

**“My Hands are Really Tied in so Many Ways”: How Children Both Constrain
and Motivate the Labor Force Participation of Mothers with Disabilities**

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Abstract. Although women's employment rates are negatively impacted by both the presence of children (Gangl and Ziefle 2009; Killewald and García-Manglano 2016) and the presence of a disability (Bureau of Labor Statistics 2021), these distinct statuses have largely been explored in isolation from each other. Therefore, little is known about women who live with a disability while simultaneously raising children. One notable exception is recent analysis by Amorim (2019), which revealed that mothers with a disability are 10.5% *more* likely to be in the labor force than similar non-mothers without a disability. This research employed in-depth interviews with 32 current and former disability benefit recipients to explore possible sources of this contradiction.

Findings indicate that while mothers with disabilities are far from a homogenous group, children impact their lived experience in ways that in turn influence their labor market behaviors. Motherhood served as both a motivation for and a constraint to pursuing employment, with variation based on the severity of the mother's disability and her financial circumstances, labor market prospects, and childcare needs. While children increase household expenses and frequently motivate wage-earning via employment, mothers with disabilities are simultaneously constricted by caretaking responsibilities and heightened fears of jeopardizing their benefit. These barriers mean that survey-based self-reports of work-seeking and employment behaviors fail to capture the difficulties mothers with disabilities face as they translate a desire (or need) to work into locating and then securing employment.

Given the role that waged work can play in ameliorating the robust connection between disability and poverty (Pettinicchio and Maroto 2017), identifying the factors that motivate and constrain disabled mothers' work decisions is a crucial prerequisite for effectively facilitating rehabilitation back into the labor force. The report concludes with recommendations for programs and policies that could more most effectively facilitate these mothers' re-engagement with the labor market.

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LITERATURE REVIEW

The Disability Benefit System

The Social Security Administration (SSA) provides benefits for individuals with disabilities through two distinct programs: The Social Security Disability Insurance (SSDI) program and the Supplemental Security Income (SSI) program. Individuals with a history of paid employment are eligible for SSDI, which is financed primarily by payroll tax contributions¹. SSI, in contrast, is designed for individuals with sparse or no work histories who have little income and few assets. The SSI benefit is set at 75% of the Federal Poverty Threshold, or \$794 a month for an individual in 2021. Individuals who receive disability benefits have lower labor force participation rates than the general public without disabilities (Bureau of Labor Statistics 2021) and, given the paucity of these benefits, disability recipients experience higher rates of poverty than similar individuals without disabilities (DeNavas-Walt and Proctor 2015).

Because not all forms of disability preclude employment entirely, the SSA encourages rehabilitation back to work (Mamun 2011), allowing individuals receiving disability benefits to earn income up to a threshold considered "substantial gainful employment" (SGA). SSI benefits are gradually reduced as individuals earn income, and then cut altogether when an individual's monthly income surpasses the SGA threshold of \$783 (or \$1,175 for a married couple). SSDI benefits, on the other hand, remain consistent until an individual's earnings exceed the SGA threshold of \$1,260 a month. Some economists have argued that these income thresholds serve to disincentivize employment. By comparing SSDI beneficiaries to similar individuals who receive benefits through the Veteran's Affairs disability system, which has no SGA income limits, researchers estimated that removing earnings thresholds would increase SSDI beneficiaries' employment rates by 16% and raise their incomes by up to \$22,500 (May et al. 2019).

Mothers' Labor Force Participation

The percentage of women who return to paid employment within one year of their first birth has skyrocketed from 17% in 1965 to 64% in 2007 (Laughlin 2011), and 71% of American mothers with a child under the age of 18 now work for pay (Bureau of Labor Statistics 2014). However, women continue to bear a disproportionate responsibility for child rearing (Milkie, Raley, and Bianchi 2016), and public policies for working families such as paid parental leave or subsidized childcare remain "virtually non-existent" (Williams 2010). The competing obligations to work and to family cause American mothers to work fewer hours than non-mothers (Budig and

¹ The average 2019 benefit of \$1,236 a month equates to only about half of a worker's previous average monthly earnings (Center on Budget and Policy Priorities 2021)

England 2001; Yu and Kuo 2017), take employment breaks for childbearing (Budig and England 2001), and more frequently change employers (Aisenbrey, Evertsson, and Grunow 2009)—all of which reduce human capital and suppress earnings.

The resultant wage and career consequences that women with children experience have been called the “motherhood penalty” (Budig & England, 2001). These negative financial impacts of motherhood are disproportionately larger for women who already experience disadvantages in the labor market: unmarried mothers (Gangl and Ziefle 2009; Pal and Waldfogel 2016), those with lower levels of education (Amuedo-Dorantes and Kimmel 2005; Pal and Waldfogel 2016), and Black mothers as opposed to White mothers (Pal and Waldfogel 2016).

Mothers with Disabilities in the Labor Force

Women with disabilities are said to face a “double-handicap” of occupying two concurrent minority statuses (Deegan et al. 1985), and they are more than twice as likely to live in poverty than women without disabilities (Bleiweis 2020). Despite the documented impacts of motherhood on women’s paid work, the SSA does not collect data on how many of its beneficiaries are actively parenting children. In fact, the axis of parenthood is largely absent from the extensive body of research dedicated to individuals with disabilities and their labor force participation. One exception is Amorim’s (2019) analysis of data from the Current Population Survey and the National Survey of Beneficiaries, which revealed that mothers with a disability are 10.5% *more* likely to be in the labor force (either employed or looking to work) than comparable non-mothers with a disability. Among women with disabilities who are in the labor force, having a child is associated with decreased likelihood of having a job for SSDI recipients, but with an increased likelihood of having a job for SSI recipients. Mothers with disabilities experienced lower employment rates and lower earnings than similar women without children across all benefit types.

