



Lived Experiences of Direct Support Professionals

in New York State

FEBRUARY 2024



NEW YORK
**DISABILITY
ADVOCATES**
Life. Supported.

Summary Report

Study Introduction¹

This Miami University-based study was supported by New York Disability Advocates (NYDA), an umbrella organization for non-profit entities (“providers”) that employ Direct Support Professionals (DSP) and other frontline staff, including the Cerebral Palsy Associations of New York and AHRC NYC, among others.

The study aims to better understand New York State (NYS)-based DSPs’ experiences and identify factors impacting DSPs’ quality of life. The data may support efforts to mitigate the crisis-level shortage of DSPs by providing the information needed to refine strategies to attract, recruit, and retain members of this critically important workforce. An end goal is to contribute to a healthier, more rewarding work environment that can improve DSPs’ financial, social, and overall well-being.

The 4,497 respondents’ time spent on the survey aggregates to over 2,000 hours – equivalent to a year of a 40-hour workweek job.² *The mass investment of time, energy, and effort; the large number of respondents and the depth of many of the 2,967 comments left in the open-ended questions all suggest that the survey struck a chord.* The comments are incredibly rich sources of information that several hundred participants took the time to write. Many DSPs want to be heard by state officials and employers who can better understand the unsustainable positions they occupy and can act to improve their lives.

Survey Overview



4,497 Direct Support Professionals completed the survey

The survey was developed by the Primary Investigator (PI), Dr. Jennifer Cohen, an economist at Miami University, in consultation with individual Direct Support Professionals and institutional supporters like NYDA and National Alliance for Direct Support Professionals (NADSP).

The purpose of the questionnaire is to understand DSPs’ experiences in paid work and in their households and to identify connections between the two that influence DSPs’ quality of life. Data were collected using validated questions from existing surveys and novel, validated questions based on past research.

All NYS DSPs over 18 were eligible to complete the questionnaire.

The survey questionnaire was piloted and revised before it was administered using Qualtrics between November 2022 and July 2023.³ The questionnaire was sent out to N providers by NYDA with N DSPs [[include frontline supervisors]]⁴ and to DSPs by the New York State Office for People with Developmental Disabilities (OPWDD). Providers shared the survey link and QR code with employees.

Gender Matters

It is no surprise that most DSPs and most survey respondents are women. Women-dominated occupations merit special consideration in human resource planning.

Care delivery depends on women's continued participation as suppliers of support for the I/DD community. Gender roles combine with occupational demands to function as a determinant of care delivery systems' capacity and continuity.

Systemic challenges that compromise the well-being of women workers constitute systemic challenges to the stability of the existing care delivery model. Politicians, providers, and employers must think beyond paid work: planning for a workforce composed primarily of women requires considering the reproductive and productive roles women workers play.

Acknowledgments

To the DSPs who completed the survey, thank you for your contribution. You make better research and stronger advocacy possible. We are grateful to the many providers and agencies who shared the survey with employees, especially those who allowed DSPs to take the survey during working hours.

What's new about this survey compared to other surveys of DSPs?

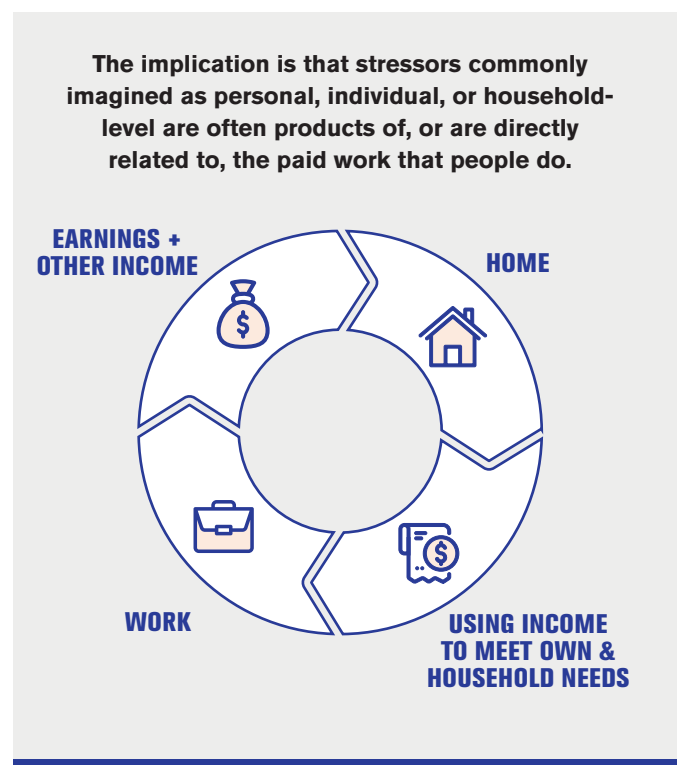
The study goes beyond typical labor force surveys by collecting information about DSPs' households and experiences outside of paid work in addition to standard data about things like pay and turnover.

