# How young adults with disabilities develop axes of independence by rebalancing self-reliance, family-reliance, and state-reliance: A qualitative analysis of life history interviews.

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## Abstract

How do young adults with disabilities rely on social assistance programs to rebalance self-reliance and family-reliance as they develop axes of independence in education, employment, independent living, and care? Understanding how young adults arrange support during the transition to adulthood can identify how family and state support facilitates or hinders educational attainment, employment, independent living, and care. I conduct grounded theory analysis on transcript data from 28 interviews with young adults ages 25-36 with various disabilities to answer this question. The analysis shows that education, employment, independent living, and care are interconnected and could lead to independence – *the axes of independence*. Progress, delays, or regression in one area affects other transitions along the axes. Social barriers inhibit progress along axes of independence for participants. While pursuing goals along the axes of independence, participants rebalance self-reliance, family-reliance, and state-reliance in four distinct ways: 1) some want to obtain social assistance to enhance self-reliance and shift support from family-reliance to the state; 2) some want to leave social assistance to end state-reliance and maximize self-reliance; 3) some want to continue receiving social assistance while working, balancing self-reliance, family-reliance, and state-reliance; and 4) others never engage with social assistance programs by leveraging self-reliance and family-reliance. Ultimately, while young adults with disabilities rebalance self-reliance, family-reliance, and state-reliance, they find that supports are inadequate at promoting independence and can create barriers to education, employment, independent living, and care. Social Security, Medicaid, and Vocational Rehabilitation may leverage the axes of independence to address policy barriers.

## Acronyms

HCBS – Home and community-based services
SSI – Supplemental Security Income
VR – Vocational Rehabilitation

## Introduction

How do young adults with disabilities rely on social assistance programs to rebalance self-reliance and family-reliance as they develop axes of independence in education, employment, independent living, and care? Understanding how young adults arrange support during the transition to adulthood can identify how family and state support facilitates or hinders educational attainment, employment, independent living, and care. I conducted grounded theory analysis on transcript data from 28 interviews with young adults ages 25-36 with various disabilities to answer this question. The analysis shows that education, employment, independent living, and care are interconnected and could lead to independence – *the axes of independence*. Progress, delays, or regression in one area affects other transitions along the axes. Social barriers inhibit progress along axes of independence for participants. While pursuing goals along the axes of independence, participants rebalance self-reliance, family-reliance, and state-reliance in four distinct ways: 1) some want to obtain social assistance to enhance self-reliance and shift support from family-reliance to the state; 2) some want to leave social assistance to end state-reliance and maximize self-reliance; 3) some want to continue receiving social assistance while working, balancing self-reliance, family-reliance, and state-reliance; and 4) others never engage with social assistance programs by leveraging self-reliance and family-reliance. Ultimately, while young adults with disabilities rebalance self-reliance, family-reliance, and state-reliance, they find that supports are inadequate at promoting independence and can create barriers to education, employment, independent living, and care. Social Security, Medicaid, and Vocational Rehabilitation may leverage the axes of independence to address policy barriers.

### *Disability, Support, and the Transition to Adulthood*

The number of young adults with disabilities is growing as an estimated 52 million millennials with disabilities enter adulthood (1); however, this growing population faces extensive barriers to education, employment, independent living, and care during the transition to adulthood (2–6). Disparities in educational attainment, employment and earnings, residential independence, and care needs between those with and without disabilities persist (3,6–12). At the juncture between high school and adulthood, as they develop axes of independence, many young adults with disabilities rely on themselves, their families, and the state for various forms of support. These resources are critical when young adults with disabilities transition to colleges and universities; vocational programs and jobs; independent living arrangements including apartments, houses, and group homes; non-family care arrangements; and adult social assistance programs (3,13–17). This section reviews the research on the benefits and limitations of self-reliance, family-reliance, and state-reliance for young adults with disabilities while transitioning to adulthood.

Many young adults with disabilities begin taking on more responsibility for their future, becoming more self-reliant and independent while pursuing education, employment, independent living, and care (3,18,19). Earning a degree can be difficult for young adults with disabilities because they have to consider other factors like accessible colleges, coordinating supports, and adapting to new settings (3,20). For those young adults with disabilities who gain admission, going to college is often the beginning of arranging their lives without their parents, demonstrating increased self-reliance (3,20,21). Often, people with disabilities struggle to find employment despite wanting and searching for work (3). Those who have early work experiences tend to achieve more success in the labor market (22). Many young adults with disabilities are motivated to move out of their family homes to achieve independence. Others work with families to enhance their independence in interdependent family homes (3,4,14). Lastly, some young adults with daily support needs must wrestle with goals for independence while balancing care (23). Grossman (2019) found that among 18 Medicaid beneficiaries receiving personal care attendant services, Medicaid policy complicated and prevented cross-state moves for education or careers due to potential gaps or delays in needed support.

Young adults with disabilities rely on family support during the transition to adulthood to address barriers stymying their progress in education, employment, independent living, and care. Young adults with disabilities regularly identify parents as the most crucial relationship while making these transitions (3,24). Young adults with involved and well-connected parents tend to have more precise roadmaps, although not perfect, to follow when pursuing education, finding jobs, and locating housing and care. At the same time, those without connections face even more difficult pathways (3). Having savvy parents makes it easier to find material, instrumental, and employment support through Social Security, Medicaid, VR, and universities (3,4,21). Material support includes cash transfers, including those with specific purposes like food, housing, or college tuition (12). Instrumental support includes tangible support that assists with daily tasks (25). Employment support includes providing education, training, and other skill development (15). When young adults with disabilities access these programs, they often do so to address poverty. Young adults with disabilities also rely on siblings and other family members for support if parents can no longer provide (17,26,27).