RESEARCH QUESTIONS

Amorim’s findings suggest that motherhood might operate differently for women with disabilities than it does for the population of mothers without disabilities. Yet it remains unclear how motherhood shapes job-seeking behaviors, employment opportunities, or job retention for women with disabilities who receive either SSI or SSDI benefits. Also unknown are the barriers to working uniquely experienced by mothers with disabilities. To address these gaps in the literature, I conducted in-depth interviews with mothers who were current or former SSI or SSDI recipients to answer the following research questions:

- #1:** How do children shape the labor market behaviors of mothers with disabilities—from decisions about pursuing work to locating suitable employment?
- #2:** What additional resources and accommodations might facilitate mothers with disabilities returning to work?

While quantitative data is useful for uncovering patterns and trends within a large population, qualitative methods are better suited for understanding the processes that motivate individuals’

decisions and behaviors and the way that multiple factors interact as they do so. For example, mothers with disabilities are more likely than non-mothers with disabilities to say they cannot work because they are taking care of someone (*National Beneficiary Survey: Disability Statistics, 2015, 2018*). Interviews can then be employed to build upon such a finding, shedding light on *how* caretaking is experienced as a barrier, and how other challenges faced specifically by mothers might come to bear on their work-related decisions.

METHODS

This research employed in-depth, semi-structured interviews with 32 mothers who either currently or formerly received SSI or SSDI benefits for a disability. Prior to recruiting participants, a comprehensive outline of the research plan was submitted to the Institutional Review Board at Washington State University, who classified the project as Exempt Research. Volunteers read and signed a detailed informed consent document prior to their participation.

Sample

I employed a targeted, nonprobability sampling approach to recruit interviewees. My recruitment efforts took place in the Spring and Summer of 2020, when the Covid-19 pandemic had closed most in-person services at SSA offices as well as other support centers for disability recipients. Given these constraints, I pivoted my recruitment efforts to online platforms. I asked several offices and agencies that served disability recipients to share a flier advertising the survey in the electronic communications they disseminated to clients. I posted the same flier in several Facebook groups dedicated to individuals with disabilities. Finally, I advertised the project in the “gigs” section of several metropolitan Craigslist sites.

I incentivized participation in two ways: 1) I offered participants \$40 to compensate for their time, and 2) I framed the research as an opportunity to share their experiences and potentially help initiate change within the disability benefit system. Comments from interviewees suggest that the financial incentive was highly motivating; women frequently referenced how they planned to spend the \$40: fixing a broken cell phone screen, buying a birthday present, or making a payment on a credit card.

The flier directed interested participants to a brief online form that served to confirm they were eligible for inclusion. The form collected basic information about their disability, how long they had received benefits, their current labor market status, and a handful of demographic and household characteristics. The screening form concluded by requiring a signature in response to the informed consent form. I intended to use the screening criteria to select a diverse sample, but I achieved diversity across various characteristics organically as I responded to each eligible volunteer in the order their submission was received.

After initially obtaining few responses from *former* disability recipients. I re-designed the flier to specify that I was looking for “former beneficiaries” and placed a Craigslist ad with the revised request. This effort garnered only two additional volunteers, a limitation I discuss later in the report. In total, 55 women completed the screening form, 8 were ineligible for inclusion, and the remaining 15 not included in the sample either failed to show up for interviews as scheduled or failed to respond to my scheduling attempts.

Although I allowed women to self-identify as mothers whether children were theirs biologically or through adoption or step-parenting, the mothers I spoke with were all parenting their own biological children. I limited my sample to mothers who had children 18 years old or younger and whose children resided in the same house with them at least 50% of the time because I was specifically interested in the way that caretaking responsibilities might influence labor force behaviors. I sought mothers with disabilities who either currently received SSI or SSDI benefits, or had received such benefits within the last five years. Including mothers who had formerly utilized benefits allowed for identification of the supports they credited with their successful transitions away from receiving benefits. Because I was exploring the specific experience of being a mother while navigating the disability benefit system, I excluded former recipients who were not mothers at the time when they received benefits.

Table 1 illustrates the demographic characteristics of my final sample of 32 mothers. More than half (N=20) were current SSDI recipients, five were receiving only SSI, four received a combination of SSI and SSDI, and three were former beneficiaries. The sample was equally split between single and married or cohabiting mothers. Nearly 60% of the sample reported household incomes of less than \$25,000. Roughly half the sample was White, one-third was Black, and 81% was non-Hispanic. Eighteen of the women reported hearing about the project from a Craigslist ad (placed in Atlanta, GA; Philadelphia, PA; Seattle, WA; Los Angeles, CA); six saw the flier in a disability support group Facebook page; and the remaining eight participants had seen the flier via local (Eastern Washington/North Idaho) community organization bulletin boards and email lists. Table 2 outlines each participants' pseudonym, select demographic characteristics, and their current work status.

Procedures

Interviews were conducted between August and October of 2020. The social distancing requirements of Covid-19 meant that interviews were conducted either over the phone or via Zoom video calling—whichever respondents preferred. Fewer than 20% of the volunteers opted for a Zoom interview; most interviews were conducted over a Google voice line and audio recorded. While qualitative researchers generally prefer in-person interviews because they facilitate the observation of non-verbal cues and body language, several participants who dealt with anxiety and post-traumatic stress disorders noted that phone interviews allowed them to converse more comfortably than an in-person interview might have. Two participants explicitly mentioned that they would never have volunteered to be interviewed in person.

Interviews conducted via Zoom allowed for more observation of interviewees' body language, their living spaces, and often their children, who made several spontaneous appearances. At the conclusion of each interview, I wrote field notes about the call, my initial impressions of the interviewee and their narrative, and any sense I had about the undertone of the conversation: Did they seem tired or defensive? Did we establish a comfortable rapport, or did I sense that they were holding back information? I referred to these field notes repeatedly as I interpreted and coded interviews in the later stages of data analysis.

