UNDERSTANDING INEQUITIES IN HUMAN SERVICES PROVISION TO PEOPLE WITH DISABILITIES

Introduction

Inequities in human services provision related to disability status is influenced by policies, programs, and staff who are often unprepared to serve people with disabilities. The population of people with disabilities is large, diverse, and includes individuals with a range of conditions. Approximately 39 million people in the United States had a disability according to the 2015 Census.[1] (See Appendix A for a brief overview of disability status). People with disabilities are more likely than people without disabilities to live in poverty, be unemployed, and earn low wages, making it difficult for some individuals with disabilities to meet basic needs and attain life goals (Erickson, Lee & von Schrader, 2010; Paul et al., 2020). Adults and children with disabilities experience poorer outcomes in human services programs compared to people without disabilities, in part because services are not designed to meet their needs and caseworkers may be ill-equipped to serve them. This memo discusses three groups: adults with disabilities, children with disabilities, and family caregivers. Solutions for reducing inequities experienced by people affected by disabilities include implementing new and improved policies and programs to address low levels of employment and income, updating federal policy to better support people with disabilities and their families, and creating disability-focused trainings for child welfare system and other human services caseworkers.

Key Takeaways

- Individuals with disabilities and their caregivers may experience disparate outcomes in federal and state human services systems due to inadequate program and policy design and limited caseworker training.

- Individuals with disabilities experience higher rates of poverty and poorer outcomes in human services programs compared to people without disabilities.

- Practices to reduce disparities in human services include:
  - Addressing disparities in income and employment;
  - Federal policy updates including increased access to and increasing amounts of childcare subsidies; and
  - Increased disability-focused training of human services caseworkers.

People with disabilities are served by a range of programs; this memo focuses on interactions with broad human services programs not specifically designed to serve clients with disabilities. Major federal programs and policies specifically intended to benefit and protect people with disabilities include Medicaid, Medicaid Home & Community Based Services, the Social Security Disability Insurance (SSDI) program, Supplemental Security Income (SSI) program, the Vocational Rehabilitation Service program, the Americans with Disabilities Act (1990), the Individuals with Disabilities Education Act (1975), and the Rehabilitation Act (1973) (see Appendix

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[1] The U.S. Census Bureau gathers information on populations with disabilities using data from the American Community Survey, the Survey of Income and Program Participation (SIPP), and the Current Population Survey (CPS). Respondents who report having a hearing, vision, cognitive, ambulatory, self-care, and/or independent living difficulty are considered to have a disability (U.S. Census Bureau, 2017).

B for details). This memo focuses on interactions and outcomes people with disabilities have with human services programs designed to serve a broader range of participants such as the Temporary Assistance for Needy Families (TANF) program, the Supplemental Nutrition Assistance Program (SNAP), childcare, and the child welfare system.

This memo begins with a discussion of poverty rates for those impacted by disability status and the disparities in human services that people with disabilities may face. It then draws upon theories regarding the structure of federal- and state-level human services systems to explain these disparities and offers suggestions for policy changes to promote equity in human services provision.

Current State of Inequities Faced by Individuals with Disabilities and Their Family Caregivers

People with disabilities and families with a child or other family member with a disability are more likely to experience poverty compared to individuals without disabilities. Approximately 25% of adults and 4.3% of children under age 18 in the United States have some form of disability (Centers for Disease Control and Prevention, 2019; U.S. Census Bureau, 2021a). In 2019, adults with a disability were twice as likely to be living in poverty than those without disabilities (26% vs. 11%) (Paul et al., 2020)[2]. In addition, families with members with a disability have lower incomes on average and are more likely to experience food insecurity than the general population (Erickson, Lee & von Schrader, 2010; Fujiura, 2014; Huang et al., 2009; U.S. Census Bureau, 2017). Children in families living below the poverty line are more likely to have a disability (6.5%) compared to children living in families not in poverty (3.8%) (U.S. Census Bureau, 2021a). Additionally, children with a parent with a disability that prevents the parent from working have less economic mobility than children with a parent without a disability (Jajtner, 2020). The relationship between poverty and disability is bidirectional. Having a disability may result in higher rates of household poverty because of the financial strains some families face when an adult cannot work full time due to a disability or caring for a child with a disability (U.S. Census Bureau, 2021a). Conversely, household poverty may cause higher rates of disability because of inadequate health care access and increased exposure to poor home or work environments that adversely impact health (Lustig & Strauser, 2007).