Many young adults with disabilities turn to means-tested social assistance programs for material and instrumental support. Programs like SSI, Medicaid, and VR help alleviate poverty for beneficiaries by replacing incomes up to ¾ of the federal poverty line (28), providing medical insurance and disability services and supports (29), and employment training and services (30), respectively. Of the 8 million people receiving cash assistance from SSI in December 2020, 57%, or 4,560,000 beneficiaries, were adults with disabilities under age 65 (28). Using data from 2016, Medicaid (2020) reports that 15% of the 72 million beneficiaries (32) were adults with disabilities under age 65. Of adult Medicaid recipients with disabilities in 2017, 42% had basic activity difficulty, 30% had complex activity limitation, 27% had a work-limiting health condition, 21% had functional limitations, and 19% had work-limiting health problems (31). Many of these beneficiaries receive instrumental support through Medicaid home and community-based services (HCBS) waivers (33). Historically, transition-age youth with disabilities received significant support from VR, comprising 31% to 81% of VR service recipients from 2004 to 2006 (34,35).

By design, US social assistance programs provide limited support due to temporariness of assistance, modest funding and benefit levels, extensive administrative burden, and the complicated and interconnected array of general and disability-specific programs (3,29,36–40). Though vitally important for some, the modest and temporary cash assistance from SSI and low reimbursement rates of Medicaid are insufficient in addressing all needs (40). For example, VR is necessarily temporary because it helps beneficiaries transition to employment (35). SSI and Medicaid routinely reverify eligibility for beneficiaries to ensure they have not transitioned to work and are no longer eligible for assistance (37). Despite state support, many beneficiaries struggle in poverty (36,41–43). Means-testing, characteristic of the U.S. liberal welfare state, limits support in various ways. Some people with disabilities need support but cannot access it because of eligibility criteria. For example, Medicaid is one of the only insurers offering long-term supports. However, many do not qualify due to strict financial and disability eligibility requirements (29). Alternatively, those who receive SSI and Medicaid report that employment can jeopardize their eligibility and, therefore, their income stability, health, and care (23,36,39,44). Simultaneously, young adults with disabilities must find and apply for social assistance programs, universities, jobs, and housing (3,29,37,45,46).

### *Theorizing Transition, Reliance, and Disability*

I use life course theory (47–50) to investigate how young adults with disabilities rebalance self-reliance, family-reliance, and state-reliance during the transition to adulthood. During the life history interviews, I asked participants about their past, present, and future goals for adulthood and their experiences while pursuing them. Without fail, participants described goals and experiences involving education, employment, independent living, and care. Life course theory suggests that historical and social structural contexts, the timing of transitions, linked lives (social relationships herein), and human agency determine life course outcomes like education, employment, independent living, and care (48,50,51). Therefore, life course theory provides a solid theoretical framework to understand how young adults rebalance self-reliance, family-reliance, and state-reliance to pursue goals for education, employment, independent living, and care during the transition to adulthood.

Life course theory provides a clear framework for understanding movement through the transition to adulthood. It suggests that social transitions in education, employment, independent living, and care during the transition to adulthood lead to statuses that structure and indicate adulthood for most (3,6,18,47,52). Some disability theorists argue that because life course theory focuses on typical pathways to adulthood, life course theory disregards and devalues those who do not reach these statuses (14,45,53,54). Recent contributions have brought disability perspectives into life course theory (4,49,50). Contemporary life course theorists have started investigating the growing diversity in pathways people take to adulthood across race, class, gender, ability, sexuality, and immigration status (19,52,55–58). Many people with disabilities want and make significant status transitions like going to college, entering the labor market, and establishing independent residences (14,18). However, many young adults with disabilities confront social structural barriers while navigating transitions and must make additional transitions such as arranging care (3,21,45). Social structural contexts that limit transitions in education, employment, independent living, and care contribute to the achievement gap and delay in these areas between those with and without disabilities (5–7,17).

Because participants rebalance self-reliance, family-reliance, and state-reliance while pursuing their goals for adulthood, life course concepts such as human agency, social relationships, and social structural contexts are central to this research. *Human agency* is the idea that individuals can make concerted decisions and take specific actions to control their future (49,59,60). Young adults with disabilities exercise agency when they decide if they want to go to college and where to attend; pursue a career and where to work; live with mom and dad, on their own, or with others; and find non-family care workers. Participants described their actions to pursue adulthood goals focused on education, employment, independent living, and care as "self-reliance." They emphasized "independence" or "autonomy" to refer to the state of possessing control over life decisions. Agency is not absolute because no one can dictate their future exactly, and they certainly cannot control all their social and environmental contexts (61,62).

Life course theory suggests that one's life course outcomes depend on the lives of others because social relationships link humans together (49,63). *Social relationships* and *social structural contexts* can promote or restrict agency, and the level of that restriction depends on how much power an individual holds in society (49,60–62). Indeed, no participants achieved their goals without support from families or the state. Participants reported that their social relationships facilitated or hindered their goals. They accessed resources from their parents, siblings, grandparents, friends, care workers, teachers, and acquaintances. All participants appreciated the support and recognized its necessity in establishing independence in adulthood. Additionally, participants reported various social structural contexts that helped or hurt progress towards education, employment, independent living, and care. Participants addressed Social Security, Medicaid, and VR as social structural contexts that enabled and limited these transitions, consistent with other life course research on disability and the transition to adulthood (3).

Axes of independence.

Informed by life course theory (48,49,61,62), I use the term *axes of independence* to refer to the interdependent nature of transitions in education, employment, independent living, and care that participants described during the interviews. These four *transitions* operate together on shifting axes; success in one domain depended on the achievement and maintenance of another. While participants navigated the axes of independence, they used self-reliance (*human agency*), family-reliance (*social relationships*), and state-reliance (*social structural contexts*) to achieve their independence-oriented goals to varying degrees of success.