I prefaced each interview by explaining that while my research was funded by a grant from the Social Security Administration, I was concerned only with generating an honest account of the

lived experiences of mothers with disabilities, and did not represent the SSA in any way. I explained that my past research efforts had explored how children influence the work paths of mothers, and that I was curious to see how women with disabilities were similarly or differentially influenced by their concurrent roles as mothers. Women frequently began our conversations with apologetic disclaimers that their children were out of school and thus underfoot; I used my own position as a mother to generate a sense of commiseration (“my three kids are home, too!”) and increase trust. I believe this preface helped reassure interviewees of my neutrality and encouraged more honest disclosure. Zoom interviews were video recorded and telephone interviews were audio recorded. On average, interviews lasted 50-60 minutes; the shortest lasted only 35 minutes and a few others spanned upwards of two hours.

Interviews were guided with a semi-structured protocol designed to elicit how motherhood and its accompanying caretaking responsibilities influence the labor market activities of women with disabilities. Each interview began with an open-ended question about the individual’s experience prior to and across the onset or development of the disability. Further questions probed about how the presence of children influenced their plans to pursue paid work, their overall experiences in the disability system, and their ideas for how mothers with disabilities could be better supported by the SSA.

Data Analysis

Every interview was transcribed verbatim from the audio recording—roughly 80% by me personally and the remaining 20% by a paid transcription service. The transcriptions were uploaded into the qualitative software program NVivo.

I employed Charmaz’s (2006) grounded theory approach of letting the data dictate the codes I created. This inductive process began by reading every transcript in its entirety while open-coding recurring words, themes, and ideas that emerged. At this stage, codes were as broad as *Challenges*, *Supporting strategies*, and *the SSA system*. After making these preliminary decisions about the data, I re-approached the data in a second phase of focused coding. In this more concentrated reading of the transcripts, I created sub-codes that more closely captured distinct ideas and themes. During a third reading of the transcripts, I continued to combine and refine existing codes as well as create new codes when concepts emerged that did not fit into the already-established framework. Through this on-going dialogue with the data and the careful, systematic, and repeated reading of every transcript, a code that began as broadly as *influence of children* ended with eight sub-categories including *being a ‘good mom’* and as *impediment to work*. The *impediment to work* category was further distilled into three distinct categories of how children specifically impeded work: *covid complications*, *childcare*, and *disabled/special-needs*.

RESULTS

The Lived Experience of Mothering with a Disability

It became apparent, as I conducted interviews, that motherhood influences the lived experience of women with disabilities in ways that *in turn* influence their labor market decisions and behaviors. Three themes emerged as challenges that mothers with disabilities uniquely face: (i) the insufficiency of the benefit amount for supporting a family; (ii) the difficulty of caring for children while balancing the limits of their disability; (iii) and the added sense of responsibility

that children create in women's lives. While poverty rates are high among SSI and SSDI beneficiaries across the board, the increased household size of women with children exacerbates this struggle. Claudia, a White mother of two, was a college student studying business when she was brutally assaulted. Because her work history was limited at the time of the assault, her SSDI benefit is supplemented by SSI. She recalled how the benefit amount felt adequate prior to the arrival of her son: "Back then I was probably getting like \$750 a month. That was managing me ok, I could pay my bills, still have a little bit left over. I was okay . . . I was just taking care of *me* on that." Later in our conversation, however, I asked Claudia what she wished the SSA understood about her circumstances. She responded:

I just wish . . . they could just imagine trying to live off of \$799 a month. If they could just imagine that, then that really says it all right there . . . Trying to raise a child! . . . [T]his person is highly dependent upon me for *everything*, and I have \$799 a month to make it happen. . . [A]nything for myself is completely out the window.

A theme of "kids are expensive!" permeated most interviews. Women with babies spoke of the cost of diapers and formula, while mothers of teens lamented how growth spurts and fashion conscientiousness strained clothing budgets. Linda, a White, single mom of four who receives \$1,700 in SSDI payments as a result of an accident explained: "I mean, the kids, they can go two and three sizes on their shoes and it's like . . . they don't even want to go outside unless they're wearing Vans or Adidas so that people aren't laughing at them."

While the children of SSDI recipients are eligible for dependent benefits, the children of women receiving SSI are not eligible for additional support. Nearly half of my sample (N=14) was living exclusively on their benefit amount, without additional financial support from the wages or child support of a husband, partner, or their children's father(s). References to financial challenges were woven throughout nearly every interview, but the mothers who lived exclusively on their disability checks seemed to experience the most notable poverty. Three such interviewees had experienced homelessness as mothers.

The second theme referred to the balancing act required to care for children while simultaneously managing the challenges posed by their disability. Three mothers mentioned both personal and anecdotal accounts of SSA judges taking parenting status into account as they made determinations about whether an applicant was truly disabled, inferring that the act of mothering children (especially young children) was evidence that women might be capable of working after all. Taking issue with this logic, these mothers explained that they had little choice but to accommodate the demands of children—often at the expense of their health. Sharon explained:

My judge did ask me what I do in the morning and the first thing that I said: "I give my daughter her iPad," because she was young at the time . . . [C]ause it was hard for me to get up in the morning, I gave her the iPad and she would sit there on her iPad until I was able to wake up . . . Just because I'm parenting, doesn't mean that I'm running around.

These challenges of providing care in a context of disability were even more pronounced for women whose children had disabilities of their own (N=3), and for unpartnered mothers who shouldered the caretaking burdens without the support of another adult in the household (N=16).

Finally, nearly every interviewee spoke of the strain they felt balancing a desire to be a “good mom” against a backdrop of disability-related limitations. Mothers were acutely aware of the negative impacts that their disabilities had on their children, speaking defeatedly at times about how their disabilities kept them in bed or precluded them from attending events. SSDI recipients disabled as the result of an accident mentioned how children were adversely affected by the dramatic reductions in their overall standard of living as paychecks were replaced with (much smaller) benefit checks. In five instances, the onset of disability was cited as the impetus for a couples’ divorce—further reducing household income.

