

Research Articles and Essays

**They Deserve More:
Social Justice and the Disability Support Workforce Crisis**

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Abstract

Internationally, a shortage of support workers caused by low pay is threatening the quality of life for adults with intellectual disabilities. In Illinois in the United States, advocates formed the *They Deserve More* coalition to raise wages. This paper uses insights from moral and political philosophy to analyze its motto—who is the *they*, what does it mean to *deserve*, and what is the *more*.

Keywords: direct support professionals, disability rights, moral desert, social justice

They Deserve More:**Social Justice and the Disability Support Workforce Crisis**

“I’m not going to learn your name for a year,” the disability agency manager announced. “I heard that said by an adult with intellectual and developmental disabilities (IDD) to a new staff member at his group home.” I interrupted: “I know why. It’s about turnover. The resident knew the worker would probably leave the job soon.” The manager smiled sadly and nodded.

Developed nations are in the process of deinstitutionalization—moving disabled people out of segregated settings with standardized services into integrated community locations with individualized support. In the United States, 225,000 adults with IDD live in small group homes and attend day activity centers (Residential Information Systems Project, 2021). My son David is one. Many like him have a range of limitations and require lifelong supervision with everything from eating, bathing, and taking medication to job and life skills training. That assistance comes from Direct Service Professionals (DSPs).¹ But a severe shortage of DSPs is threatening services for people with IDD. Litigation and advocacy have nudged states toward boosting wages and improving staff levels. In Illinois in the United States where David lives, advocates formed the *They Deserve More* coalition to lobby state lawmakers to raise DSP pay.

Eva Feder Kittay (1999) highlights the burdens of unpaid caregivers—family members, usually women—who look after dependents at home.² In this paper, I discuss paid caregivers—DSPs who support people with IDD. I focus on agency-employed staff, but there is also a shortage of workers for self-directed care. I emphasize wages, although lack of

career opportunities also contributes to the workforce crisis. I spotlight Illinois as a case study of a prevalent and persistent national and international problem.

Disability studies examines disability within social, cultural and political contexts. It promotes awareness of the experience of disabled people and advocates for social change (since disability is more a socio-political than a medical phenomenon). In this paper, I reflect philosophically on a grassroots effort to influence public policy. Sometimes—Christopher Bennett (2017, p. xviii) says—philosophers are “humbled by the wisdom of highly skilled practitioners [and] all philosophy can do is to seek to give a theoretical articulation to such wisdom.” The professionals and advocates who chose the name *They Deserve More* knew what they were doing. My aim is to interpret the label: they (people with IDD and DSPs) deserve (as an entitlement, not a favor) more (generous funding from a wealthy nation). I first summarize empirical evidence concerning staff shortages internationally, across the United States and in Illinois. I then use moral reasoning to shed light on the meaning of each aspect of the *They Deserve More* slogan.

Empirical Evidence

Around the world and across the United States, service agencies face staff shortages and its result—decreasing program quality for people with IDD.

Personal Testimony

Personal narratives enable understanding of social contexts. Before presenting quantitative data, I give qualitative description of the lived experience of one adult with IDD. While anecdotal, my son’s story is typical.³

David's group home of four high-need men is often understaffed—it requires two DSPs, but often only has one. Basic care can be inadequate. David cannot brush teeth without supervision, but a single worker finds it difficult to assist him with three other residents to monitor. He is—at age 32—showing signs of gum disease. David is nonverbal, so it takes months for a DSP to learn how to work with him and understand his communication patterns. But there is a constant turnover of regular and substitute staff who do not know his unique needs, strangers with whom he is not comfortable. Having only one DSP limits community outings: all four men have to want to go to McDonald's or a holiday parade—if even one does not, then the group cannot go since none can be left alone. Weekends are particularly difficult with rotating and unfamiliar house staff.

David's typical day is spent in a segregated activity center. It lacks sufficient staff to take him into the community or conduct meaningful activities. What he should be doing is integrated recreation (as when his mother or I take him to Special Olympics sports programs) and volunteering (as when he and I stock shelves at a food pantry). At his congregate center, he is in a group of 10 individuals supervised by one DSP. Community recreation or volunteering would mean small groups with a staff-client ratio of 1:3. Worker shortages make that impossible.

The barely adequate services David receives are not the fault of his agency, which meets the highest accreditation standards. It is the fault of a poorly funded public disability system that harms both service-users and DSPs.

Sociological Facts

A skilled and reliable DSP workforce is the linchpin of disability services, but staff shortfalls affect all developed countries.