## Methods

To answer the question: How do young adults with disabilities rely on social assistance programs to rebalance self-reliance and family-reliance as they develop axes of independence in education, employment, independent living, and care? I analyzed 28 audio-recorded and professionally transcribed in-depth life history interview transcripts. I interviewed 28 young adults with disabilities ages 25-36 diagnosed with any disability before age 18 between January 2020 and January 2021 for a broader project on disability, social relationships, and the transition to adulthood. The interviews were flexible but semi-structured, with sections on social relationships, goals for adulthood, life history from high school, education, employment, housing, romantic and intimate relationships, and parenthood. I used an iterative grounded theory approach to analyze the data. The themes presented in this paper focus on transitions participants considered independence-oriented, including education, employment, residential independence, and care. While pursuing independence-oriented goals, participants engaged with support from families and the state in four distinct ways. I address these findings in this paper. The Syracuse University Institutional Review Board approved this research project in December 2019 (IRB#19-289).

### *Recruitment, accessibility, and informed consent practices*

Recruitment.

To reach a broad range of individuals with disabilities, I used recruitment materials with visualizations for accessibility purposes, disseminating them through online disability communities, disability agencies, universities and their disability networks, and personal contacts. Therefore, the sample is a maximum variation purposive sample (64) of young adults with physical, intellectual, cognitive, sensory, mental health, health disability, or multiple disabilities acquired before age 18 currently aged 25-36 (Born 1983-1994). Each participant completed a social demographic and support survey before the interviews for screening. The age criteria for participation reflect the ages when many young adults with disabilities have completed social transitions associated with adulthood (2,5,6,17). This factor enabled participants to speak about recent or ongoing experiences receiving support from families and the state while pursuing or having achieved their goals. Participants had to be able to communicate experiences independently or with any help necessary to achieve participation.

### Accessibility and Informed Consent Practices.

To make this research accessible, I employed several accessibility measures: (1) simple English and visualizations (TheNounProject.com) on recruitment and informed consent documents, (2) dyadic interviewing (65), (3) multiple interviews, and (4) life history calendars. (1) Simple English and visualizations help with the interpretation of texts. I used these aids with individuals with intellectual and cognitive disabilities who may have trouble reading. (2) Dyadic interviewing is an inclusive practice that involves including a participant selected support to assist during an interview (65). For those who needed support during the interview, the support person was integrated into the interview for either translation, interpretation, or facilitation or to fill in gaps participants might have forgotten. Participants either corrected or agreed with additions made by support persons. (3) Due to the extended interview and potential for cognitive or physical fatigue, participants were offered the opportunity to break interviews into several sessions. No attrition resulted. (4) Life history calendars (Excel Spreadsheets) aided participants' recall by allowing participants to see the sequence of events they reported and correct time sequencing errors.

I took an educational approach to informed consent to ensure ethical inclusion of participants with cognitive-decision-making impairment and those who were not their guardian (66). After going through the informed consent document with a potential participant, I asked participants to explain the primary objectives of the research, voluntariness, and potential harms and benefits. If participants had trouble articulating their understanding of the research, I clarified parts of the research that were confusing. One participant's parents were their guardians. In this case, I obtained participant assent and consent from their legally authorized representative (67). I use pseudonyms for all identifying material.

### *Participants and Summary Statistics*

Table 1 (end of manuscript) presents the demographic variation obtained in the maximum variation (age/disability) sample of 28 individuals with disabilities. The average age of participants was 30 years. Most participants were women, white, employed, living independently, childless, and single. All participants had earned at least some college credit. Because I focused the maximum variation sample on disability type, the sample had various disability types, diagnoses, and functional limitations. In terms of disability type, most participants were diagnosed with multiple types of disability, and the fewest number of participants reported intellectual disability. The most frequently reported single disability type was mental disability. The average number of limitations in activities of daily living (ADLs) was 2.7, and instrumental activities of daily living was 3. Of activity limitations, eating and shopping for groceries were the most prevalent. Sixty percent of participants currently or previously received support from the state; Table 1 reports on specific program utilization.

### *Analytic Process*

I used an iterative approach to grounded theory analysis (68,69), beginning with inductive coding of transcripts and moving to cross-case comparison and abductive analysis to fit emergent themes with existing theoretical and policy-oriented frameworks (70). I ended the analysis with new cases stopped contributing new insights to the analysis, saturation (71).

While inductively coding transcripts, I created descriptive and in-vivo codes for “contingent goals,” “independence,” “independent goal,” “self-reliance,” “autonomy,” “taking care of one’s self,” “being on own/in control,” “asking for help,” “dependence,” “family support,” “family-benefits,” “benefits,” “SSI,” “SSDI,” “Medicaid,” “Medicare,” “Vocational Rehabilitation,” “food stamps,” and “SNAP.” These codes relate directly to the research question. I refined these codes and connected them through sorting and comparing cases.

As I moved to cross-case comparison, I refined the original codes into the theme “axes of independence” with subthemes for “self-reliance,” “family-reliance,” and “state-reliance.” I started with sorting “contingent goals,” as it appeared in every transcript. “Contingent goals” originally described how participants talked about taking incremental steps toward their goals for adulthood. Each participant described “small,” “baby,” or “incremental” steps needed to achieve their goals for adulthood. As I compared cases, the code, “contingent goals” was insufficient to understand how young adults rebalance support.

