” – observations at the transition fair

I walk into the occupational high school on the southside of Chicago into a small gymnasium where they are setting up for their transition fair. Amber, the school counselor, tells me that this fair occurs twice a year when they host an open house and distribute report cards to their students and families. Amber generously makes me a sign, “The University of Chicago,” and includes me in the fair for the purposes of recruiting families for my research examining the transition out of high school for young adults with intellectual and developmental disabilities and their families.

The transition fair consists of several tables lined against the walls of the small gymnasium, each with a sign revealing the name of an organization that Amber invited to share information with families about their services in Chicago. The organizations include two agencies that provide community-based services for adults with IDD and their families in the Chicago area, Chicago’s Center for Disability and Elder Law, the Chicago Park District, and two tables which are devoted to the high school’s merchandise such as t-shirts and a general “check-in” table.

Finally, there are about four tables devoted to Community Service Options, Inc. In the center of the gymnasium there are chairs for families and students to sit and wait.

I ask Amber what the families and students are waiting for. She explains that they “are waiting to get on the waitlist.”

The proverbial “waitlist” or the Prioritization for Urgency of Needs for Services (PUNS) list as most families and stakeholders refer to it, is of prominent focus as it is this list that determines if and when an adult with IDD will receive community-based services following high school. Just as the PUNS list is of focus conversationally among families and stakeholders, it becomes clear that it is also a focus of this transition fair as parents continue to fill the chairs and wait.

Formal IDD services vary by state and are typically funded through a combination of private funding efforts and Medicaid Waiver funded long-term supports and services (LTSS), particularly the Medicaid Home and Community-Based (HCBS) Waivers. These services are limited and the majority of those offered are not entitlement programs where those who need them will receive them.

As noted, Illinois’ investment in HCBS services is significantly lacking compared to other states. Burke and Heller note that 20,000 people were on Illinois’ waitlist for services under the Medicaid Home and Community-Based Services waiver in 2016. In a joint statement released by the American Association on Intellectual and Developmental Disabilities and the Arc of the U.S., they declared a crisis in access to long term supports and services for people with IDD noting that “Individuals with IDD remain on waiting lists for years—in some states it can take a decade or more –after requesting necessary supports and services.”²

At the transition fair, Marianna, an Individual Service Coordinator who manages the PUNS list on the Southside of Chicago, explained that waiting for services is a long process. The only way to move up on the waitlist is if your case is deemed a crisis. I ask Marianna what constitutes an emergency for someone to be pushed up on the PUNS list. She says with a bit of disgust at the policy she works under that there are only three circumstances that are deemed an emergency; “death of their caregiver, abuse and neglect by a caregiver, and homelessness.”

Alice, the mother of a young adult with profound need for assistance with her Activities of Daily Living (ADL’s) explained that in order for her daughter to receive residential services, she was taught how to use “certain language” which illuminates her crisis to the Individual Service Coordination (ISC) agency that manages the PUNS list. Alice had to express that she will “neglect” her children if her daughter does not receive disability services. She also told them that they were at risk of homelessness if she had to quit her job to care full time for her daughter. Alice further explained that families are hesitant to use the language necessary to illuminate their case as a crisis because this incites feelings of failure as a parent.

Unfortunately, stories like these are not uncommon. Crystal, a clinical social worker and supervisor at another occupational high school on the west side of Chicago described the

² <https://www.aidd.org/news-policy/policy/position-statements/long-term-supports-and-services#:~:targetText=Individuals%20with%20IDD%20remain%20on,requesting%20necessary%20support%20and%20services.>

experience of comparing a family's hopes and goals with the grim reality of the resources available and how to get them after their child with IDD leaves the school system.

A formal 'transition' meeting is not held until a month before the student ages out. The goal of that meeting is that pretty much everything has been secured and we are all sitting down as an interdisciplinary team to talk about how we are actually transitioning the kid from special education services to the world of adulthood... typically what that meeting looks like in practice is we still don't have funding, we don't have anywhere for our kid to go, what do we do? So often times those actual transition meetings when they are almost at the transition age, um, is us trying to help the family build a case to PUNS that their kid is about to be... fall into an emergency category once they age out of the school system... but often times PUNS won't even listen to you until you are in a crisis state and so, um, really that's how 95% of our families experience PUNS is unless there's an emergency and they're actively in crisis, they are not going to get funding or services and you have to really prove an emergency... a lot of parents don't want to say that their kid is being abused or neglected, that is a really intense thing to have to do, like, advocate for that your child is going to be abused or neglected if they don't get services.