The International Staffing Shortage

Social services in Europe face a labor shortage with high turnover and vacancy rates (European Association of Service Providers for Persons with Disabilities, 2019; European Public Service Union & Federation of European Social Employers, 2020; Federation of European Social Employers, 2024; Lethbridge, 2017). Agencies have difficulty recruiting and retaining qualified staff. Pay is poor (hourly wages are 21 percent lower than the average for all workers) and career development opportunities are insufficient. Working conditions—variable hours in jobs that are emotionally and physically demanding—are undesirable. In Finland, the shortage of care workers means that some agencies cannot provide necessary support (S. Miettinen, personal communication, September 2023). In England, where government has tightened budgets, agencies struggle to find and keep staff (Courtenay, 2018; Equality and Human Rights Commission, 2017; Public Health England, 2019). In Ireland, low pay, unpredictable schedules and increased responsibility create a shortfall of care staff (Fleming & Taylor, 2006). In The Netherlands, 180,000 of the 1.2 million care workers change jobs every year—and almost half leave social care (European Public Service Union & Federation of European Social Employers, 2020, p. 5).

Australia has thousands of unfilled care positions. Turnover is high; the disability workforce lost 200,000 employees between 2021 and 2024 because of poor pay and limited career pathways. Staffing challenges are particularly acute in remote communities and for individuals with complex needs (Commonwealth of Australia, 2021, pp. 10-20). New

Zealand also has a shortage of caregivers. Workers leave because the job is stressful, hourly pay is near minimum wage, and there are few chances to advance in the field. Agencies hire less experienced workers, resulting in compromised care (Jorgensen et al., 2009).

The underlying cause in all jurisdictions is lack of resources. Employees have trouble finding jobs with fair pay, stable working conditions and career development. Service-users experience denial of services, closure of programs, decreased quality of support and long wait lists (Federation of European Social Employers, 2024, pp. 2-3). According to the European Association of Service Providers for Persons with Disabilities (2019, p. 4), the “detrimental impact [that lack of staff has] on ... person-centered and community-based forms of care and support ... cannot be underestimated.” Improving recruitment and retention must become a budget priority for policymakers.

The U.S. Staffing Shortage

In the United States, 1.28 million DSPs work in various settings. Numerous reports (American Network of Community Options and Resources, 2022 and 2023; Institute on Community Integration, 2018; National Alliance for Direct Support Professionals, 2024; National Core Indicators, 2022; President’s Committee for People with Intellectual Disabilities, 2017; Anderson & Pettingell, 2023) describe a widespread shortage of staff. The National Core Indicators workforce report (2022) reveals the average turnover rate for DSPs is 43 percent, average vacancy rate is 15 percent and average hourly wage is \$14.50 (below jobs in retail, warehouse and food service). Adjusted for inflation, wages nationally are lower now than 10 years ago.

To correct the institutional legacy of community services, the Medicaid “Settings Rule,” implemented in 2023, cut funding for housing and workplaces that isolate individuals from the public. It requires individualized support and social integration. These services are more staff-intensive than institutional care—but no additional resources are allocated to improve staff levels (Medicaid, 2014).

The workforce shortage has multiple causes (Hewitt et al., 2018b; President’s Committee for People with Intellectual Disabilities, 2017, pp. 26-32). One is low pay and poor benefits. Average DSP wages fall below the federal poverty level; half of DSPs rely on government-funded benefits and most work multiple jobs. Another is limited credentialing and career pathways. A lack of occupational recognition means that DSPs have little earning potential. Third is a shift in the type of services delivered. The role of DSPs has evolved from providing custodial care to giving coaching support—working with people to enable quality of life outcomes. Special education trains individuals with fewer challenges to live in a semi-independent manner, leaving adults with more challenges, who are harder to serve, clustered in staffed group homes and day centers.

Staff shortages negatively impact families (who must constantly advocate to ensure their loved one receives needed support). Staff shortages damage agencies (which make substantial overtime payments and waste resources continually replacing staff). Staff shortages hurt DSPs (many of whom work overtime or multiple jobs, causing burnout and adding to turnover and vacancies). Staff shortages harm service-users (who do not receive the person-centered support and community integration to which they are entitled by law). Because of inadequate staff, 92 percent of agencies are struggling to manage existing services

and achieve quality standards. Sixty-three percent have discontinued programs and discharged individuals and 55 percent are considering further service cuts. Eighty-three percent are refusing new referrals—nationwide, 473,000 people remain on wait lists (American Network of Community Options and Resources, 2022; United Cerebral Palsy, 2020, p. 14).

Addressing the staffing shortage requires paying competitive wages and creating competency-based career ladders (American Network of Community Options and Resources, 2022; Hewitt et al., 2018c; President’s Committee for People with Intellectual Disabilities, 2017, pp. 33-41). These measures cannot happen without generous funding. Most IDD services are paid for by Medicaid, a joint federal-state finance arrangement. Unlike businesses, agencies cannot raise the price of services to pay staff more. Non-negotiable wage rates are set by state legislatures, and because of inadequate reimbursement, agencies cannot be competitive employers.