The presence of children also increased mothers’ fears about jeopardizing their benefits (and health insurance) by earning too much in a paid job and being subsequently deemed no longer disabled. Like many mothers, Claudia spoke of prioritizing her children above everything else: “If I go back to work, I lose my insurance. I might get insurance through a job, but I might not. It’s a really, really scary process to think of. I couldn’t take care of my child if I can’t function . . . That’s the most important thing to me is taking care of the girl.”

In contrast, other mothers spoke passionately about doing anything necessary to ensure their children were taken care of. For these mothers, children created additional responsibility that prompted their pursuit of additional income—both waged work as well as under the table forms of income generation. Deja, a married Black mother who receives SSDI benefits for anxiety and depression as well as benefits for her 3-year-old son with autism, recalled a stressful period where a bureaucratic error had caused her to lose benefits for two months. When I asked how she managed to survive without her income, she began talking but then abruptly interrupted herself to ask me whether the SSA would be reading my report. Despite assurances that I would only be reporting my findings in the aggregate, and with complete anonymity, she responded:

Yeah. I’m not gonna share a certain thing, but thank God, you know, I made it through that. I was cut off for . . . maybe like almost two months—and two months with a child! Oh my God. But I survived though. Like I said, I’m not gonna reveal it. Nope. Nope. I’m not going to talk too much. But I—I did survive. Moms do what they have to do.

Mothers’ Labor Market Decisions

For the 22 mothers in my sample who were not currently employed, decisions about whether to pursue paid work varied along four different axes: (i) severity of disability, (ii) availability of household resources, (iii) labor market prospects, and (iv) the needs versus supports available for childcare. For women with severe disabilities (those likely classified by the SSA as “improvement not expected”), decisions about future labor market participation were dictated primarily by their disabilities. Seven mothers fell into this category, where motherhood status played little or no role in their employment-related plans; rather, their disabilities made it unlikely they would ever be able to work. As Linda, a White, single mom to four kids living on SSDI benefit as a result of an injury explained, “I’m not going to grow a new spine.” Notably, the majority (N=5 of the 7) of women who suspected they would never work again were SSDI beneficiaries whose household incomes were higher than the sample average either because of a partner’s earnings and/or their higher benefit amounts (which stem from more extensive and/or higher-earning work histories).

Fifteen of the 22 mothers in the sample who were not currently working indicated they were either looking for work (N=9) or hoped to return to work in the future (N=6). While one's ability to perform paid work, given the limitations of their disability, was commonly the first consideration these women raised as they discussed future work plans, at times financial need trumped a woman's physical or emotional ability to work. Several women described trying to work, despite knowing it might exacerbate an injury or set back their progress in healing. As I explained to Ashley that the research was designed to examine why mothers with disabilities might have higher labor force participation rates than non-mothers, she interrupted me to state matter-of-factly "that's out of necessity, I'm sure." Single mothers were especially likely to cite financial need as a primary motivator for pursuing paid work—almost regardless of whether doing so was in the best interest of their disability.

When deciding whether to pursue employment, women's financial needs were counterbalanced by their labor market prospects, which were in turn heavily dictated by education level and past labor market experience. In cases where the conditions of their disability might allow for it and financial need really necessitated it, some women still found themselves in a predicament where the amount they would likely earn via employment was insufficient to make employment feel "worth it." Among SSI recipients with typically lower levels of education and work experience, paid work options were less lucrative. Coupled with the fact that SSI benefits are gradually reduced as income is earned, it is perhaps unsurprising that SSI beneficiaries were more likely to report that they were "looking for work," but without any evidence of proactive job searching. Danielle is a Black, single mom with one grown daughter and a 17-year-old son she supports with her \$740 monthly SSI check in a metropolitan area. As a victim of childhood trauma and with a diagnosis of bipolar disorder, she has been on SSI since she was 15 and has never worked consistently. When discussing options for future work she explained how her limited labor market prospects influence her motivation:

They [SSA] do offer like job trainings and stuff like that. But, you know, they are really, really minimum wage jobs that, you know, they won't pay—they won't help me with bills, they won't even help me with groceries. So, you know, I don't even bother, honestly.

While this statement ignores the fact that even a minimum wage job *would*, in fact, serve to increase her household resources, it captures a not-uncommon sentiment of hopelessness echoed by many of the poorest women I spoke to. Despite clear financial need, the threat of benefit reduction or loss coupled with the challenges of her disability and the low-wage she expects she would earn tips the scales away from Danielle "bothering with" job-seeking.

The final consideration that women weighed in their decision-making about pursuing or considering paid work—and the factor most related to the project's focus on the role of motherhood—was childcare. When faced with a mismatch between childcare needs and outside support for meeting those needs, motherhood became a highly salient decision-making factor. Naomi, a White, single mom to a 12-year-old son who has received SSDI since a car accident nearly two years ago left her quadriplegic, explains:

We live on a very tight budget and going back to work... I do want to go back to work. I'm trying to figure it out, but at the same time, . . . I don't know. It's . . . very difficult. . . . I'm already limited on what I can do [as a quadriplegic], but . . . it's just really difficult finding a career or job

path that also meets . . . I'm the only one that's home. He doesn't have a dad at home. I need to make sure I'm there for homework and keeping him on track and making sure he's not . . . getting on YouTube or whatever all the time. . . . It's—not only are you limited on what you can do, but it's just . . . everything. <defeatedly>

The women for whom motherhood was most constrictive were those with younger children whose low levels of education and employment-related skills limited their potential earnings and tipped the scales to where it simply would not make sense to pay for childcare. In addition, several mothers of young children cited a distrust of formal childcare. Women with older children were less likely to specifically cite their children—particularly their need for care—in their decision-making processes about pursuing paid work. When mothers had access to childcare (typically through friends and relatives) or had children who were old enough to require less care, their labor force calculations were centered less on children and more on potential earnings. In cases where caretaking needs were high and not outweighed by the earnings women could realistically expect via employment, then mothers were more likely to report that they were “not working, not looking for work.”