While the wait for people with IDD to receive services following high school is pervasive across Illinois, poor families on the South and West sides of Chicago experience a profound burden, given the dual struggle with experiencing poverty while advocating for and coordinating disability accommodations and services. While I explain my research to a mother of a student with IDD, she says shaking her head back and forth, "I just don't know what I am going to do. I just don't know." Her son will be "aging out" of the education system in 2020 and she did not find out about the PUNS list until she came to this high school when her son turned 18 years old.

Children can be added to the PUNS list at any age with a diagnosis of a developmental disability in Illinois. Once the child is on the PUNS list, they must renew their information every year or they will be dropped from the list. Amber explains to me that it is not uncommon for families to be unaware of the PUNS list when their student arrives at a transition high school when they turn 18 years old. I ask her if she had a rough estimate of how many and she tells me "it's bad... I'd say about 75%." Amber further explains that some of her students will never be approved for services and many will have to wait well into their 30s before their name is pulled on the PUNS list. I ask Amber why families do not know about the PUNS list. She believes that it has to do with lack of education and knowledge disseminated to poor families in Chicago through the public-school system and outreach efforts.

Accessing and waiting for community services following high school is just one significant hurdle families face when aging out of education services at the age of 22. In addition to this complicated and sometimes grueling process, many families are also trying to access other disability benefits like SSI. Unlike the Medicaid HCBS PUNS list, many transition work stakeholders are not directly involved with assisting families with applying for SSI benefits. Reasons cited include the complicated application process, having too much already on their plate, and lacking basic knowledge of the program.

Supplemental Security Insurance (SSI)

Administrative Access Challenges

Applying for SSI/SSDI benefits can be a challenging and time-consuming process that frequently involves multiple appeals and federal court hearings to determine eligibility. About 70% of applications are initially denied. “After all levels of appeal, less than half of all applications to SSA for disability benefits ultimately are approved” (Lang, 2020). Additionally, the average waiting time from requesting a hearing date until the actual hearing ranges between seven months to two years, varying by district³. Administrative challenges such as complicated application and filing procedures, recent declines in SSA’s operating budget, as well as the redetermination process from children SSI to adult SSI cause significant barriers for young adults with IDD access SSI benefits.

One reason for the difficulty in accessing this federal benefit program is attributed to the strict and complicated medical criteria to be legally considered “disabled” to the extent that one cannot participate in “substantial gainful activity.”⁴ Evelyn, a disability legal stakeholder located in downtown Chicago who has worked on SSI cases for over 40 years affirmed people face substantial challenges in accessing SSI benefits especially if there is any room for a subjective interpretation of their medical records. In fact, because applying for SSA can be so complicated, she started offering services with the application process as well as the appeals process in 2008 following the economic crash. She explained they used to only take clients that had been denied twice;

We didn’t represent anyone normally unless there had been two denials...uh... by the government, we would say to these people ‘ya know what, you don’t need lawyers for this, this is a public benefit or an insurance entitlement. Just go get it and if you are denied twice, you might need a lawyer’...[but] I completely changed my thinking on that 12 years ago, now.

According to Evelyn, before the recession, disability lawyers were winning a lot of their appeals and SSA was moving along well. However, when the market collapsed in 2008, everything tightened up and her firms allowance rate plummeted from about 85%-95% to less than 15% approvals after all appeals.

In addition to the complicated application and appeals procedures, Social Security Administration’s “operating budget fell nearly 9% between 2010 and 2018, after adjusting for inflation — even as the number of beneficiaries (including retirement, survivors, and disability benefits) grew by nearly 15%” (Romig 2018). Consequently, administrative budgets cuts have led to longer waits and processing times. Many families cite complications using the online application as they are almost always directed to visit their local SSA office. In person office visits can also be a significant burden for families who may need to take a day off from work to speak with an SSA worker. Evelyn explains that many cases where eligibility may be subjective involves multiple appeals and federal court hearing before they can remedy or close.

Typically it’s a matter of months to get a decision on an application, [then] a matter of months to get a reconsideration decision, and anywhere from 8 months to a year and a half to get a hearing, few months to get a decision after a hearing, although that’s getting

³ https://www.ssa.gov/appeals/DataSets/01_NetStat_Report.html

⁴ <https://www.ssa.gov/ssi/text-eligibility-ussi.htm>

shorter, could be months to two years at the appeals council, 12-24 months in federal court. If we prevail in federal court we get a remand which is a re-do so we are back before the agency, that can take another year and sometimes we have to go back to federal court...And so that is why some cases are with us for 5, 6, 7, 8 years.