A basic premise of this economic study is that working conditions, such as pay, are inseparable from household conditions, such as food insecurity. There is a circular flow connecting working conditions to household conditions through earning and spending income on household needs (Figure 1).

This relationship is not limited to pay.

Workers use the same pools of resources in both spaces: time, energy, capacity, etc.

Drawing from those pools – or replenishing them – in one space necessarily impacts their availability for use in other spaces.⁵



Highlights

1

Satisfaction gap.

There is a large gap between satisfaction with work (85%) and satisfaction with pay (26%). Over half of respondents are dissatisfied with pay. The biggest draw to the occupation and the most important factor keeping people in their jobs is wanting to help people. The tension between these forces – low pay pushing people away while the desire to support individuals pulls them in – is palpable in DSPs' comments. Over the past several decades, pay has deteriorated relative to the cost of living due to the high rise of inflation and the decades-long lack of underfunding from New York State, putting DSPs in the unwelcome position of choosing between a job many love and the ability to support themselves and their families. Some have taken multiple jobs or work hours and overtime to continue being DSPs. This is unsustainable and has triggered a decades-long negative cycle of a worker shortage and higher pressure on those remaining, leading to burnout and severely impaired recruitment efforts for replacement hires.

2

Support.

Support from co-worker DSPs, frontline supervisors, and higher levels of management all impact job attachment or intentions to leave one's position. Feeling unsupported by upper management is strongly associated with thinking about quitting and planning to find a new employer. DSPs of color feel significantly less supported by upper levels of management compared to those who identified as white alone. Women feel less supported than men by colleagues at all levels.

3

Gender and race/ethnicity inequities at work contribute to inequities in distress at home.

Gaps in status as a non-supervisor DSP or a frontline supervisor DSP and pay are significant. Still, gaps in hourly pay for DSP work persist even after accounting for status: among non-supervisor DSPs, there are disparities between white women and women of color, white men and women of color, and white men and men of color. Gaps in pay are gaps in income. Hence, women have lower incomes than men, and people of color have lower incomes than people who identify as white alone. Gaps can accumulate across multiple jobs, DSP work and otherwise, to generate and reinforce gender and race/ethnicity-based inequality in household income. Men have higher household incomes partly because of pay inequity but also because they are more likely than women to live with a spouse or partner who is also earning income. In addition to simply meaning more income, having multiple sources of household income typically enhances a household's economic security.

DSPs often struggle to meet household demands: financial, emotional, mental, and physical. Referring to the note about resources on the previous page, struggles may result from a person having inadequate resources, a person having a relatively higher level of demands, or both. DSPs who are women and DSPs of color disproportionately struggle to meet financial demands. These gendered and racialized struggles to meet household needs are inseparable from gendered and racialized conditions in DSPs' paid work.

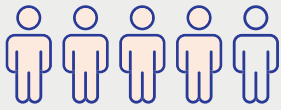
4

Food and housing insecurity are each experienced by half of all DSPs.

Food insecurity is most common among DSPs who are women of color (60%) and least common among white men (42%), while housing insecurity disproportionately impacts men and women of color (60% and 56%, respectively). White women experience the least housing insecurity (39%). Insecurities are concrete manifestations of the linkages between conditions at work and distress at home. Also, like support in the workplace, insecurity is strongly associated with job attachment.