The Illinois Staffing Shortage

The 1990 Americans with Disabilities Act’s (ADA) “Integration Mandate” requires that services be provided in the most integrated setting appropriate to a person’s needs. Many states disregarded this demand. The state of Georgia was sued, and the 1999 Supreme Court ruling in *Olmstead v. L.C.* (1999) declared that unjustified segregation constitutes discrimination and directed states to provide suitably-funded services in community settings. Illinois continued to ignore ADA and *Olmstead* integration mandates, so lawsuits were brought by people with IDD living in segregated facilities (Illinois Department of Human Services, n.d.). Following the 2011 Illinois *Ligas v. Hamos* settlement, thousands of

individuals—including David—moved into the community. The consent decree requires adequate resources to ensure services that support person-centered inclusion, but Illinois has deprived agencies of necessary funds. Staff turnover is 42 percent, vacancy rates are 16 percent and average hourly wage is \$16.24 (National Core Indicators, 2022, pp. 22, 24 and 34). Staff shortages hinder community participation—many individuals have limited outings and spend time in sheltered activity centers and group homes. Staff shortages also compromise person-centered care. High turnover makes it difficult for inexperienced DSPs to implement service-users' personal goals, maintain their skills, and build independence.

One response has been litigation. In 2017, disability rights groups filed a motion arguing that poor care resulting from low reimbursement violated the Ligas settlement. The court ordered an update of the state's payment methodology. The 2020 Guidehouse Plan provided a roadmap to stabilize community services—but the legislature refuses to fully fund its recommendations (Illinois Department of Human Services, n.d.). A second response has been advocacy. In 2017, a coalition of families, service agencies, and advocacy organizations formed *They Deserve More* to increase state funding. Despite incremental investments, DSP pay has not kept pace with minimum wage increases, inflation, the competitive job market, or the actual cost of delivering services (They Deserve More, n.d.).

Staffing Shortage Summary

There are no services without a qualified and reliable workforce. Support from knowledgeable and familiar staff is necessary for individuals with IDD to achieve integrated and individualized lives. Staff shortages occur because agencies are not reimbursed enough to offer competitive wages and career pathways. Turnover and vacancies create an unstable

environment for both service-users (whose needs cannot be met by inexperienced staff) and DSPs (who have increased stress from working overtime at several jobs).

Philosophical Analysis

In developed nations, service agencies face significant challenges recruiting and retaining staff, with adverse outcomes to people with IDD. I now use philosophical concepts to analyze each element of the *They Deserve More* motto—who is the *they*, what does it mean to *deserve* and what is the *more*.

They Deserve More

The *they* who deserve more is both people with IDD and the DSPs who support them. As Kittay (1999) points out, the interests of care-receivers and of care-givers are intertwined. David's prenatal brain injury adversely impacts his functioning in every area. He does not read, is nonverbal, cannot understand significant choices, and needs assistance with all activities of daily living. Because David requires support from DSPs, caring for him is inseparable from caring for them. To deny them a living wage and feasible career path (resulting in high turnover and vacancy rates) is *eo ipso*—and as an inevitable result—to deny him quality care.

The intertwining of care-receiver and care-giver needs entails what Kittay (1999) calls the *doulia* principle. A *doula* is the postpartum caregiver who cares for a mother so that she can care for her infant. In a public conception, the *doulia* relation concerns social support: as the *doula* cares for the mother who cares for the newborn, so society should care for DSPs MacKenzie and Carl through generous compensation so they can care for David. The *doulia* principle “links those who need help to those who help, and links the helpers to a set of

supports Just as the caregiver has a responsibility to care for the dependent, the larger society has an obligation to attend to the well-being of the caregiver. Only so can the caregiver fulfill responsibilities to the dependent” (Kittay, 1999, pp. 132-133).

There are two levels of obligation in caring for David—the personal obligation of his DSPs and the social obligation to his DSPs. These duties cannot be separated since care for David is constituted by care for his caregivers. Society has care for people with IDD as a necessary obligation—and since care for them requires DSPs who provide that support, a just society also has care for DSPs as a necessary obligation.

Society must support DSPs so they can support people with IDD. But MacKenzie and Carl deserve to be treated fairly for their own sakes, not simply because it will benefit David. DSPs are subjects of moral consideration apart from their usefulness as a means to some other end (i.e., care for disabled people). Society has direct duties *to* them, not indirect duties *concerning* them (Regan, 1986, pp. 180-181). Suppose I consider smashing your car’s windshield. My indirect duty to not damage your car is not owed to the car but is simply a direct duty to you. Now suppose I think about kicking your dog. Here I have both a direct duty to the dog (not to hurt it) and a direct duty to you (not to upset you). DSPs do not only indirectly deserve good treatment because society has a direct duty to adults with IDD. They have intrinsic, not just instrumental, value. DSPs deserve good treatment directly, not derivatively.