Disability severity, financial resources, labor market prospects, and childcare needs all interacted to create wide variation in the costs and opportunities of women pursuing employment. Considered together, the salience of motherhood in decisions about whether women with disabilities pursue paid work varies depending on circumstances. After first considering their disability, women next seem to consider the financial necessity of work based on the other sources of household income, the cost of living in their area, and other social supports they may receive (such as food stamps or subsidized housing). When financial need dictates it and disability allows for it, women next weigh the costs of employment against the potential benefits that employment might confer. It is at this point in the decision-making process that motherhood most often enters the picture.

For mothers with younger children in particular, caretaking needs present an additional cost to possible employment, both materially and emotionally. Unless women had access to outside childcare support—either through subsidized childcare or a partner/family member/friend available to provide childcare—then mothers were constrained to pursuing either work opportunities when children would be in school or work that could be completed from home. Although only four interviewees cited motherhood as the sole or even primary reason that they were not currently pursuing employment, the costs of childcare and other responsibilities of caretaking interacted with other factors such as earning potential, financial need, and disability-related limitations in ways that influenced mothers' calculations about pursuing work.

Barriers to Employment

After women decide that they would like to work, or begin actively looking for work, the presence of children continues to impact their attempts to locate and then secure employment. Although the American with Disabilities Act prohibits hiring discrimination, research shows—and my interviews confirmed—employers still find ways to impede individuals with disabilities from employment (Baker et al. 2018). Coupled with the documented fact that mothers are similarly discriminated against in hiring, wage-setting, and promotion practices (Correll et al., 2007), mothers with disabilities are further challenged as they attempt to secure employment. Interviewees were asked how their experiences receiving disability benefits might differ if they

did not have children; their answers revealed a variety of barriers that motherhood creates in women's decisions about, and attempts to, pursue a return to the labor market.

Childcare. In addition to the earlier-discussed role that the cost of childcare plays in mothers' decision-making, the requirements of childcare also influenced the paid work schedules mothers felt they could reasonably pursue. Ashley, a single White mom to one 15-year-old daughter, earns a higher-than-sample-average SSDI benefit of \$2,400 a month (in an expensive metropolitan area) due to her work history as a manager at a large warehouse retailer. In addition to having to balance the physical challenges of her disability (she has a "body full of titanium" after several surgeries to correct an undiagnosed birth defect), her daughter further constrained the hours she was available for paid employment, making it increasingly difficult to locate work.

The types of jobs have to fall into like--after I drop my daughter off to school, but before I have to pick her up at 2:30 . . . So it's like, what am I going to do? Because back then--now she's 15, that's fine. But a couple of years ago I couldn't just leave her or just let her bus home. I mean, what do I do between 8am and 2:15sh pm, a couple days a week? So it was severely limiting. It's like, who wants to hire mornings Monday through Friday? Oh wait, no one....

Even when mothers locate waged work that accommodates their disabilities and falls within the confines of their available childcare, the precarity of these care arrangements often disrupts women's ability to maintain employment. Only one of the 32 mothers I interviewed mentioned utilizing any kind of formal childcare over the course of raising her children. More commonly mothers used informal care from parents, older siblings, and neighbors. While these arrangements are typically free or less expensive than formal childcare options, they are often less reliable. Danielle, a Black single mom with two children, recalled how the death of her mother—a crucial source of both emotional and tangible childcare support—forced her to quit a well-paying job she had secured as a secretary for a school board:

I feel like if I haven't had kids . . . I probably would've had a great career and I probably definitely would have been like, been off of SSI a *long* time ago . . . So because of my kids, when they were younger and everything, I did have to quit my job at the school board because I didn't have a babysitter. And that was a really, really great job. That's probably the biggest loss for me, I would say, as far as children and SSI-- having to quit my job at the school board to be a stay at home mother . . . but I *had* to do that, you know? . . . I didn't really have anyone to watch the kids and I did—besides bills and everything, I couldn't really afford to have them in daycare, for both of them to be in daycare, that was the thing.

Without her mother as a source of free childcare, and given the prohibitive cost of paying for care for two children, Danielle quit a job that could have facilitated a rehabilitation off of disability benefits.

The Covid-19 pandemic put the constraints of caretaking into stark relief for many of the women I spoke to—particularly those whose children were school-aged and were now doing school virtually, from home. One mother had lined up promising work prior to the pandemic, only to have the position close as a result of stay-at-home orders. Several other mothers discussed how their plans to pursue work were on pause until they could again utilize the part-time care public schools provide.

Fear of benefit loss. In line with the fact that mothers in the study felt an added sense of responsibility to their children, another significant barrier to employment was a heightened fear of losing disability benefits, as well as the health insurance typically provided via benefits. While non-mothers with disabilities might also experience trepidation about risking their benefits by engaging in paid work, mothers expressed a particular anxiety about the negative impacts such a loss might have on their children. This dialogue with Tasha, a single Black mom who lived on SSI benefits for depression throughout the duration of raising her now 19 and 17-year-old children, explained how she experienced her children as an additional constraint:

I probably wouldn't care as much [if I didn't have children], I probably would try to work more and I probably would have tried to get off disability faster because I wouldn't have been so worried about income . . . I wouldn't be so worried about losing housing or, you know, worried about losing the check, I could just do whatever I wanted. It would kind of feel like, "Oh, well, if this doesn't work out I can move here" or "If this didn't work out, I could go stay here or do this...", you know? You can't just take the risk . . . I know I can struggle and go live in this little place or whatever, and not have food for a little bit, or just eat a little bit of this, but you can't do that when you have kids . . . I have to sit here on SSI until he leaves, you know, then I can try to do all that.