People with disabilities have lower educational attainment and skills training compared to individuals without disabilities, which may contribute to higher poverty rates (Ameri et al., 2015; Thomas & Vercruysse, 2019). According to the 2015 Census, among adults over the age of 25, those without disabilities are more than twice as likely to have obtained at least a bachelor's degree compared to individuals with disabilities (33% compared to 15%). Disability status is also associated with reduced earnings and labor market participation, which can be explained in part by inability to work, lower education levels, lower skill levels, inadequate transportation, societal prejudice and stereotypes held against people with disabilities, and income eligibility restrictions imposed by Social Security Disability Insurance (SSDI) (Ameri et al., 2015; Friedman, 2020; Meyer & Mok, 2018). A relatively small subset of people with disabilities work in sheltered workshops earning subminimum wages allowed by the Fair Labor Standards Act, and many disability-rights advocates argue that such working conditions allow employers to exploit workers while perpetuating poverty (Friedman, 2019; Friedman, 2020; Guilfoyle, 2015; Preedy, 2014). Lower socioeconomic standing due to limited educational attainment and lower incomes is linked to poor health and quality-of-life outcomes for individuals with disabilities and their families (American Psychological Association, 2010). Accessibility concerns (e.g., inadequate transportation, communication issues, and lack of insurance) create increased barriers to obtaining quality health care for people with disabilities (Drainoni et al., 2006; Havercamp & Scott, 2015; Meade et al., 2014).

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[2]Based on data from the American Community Survey, 2019, in which individuals self-report disability status and income levels.

Individuals with disabilities also have higher rates of interaction with human services programs compared to people without disabilities. People who receive TANF have higher rates of disability compared to other adults, and SNAP and TANF recipients are more likely to have a family member with a disability than the general population; parental disabilities also increase the rate at which families re-enter TANF after they leave assistance (Brandon et al., 2008; Coleman-Jensen & Nord, 2013; Loprest & Maag, 2009). This pattern also holds for the child welfare system where almost one in five children (19%) in foster care were removed from their home at least in part due to a parental disability and 5 percent of children in foster care were removed from their home solely because of parental disability; this risk increases for children who themselves have a disability, who are twice as likely as children without a disability to have parental disability listed as the sole reason for removal (DeZelar & Lightfoot, 2018). In addition, parents with intellectual disabilities are more frequently and chronically involved with the child protection system compared to parents without such disabilities (Azar et al., 2012).

Theories Explaining Inequitable Service Delivery & Outcomes

Historically, disability has been understood using the medical model, which argues that disabilities are individual problems or limitations that arise from individual "deficits" and which must be "fixed" with medical intervention (Oliver, 1998, as cited in Hiranandani, 2004). Beginning in the 1980s and 1990s, academic critiques of the medical model of disability emphasized the role of social and cultural factors in understandings of disability and have informed human services practice with, and research about, individuals with disabilities (Hiranandani, 2004; Pope & Tarlov, 1991). The theories described below focus on systemic and social conditions which contribute to the discrimination and inequities faced by people with disabilities.