Many frontline staff are racialized women. In the United States, 89 percent of DSPs are women, and 50 percent are people of color. Women of color are the largest and fastest growing segment of the workforce (Campbell, 2017). In Europe, too, there is gender

imbalance—82 percent of the social service workforce is female (European Public Service Union & Federation of European Social Employers, 2020, p. 4). Many have limited education and few employment options, but DSP jobs do not provide economic stability. Women caregivers—especially women of color—are more likely to live in poverty and rely on public benefits. As care needs grow, more countries are relying on migrant workers (Anderson, 2012). In addition to being an economic justice issue, underpaying DSPs is a gender and race justice issue.⁴

They Deserve More (n.d.) puts it well: “It is time to make a stand for Illinoisans with developmental disabilities and those who serve them. They both deserve more.”

They Deserve More

People with IDD and DSPs *deserve* more. In common usage, the word “deserve” has a narrow meaning that is nearly interchangeable with “earn.” What someone deserves is based on past choices and actions for which they are responsible. Students deserve—they earn—grades by their academic performance (Schmidtz, 2006, chapter 9). But I am using the term in a broad philosophical sense that covers all forms of distribution.⁵ In this understanding, to deserve is to merit, be worthy of, or have a claim to something (either reward or punishment, merit, or demerit). What someone deserves can be based on their actions, but also on their qualities or situation (Oxford English Dictionary, n.d.). A drowning child deserves to be rescued—this benefit is unearned but deserved. The philosophical definition of “desert” (referring to what a person deserves, as in common usage such as “he got his just deserts”) is part of a group of closely related concepts: rights, entitlement, justice, and obligation.

First, desert involves *rights*. A right is a justified claim to be treated in a certain way. Rights impose duties on others. Rights are more than favors that depend on sympathy and may be given or withheld at will—they are owed and must be respected. Rights are both negative (to not be harmed) and positive (to be helped)—they can be violated both by causing injustice and refusing to correct it.

Second, desert is related to *entitlement*. To be entitled to something is to have a proper claim to it. Fred Feldman and Brian Skow (2015) suggest that the concepts are not identical: desert is prescriptive and moral while entitlement is descriptive and legal. Entitlements exist when institutional rules establish the conditions under which someone should receive something—the ADA, for example, grants people with IDD the legal right to community living. There can, however, be entitlement without institutional acknowledgment. People with IDD were morally entitled to inclusion before the ADA legally required it—and DSPs are morally entitled to, though not politically granted, a living wage. Legislation and litigation are necessary to convert moral entitlements into legal entitlements.

Third, desert concerns *justice*. Justice—giving people what they are due—differs from benevolence. Joel Feinberg (1980a, p. 142) identifies two kinds of moral transactions. “On the one hand, there are gifts ... and favors motivated by love or pity or mercy and for which gratitude is the sole fitting response. On the other hand, there are dutiful actions and omissions called for by ... rights These can be demanded, claimed, insisted upon.” Charity is optional—justice is required.

Finally, desert is connected with *obligation*. Obligatory actions are mandatory—they must be done whether a person or institution wants to or not. Supererogatory actions are

discretionary—while good to do, they are not required. Unlike elective gratuities, deserved treatment is called for by rights that impose duties which must be performed.

The conceptual structure of desert has four elements: (1) a deserving subject—a person who deserves something; (2) a deserved object—a mode of treatment the subject deserves to receive; (3) a desert basis—facts about the subject because of which they deserve the object; (4) a desert source—the person or institution from whom the subject deserves the object. The four-part relation between subject, object, basis, and source can be expressed in the formula: person A deserves item X from person or institution B because of feature Y (Feldman & Skow, 2015).

These four elements apply to disability policy. The deserving *subjects* are people with IDD and the DSPs who support them. The deserved *object* is well-staffed, person-centered, integrated services for people with IDD and adequate wages and career paths for DSPs. The desert *bases* are inherent qualities of people with IDD and voluntary actions of DSPs. The desert *source* is the state—government must provide the financial resources necessary for adults with IDD and DSPs to achieve well-being. Desert ranges from weak to strong depending on its importance. The strong desert of people with IDD is based on essential needs they have. The strong desert of DSPs is based on the complex and vital work they do.

The Desert Bases

Two distinct considerations constitute the desert *bases* for what people are owed (Darwall, 1992). One is performing certain actions. This is what earning is—deserving to get something in return for an action. Students earn grades by their learning. Personal desert is based on what we do, on effort and achievement. The other is possessing certain attributes. A

drowning child deserves to be rescued; this benefit is unearned—and yet the child deserves it. Human desert is based on what we are, on worth and needs.

Why DSPs Deserve More

Like the student deserving high grades, DSPs deserve generous wages as a matter of personal desert. They have a right, Kittay (2001) says, to “compensation that matches the intensity of their labor” (p. 573). But the President’s Committee for People with Intellectual Disabilities (2017) points out “there is a significant discrepancy between the job responsibilities and skill expectations of DSPs and their low wages” (p. 55). Staff roles are evolving from caretaking to coaching—DSPs are expected not to do things for people but to teach and help them do things for themselves. Supporting is more demanding than caregiving; it requires a workforce with diverse skills.