Further evidence of this fear of benefit loss is the fact that all eight mothers in the sample who were working while still receiving benefits worked only part-time, expressing no intent to increase their hours or transition off benefits. Part-time employment accommodated the limitations of their disabilities without jeopardizing their disability benefits, or the health insurance that covered a portion of their often exorbitantly expensive medical supplies and medications.

The multiplicative effect of barriers. Except for individuals whose disabilities precluded them from a return to paid work, the mothers I spoke to rarely identified a single barrier to employment. More commonly, they were pushed towards a return to the labor market based on financial need, but faced a variety of intersecting and often multiplicative factors that constrained their attempts to work. Nancy, a single White mother with two adult children and a 4-year-old daughter, cited a variety of the above-mentioned barriers during our nearly two-hour conversation. Over the course of her 20 years on SSI benefits for PTSD from severe domestic abuse, Nancy gradually pursued higher education through a combination of grants and loans. She recently earned a master's degree in Applied Behavior Analysis therapy after witnessing its powerful impact on her youngest daughter (who also receives SSI benefits for a disability).

Nancy was one of the most highly educated mothers I spoke with, and yet her role as a single parent to a child with her own disability constrained her in multiple ways. Over the course of a nearly two-hour interview, she noted her lack of external support as one barrier: "When you're somebody who doesn't have a lot of family support and other types of support, it's not easy . . . Especially when you have children, you know?" Her health fluctuations were also of concern: "I'm a lot better than I used to be, 20 years ago in my disability, but I do have moments . . . times when I'm not doing so well, my depression gets really bad, you know?" Childcare for her disabled child was another factor that weighed on her calculations regarding pursuing work:

A part of me is afraid that, you know, am I going to have the support for my daughter? Let's say she gets sick . . . And plus . . . schools are hybrid and there's not even childcare! And if I do get a job and I have to pay childcare, I have to be concerned about my daughter's safety. Or am I going to just be working to pay the childcare?

Nancy was also concerned about losing her insurance: “If I go out there and work full time . . . some jobs, they don't offer a package deal in terms of medical, dental, and everything. And I do need that as a, as a parent, I need that for me and my family.” After articulating these myriad challenges precluding employment and rehabilitation off SSI benefits, Nancy concluded, “I just feel like my hands are really tied in so many ways.”

DISCUSSION

Despite evidence that children play a pivotal role in the work behaviors of mothers (Kuziemko et al. 2018), the axis of parenthood has been largely ignored in analyses of disability benefit recipients. In-depth interviews with 32 former and current SSI and SSDI beneficiaries who were also raising children revealed that motherhood creates distinct motivations and barriers to both pursuing and locating paid employment. To facilitate rehabilitation more effectively, the SSA must first acknowledge the barrier that children (especially young children) present to women's employment—above and beyond the challenges presented by their disabilities. Treating mothers with disabilities as identical to other recipients of disability benefits ignores the myriad ways children influence women's lived experience, and the primacy of the motherhood role. Deja articulates a sentiment echoed by many women I spoke with:

God gave me my child and I have to protect my child, period. I don't think nobody should tell a mother—I just don't think nobody's allowed to tell a mother what they're supposed to do because *you* know what's best for your child . . . [A]ll our decisions are based on our child . . . Every decision you make, you're not thinking about just yourself, you're thinking about your kids, first. And so, in every decision I'm making, I'm thinking about my son, period. And Social Security needs to understand that.

Measuring “Labor Force Participation”

Mothers experience a sense of responsibility to their children within a societal context where the receipt of disability benefits carries a negative social stigma. Rachel matter-of-factly explained a theme that ran through nearly every woman's account of receiving benefits: “I just feel like you're branded as you're just a piece of shit, really. You're just a piece of crap that can't do it and hack it in the real world.” This awareness of this negative public perception of disability beneficiaries might partially explain the finding that mothers with disabilities report higher labor force participation rates than similar non-mothers (Amorim 2019). These women might truly want to—and indeed, *need to*—work, but interviews reveal a chasm that exists between a mother with a disability needing or wanting to work, and their ability to actually locate and secure employment that matches their abilities and needs. Only two of the nine women who self-reported a work status of “not working, looking for work” showed evidence of actively looking for work. This finding suggests that merely being “in” the labor force is insufficient to overcome the multitude of barriers that mothers with disabilities face, including the complexity of caretaking responsibilities, access to childcare, and a heightened fear of benefit loss.

The Catch-22's of the Disability System

Scholars of poverty have described the “cliff effect” whereby means-tested social supports create an income threshold that recipients fear crossing for risk of losing benefits (May et al., 2019). This risk of benefit loss is more pronounced for individuals with disabilities whose ability to engage in paid work might fluctuate, and whose crucial access to medical insurance is often tied to their disability benefit. For mothers with disabilities, this cliff feels even more dangerous because their children’s well-being is entwined with their own. The structure of the disability system has created a catch-22 of sorts for mothers, who can rarely support their families on the meager disability benefit amounts they receive, but who face dual barriers to employment stemming from both their disabilities and their caretaking responsibilities.

The disability determination process is arduous, frequently requiring multiple attempts and even the hiring of a lawyer to establish one’s eligibility. Despite having proved their inability to participate in “substantial gainful employment,” mothers without additional sources of household income beyond their disability check are left unable to adequately support their families. Thus, these women are often forced to choose between pursuing paid work at the expense of their physical or emotional well-being, or exposing their children to the deleterious effects of living in poverty. Several mothers who chose the former recalled failed employment attempts. Claudia, who had recently quit after only three days of training at a restaurant position clarified “I really don't even feel like I'm competent to work. I wouldn't hire myself knowing what I know about myself...I feel like it's unfair for me to go and get a job because I couldn't do the job.” Danielle recalled a consequence of her own attempt to work, despite a lack of childcare:

A few times...my daughter was not old enough to babysit, but I had to leave her home sometimes to watch her little brother while I would go work under the table at the bar, to do bartending, and I would have to work really long hours and some nights, I don't even know if they ate dinner, because I was out at the bar working all night, trying to make sure that we had enough money and stuff like that. So that was a hard time for me.