Social model of disability/social oppression theory

The social model of disability argues that societal institutions including human services programs have been designed for individuals without disabilities and are not equipped to meet the needs of people with disabilities (Sullivan, 1991; Oliver, 1998). For example, parents engaged in the child welfare system who have intellectual/developmental, mental health, and/or emotional/behavioral disabilities may not receive accommodations such as repetition of information and extra time during court proceedings despite child welfare agencies being required to provide accommodations under the ADA (Lightfoot et al., 2017). This lack of access to accommodations could contribute to worse outcomes for parents and children with disabilities, including children tending to stay longer in foster care and parents having higher rates of termination of parental rights compared to children and parents without disabilities (Azar et al., 2013; LaLiberte, et al., 2015; Lightfoot & DeZelar, 2016). Similar challenges have been documented with TANF. Despite having unique needs, families of children with disabilities receiving TANF get little specialized assistance, including caseworkers with the sensitivity and skills to address complex support needs (LeRoy & Johnson, 2002). Barriers to access for services could contribute to lower employment rates for TANF recipients with family members with a disability compared to rates among other TANF recipients (Loprest & Maag, 2009).

> ## Social Model of Disability
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> The **Social Model of Disability** defines disability as the loss or limitation of opportunities to take part in general society on the same level as others due to physical and social barriers; disability is viewed as a social construction which discriminates against and oppresses people with a variety of impairments (Sullivan, 1991; Oliver, 1998).

Likewise, domestic violence and homeless shelters may not be fully equipped to work with clients with disabilities. Although people with disabilities are more likely to experience interpersonal and sexual violence compared to people without disabilities, domestic violence service providers often have limited experience providing services to women with disabilities. Providers may be insensitive to the needs of women with

disabilities, may be dismissive of their domestic violence concerns, or may be unwilling to work with women whose disability limits verbal communication (Casteel, et al., 2008; Harrell, 2017; Martin, et al., 2006; McClain, 2011; Mitra et al., 2016; Nosek et al., 1997). In addition, many homeless shelters are physically inaccessible for people with disabilities with limited mobility (Thomas & Vercruysse, 2019). Further, while nearly one quarter of individuals experiencing homelessness are people with a disability who are chronically homelessness, shelters may not have staff who are trained to work with people with disabilities (Durbin et al., 2018; Thomas & Vercruysse, 2019; United States Interagency Council on Homelessness, 2018).

In addition, often childcare systems are not designed to meet the needs of children with disabilities and their families. Parents of children with disabilities experience increased difficulty finding appropriate care compared to parents of children without disabilities (34% vs. 25%) in part due to the limited supply of caregivers trained to work with children with disabilities and the high cost of providing specialized care for childcare providers (Novoa, 2020; Weglarz-Ward et al., 2019). Childcare providers often do not have sufficient funding to make modifications to improve accessibility for children with disabilities and to pay for staff training on caring for children with disabilities and complex medical needs (Novoa, 2020). In addition, parents of children with disabilities are more likely to experience disruptions at work due to childcare issues and to report needing to leave the workforce or reduce work hours due to challenges in balancing paid employment with their child's care needs (Booth-LaForce & Kelly, 2004; Novoa, 2020; Parish & Cloud, 2006). Perhaps due to these various barriers, evidence suggests that children with disabilities enter childcare at an older age and for fewer hours compared to children without disabilities (Booth-LaForce & Kelly, 2004). Evidence also indicates that children with disabilities receive lower quality childcare and that their parents report lower levels of satisfaction with their childcare compared to parents of children without disabilities (Wall et al., 2006). This is worrying given evidence that attending high-quality early childhood education supports healthy lifespan development for children with disabilities (Odom et al., 2012, as cited in Costanzo & Magnuson, 2019).