Stephen Nathanson (1998) identifies three criteria for determining what a person deserves as fair pay: “their effort (how hard they work), their achievement (the value of the results of their work) and their abilities (the level of skill that is required to do their work)” (p. 56).

In terms of *effort*, DSPs work long hours. Because of turnover and vacancies, many do overtime or have multiple jobs. The work is difficult and demanding. As Amy Hewitt and colleagues (2018a) point out, “DSPs are generalists who have to be able to provide whatever support is needed across a wide range of activities throughout the lifespan of people with IDD” (p. 6). In David’s home, staff juggle the needs of four men simultaneously—preparing meals, dispensing medications, and helping them make beds, wash laundry, perform hygiene activities, and access the community.

In terms of *achievement*, support work is vitally important. “Essential workers” conduct a range of services necessary to the continuity of critical social functions. Like employees in healthcare, food service, and public safety, DSPs perform essential services that can never shut down. Robert Curriden (2018) describes his work providing behavioral support, supporting activities of daily living and independence, “administering complex medications, and providing medically necessary routines and interventions” (p. 14). DSPs have immense responsibility—their work is essential to the health, safety, and well-being of those in their care.

In terms of *abilities*, DSPs perform challenging and sophisticated work. As Hewitt and colleagues (2018a) state, “the direct support job is highly complex and requires sound judgment and significant skills that include independent problem-solving, decision-making, behavioral assessment, crisis prevention and intervention, and communication. Many DSPs are often isolated, without co-workers, supervisors or clinical professionals on-site to provide assistance or guidance” (p. 4). They are multidisciplinary experts: like teachers they impart skills, like nurses they dispense medications and treatments, like social workers they access community resources, like counselors they listen and advise. DSP competencies include communicating, providing person-centered support, community networking, facilitating living skills, advocating, vocational assistance, crisis intervention, documentation, enabling physical and emotional health and wellness, and helping service-users build relationships. Support work demands dedication and commitment as well as knowledge, skill, and compassion (National Alliance for Direct Support Professionals, n.d.).

DSP are essential workers, professionals performing expert work—they deserve pay that aligns with the critical nature of the job. Compensation should at least be a living wage. It should also be tied to certification—as DSPs achieve additional qualifications, their pay should increase. They deserve more as a matter of earned, personal desert.

Why People with IDD Deserve More

Like the toddler deserving rescue, people with IDD deserve quality support as a matter of human desert.⁶ Many rely on DSPs for what Feinberg (1980b) calls “basic instrumental goods of life—food, shelter, protection,” needs that create “dependency rights” , (p. 126). David wants what everyone else wants—a happy life. Flourishing consists in a bundle of basic goods given in human nature; a person’s life goes better if it includes more of them and worse if it has fewer.

Robert Schalock and Miguel Verdugo Alonso (2004) identify eight domains of a good life: physical well-being, mental well-being, personal development, social relations, participation, self-determination, material well-being, and rights. The Council on Quality and Leadership’s *Personal Outcome Measures* (n.d.) organizes quality of life around five domains: security (being safe, free from abuse and neglect), community (living in integrated environments, participating in social life), relationships (having friends and intimate partners), choices (selecting where and with whom to live, work, and spend daytime hours) and goals (choosing and achieving personal wishes). These are substantive components of human well-being.⁷ People with IDD need to have their safety ensured, be healthy physically and emotionally, engage in activities they like and can do well, enjoy social relationships, be

trained in their best competencies and experience a sense of contentment. If life can be good when these key dimensions are present, it can also be bad when they are missing.

People with IDD have deficits in intellectual and adaptive functioning. David has limited skills of self-management—communicating, solving problems, exercising good judgment, setting goals, and completing tasks. Without stable DSP support, adults like him cannot flourish. Instead of being healthy physically and settled emotionally, they become sedentary and distressed. Instead of performing meaningful activities, they spend their time in dull, repetitive tasks that leave them idle and disengaged. Instead of enjoying strong relationships, they are isolated and lonely. Instead of being trained to maximize their abilities, their personal development is stunted. Instead of having a sense of well-being, they experience a flat, one-dimensional life.

Individualized attention and social inclusion are not possible when disabled people receive poor support from overworked staff or a constant turnover of inexperienced DSPs. People with IDD deserve consistent and competent staffing for vocational and residential programs—and adequate funding that upholds them—as a matter of basic, human desert.