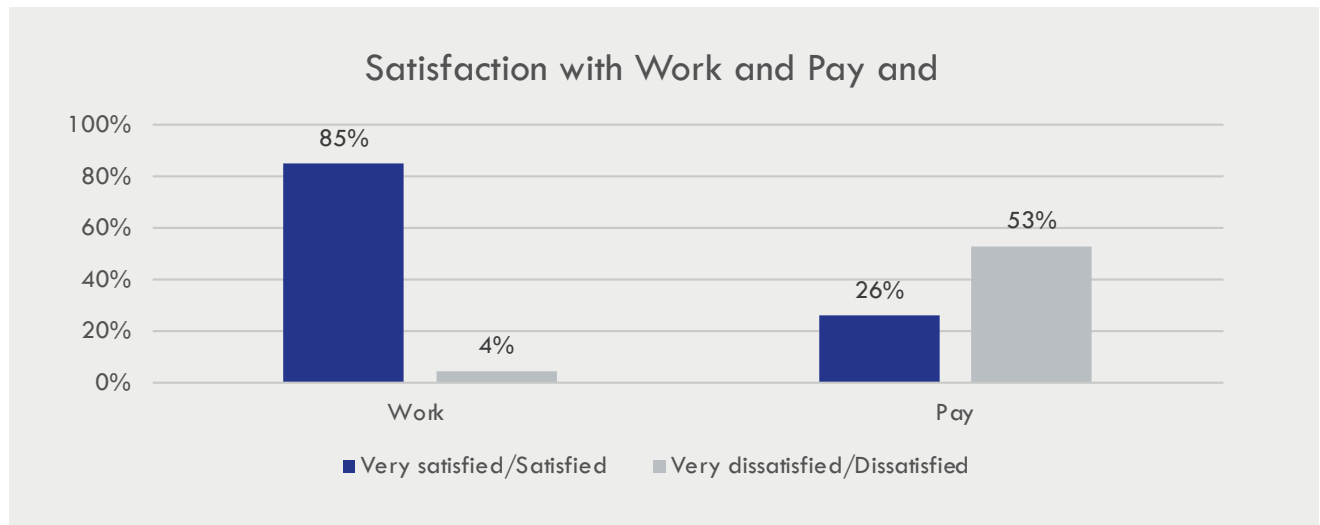
15 Key Points

- 1 DSPs are overwhelmingly satisfied with the work they do and are deeply dissatisfied with the compensation they receive for it.**



4 in 5 respondents are paid less than \$20 per hour.

Satisfaction with work was similar across gender, race/ethnicity¹, education, and frontline manager status.² There is a statistically significant difference in satisfaction with pay between women and men and between frontline supervisors and DSPs who are not frontline supervisors.³ Higher hourly pay is correlated with greater satisfaction with work.⁴



Low pay is a critical issue that is pushing people out of DSP positions according to comments left in the open-ended questions at the end of each survey section. Many write that they cannot afford to remain in the job; some describe being in a “heartbreaking” situation of being forced to choose between doing a job they love and being able to support their households financially. DSPs may love their work supporting people, but they can’t pay rent or buy groceries with love.

“Pay is not enough. Pay is not enough. Pay is not enough.

People like their jobs but literally can’t afford to stay at them because the PAY IS NOT ENOUGH.”

QUOTE FROM DSP SURVEY RESPONDENT

2 Wanting to help people is the biggest draw to the occupation and the most important factor keeping people in their jobs.

Higher pay and more support could allow DSPs to do the work that they already want to do.



“I would enjoy my job more if I was given more flexibility with the services I provide. If I was able to use my creativity and have more say.”