Another challenge occurs when a young adult ages out of children's SSI at the age of 18 criteria. Families receiving SSI for children with disabilities undergo a redetermination process after the child turns 18 years old using adult disability standards. "About one-in-three such beneficiaries lose their SSI benefits" (Wilschke, 2016). This could be attributed to the challenges noted above as well the change in disability criteria from a child to an adult where the ability to participate in substantial gainful activity in the U.S. economy is emphasized. Evelyn explained that in the last decade there has been a surplus of middle-class families hiring her to represent them as their child with IDD ages out of the children's SSI at the age of 18. These families had either tried and failed at applying for SSI or they did not want to take on the burden of completing an application without help from an expert.

Passing the Buck at the Street Level "not our turf"

Due to the significant administrative access challenges, it is not surprising that the transition work stakeholder from education and state agencies interviewed for this study did not tread deeply into assisting families with accessing SSI adult benefits. Previous studies have noted that education professionals do not feel they are knowledgeable enough to assist with the process due to the complexity of the application process and they will refer families to their local SSA office (Johnson, McEathron, Fields, & Hill, 2007). Similarly, transition work stakeholders in Chicago explain that providing assistance with accessing SSI benefits is not their priority as they do not know enough about the program and their plate is already full with the services they are already providing.

The transition work stakeholders who worked within various public education settings in the Chicago area such as social workers and education administrators explained that they typically do not provide assistance with the SSI application process. Some workers did provide referrals to the local SSA Office or a disability legal professional if parents inquired, but this was not a professional expectation. Rather it was by the discretion of the stakeholder in agreement with other education professionals. Lara, a school social worker explained that applying for SSI is "not our turf," as it does not relate directly to the education and training services they provide. Lara also explained that she has a large case load of students with Individualized Education Plans (IEP's) and keeping up with demands of paperwork, family communication, as well as student interaction is challenging enough.

Crystal, who previously described the grim realities of the formal transition meeting, explains the SSI and Medicaid applications are not their priority.

Our biggest push is PUNS...knowing that it is an average 15 year waitlist unless they are in crisis, we want them as early as five [to get them on the list]... social workers do help with like getting on Medicaid and receiving SSI but more from just connecting to the appropriate places to do that, sharing the applications and such, um... the primary role of the school social worker is to provide services to the student and school.

Similarly, other state contracted agencies including service linkage agencies and contracted education facilities had little experience or professional expectation to assist with the SSI application process. Adia, an employee at a contracted state agency that administers Pre-Admission Screening (PAS) for disability services on the south side of Chicago, explained that they provide assessments and linkages to disability services. However, she emphasized that they do not assist with SSI applications. When I probed further about how families access information and assistance with the SSI application process, she stated that she is not sure and that their agency is overworked and understaffed. Therefore, they stick to their mission of determining eligibility for services and to educate families about the disability services available to them.

Stakeholders from another contracted state agency on the west side of Chicago similarly had little experience with assisting families with their SSI applications. This education agency is an Illinois state Board of Education (ISBE) approved program that allows them to provide education services to children and young adults with IDD with an emphasis on emotional disabilities, ages 5-21 years old. They recently received a grant to create a transition program for students who will be transitioning out of high school. When talking with the newly hired transition specialist, Carrie explained that she is creating a program to provide vocational and daily living skills training to students 18-21 years old adding that she does not work with families to access services after high school. She explained that this is the job of the school social workers who manage the IEP meetings. When speaking to social worker, Anne, at this therapeutic day school, she did emphasize they help families connect with disability services after high school. However, the SSI program was not always something discussed at the student's IEP transition meetings. She also stated that she is not knowledgeable about the application process, but has referred families who are struggling financially to visit the Social Security Office.

So how do families access information regarding SSI benefits? Based on observations and interviews with transition work stakeholders in Chicago, there is not an obvious streamlined process in access to information to apply for and receive benefits outside referrals to local SSA offices. Families cite difficulty in navigating the online application and most of the time part way through the application, applicants are directed to visit the office in person. In person office visits can also be a significant burden for families who do not have the resources to take time off from work. For benefits requires gathering of extensive medical records, knowledge of language that should be used to access benefits, time, patience, and often times legal assistance and persistence through appeals processes.

Discussion and Conclusion –

This study examining transition work stakeholders' experiences with state and federal disability policies sheds light on potential policy and service gaps that lead to undesirable and sometimes crisis circumstances especially for low-income families. As professional stakeholders help to facilitate access to disability policies and programs for young adults with IDD and their families, they experience significant challenges.