The Desert Source

The desert *source* from whom people with IDD and DSPs deserve assistance is the state. The reasoning is disjunctive. People with IDD have basic needs and quality of life needs that must be met for them to enjoy a decent level of well-being. These needs cannot be met by the person themselves. Like David, many cannot care for themselves because of difficulty thinking, planning, choosing, and communicating. The needs of people with IDD cannot be met by family and friends. Some families provide care because they choose to, but

others do so because they must (since group home placements are hard to get).⁸ Families who place their loved one out of home trust service agencies, not themselves, to provide care. The needs of disabled people cannot be met by voluntary community altruism. Charitable giving in the United States is about two percent of income annually, and much of that goes to arts programs, educational institutions, and religious organizations, not social care agencies. Individuals with IDD cannot rely on neighbors, faith communities, or service clubs to look after their needs (Singer, 2009, pp. 23-24). Therefore, the only option is that their needs be met through tax-funded government services. A parallel argument applies to DSPs, whose work cannot be financed through private charities or agency grant-writing and fundraising, but only by generous public reimbursement.

Recall the desert formula: A deserves X from B because of Y. DSPs deserve adequate compensation from government because of their complex and indispensable work. People with IDD deserve generously funded services from the state because of their inherent worth and vital interests.

They Deserve More

People with IDD and their support workers deserve *more*. The government support that they deserve is either less than, the same as, or more than they already receive. To give them less will make their quality of life worse than it is now. To give them the same will perpetuate the current situation (described earlier), leaving disabled people without essential services and DSPs without adequate compensation. As I have previously discussed, only if they are given more will both groups thrive rather than survive (Gould, 2021a; 2021b).

Viable political theories hold that wealthy societies should guarantee all members a satisfactory standard of living—in particular, they should help people meet significant needs they cannot meet on their own. A social minimum, Stuart White (2015) says, is “the bundle of resources that a person needs in order to lead a minimally decent life” (“What is Social Minimum?”, para. 1). A just society enacts “institutions and policies that secures every member reasonable access to a social minimum” (“What is Social Minimum?”, para. 1). This is the deserved object.

The *content* of a social minimum can be defined in terms of needs. Needs are essential conditions that must be met if a person is not to suffer harm. Welfare interests (like physical health and financial resources) are the necessary means to higher goals (like playing an instrument or managing a restaurant). When these basic needs are not met, a person’s entire set of interests is damaged. As Feinberg (1984) says, “welfare interests most certainly are grounds for moral claims against others” (p. 112). Gillian Brock and David Miller (2024) agree that needs carry moral weight. “The needs that matter ..., especially in political distribution, are those that are necessary, indispensable and inescapable, given the kinds of creatures that we are and the requirements for functioning in social settings” (“Common Strategies for Responding to such Strategies,” para. 1). Further, a “person’s being in need always counts as a strong ... reason to aid them” (“Needs and Capabilities,” para. 3). Because the harm David and his DSPs experience suffer when their needs are not met is serious, they are a matter of political priority.

The *content* of a social minimum can also be defined in terms of capabilities. Martha Nussbaum (2006) identifies capabilities as central human functions such as physical and

emotional health, social interaction, meaningful work, engaging play, and control over one's environment. Because the core capabilities are necessary for living well, they ground political entitlements to what is necessary for their fulfillment. These deserts "should be respected and implemented ... as a bare minimum of what respect for human dignity requires" (pp. 76–78). If a capability is not adequately satisfied, then society denies that person the opportunity to lead a good life.

The *amount* of a social minimum can be defined by two broad standards (Nathanson, 1998, chapter 9). A bare minimum is meager assistance that simply prevents severe harm. It does not make people well off—while avoiding the worst, it still leaves them badly off. A comprehensive minimum is generous assistance that provides the resources necessary for a good quality of life. Harry Frankfurt (2015) states that when establishing a social minimum, each person should have enough:

Having enough money [or other resources] is far from being equivalent to having just enough to get by, or to having enough to make life marginally tolerable The point of the doctrine of sufficiency is not ... whether people have enough to avoid ... misery. A person who [has] just barely enough does not really ... have enough at all. (p. 49).

Disabled adults and DSPs deserve a generous social minimum. The notion of a decent level of well-being is vague, but not hopelessly vague (White, 2015). First, the end is identified—the needs that are essential for a good quality life. Second, the means are determined—the kind and level of resources that are necessary to adequately meet those needs. The goal for DSPs is a living wage and professional credentialing—the means is generous state funding. The goal for people with IDD is high quality vocational and

residential programs that are integrated and individualized—the means is stable staff and ample funding to pay them. The first cannot happen without the second. Without adequate compensation, DSPs will underperform, burn out, and leave for easier jobs with better pay. Without competent support, disabled adults will remain in facilities that isolate them, do little to develop their abilities, and stifle their fulfillment.

What DSPs Deserve

DSPs need sufficient income to purchase food, housing, household necessities, transportation, healthcare, and childcare. They need economic security so they do not struggle to cover these payments. They need a predictable 40-hour work week so their jobs do not take a toll on personal health, close relationships, and leisure activities. But many lack the financial resources necessary to support themselves and their families. They experience “secondary dependency” (Kittay, 1999, p. 46). The American Network of Community Options and Resources (2017) points out the paradox: “those who are caring for individuals on [public assistance] need public assistance themselves to make ends meet” (p. 12). In addition to a living wage, DSPs deserve affordable benefits: health insurance, paid time off, childcare subsidies, and retirement plans. Because the workforce is comprised largely of women of color, generous compensation, and career opportunities are matters of gender and race equity.