The social model of disability also suggests that disadvantages faced by people with disabilities are the product of societal inequality due to prejudice and discrimination (Oliver, 1998). Evidence indicates that people with disabilities face negative perceptions and attitudinal barriers in society and experience discrimination in housing, health care, employment, and wages, which makes it difficult to meet basic needs and attain life goals (Antonak & Livneh, 2000; Huskin et al., 2018; Louvet, 2007; Thomas & Vercruysse, 2019). People with disabilities may also face negative perceptions in human services programs such as the child welfare system as shown in a series of smaller studies using mixed-methods and qualitative research methods. For example, the presence or absence of a parental disability may affect CPS workers' emotional reactions, decisions about child risk, and their willingness to help particular families (Proctor & Azar, 2013). Furthermore, child welfare caseworkers may incorrectly assume parents with disabilities are unable to care for their children due to their disabilities or be more likely to assess children as having emotional and behavioral difficulties which contribute to their abuse compared to children without disabilities (Albert & Powell, 2020; Manders & Stoneman, 2009).
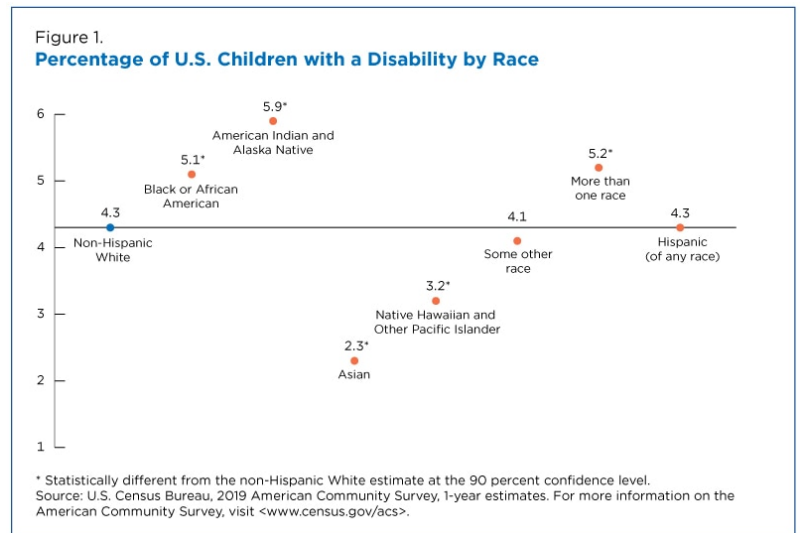
Critical disability theory

Critical disability theory argues that social conditions such as poverty and discrimination lead to the concentration of disability in marginalized populations, including people living in poverty, people of color, and LGBTQ+ individuals (Schalk, 2017). Due to their exposure to risk factors for various impairments, including insufficient nutrition, sub-standard or crowded housing, and inadequate health care, people living in poverty may be more likely to have a disability (Atkins & Guisti, 2004). Some people of color are also more likely to experience disability, perhaps due to disproportionate poverty rates (U.S. Census

> ## Critical Disability Theory
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> **Critical disability theory** argues that disability is a socio-political construction rather than a medical issue which is used to pathologize and oppress certain individuals (Hall, 2019).

Bureau, 2021b). As shown in Figure 1, American Indian and Alaska Native, multiracial, and Black children have the highest rates of disability in the United States (U.S. Census Bureau, 2021a). Additionally, people of color with disabilities may be more likely to experience disparate outcomes in human services programs than people with disabilities who are White because of racial bias (McDaniel et al., 2017). Higher rates of disability are also found among lesbian, gay, and bisexual older adults compared to other older adults, possibly due to experiences of victimization and discrimination over their life course; nearly half have a disability and about one in three report depression (Fredriksen-Goldsen et al., 2011). There is also a differential risk of specific

learning disabilities, intellectual disabilities, and emotional disabilities that impact education and identification for special education across racial groups, with Black students being overrepresented in educational and intellectual disability categories and Asian American students being underrepresented in all disability categories (Sullivan & Artiles, 2011; Cruz & Rodl, 2018). Other sociodemographic factors, including socio-economic status (SES), gender, and language, also predict identification of a learning disability. Males and low-income students are at the highest risk of disability identification in most categories of disability (Sullivan & Bal, 2013). Further, differences in SES account for 100% of disproportionality in learning disability identification among African American and Hispanic students (Shifrer et al., 2011).

Figure 1.
Percentage of U.S. Children with a Disability by Race

* Statistically different from the non-Hispanic White estimate at the 90 percent confidence level.
Source: U.S. Census Bureau, 2019 American Community Survey, 1-year estimates. For more information on the American Community Survey, visit <www.census.gov/acs>.