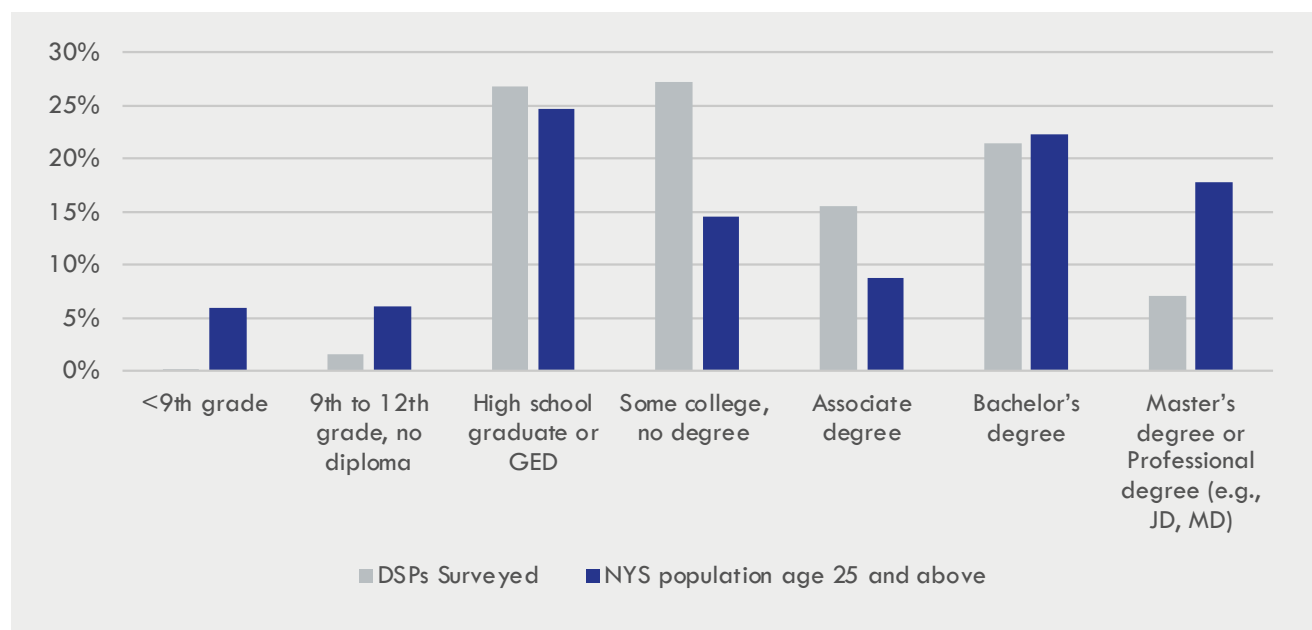
QUOTE FROM DSP SURVEY RESPONDENT

“I was attracted to my job because I feel I’m very good with the population and build rapport very fast, which in this field is not only key but will take you far. I have a special connection with all my guys and I’m sure the feeling is mutual. Love what I do - it’s just the field doesn’t love me enough to keep me around...it’s tough making a living on what we’re paid, unfortunately.”

QUOTE FROM DSP SURVEY RESPONDENT

3 Survey respondents have higher educational attainment than the population of NYS, age 25 years and above, apart from postgraduate degrees.⁵

The majority (71%) completed at least some college coursework, and 44% had a college degree. In NYS, a smaller proportion (63%) completed at least some college, and a similar proportion (49%) had a degree, including postgraduates. Based on data for NYS from the Bureau of Labor Statistics, about 45% of respondents could, in theory, get jobs paying a median of at least \$60,000.⁶



4 Pay is critical: the nearly universal sentiment from the 4,497 respondents, it is that the pay is too low for workers to maintain even a minimally decent standard of living.

Less than half of every *single demographic* reported having enough money to meet their needs. The short timeframe in the question – within the past two weeks – reflects the urgent nature of the ongoing inadequacy of DSPs’ pay.

The minimum wage is a socially determined wage floor; pay below it generates conditions in which society agrees that people should not have to live. In practice, minimum wage workers are often eligible for social support programs because a minimum wage is not a living wage. Some DSPs’ eligibility for social support is a canary in the mine: DSPs are inadequately compensated to such an extreme degree that half of them and their households experience food insecurity. It is difficult to fully focus on work when one is wondering how they will feed their kids, and ideally themselves – women are usually the ones to sacrifice their own well-being by acting as buffers for the household – that night.

“I only have enough money for food because I get government issued SNAP benefits (food stamps). If I make an income barely over and I don’t qualify for food stamps, then I would not have enough money to feed us.”

QUOTE FROM DSP SURVEY RESPONDENT

5 DSPs and frontline staff work long hours because of low pay and mandates.

In extreme cases, some work up to 30-40 consecutive hours – in their work roles as DSPs, frontline supervisors, and ADs.