To build the “contingent goals” theme, I identified the types of goals associated with “small steps.” Ultimately, participants wanted to live more independently than they had before adulthood. All participants pursued independence or independence-oriented goals for adulthood. Expectedly, the idealized route to adulthood – college, living on your own, and work – emerged quickly as a preferred pathway to independence, even among those who did not follow this pathway. Even those who did not prefer this pathway were aware of its existence, some acknowledging their pathways as “wonky.” Eight tried college and side-stepped in and out of enrollment. The rest had at least an associate’s degree. Three participants never attempted to work, others faced employment discrimination, three owned businesses, others worked with no degree, and others worked during and after college. Nine of the 28 participants lived with their parents. All but three of the other participants had briefly lived in their family home. Some participants found spouses or partners, and some divorced spouses, while others never dated.

A deeper analysis of “contingent goals” revealed that pathways were in no way linear. Pursuing goals for adulthood was less like steps on a ladder and more like steps in a dance, a dance with unfamiliar steps. While participants pursued education, employment, and independent living, they had to juggle additional transitions. Participants needed to obtain social assistance, find and train care workers, locate accessible housing and transportation, manage physical and mental health, advocate for services, and acquire assistive technology. Specific barriers blocked many participants from advancing as if someone spilled marbles on the dance floor. A few participants recovered and eventually reestablished educational, employment, residential, and care arrangements. Others did not. Like a dance, the steps participants took toward their goals depended on one another. Some were able to link one step to several others. However, one barrier or mistake, and participants had to restart the dance.

The efforts of participants and the support they received loomed in the background of the axes of independence analysis. Therefore, I turned to the data on the forms of reliance. I first had to understand participants' meaning of independence and self-reliance. Some participants used "self-reliant," "self-sufficient," "autonomy," "independence," or another term. Some did not use a specific word but gave examples of doing things their way. For participants, independence or autonomy was the overarching goal, and self-reliance described the effort to make the small steps happen. Paul clearly defined independence, "it's kind of having more choices as far as, like, how I spent my time, what I would do." Samantha clearly defined self-reliance, "To be self-reliant; you have the ability to decide what you want or need and can get some means to achieve." She continued, "If that's asking me for help, that's okay, or it's you doing it–I need to go to the grocery store and get X, Y, and Z." Others reported similar sentiments or described independence and self-reliance in their own experiences. Life course theorists studying disability have suggested that defining adulthood with independence can be exclusionary to those with disabilities (45,54). Here, participants pushed the bounds of independence by distinguishing between independence (agency, state of control over one's life) and self-reliance (agency, planning goals).

Participants also relied on families and the state. Some participants wanted to leave state-support and family-support, and one participant has done so. Other participants relied on these external supports as they served the overall goal of developing or maintaining independence. Others were between categories. Some wanted to gain support from the state to shift daily care needs to the state from themselves or their families. The others never used state support, finding a way through college with self-reliance and family-reliance. Most participants welcomed and were thankful for family and state support as it advanced many of their goals. Alternatively, external support was fraught with barriers that hampered participants' ability to achieve independence.

Once newly collected data stopped adding new features to the analysis, I started abductively fitting my data with existing facts and theories. The unique sub-themes that emerged from the data highlight the variation in how young adults with disabilities rebalanced support as they set and achieve goals, a pressing gap in the literature (72). Most literature on disability and the transition to adulthood is demographic. It shows that young adults with disabilities fair worse than those without disabilities (5–7,18). The few qualitative projects tend to have younger samples and focus on planning for transition (3,21,73). Therefore, we know little about how young adults with disabilities mobilize their plans and support to achieve those plans. I present an analysis focused on how young adults rebalance family and state support, using life course concepts agency (self-reliance, independence), linked lives (families), and social structure (policies) as a guide for identifying concepts to extend and critique.

## Findings

### *Developing axes of independence in education, employment, independent living, and care.*

Through the grounded theory analysis of interview transcripts, I identified that participants rebalance self-reliance, family-reliance, and state-reliance while pursuing independence-oriented statuses along several interconnected *axes of independence*. While pursuing simultaneous or consecutive goals focused on education, employment, independent living, and care, participants found that these goals were interconnected. Therefore, the achievement of one status or the loss of an already achieved status affects the achievement of others. Education, employment, residential independence, and care, for better or worse, operate in tandem. Participants reported that advancement in education, employment, residential independence, and establishing non-family care networks depended on successive or simultaneous steps to achieve and maintain independence-oriented goals. Alternatively, the inability to maintain an already achieved status risked other status achievements or progress for participants.

For Meagan, a 34-year-old woman diagnosed with arthrogryposis multiplex congenita and mental health and cognitive disabilities, inability to coordinate care forced her to move back in with her parents and away from her job, independent apartment, and college. After having a series of co-residing personal care attendants that were financially and emotionally abusive, Meagan's mom talked Meagan's sister into moving in with her. After several months of living together, Meagan kicked her sister out because she could not contribute half of the $1,200 rent. After this experience, Meagan reported that she:

> Got to the point where I couldn't find reliable help. I told my mom, I was like, "Look, I cannot keep up going to school, going to rehearsal, or working double shifts at Subway, for crying out loud – getting paid $7.25 an hour and trying to pay this much in rent." So, [I] moved back in with them.

After leaving her small liberal arts college, Meagan moved back home with her parents. While there, she provided care for her father while pursuing a degree at a technical college but dropped out again when they charged her $1,000 for a speed-through class. She said, "I didn't have it [$1,000]. So, I was like, alright—job." In 2008, Meagan found a job at a hospital and soon leveraged that experience to begin working at a disability service center as a work coordinator for young adults with disabilities. While she pivoted to employment, Megan's inability to find reliable care undid all her education and independent living progress. Ultimately, barriers to care thwarted her self-reliance and independence.