The inadequacy of benefit amounts motivates mothers to pursue paid work, but a variety of structural constraints relating to both their disabilities and their responsibility for children often impede their employment-seeking. Complementary support in the form of childcare, education and job training, flexibility on the part of employers in terms of hours and duties, and flexibility on the part of the SSA in terms of earnings thresholds to prevent benefit loss is needed to break this cycle of making mothers choose between poverty and unsustainable work situations.

Who is the System Working For?

Of the three mothers who had transitioned off disability benefits and back to work, two had lost their benefits during the recertification process when they were deemed able to work (although their subsequent experiences in the labor market have been challenging, and not what one might deem a “success”). The third former beneficiary I spoke with was Gabriella, a Hispanic mother of two who injured her back and received SSDI benefits for two years before transitioning off benefits to full-time employment. She explained that she sought employment not because her

injury had healed—she was still experiencing immense pain and was significantly debilitated when we spoke—but because “It wasn't something that I could stay on it. It wasn't feasible. I couldn't support my household.” In short, the sample did not include a single “successful rehabilitation” back to gainful employment.

Among the sample of current beneficiaries, seemingly only those who were supported by income beyond their disability benefits were doing what one might reasonably consider “ok.” Married or cohabiting women who shared income with an employed partner, those who had received a legal settlement of some kind in conjunction with an injury, and women who lived in homes that were paid off (in both cases the result of an inheritance) all experienced notably less fiscal distress than others in the sample. Other safety nets utilized by the women in my sample to keep afloat included social service organizations and nonprofits outside of the SSA; parents who paid bills, provided free childcare, or allowed mothers and their children to move into their homes; “Go Fund Me” accounts set up by friends in the aftermath of an accident; settlements from accident-related lawsuits; and a lump sum of back-dated benefits for SSDI determinations. In many ways, the women who most needed additional income to support themselves and their children were the same mothers who experienced the most economic disadvantage: single mothers and those without external sources of fiscal and instrumental support.

Policies to Address Mothers' Needs

When I asked what types of policies, programs or supports the SSA could offer that might specifically ameliorate the challenges encountered by mothers with disabilities, indubitably the most common first response was a plea to increase the benefit amount. Other suggestions for improvement aligned with the barriers mothers reported as most salient for securing employment: childcare; a fear of benefit loss, and often limited labor market prospects.

The mothers most constrained by childcare needs (or whose potential employment in earlier phases of mothering was similarly constrained) were most fervent in their suggestions that the SSA should offer subsidized or even free childcare to mothers, especially as they move towards a place of rehabilitation back to paid work. To ensure its usefulness to mothers' specific concerns, the care should be made affordable, high-quality, and offer a flexibility of hours to accommodate mothers with disabilities who can work only part-time or non-standard schedules. Gabriella, the Hispanic mother of two who rehabilitated off her injury-related SSDI benefit, noted the dearth of childcare support available to mothers in the job-seeking stage of rehabilitation:

I would have had to have found childcare through another agency and see if I would have qualified. But most of the time you don't qualify unless you're able and willing to work, or you have proof of employment, or there's a reason why you need to go to work. But if you're disabled and you're looking for work, you know?

Although a fear of losing benefits is not unique to mothers with disabilities, the presence of children heightens the anxiety many women experience as they think about pursuing a return to work. Very few women I spoke with envisioned that they might ever be able to return to full-time, traditional employment. Many women's plans involved pursuing self-employment, largely for the flexibility it would offer. Suggestions to address a concern about jeopardizing benefits include changing the threshold structures to allow more flexibility of earnings (in recognition

that individuals with disabilities often cycle through periods where their disabilities are more and less impactful), and allowing mothers to “bank” income from periods when they are more physically or emotionally able to work, to help supplement them during times when their disability might “flare up” or entirely prohibit them from working. Ashley explained that she outlined a solution echoed by other mothers:

They [SSA] could at least eliminate a lot of their financial responsibilities by allowing us to work. And then, you know, let's say five years goes by and more often than not, you have exceeded that [income threshold], *then* you'd get reevaluated. I'm not saying I want *both*, you know, I don't want to work *and* get the disability, I just want the opportunity to make more money. But you know, there's going to be dry spells. There's going to be slow periods, and there's going to be health flares. So—I don't know, an intermittent type of work program [would be beneficial].

Rather than disincentivizing work, such adjustments could allow mothers to work within the competing confines of their disabilities and their caretaking responsibilities.

Another policy implication of the study's findings is that mothers' labor market prospects often are limited, especially for SSI recipients who have typically lower levels of education and limited work experience. Women who would need to pay for childcare with a share of their earnings stand to net even less from paid employment. Supporting the educational pursuits and training opportunities available to women with children could help change these calculations and tip the scales so that employment might feel like it would “pay off”—especially for women needing to pay for childcare. Courtney responded to my question about what the SSA could do to better serve its beneficiaries without hesitation:

Education! If they could have paid for any type of college. I have my BA, but in today's world, a BA is going to get you \$17 an hour instead of \$15. If I could have had a master's or a certificate...? But they won't pay for school. If tuition would have been a thing, *that* would have been a big—I searched for *so* many ways to get a certificate or like, you know, programming for computers, anything paid for so I could do something higher paying as a stay at home mom, you know? But paying for continuing education, instead of just getting you trained to do something that is already on *their* list is—would have been beneficial.

Limitations

Given the lack of an established theoretical framework, this research was primarily exploratory in nature. The fact that my sample was small, and not randomly selected, precludes generalizing about the entirety of disabled mothers who receive SSA benefits. The individuals who volunteered to be interviewed might be different in systematic and important ways from other mothers who receive disability benefits. A heavy reliance on online recruitment efforts likely excluded potential respondents without access to the internet, and beneficiaries looking for short-term work on Craigslist might have more pronounced financial needs. Further, the closure of schools and daycares in the Covid-19 pandemic added strain to the lives of many of my participants above and beyond those strains faced in more typical circumstances.