Mechanisms to Disrupt Inequities

Federal legislation and federal and state human services systems may be able to improve outcomes for individuals with disabilities and their families through the reimagining of existing policies and programs, the creation of new policies and programs, and increased training for caseworkers to more equitably meet the needs of people with disabilities and their families.

Providing employment support for the unmet needs of people with disabilities and their families could decrease rates of poverty and reliance on means-tested human services programs. Instituting a refundable tax credit for employers of workers with disabilities could increase employment opportunities for people with disabilities by counteracting additional disability-related costs incurred by employers, such as purchasing supportive equipment to provide workplace accommodations (Altiraifi, 2019). Ensuring access to comprehensive paid family and sick leave to all workers could enhance the financial situation of families which include a member with a disability by reducing wage loss and financial insecurity associated with caregiving requirements (Altiraifi, 2019; Earle & Heymann, 2012). Guaranteeing universal health coverage that incorporates long-term services and supports and mental health care for all Americans could also mitigate the negative financial impacts that a family member's disability may have on the incomes and financial stability of families living in poverty and, perhaps, reduce disability incidence caused by unmet health care needs (Altiraifi, 2019). Increasing funding to Federal Transit Administration programs (e.g., paratransit) could enable more people with disabilities to access services, supports, and employment opportunities (Altiraifi, 2019).

Revamping existing public policies and programs to better support the needs of people with disabilities and their families could increase equity across human services programs. Implementing methods of appropriate screening, identification, and evaluation of children and parents with intellectual and other disabilities in order to offer accommodations, supports, and services based on learning style (e.g., visual aids or adjusting the rate at which material is presented) or other needs could improve the experiences and outcomes of parents and children in the child welfare system (Azar et al., 2012). Altering TANF policies which may be barriers to self-sufficiency for parents of children with disabilities, such as modifying work requirements, improving job training, and providing funding for organizations willing to offer alternative work schedules to employ such parents, may also improve families' outcomes (LeRoy & Johnson, 2002). Increasing childcare subsidies directed at families of children with disabilities could increase the rate at which children with disabilities attend high-quality childcare programs by providing sufficient funding for childcare providers to make necessary modifications and train staff to care for children with disabilities (LeRoy & Johnson, 2002; Novoa, 2020; Parish et al., 2005; Sullivan et al., 2018). Enhancing federal funding provided to domestic violence and homeless shelters to become more easily accessible (e.g., by adding or updating elevators and ramps beyond what is required by the Americans with Disabilities Act) to people with physical disabilities could increase the rate at which people with disabilities utilize these services (United States Interagency Council on Homelessness, 2018).

Enhancing caseworker training in working with individuals with disabilities and their families could improve the experiences and outcomes of individuals with disabilities involved with human services programs. Improving caseworker training in serving people with disabilities could encourage more positive outcomes for children and parents with disabilities involved with the child welfare system; child welfare caseworkers with more training in working with children with developmental disabilities felt more knowledgeable and comfortable working with this population compared to caseworkers with less training, and almost 87% of child welfare workers in one study indicated that they needed additional training to work with parents with intellectual or developmental disabilities (Rao et al., 2019; LaLiberte, 2013). Increasing childcare staff training in working with children with disabilities could improve access to high-quality childcare, as evidence suggests that childcare centers are more likely to include children with disabilities when directors and teachers have taken coursework related to working with this population; inclusive childcare centers are shown to be of higher quality overall compared to non-inclusive programs (Essa et al., 2008; Grisham-Brown et al., 2010). Creating a corps of caseworkers who specialize in working with families with disabilities could lead to improved outcomes for this population; mothers of children with disabilities have reported having TANF caseworkers without the sensitivity or skills to assist them with complex support needs, such as having limited transportation and inadequate childcare, which limited their ability to attain self-sufficiency (LeRoy & Johnson, 2002).