Similarly, difficulty with unreliable care arrangements forced Kenny, a 33-year-old man diagnosed with quadriplegia from a spinal cord injury and depression, to stop pursuing a bachelor's degree at the University of California – Berkeley. However, Kenny maintained residential independence from his parents by renting an apartment with his then-girlfriend and her child, whom Kenny fathered during the 4-year relationship. During the relationship, Kenny's girlfriend provided him care along with a series of care attendants. However, when Kenny's girlfriend left him in the middle of a prolonged disability-related illness, he moved back to his mother's home. He found that his progress toward his goals regressed to the start. He was single. He no longer played the fathering role he wanted. He had not earned a degree as he had intended. And worst of all, his mother was his primary care provider, something he never wanted to happen in adulthood. Now six years removed from this experience, Kenny has made significant progress toward his goals. He has moved out of his mother's house, purchased a home, organized his care, and is back in college. To get to this point, Kenny had to set and achieve incremental or "small steps" to pursue residential independence:

> I had to have time to settle mental health. I hadn't had time to settle my financial issues, and I hadn't had time to find a house. Finally, I had to find stable caregivers. Those four things, when they came together along with good health—my health has gotten a lot better. So, those five things health, caregivers, housing, income, and mental health. Once I had all those things, which took me years of just self-analyzing and self-care. Now that all those came together, I've really gotten to a point where I'm satisfied with just independent living.

On the other hand, because of the interconnected nature of transitions to independence, the axes of independence can also simultaneously promote several transitions. This was the case for Phoebe, a 36-year-old woman diagnosed with cerebral palsy and a seizure disorder. After graduating with a bachelor's degree in psychology from a large public university in 2004, Phoebe spent the next 14 years living with her parents while unsuccessfully hunting for jobs. After experiencing gaps in mental health services during undergraduate and ableism firsthand during several job interviews, Phoebe decided to apply to a graduate program in mental health counseling. Phoebe spent 2017 and part of 2018 applying to different programs, contacting key professors in potential programs, and persuading VR to fund a graduate degree. Phoebe gained admission to a leading public institution and earned a paid graduate research assistantship with a tuition waiver. Fortunately for Phoebe, issues with VR did not deter her from moving forward. Phoebe shifted her care to the state through a Medicaid waiver when she moved out of her parents' home. She found an apartment and organized a team of care workers by her start date in August 2018. A few months from graduation, Phoebe had set her sights on finding a job providing mental health services to people with disabilities. However, to do so, she needed to convince Medicaid to increase her PCA hours to address gaps in her care.

> Another one of my goals is getting my hours increased from 8 to 12 hours. I've been denied for an increase in my hours four times. I was promised that would be upped when I went to school. I was not in my parent's home anymore, and I was not where they could help me. I am living entirely on my own with just PCA support. They cycle in and out. I have to do some creative math to figure out how to turn 8 hours into 24. Sometimes I have to pay them out of pocket to make the hours work.

### Rebalancing self-reliance, family-reliance, and state-reliance.

While pursuing transitions along the axes of independence, participants rebalanced self-reliance, family-reliance, and state-reliance in four distinct ways:

1) Some wanted to obtain social assistance to enhance self-reliance and shift support from family-reliance to the state.
2) Some wanted to leave social assistance to end state-reliance and maximize self-reliance.
3) Some wanted to continue receiving social assistance while working, balancing self-reliance, family-reliance, and state-reliance.
4) Others never engaged with social assistance programs by leveraging self-reliance and family-reliance.

#### 1) Accessing assistance programs.

Some participants who did not receive support from the state wanted to access social assistance programs to pursue and maintain their goals for adulthood. Most often, participants wanted to access social assistance programs to shift their support from families to the state.

Ernie, a 32-year-old non-binary autistic person (preferred language) diagnosed with mental health, learning, and health disabilities, had lived away from their parents for several periods since attending a residential school for autistic children in high school. However, they faced significant problems after moving states away from their parents because Ernie struggled to find personal care attendants and community supports. Having been denied Medicaid on two occasions, Ernie tried to piecemeal a support team. They used self-reliance to put together a spotty network of support composed mainly of young adults and acquaintances. Only one person, Beckett, had formal training in providing support for adults with intellectual and developmental disabilities. Beckett coordinated the others. Ernie lamented that their state does not allow adults with disabilities to pay for their own Medicaid insurance to access long-term services and support:

> They [support staff] do it under the table, so not technically. I can't technically get it because this state doesn't allow you—at least the providers around here don't unless you go through the front door, which means you have to get Medicaid, and they won't let me get Medicaid. It's very frustrating because, like, I'd pay for my things. I don't know. They say I have too much money and I don't qualify—well, first they said I wasn't disabled enough, and this time they rejected it again, and I think it was about the money.

Some participants, like Emma, had received and stopped receiving assistance from Social Security and Medicaid several times during the transition to adulthood. Most recently, Emma, a 25-year-old woman diagnosed with multiple health, physical, and mental health disabilities, needed to obtain Medicaid for herself and her kids. When she applied, Emma had to be exceptionally prepared for the application and have considerable forethought to refuse her husband's signature on their son's birth certificate. She did so to maintain eligibility for Medicaid but could not for Supplemental Security Income.

> I have to think really ahead on that. Like, I'm married, but in terms of insurance, I did not let my husband sign my son's birth certificate because I knew that would mean he wouldn't be able to get health insurance. My husband doesn't make that much. I don't make that much. Me, as an individual, can qualify. Us together can't. So, we would have to go through his job for insurance and his Volvo insurance. It's super, super expensive, a very high deductible. Can you imagine that? [It would] deter me, even more, to go to [mental health unit] knowing I'd pay $100 every time I talk to somebody. Can't do. Awful to think about. Before my daughter got OPWDD, she would have had the Volvo insurance. Imagine trying to, like, fill medications between her brother and my mental health. I can't plan to afford all of that. It's her life.