6 Half of DSPs experience food insecurity. Half experience housing insecurity.

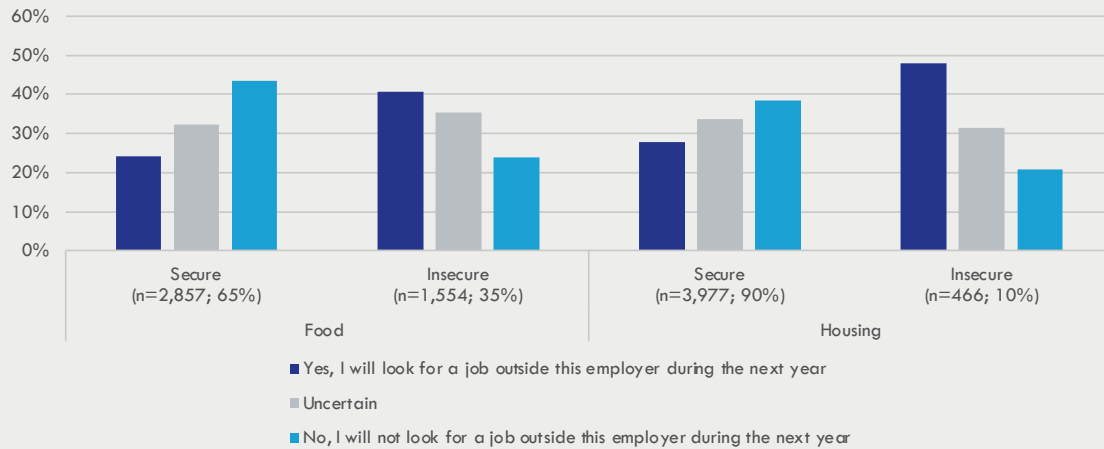
“My children and husband always ate without worry. I never let them know we didn’t have enough for me to eat. I would tell them I already ate.”

QUOTE FROM DSP SURVEY RESPONDENT

Race/ethnicity and gender disparities are present: 60% of women of color, 58% of men of color, 43% of white women, and 42% of white men experience food insecurity. One-in-four DSPs are materially food insecure; they and the people in their households do not have enough to eat. In addition to support from co-workers, supervisors, and management, food insecurity impacts job intentions.

Over 60% (n=197) of men of color and 56% (n=601) of women of color experience housing insecurity compared to white men 48% (n=258) and white women 39% (n=790). Like food insecurity, housing insecurity is related to potential turnover. The less secure a DSP is, the more likely they were to report that they will seek a new employer next year.

Data for material food insecurity and material housing insecurity, meaning DSPs who are hungry and DSPs in unstable housing situations. The pattern persists as the definitions broaden to include worry and, in the case of housing, problems with housing.

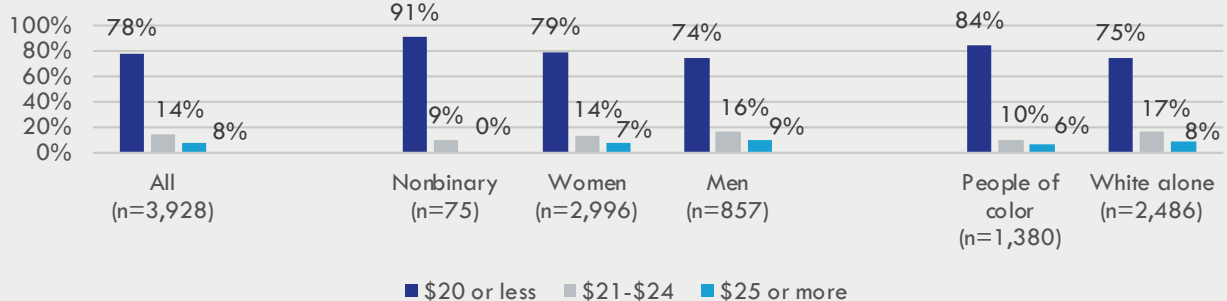


7 Men are overrepresented among frontline supervisors by gender; white men are statistically significantly overrepresented among frontline supervisors by race/ethnicity and gender.⁷

Over 50% of the white men who responded to the survey are frontline supervisors. This suggests that men, especially white men, have higher pay relative to other demographic groups.