The difficulty of accessing disability recipients who successfully transitioned away from benefits further limits the conclusions this research can draw about the population of former beneficiaries. Many of these limitations can be viewed as questions for future research endeavors. Conducting

a probability survey of mothers who receive disability benefits could identify whether the decision-making factors identified here reflect the experiences of the entirety of the population of mothers with disabilities. Additional qualitative research should be conducted in order to reach true saturation among the various sub-populations of mothers with disabilities, with a goal of both confirming and expanding upon the findings presented herein.

CONCLUSION

Considering the extensive negative impacts of living in poverty, moving the needle to increase a family's resources can produce gains to physical, mental, and emotional health for adults and children alike (Edin and Kissane 2010). In a policy context where the financial supports available to individuals with disabilities are relatively sparse, engagement (or re-engagement) with the paid labor force is one way to improve the financial standing of individuals with disabilities. Conversations with current and former SSI and SSDI recipients tell a crucial, but currently missing, component of the story. Disability beneficiaries with children have unique motivations and barriers to both pursuing and securing paid employment as a direct result of their caretaking responsibilities.

The salience of motherhood is particularly pronounced for single mothers who typically live on smaller household incomes and who also have fewer options for sharing child-related responsibilities. Results suggest that existing SSA supports designed to encourage and facilitate a return to the labor market do not sufficiently address the myriad challenges that mothers with disabilities face. To support this population more fully, the SSA should identify beneficiaries who have children in order to tailor return-to-work programs to their unique barriers to employment: caretaking responsibilities that impede labor market prospects and a heightened fear of benefit loss.

Table 1: Demographic Characteristics of Sample (N=32)

<i>Variable</i>	<i>n</i>	<i>%</i>
Income		
Less than \$25,000	19	59%
\$25,000 to \$34,999	5	16%
\$35,000 to \$49,999	4	13%
\$50,000 to \$74,999	3	9%
\$75,000 to \$99,999		
Partnership Status		
Married or Cohabiting	16	50%
Single	16	50%
Race		
White	17	53%
Black	9	28%
American Indian or Alaska Native	2	6%
Asian	1	3%
Ethnicity		
Hispanic	6	19%
Non-Hispanic	26	81%
Disability Benefit Status		
SSI	5	16%
SSDI	20	63%
SSI + SSDI combo	4	13%
Former beneficiary	3	9%
Labor Force Status		
Not working or looking, <u>unlikely</u> to work	7	22%
Not working or looking, possible <u>future</u> work	6	19%
Not working, <u>actively</u> looking	2	6%
Reported "Not working, looking" (but no evidence of job-seeking)	7	22%
Currently working	10	31%
		<u>Mean</u>
Years on benefit		8.2
Number of children in household		1.9

Table 2: Demographic Characteristics of Sample

Name	Income	Partnership Status	Benefit Type	Years on benefit	Number children	Race
Ashley	25-35k	Single	SSDI	6	1	White (non-Hispanic)
Claudia	Less than \$25k	Coupled	SSI + SSDI	8	2	White (non-Hispanic)
Danielle	Less than \$25k-	Single	SSI	10	2	Black
Daphne	Less than \$25k	Single	SSI	14	3	Black
Janice	less than \$25k	Coupled	SSDI	13	1	Asian
Keneesha	Less than \$25k	Coupled	SSDI	10	2	Black
Tasha	Less than \$25k	Single	SSI	12	2	Black
Brittany	Less than \$25k	Single	SSDI	18	2	White (non-Hispanic)
Courtney	\$35k-49,999	Coupled	SSDI	10	1	White (non-Hispanic)
Deja	Less than \$25k	Coupled	SSDI	6	1	Black
Nancy	Less than \$25k	Single	SSI	20	3	White (non-Hispanic)
Naomi	Less than \$25k	Single	SSDI	1.5	1	White (non-Hispanic)
Rosa	\$35,000 to 49,999	Coupled	SSDI	1	2	Hispanic, white
Laura	\$35,000 to \$49,999	Coupled	SSDI	5	3	White (non-Hispanic)
Linda	25-35k	Single	SSDI	3	4	White (non-Hispanic)
Maria	Less than \$25k	Single	SSI + SSDI	2	2	White (non-Hispanic)
Olivia	Less than \$25k	Coupled	SSI + SSDI	10	1	White (non-Hispanic)
Phoebe	25-35k	Single	SSDI	7	3	White (non-Hispanic)
Sharon	25-35k	Coupled	SSDI	3	2	White (non-Hispanic)
Stacy	Less than \$25k	Single	SSDI	1	5	Alaska Native
Jessica	25-35k	Coupled	SSDI	4	1	White (non-Hispanic)
Mindy	Less than \$25k	Single	Former SSI	5	2	Black
Rachel	Less than \$25k	Single	SSDI	7	1	White (non-Hispanic)
Aaliyah	Less than \$25k	Separated	SSDI	9	3	Black
Camila	\$35,000 to \$49,999	Coupled	Former SSDI	3	4	Hispanic Black
Nikki	Less than \$25k	Coupled	SSI + SSDI	10	3	White (non-Hispanic)
Faith	\$75,000 to \$99,999	Coupled	SSDI	19	1	Hispanic, White
Gabriella	Less than \$25k	Single	Former SSDI	2	2	Hispanic White
Krystal	\$50,000 to \$74,999	Coupled	SSDI	27	1	White (non-Hispanic)
Mona	\$50,000 to \$74,999	Coupled	SSDI	8	2	White (non-Hispanic)
Whitney	Less than \$25k	Single	SSI	20	3	Black
Iris	Less than \$25k	Coupled	SSDI	7	3	Hispanic, American Indian or Alaska Native

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