2) Leaving social assistance programs.

Some participants who received social assistance throughout the transition to adulthood reported they wanted to leave programs, making independence the ultimate goal for adulthood. Some recognized the high price of care and acknowledged the aspiration as lofty. Others had to hide employment because their parents were concerned about them losing assistance. However, at the time of the interview, only one person, Lana, had successfully achieved the goal of leaving social assistance programs.

Bailey, a 25-year-old woman, diagnosed with osteogenesis imperfecta, scoliosis, obstructive sleep apnea, and restrictive lung disease, wanted to obtain enough financial stability to sustain herself:

> I feel like this sounds really bad, and I would not say this to a lot of my friends with disabilities, but I want to get off Social Security. I don't want to have to live on $2,000 a month. That's not sustainable for anybody, but that's a whole other topic. But, if I can make enough money to support myself and live as independently as I'll be able to, whatever that looks like, I will be a happy camper.

However, Bailey recognized that the care she received through Medicaid would likely outpace her earnings:

> I know that as somebody with a complicated disability with a lot of comorbidities, I am a very expensive person to maintain. My medical costs are probably only going to get higher the older I get, especially if my respiratory issues end up getting worse…But I know that there are a lot of expensive things that go into making sure that somebody like me stays alive and healthy and safe.

For Patricia, a 36-year-old woman diagnosed with several mental health conditions, going to school and working were long-held goals that she had to pursue without her father's knowledge because he is worried about her losing cash assistance from SSI.

> I didn't convince him because I basically did it without his knowledge, you know? I applied [for college], and he didn't even really know when I told him. After I did it, I said, "Okay, Dad, I'm doing this, and I hope you're okay with it." I sort of did the same thing with working because—he's not really as excited about me working as I am because of the whole thing with the government—because he doesn't want me to lose my money. I feel for that too. but I feel like I need to contribute in some kind of way. I need to feel normal in some kind of way. I'm just so blessed to have it [SSI]. I mean, I don't—I'm not especially happy to have it because I'd love to be independent. I'd love to be.

Lana was the only participant who set and achieved her goal to leave social assistance behind. As the daughter of undocumented Mexican immigrants in the Western U.S., Lana qualified for Supplemental Security Income, Medicaid, and Medicare when she was a child. Lana was diagnosed with muscular dystrophy and depression and is now a 30-year-old information technology manager, earning a six-figure salary in the northeastern U.S. The cash and medical benefits from social assistance programs followed her through her studies at a highly selective university in a western state. She relied on social assistance programs until she landed her first job as an accountant. After working and receiving assistance simultaneously for two years, she received a notice of overpayment from Social Security. She owed over $20,000. She was immediately able to pay it back because she had caught the issue before Social Security and kept the money set aside preemptively.

3) Maintaining eligibility for social assistance while working.

Most of the participants who received state support frequently wanted to maintain their eligibility while working. These young adults balanced self-reliance and state-reliance to maintain consistent and necessary health and daily care independent of families. Rebalancing support in this way enabled participants to follow their goals for education, employment, and residential independence.

Paul, a 33-year-old man with Duchenne muscular dystrophy, osteoporosis, and generalized anxiety disorder, owns a law firm that has won several multi-million-dollar lawsuits. However, he has taken extensive precautions to maintain his eligibility for social assistance programs. Specifically, he ensures that his annual income is just below the eligibility limit for SSI so he can continue receiving Medicaid. However, because of his arrangement, Paul ends up depending on his family financially:

> Obviously, just given my disability and being on benefits and kind of, like, so much of that you have to figure out with your family. You're not able to be as independent with it [finances] as you'd like. Just because of how things are, and, like, not wanting to jeopardize my benefits so depending on others more financially than I would've preferred. I've kind of figured it out with my family, even though I am making a lot of money for the firm and whatnot, not having it go directly to me so that it would jeopardize my benefits. It's just that I've been able to kind of set my own pay so that I can make up to the limit of what might cause a problem.

Paul has sought alternatives, but "it's been difficult to get to the bottom of…individualized threshold – where they can kind of factor in your medical expenses and caregiving expenses and then gives you a much higher number." He and his family "found that that [programs like Ticket to Work] would end up being far more complicated to deal with."

Others relied on family to hold onto trusts made in their name or large sums of money. For some, like Kenny, this was an efficient way to maintain eligibility while living independently and pursuing education and employment. While Kenny did not have full-time work, he recycled cans to raise the income limit of Medicaid from 138% of the federal poverty line to 250% of the federal poverty line. Doing so allowed him to receive his total Social Security Disability Income and Survivor Benefits from his late father while receiving HCBS through Medicaid.

> I'm too scared of losing financial incentives like Medicaid. If I lose Medicaid, I lose in-home support services, and I lose my ability to live independently. I've always been scared of any employment whatsoever. I'm at the cusp. Actually, I'm over the cusp of what should qualify me for Medicaid. The only reason I'm able to do it is because of a loophole I found. It's called the 250% Disabled Workers program. Essentially, your income, up to 250% of the poverty line, is exempted from Medicaid, as long as you have other types of employment. My other employment is, I recycle about $5 a month. That's what gets in Medicaid, is my recycling $5 a month.

4) Never used social assistance programs.

Those who never used and did not report wanting to use social assistance programs used self-reliance and family-reliance while pursuing their goals for adulthood. These participants often had parents who helped pave the way to college financially and with loads of encouragement. Following college graduation, these participants often found careers and experienced less instability in residential independence as a result. That is not to say these participants did not struggle and could have benefited from social assistance programs. However, seven of the eight participants who fit this theme had parents that paid for college and insurance and provided allowances or financial support when needed.