Hourly pay in main job as a DSP by gender and race/ethnicity (includes frontline supervisors)



8 There are disparities in pay by race/ethnicity and gender, some of which are not accounted for by frontline supervisor status.⁸

Among DSPs who are not frontline supervisors, there are significant gaps by race/ethnicity for both women and men and women of color and white men.⁹

9 Men (85%) are more likely than women (76%) to live in households with a spouse or partner who is earning income.¹⁰

The majority of women live in households with income below \$60,000 while men are almost twice as likely to live in households with income above \$125,000 as women.¹¹ The gender gap in household income reflects women's lower earnings from working as a DSP and other paid work as well as household composition. Men have higher household incomes partly because they are more likely than women to live with a spouse or partner who is also earning income. In addition to simply meaning more income, having multiple sources of household income typically enhances a household's economic security. Women of color have significantly lower household income than white women and men of color.¹²

10 Women and men were equally likely to identify as the primary caregiver for at least one child, if their household had children in it (56%) – but women primary caregivers spent 2.5 times the hours per day in childcare as men primary caregivers (medians: 10 hours for women, 4 hours for men).

Men who identify as primary caregivers also do a smaller share of caregiving than their own spouse/partner. Hence, women, at least those who are primary caregivers, have a substantively different life experience of having children than men, including men who also identify as primary caregivers.

11 Flexible schedules are highly valued.

The organization of paid work may appear to be gender-neutral, but it has gendered impacts because social context is gendered. Instead of a flexible schedule being a “bonus,” flexibility is an accommodation to women's realities: being responsible for unpaid work at home, childcare, and other family needs by gender roles/norms.

Occupational demands, such as inflexible work schedules or long shifts, whether they are due to freely chosen overtime or are mandated, can conflict with women's responsibility for care and other household work. Paid occupations are not designed to accommodate women's lives. Even in those feminized occupations dominated by women, the organization of paid work typically makes little allowance for the demands of unpaid work.

“I was originally attracted to the job because:

The hours were convenient and flexible with a young child (no weekends). [The] workplace no longer honors our availability as they once did, and we're made to take a weekend day.”

QUOTE FROM DSP SURVEY RESPONDENT

12 Benefits can make a job more attractive and may improve retention, however DSPs left comments about the benefits not being very beneficial due to high deductibles and restrictions on availability for years of employment.

Others noted the difficulty of navigating their employer-based coverage during and after medical emergencies. DSPs - women and men - need flexible schedules to take advantage of some benefits both individually and as primary caregivers in their households. Instituting benefits managers at the provider level to help people use their employer-based benefits could improve DSPs' physical and mental health.



“Putting things like medical and other benefits behind paywalls until you’ve been working there for five years is harmful not to mention disrespectful....my job is holding my happiness and health hostage behind a paywall.”

QUOTE FROM DSP SURVEY RESPONDENT

13 Support from co-workers, frontline supervisors, and especially from higher levels of management are all critical influences on DSPs intentions.

Thinking about quitting, looking for a new employer, leaving their current job, leaving the occupation, and leaving the health and human services sector entirely are all related to feeling supported.

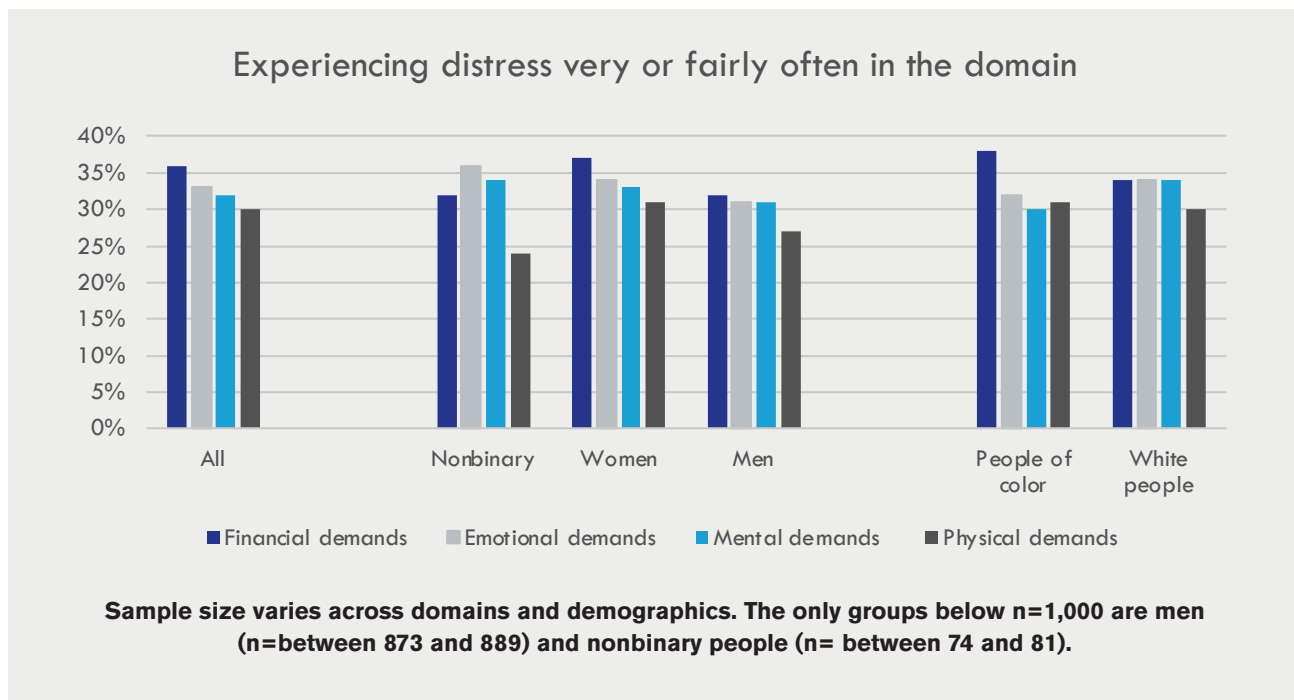
Women feel less supported by people at all levels compared to men. DSPs of color feel significantly less supported by upper levels of management compared to those who identified as white alone.¹³ “Support” was not defined in the questionnaire, but DSPs left comments describing what support means to them.