Conclusion

Individuals with disabilities and their families experience a range of disparities in outcomes which result, in part, from the failure of human services programs, policies, and caseworkers to adequately meet the needs of this population. Although the Americans with Disabilities Act was passed more than 30 years ago and guarantees equal opportunities for people with disabilities in public services and employment and prohibits discrimination against people with disabilities, Americans with disabilities remain disproportionately affected by poverty and overrepresented in means-tested welfare and other human services programs, in which they experience poorer outcomes compared to the general public (American Psychological Association, 2010). Increased support for complex and unmet needs through new public policies and improvements to existing policies and programs, as well as enhanced training provided to human services caseworkers, may reduce the inequities faced by people with disabilities and their families.

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Appendix A: Disability Status Definitions

Disability status may be singular or overlapping. Individuals with disabilities may experience:

- mental, emotional, sensory, cognitive, movement, and/or social limitations;

- limitations in self-care activities and other routine activities; and

- work limitations due to physical, emotional, and/or mental limitations or conditions (Loprest & Maag, 2009).

Disability Status	Specific measure of:
Communication Related	… difficulty hearing, talking, or other communication-related condition (including speech and language delays)
Intellectual Disability	… intellectual disability (e.g., Down Syndrome, Turner Syndrome)
Emotional or Mental Health	… emotional or mental health conditions (e.g., oppositional defiant disorder, ADD, ADHD)
Autism	… autism spectrum
Physical / Orthopedic	… challenges with mobility, limbs, or a diagnosis of spina bifida
Chronic Condition	… chronic conditions, including heart conditions, epilepsy, diabetes, or anemia
Congenital Syndromes, Identifiable at Birth	… Down Syndrome, Turner Syndrome, or spina bifida

(Costanzo & Magnuson 2019).

Appendix B: U.S. Programs and Policies Specifically for People with Disabilities

<u>Americans with Disabilities Act</u>

Americans with disabilities receive protection from the Americans with Disabilities Act (1990) which guarantees equal opportunities for, and prohibits discrimination against, people with disabilities in public services and employment.

<u>Individuals with Disabilities Education Act</u>

The Individuals with Disabilities Education Act (1975) mandates that states receiving federal funds provide services for families of infants and toddlers with disabilities and developmental delays and special education services for children and youth with disabilities (ada.gov, 2020; U.S. Department of Education, 2021).

<u>Medicaid</u>

Medicaid provides health insurance for some individuals with disabilities who meet the income requirements set by states (Musumeci et al., 2019). In 2019, 5.8 million adults with disabilities were covered by Medicaid (Musumeci & Orgera, 2020).

<u>Medicaid Home & Community Based Services</u>

Medicaid Home and Community Based Services allow Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. These programs primarily serve people with intellectual or developmental disabilities and physical disabilities. In 2014, over half of Medicaid long term care spending was on home and community-based services (Medicaid.gov, n.d.)

<u>Rehabilitation Act</u>

The Rehabilitation Act (1973) prohibits discrimination against people with disabilities in public programs, financial assistance, and employment (ada.gov, 2020).

<u>Social Security Disability Insurance program (SSDI)</u>

SSDI provides insurance for workers who are disabled and unable to work after having paid Social Security taxes for at least 40 quarters. In December 2019, 9.9 million people were receiving SSDI, including spouses and children of workers with disabilities (Social Security Administration, n.d.-b).

<u>Supplemental Security Income program (SSI)</u>

SSI is a welfare program for people with low incomes and little or no work history that provides monthly monetary benefits (American Psychological Association, 2010). As of December 2019, approximately 8 million Americans were receiving benefits, averaging about $566 monthly per recipient (Social Security Administration, n.d.-a).

<u>Vocational Rehabilitation Service Program</u>

Approximately 1.2 million people with disabilities participate in the Vocational Rehabilitation Service program which is implemented jointly by federal and state governments (U.S. Department of Education, 2020). This program helps people with disabilities obtain and retain employment (Dutta et al., 2008).