DSPs also deserve career advancement through competency-based credentialing that professionalizes their work. In addition to poor wages and benefits, inadequate preparation and career development opportunities contribute to the staffing challenge. The President’s Committee for People with Intellectual Disabilities (2017) acknowledges the “failure to

create an occupation of DSP with sufficient pay, benefits, training and career trajectories and status to recruit and retain a stable, skilled workforce” (p. 26). The issue is not just how they are paid, but how DSPs are developed and promoted. In 1996, the National Alliance for Direct Support Professionals (2011; 2019) created a multi-level certification program based on core competencies—the knowledge, skills, and attitudes needed for high quality support. Credentialing provides a career path with wage incentives and recognition of DSP work as a professional career, not a low-skill, temporary job. Provider agencies and community colleges in multiple states have established certificate and mentoring programs. Competency training and standardized credentialing decrease turnover rates, but education and certification remain voluntary and are not widely utilized (Bogenschutz et al., 2015; Kramme, 2018). The Recognizing the Role of Direct Support Professionals Act was recently introduced in Congress. It would have revised the federal Standard Occupational Classification system to establish a separate code for DSPs and would have created better understanding of the labor market shortage and high turnover rates. The legislation did not pass (Congress, 2023).

The means of meeting DSP needs is generous funding for wages and benefits, training, and certification. Poverty-level pay is the primary reason many leave employment. The American Network of Community Options and Resources (2017) asserts that “low wages occur because agencies are constrained by low, non-negotiable reimbursement rates set by their states’ Medicaid agencies This difficult situation must be remedied by state legislatures and the federal government by prioritizing increased Medicaid rates to IDD services” (pp. 12–13). The same is true internationally: as the European Association of

Service Providers for Persons with Disabilities (2019) says “the single biggest solution to staff shortages ... is to ensure that the sector is adequately resourced by public funding” (p. 12).

What People with IDD Deserve

Limited executive and adaptive behavior impact the health and wellness, community involvement, social relationships, and employment of disabled adults. David cannot meet his own *basic living needs*. He cannot wash himself clean if he loses bowel control; he cannot care for himself when sick; he cannot prepare food without assistance; he may not choose weather-appropriate clothes; he cannot effectively perform oral hygiene. Nor can David meet his own *quality of life needs*. Without staff support, he would sit around all day playing computer games rather than interacting with other people, engaging in work or recreation, and participating in the larger community. Like him, many people with IDD depend on DSPs for everything: preparing food, bathing, managing social situations, healthcare visits, transportation, and jobs.

To meet their needs, people with IDD require high quality vocational and residential programs that are well-staffed. Yet many are harmed by inadequate services due primarily to inconsistent staffing. Individualized attention and community inclusion are not possible when they receive deficient support from overworked or inexperienced DSPs. The results are social isolation, a lack of productive activities, limited skill development, and increased anxiety, depression, and aggression (Wolf, 2017).

The means of meeting disabled people’s needs is generous resources for vocational and residential services. In particular, agencies must receive ample funding to hire, train, and

retain DSPs long-term. The American Network of Community Options and Resources (2017, p. 16) advocates indexing pay to minimum wage levels or the Consumer Price Index and setting rates based on actual costs incurred by agencies. In Illinois, the Guidehouse Plan recommends a DSP wage at least 150 percent of the minimum wage. The legislature refuses to fund this amount, and recent expenditure increases do not compensate for decades of underinvestment.

Nussbaum (2010) reminds us that “people are entitled not only to mere life but to a life compatible with human dignity, and this means that the relevant goods must be available at a sufficiently high level” (p. 79). DSPs deserve compensation that does more than prevent poverty, which it often fails to do. They deserve to support themselves comfortably without working overtime, taking multiple jobs or relying on government benefits. They deserve a living wage and open career paths. People with IDD deserve services that do more than prevent harm but leave them missing out on many things necessary to a full life. They deserve continuity of support, rather than instability because of staff turnover and vacancies. They deserve person-centered and community-integrated services—legal entitlements that cannot be met without sufficient staff.

Conclusion

A few months ago, I received this email from the supervisor of David’s group home: “[Worker A] resigned last night three hours before her scheduled shift. [Worker B] stayed until 10 p.m. and [worker C] came in last minute for the overnight. The guys were concerned about where [worker A] was. I will do my best to fill her shifts with staff the guys know, but

this will be an adjustment for them.” The churn of DSPs, especially in stressful locations with high service needs, is common. Hewitt and colleagues (2018a) summarize:

[T]he health, safety and well-being of people with IDD is at risk daily because of the workforce problems. A revolving door of strangers coming in and out of a person’s life, often required to support in the most intimate personal care routines, means that far too often they may not trust or develop a meaningful professional relationship with the DSP. Signs and symptoms of illness are missed, opportunities for community participation are lost, and people with an IDD have few choices other than congregate models, such as group homes or sheltered work settings, because community staffing is unstable. (p. 7).