“Constant changes and inconsistencies in my current program have led to a negative working environment for my coworkers as well as participants. As staff, we are micromanaged, not given the ability to voice our judgements/beliefs without worrying about the backlash.”

QUOTE FROM DSP SURVEY RESPONDENT

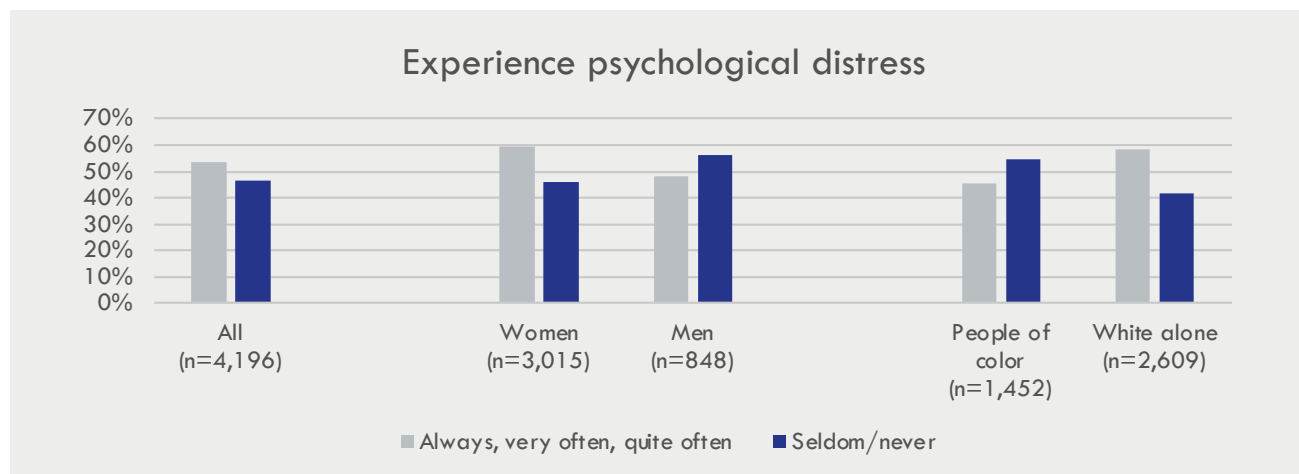
11 About one in three DSPs often struggle to meet financial (36%), emotional (33%), mental (32%), and physical (30%) demands.

There are several potential explanations for struggling to meet each type of demand: the person does not have enough resources, they have a relatively higher level of demand, or both. DSPs who are women and DSPs of color disproportionately struggle to meet financial demands. Is this because women and DSPs of color have lower incomes than men because they have more demands on their financial resources, or both?¹⁴



12 Over 50% of DSPs often experience psychological distress in the forms of blue mood, despair, anxiety, or depression.

Women, especially white women, more frequently experience distress.