For Flo, her father was integral during her transition to adulthood at the most challenging time – graduate school. While others may struggle to find housing, Flo's father purchased a home during her graduate school career. They lived there together with a series of boarders who rented rooms from Flo's father. Similarly, Samantha's parents funded her undergraduate and graduate degrees, but instead of living with Samantha, they helped her find an apartment that they paid for while she studied. Heather, a 27-year-old woman with multiple disabilities, another well-resourced participant, experienced the same support but found that the support from her parents was precarious considering her adult life. Heather said,

> I'm the only child, and my parents are only children, so I'm the only grandchild. So, I think, like, some of the money that my grandparents left me was used for college, and I think my parents kind of, like, paid as needed. I will say there was a time in 2014, unfortunately, when things were kind of at a bad point regarding my girlfriend that I did think they were going to stop paying my tuition, which was very stressful…Yale has, like, a fund set up for kids who come out to their parents and their parents cut them off. I didn't [have to use it] luckily.

## Discussion

The findings demonstrate that young adults with disabilities often rebalance self-reliance with family-reliance and state-reliance while pursuing independence-oriented statuses along several interconnected axes – education, employment, housing, and care. During the transition to adulthood, participants reported that independence-oriented statuses often depend on one another. Participants pursued these goals simultaneously or often in conjunction with one another – the axes of independence. The qualitative data suggest that state support in one area of life can facilitate independence-oriented goals in others. State support often shifted dependence from families to self and state reliance for participants. In this way, participants leveraged their abilities in conjunction with help from the state and families to achieve successful transitions in education, employment, housing, and care.

Those who received assistance wanted to either leave programs or remain employed while maintaining assistance eligibility. To those who wished to leave assistance, maximizing independence and self-reliance were the goals. However, some participants reported that families were either unhelpful or skeptical about goals focused on exiting assistance programs. Families often provided participants with material and informational support to juggle their income and assistance program eligibility. Participants who wanted to maintain eligibility while working juggled self-reliance, family-reliance, and state-reliance to obtain degrees, work, live independently, and receive non-family care. Of participants who never used social assistance programs, some wanted to acquire support from the state. In contrast, others navigated the axes of independence without a desire or need for state support.

The analysis has important implications for Social Security Administration, Medicaid, and VR because it enhances our understanding of how support provision influences outcomes for young beneficiaries with disabilities. Moreover, as Medicaid shifts toward person-centered care, understanding how young adults with disabilities rebalance support can help build person-centered systems. It also extends the literature on disability and the transition to adulthood.

### *Policy implications*

Participants reported that SSI was crucial to but limited their success in achieving degrees, employment, and residential independence. Participants relied on SSI to pay for housing, food, care, daily or intermittent physical support, assistive technology, education, and transportation. This support addressed the effects of employment barriers during the transition to adulthood. It enabled participants to pursue education and residential independence. However, several participants reported that eligibility parameters posed significant barriers to employment that delayed, prevented, or reversed status achievement. Extant research suggests SSI eligibility criteria hampers potential beneficiaries from obtaining assistance and current beneficiaries from taking on paid employment (74–76). By increasing or pausing financial eligibility criteria for this population, the Social Security Administration would decrease the tension between assistance and work when young adults pursue education, careers, homes, and care. Existing programs like Ticket-to-Work seek to ease this tension. However, these programs increase administrative burden by introducing additional eligibility determination, agencies to report to, accounts to establish, and unclear benefits (30,37). Participants said that this burden contributed to their decision to balance careers and eligibility by taking low-paying jobs or forgoing employment altogether. Decreasing the administrative burden for young adults with disabilities is essential to uptake because this population often juggles simultaneous life course transition and faces already burdensome programs (3,4,21,29,37,77). Extending eligibility beyond typical parameters or pausing eligibility for a period would likely be beneficial. Doing so would enable young adults with disabilities to pursue and reach their full potential without concern for earning too much money as they begin their careers.

The unclear relationship between SSI and Medicaid created social structural barriers for participants as they set and achieved their goals for adulthood. To qualify for Medicaid, many people with disabilities rely on their SSI determination (29). Medicaid PCA and in-home support allowed participants to begin building non-family care networks to meet their needs as they went to college and work. Existing research suggests parents of people with disabilities often work to establish care networks to support adult-children with disabilities when they can no longer provide (3,17,78). This research extends this concern to young adults with disabilities and highlights the importance of care arrangements to education, employment, and independent living. The state supports many young adults by providing funds to hire and pay care workers of their choice. Most beneficiaries with access to these programs select family members and report a higher quality of care (79). However, others reported extreme anxiety about taking on employment or too highly paid jobs due to the necessary care support that depends on eligibility. This finding aligns with extant literature on social assistance eligibility and disability (23,29,75,80–82). I have presented empirical support demonstrating how the tie between cash (SSI) and health assistance (Medicaid) limits transitions in education, employment, independent living, and care. This finding amplifies needed attention to Medicaid eligibility pathways for young adults with disabilities.

Medicaid alone presented unique obstacles to participants. The findings suggest that addressing care needs is often necessary for young adults with disabilities to pursue education, independent living, and employment. Because Medicaid is one of the only insurance programs offering access to long-term services and supports (29,83), expanding financial eligibility criteria for young adults with disabilities would likely facilitate independence-oriented goals. However, any changes for Medicaid eligibility should correspond with expansions in HCBS and investment in the training, retention, and professionalization of care workers. These changes would address waitlists and labor gaps while ensuring that those who can live in the community can with daily support (84–89).