For SSI benefits, the complicated application process deterred almost all education and state transition stakeholders from engaging with the program. They felt that they were not knowledgeable enough and did not have the time to assist families with their SSI applications. They would often refer them to legal aids or their local SSA office for assistance. It is not surprising that education and state transition work stakeholders avoid engagement with the SSI

program as administrative access barriers result in only 30% of initial applications being approved and only about 50% of applications are approved after all appeals. Even in the hands of legal experts, challenges such as complicated application and filing procedures, recent declines in SSA's operating budget, as well as the redetermination process are difficult to overcome.

Access to adult disability services after high school also pose significant challenges for transition work stakeholders. In order to access these services without significant out-of-pocket costs to families, young adults must apply for a Medicaid HCBS Waiver. The average wait to receive a waiver in the state of Illinois is about seven years and families are required to re-register every year or they will lose their spot on the PUNs list. If a family is experiencing a crisis, they may have the opportunity to move up on the list. However, crisis criteria are strict and families are typically not comfortable using the access language required to deem their case a crisis. Finally, many families fall through the cracks and do not become aware of the PUNs list until their child turns 18. Therefore, these individuals may have to wait well into their thirties to receive services.

The significant wait to access Medicaid HCBS services in Illinois highlights the need for a substantial increase in fiscal effort toward IDD services. Additionally, transition programs that provide cash assistance while families wait for services could alleviate some of the burden families experience with unemployment and economic insecurity during this time. Another challenge in access to cash assistance through the SSA could be eased by connecting families and schools directly to legal assistance as part of an additional mandate provided through the Individuals with Disabilities Education Act (IDEA, 1990).

Policy Implications

Expansion of SOAR

The SSI/SSDI Outreach, Access, and Recovery (SOAR) program established by the Substance Abuse and Mental Health Services Administration (SAMHSA) is a program "helping states and communities increase access to SSI and SSDI for adults with disabilities who are homeless or at risk for homelessness" (Dennis et. al., 2011, p. 1373). The Illinois SOAR website explains that the "SOAR process trains caseworkers in a proactive approach to the [SSI/SSDI] application process that engages the client and reduces the days to decision while increasing approval rate." An evaluation examining 37 states that adopted the SOAR program found that 73% of applications they were processing through the program were approved compared to an initial approval rate of 10% for this population (Dennis et. al., 2011). If expanded to target populations with IDD transitioning out of high school, access to SSI benefits may become a more streamlined process for transition work stakeholders and families alike. Partnering SOAR with PAS agencies and occupational learning facilities is an important step in connecting professionals and families with the assistance they need to access their SSI benefits.

Expansion of children's SSI to age 22

"There are inconsistencies in the age definition for youth, as child SSI benefits expire at age 18, while coverage for other programs, such as IDEA, continue through to age 22" (Wittenburg & Loprest, 2006). The misalignment of these policies can cause significant challenges for young adults with IDD. The criteria of what determines if an individual is disabled under the SSA standards changes when a child turns 18 years old. Therefore, those who are receiving children's

SSA benefits must apply under the adult standards of disability. The major change in eligibility when a child becomes an adult is that their disability must “result in the inability to do any substantial gainful activity.”⁵ At this time, young adults with IDD must reapply for benefits under the adult standards even though they are still receiving education services and are unable to work. As cited, the application process is complicated and time consuming and often takes several months to process. This becomes a significant burden for low income adults with IDD who are still receiving education services. Also, education services for young adults, 18-22, with IDD provided at occupational learning facilities are typically focused on daily living skills and vocational training. It is during this time, that adults with IDD are preparing to enter the workforce to best of their capacity after turning 22. Aligning IDEA and adult SSI policies would ease family financial burden while young adults with IDD finish their education.

Cash assistance for low-income families waiting for services

Access to adult disability services for individuals with IDD is often fraught with long waitlists to receive Medicaid HCBS Waivers to help pay for vocational, day, and residential services. The average wait in Illinois is seven years. As young adults with IDD exit high school, families often scramble to piece together a patchwork of supports as they wait for access to services. During this time, families can experience significant financial burden as they coordinate care for their young adult with IDD. While families are waiting to access services, cash assistance for these families to help pay for respite and other home-based care should be considered so that caregivers can continue to work and provide for their families.

Limitations.

This is a case study where a particular phenomenon is examined within a closed case or set of cases within a policy and historical context. Therefore, these findings are not representative of the IDD population. Transition work stakeholder experiences with disability policies will invariably differ depending on geographical, political, and historical contexts. This study provides a unique look into how disability policies are experienced at the street-level in the Chicago metropolitan area.

⁵ <https://www.ssa.gov/ssi/text-eligibility-ussi.htm#disabled-child>

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