Endnotes

1 The race/ethnicity data are divided into those who identified as white alone, 64% (n=2,616) and people of color 36% (n=1,466). We do this for simplicity in this early stage of analysis and do not mean to imply that 'people of color' as a group are homogeneous or have the same experiences.

2 Chart n=4,483 and 4,482. In Pew's 2023 nationally representative survey of 5,902 U.S. workers, 51% were extremely or very satisfied with their job overall. Center's American Trends Panel. We divided job satisfaction into work and pay because of the predictable gap between them.

3 The gaps by gender and frontline supervisor status are statistically significant in a 2-tailed, 95% confidence interval Spearman's correlation coefficient test ($p=0.1417$, $n=4,071$, 95% CI: 0.111 to 0.172) and ($p=0.1136$, $n=4,427$, 95% CI: -0.143 to -0.084 respectively) and at $p<.001$.

Note: the selected threshold for statistical significance is $p=0.1000$ due to the possibility of statistical significance arising from the large sample size ($N=4,497$) alone. This threshold is applied throughout the results reported in this document.

4 The relationship between pay and satisfaction with work statistically significant in a 2-tailed, 95% confidence interval Spearman's correlation coefficient test ($p=-0.1989$, $n=4,463$, 95% CI: -0.227 to -0.171) at $p<.001$.

5 Chart n=4,178. NYS education data are drawn from the 2022 American Community Survey.

6 Pay data from 2022 for people 25 and older in NYS who worked full-time are from "Education pays, 2022," Career Outlook, U.S. Bureau of Labor Statistics, May 2023.

7 The gap by gender is statistically significant in a 2-tailed, 95% confidence interval Spearman's correlation coefficient test ($p=-0.1057$, $n=4,030$, 95% CI: -0.136 to -0.075) at $p<.001$. The gap between women of color and white men is statistically significant ($p=-0.2045$, $n=1,599$, 95% CI: -0.251 to -0.157) at $p<.001$. The gap between men of color and white men is statistically significant ($p=0.1576$, $n=855$, 95% CI: 0.092 to 0.222) at $p<.001$. The gap between white women and white men is statistically significant ($p=-0.1528$, $n=2,552$, 95% CI: -0.190 to -0.115) at $p<.001$.

8 The gap by race/ethnicity is statistically significant in a 2-tailed, 95% confidence interval Spearman's correlation coefficient test ($p=0.1642$) at $p<.001$.

9 The gap by race/ethnicity among nonfrontline supervisor DSPs is statistically significant in a 2-tailed, 95% confidence interval Spearman's correlation coefficient test ($p=0.1842$, $n=2,589$, 95% CI: 0.147 to 0.221) at $p<.001$. The gap between non-frontline supervisor women of color and white women is statistically significant ($p=0.1644$, $n=2,053$, 95% CI: 0.122 to 0.206) at $p<.001$. The gap between non-frontline supervisor men of color and white men is statistically significant ($p=0.2264$, $n=456$, 95% CI: 0.137 to 0.312) at $p<.001$. The gap between non-frontline supervisor women of color and white men is statistically significant ($p=-0.1769$, $n=981$, 95% CI: -0.237 to -0.116) at $p<.001$.

10 Our extremely detailed data on household composition are still under examination. Response rates by gender are both about 75% of women and men who live with household members, thus there does not appear to be response rate bias in this demanding/tedious section of the survey.

11 These data are not reported for nonbinary people due to small sample size in the demographic.

12 The gap by gender is statistically significant in a 2-tailed, 95% confidence interval Spearman's correlation coefficient test ($p=0.1335$, $n=1,224$, 95% CI: -0.188 to -0.078) at $p<.001$. The gap by among women by race/ethnicity is statistically significant in a 2-tailed, 95% confidence interval Spearman's correlation coefficient test ($p=0.127$, $n=2,781$, 95% CI: 0.076 to 0.149) at $p<.001$.

13 The gap by race/ethnicity is statistically significant in a 2-tailed, 95% confidence interval Spearman's correlation coefficient test ($p=0.1049$, $n=4,006$, 95% CI: 0.074 to 0.135) at $p<.001$.

14 Income is a known contributor. The data that will confirm dependency ratios by gender are still under examination.

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