Decreased service quality results from inadequate staffing, which results from insufficient funding.

Let me again make clear that I am not blaming service agencies or DSPs. Instead, I am criticizing the public disability system that does not provide economic stability to DSPs or suitable programs to people with IDD. These pervasive deficiencies have persisted for decades. The failure, Hewitt and colleagues (2018a) assert, is rooted in “a fundamental lack of respect for people with disabilities and the staff who choose careers in providing support to them” (p. 3). Society, Curriden (2018) adds, is:

[C]aring for ... the weakest and most vulnerable ... through abusing the good will of DSPs who work two and three jobs; who must have public assistance to feed their families ... ; and who willingly work holidays, weekends, and sixteen-hour double shifts In so doing, we are abusing those individuals that we, as a society, have

an obligation to provide for and protect. (p. 14).

By violating the *doulia* principle, public disability systems mistreat both support workers and service-users.

People with IDD and DSPs deserve more on a *naturalist* theory of justice, because they possess human rights grounded in inherent human worth, vital human interests, and vital work. People with IDD (and, by extension, DSPs) also deserve more on a *conventionalist* theory of justice, because they possess legal rights established by civil legislation and court rulings. The ADA and Olmstead ruling give disabled people the right to personalized participation in the major spheres of life and the financial support required to realize their potential. Similar legal entitlements exist in other jurisdictions. A stable workforce is necessary for states to comply with integration mandates. People with IDD will not have quality residential and vocational services until the staffing crisis is resolved through better wages and professional recognition. As Carli Friedman (2018) says: “DSP continuity is central to quality of life of people, including human security, community, relationships, choice and goals. States cannot continue to provide near-poverty level reimbursement rates for DSPs and still ensure quality of life” for adults with IDD and their support staff (p. 234).

Government budgets are moral documents that do not simply concern economics but indicate national values. There are real human persons attached to legislative appropriations and budget numbers (Smith, 2023, p. 20). Generous funding that addresses the staffing shortage through wage stabilization and career professionalization is not an optional gratuity but a duty owed as a matter of justice. *They* (people with IDD and DSPs) *deserve* (as an entitlement, not a favor) *more* (plentiful resources from a wealthy nation).

At this moment in the United States, however, there appears to be little hope for these positive changes. Instead, the second Trump administration is inflicting havoc on Americans and threatening dire consequences to adults with IDD. Republican legislators plan to substantially reduce Medicaid funding, cutting hundreds of billions of dollars to offset tax cuts for wealthy individuals and profitable corporations (Orris & Zhang, 2025). The Administration for Community Living—a federal agency supporting independence for people with disabilities through accessible transportation, alternatives to guardianship, respite care, improving home and community-based services, and enhancing the direct care workforce—is being dismantled through funding cuts, mass firings, and program closures (Diamant, 2025). In Illinois, the governor’s proposed 2026 budget adds \$20 million in wage increases for DSPs—but also cuts \$32 million in staffed support hours (which will force agencies to eliminate vital frontline positions and threaten essential care for individuals in group homes). This reduction in services will harm people in the system much more than the wage increase will help (They Deserve More, 2025). As I have noted before, in the face of these challenges, adults with IDD and their allies must remain hopeful and motivated to concrete social justice activism (Gould, 2024). Because they deserve more!

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Footnotes

¹ In other countries, “DSP” stands for “Disability Support Personnel.”

² Traditional services pay nonprofit agencies to operate residential and vocational programs, while self-directed services provide personal budgets allowing individuals to live at home, design their own service plans and hire support staff. In the United States, the residence for most adults with IDD—61 percent—is their family home (Residential Information Systems Project, 2021).

³ A similar anecdote—of Hugo, a disabled young man in Finland—is related in Vehmas & Mietola, 2021, pp. 116-118.

⁴ Nadasen (2023) argues that today’s care economy—which includes DSPs—exploits low-wage workers, immigrants, and women of color.

⁵ The contrast between desert as a *distributive principle* for assigning goods to individuals and desert as a *corrective principle* that requires remedy when one person wrongs another goes back to Aristotle (Miller, 2021).

⁶ I am not equating people with IDD to toddlers but am referencing the earlier example of rescuing a drowning child as something unearned but deserved.

⁷ These approaches correlate with positive psychology models, from Maslow (1970) to Seligman (2011).

⁸ Family members who provide care spend, on average, 57 hours each week in a support role. Many family carers are aging: 24 percent are over age 60. Caregiving is hard work that creates practical, psychological, and financial stress—especially for women, who provide the most care (Braddock et al., 2017; Anderson et al., 2018).



They Deserve More: Social Justice and the Disability Support Workforce Crisis by James Gould.

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