VR was helpful to some research participants, but others had problems with the program when obtaining college tuition support. VR is administered locally and is partially funded through Social Security via reimbursements to state VR agencies. Moreover, VR is currently expanding services for young adults with disabilities (90). Administrators should consider that education promotes social mobility and is central to the transition to adulthood (18,52,91). The findings suggest that VR could improve career transitions by developing disability-informed financial literacy programs and broadening educational pathways. Although VR is committed to improving employment opportunities by funding degree attainment (U.S. Department of Education 2020), multiple participants reported receiving discouragement and denials from VR employees when trying to use the program to fund undergraduate and graduate degrees. Some participants were able to find alternative pathways to education, while others abandoned educational pursuits. Expanding academic support for young adults with disabilities through VR could help address stagnation during the transition to adulthood by addressing financial and job-readiness obstacles (9,92). VR programs should also consider developing training on disability and educational pathways for employees (15).

This research also clarifies how young adults with disabilities arrange support during the transition to adulthood, a pressing gap in the literature (72). Participants did so by rebalancing self-reliance, family-reliance, and state-reliance while pursuing their goals along several interrelated axes – education, employment, housing, and care. The axes of independence demonstrate that transitions during the early adult years occur like a dance. For young adults with disabilities, education, employment, independent living, and care transitions depend on one another. When various social barriers undo previous success, it jeopardizes all other progress. Therefore, research and policy must consider leveraging the axes of independence by addressing the disjointed support system available to young adults with disabilities. Extant literature suggests that the state should develop bridges between programs for young people with disabilities (3). The findings of this research support this conclusion. However, the grounded theory analysis informed by life course theory suggests that policy efforts must be committed to long-term investments because of the prolonged transition to adult statuses experienced by young adults with disabilities. To date, 39 states have adopted employment first policies (93). These policies seek to foster community-integrated employment experiences for adults with disabilities by coordinating with schools, assistance programs, and employers to create internships and jobs. While named employment first, these programs tend to think across transitions, beginning with education, and provide a robust model for promoting early employment experiences for young people with disabilities (93). More research on the potential benefits and limitations of employment first policies on transitions in education, employment, housing, and care of adults with disabilities is pressing.

Additionally, this research provides more nuance to life course theorists studying agency. Life course theorists have suggested that agency does not extend to developmentally abnormal populations (49,59). The findings challenge this notion by showing how young adults with disabilities use their agency (*self-reliance*) to set and pursue adulthood goals (*independence)*. Notably, the agency participants displayed was never an individual practice; agency was continuously aided and foiled by structural and social-relational contexts. Other research argues that agency is constrained or facilitated by social structure and social relationships (49,59). People are not agentic in vacuums. However, the differential use of self-reliance and independence among participants draws attention to different types of agency – planned decision making (self-reliance) and control (independence) (60,61). Here, participants used their self-reliance, sometimes to access external support from families and the state or avoid barriers from families and the state, to increase their independence. Therefore, when policy-makers institute changes, they must consider how the policy extends or limits the agency of young adults with disabilities when pursuing goals along the axes of independence.

## Conclusion

Grounded theory analysis of 28 transcripts of qualitative life history interviews with young adults with disabilities shows that participants pursued independence-oriented goals simultaneously along several axes. Participants rebalanced self-reliance, family-reliance, and state-reliance while seeking education, employment, and residential independence – axes of independence. Success or disaster in one transition could promote or completely undo achievement in others. Various structural and social-relational contexts created barriers to and shaped participant's goals in significant ways. Social assistance programs may use the axes of independence to identify and provide the proper support to young adults with disabilities in their journey to achieving their goals for adulthood. Because transitions in education, employment, housing, and care are interconnected, support in one area can lead to success in other areas and ultimately facilitate transitions to independence-oriented statuses. Programs could leverage the axes of independence by expanding eligibility criteria, decreasing administrative burden, increasing educational opportunities for beneficiaries, and developing VR counselor training on disability and educational pathways.

*Table 1*. Descriptive statistics.

| | |
|---|---|
| Avg. Age | 30 |
| *Gender* | |
| Woman | 82% |
| Man | 11% |
| Non-Binary | 7% |
| *Race* | |
| White | 96% |
| Mixed | 4% |
| *Highest level of Education* | |
| Some college, no degree | 29% |
| 2-year degree | 7% |
| 4-year degree | 32% |
| Advanced degree | 32% |
| *Employment* | |
| Employed | 82% |
| Unemployed | 18% |
| *Residence* | |

| | |
|---|---|
| Independent (with/without roommate) | 68% |
| Co-reside Parents | 32% |
| *Marital Status* | |
| Married | 32% |
| Single | 75% |
| *Parenting* | |
| Non-Parent | 86% |
| Parent | 14% |
| *Diagnosed Disability Type*[*] | |
| Physical | 50% |
| Mental health | 61% |
| Health | 36% |
| Cognitive | 25% |
| Sensory | 18% |
| Intellectual | 14% |
| Multiple | 86% |
| *Functional Status* | |
| Avg. Number of ADLs | 2.7 |
| Avg. Number of IADLs | 3 |
| Identify as disabled | 93% |
| *Social assistance program receipt* | |
| SSI (Currently) | 18% |
| SSI (Previously) | 14% |
| SSDI (Currently) | 14% |
| SSDI (Previously) | 4% |
| Medicaid (Currently) | 43% |
| Medicaid (Previously) | 14% |
| Medicare (Currently) | 32% |
| Medicare (Previously) | 7% |
| SNAP/TANF (Currently) | 18% |
| SNAP/TANF (Previously) | 4% |

[*] Totals beyond 100% due to overwhelming majority with multiple disabilities within multiple types of disability.

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