



CA Policy Center

for Intellectual & Developmental Disabilities

—RESEARCH, POLICY AND ACTION—

THE IMPACT OF THE DIRECT SUPPORT PROFESSIONAL WORKFORCE SHORTAGE

**on Individuals and Families
Served by the Regional Center
System in California**

JANUARY 2025

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EXECUTIVE SUMMARY

The California Department of Developmental Services (DDS) serves just over 458,000 individuals with intellectual and developmental disabilities (IDD). California, along with the rest of the nation, struggles to meet the service and support needs of individuals with IDD due to a severe and persistent shortage of Direct Support Professionals (DSPs). DSPs provide the day-to-day support to individuals with IDD to live full lives, and as independent as possible, in the community of their choice. The DSP workforce shortage is harmful to people with IDD as it is the single greatest barrier to inclusion and independence for people with IDD. For many people with IDD, the workforce shortage serves to drastically limit opportunities for employment, choice of where and with whom they live, social activities, the type of services they receive, and overall access to their communities.

There are several factors that contribute to the on-going DSP workforce shortage but the main factor is the historically low wages paid in relation to the high levels of skill and responsibility required for the job. Other factors include staff burnout, high turnover rates, inadequate training for both new and experienced DSPs, and limited resources for enriching levels of support for the individuals they support. Additionally, awareness about the profession is lagging so it is often overlooked as people are entering the workforce or seeking employment. Finally, low reimbursement rates limit service providers' ability to compete in the labor market and pay a competitive wage such that they could consistently attract and retain DSPs.

This report takes an in-depth look at how the DSP workforce shortage impacts individuals and families, served under the Lanterman Act, by the DDS and the Regional Center System in California. It should be noted that Early Start services are separate, and apart, from Lanterman Act services and are not covered in-depth in this workforce report. However, a separate workforce report specific to Early Start services will follow this report. The information and data used to inform the report was collected through surveys, focus groups, and one-to-one interviews with DSPs, individuals served by the regional centers, family members, disability service providers (known as vendors), and regional center services coordinators. In addition, existing state and national data sets, policy research, and analysis of existing workforce initiatives were used to support the findings in the report.

KEY FINDINGS

INDIVIDUALS WITH IDD

- Individuals with IDD who had previously experienced living in more restrictive settings have higher levels of concern about losing their independence if there are not enough DSPs to provide support for them.
- Staff turnover, especially high levels and frequent turnover, increases feelings of sadness, fear, anxiety, anger, and disruption for people with IDD.
- 64% have experienced DSPs leaving in the last 12 months
- The DSP workforce shortage is severely limiting choices and opportunities for people with IDD.

FAMILY MEMBERS

- In 2023, over half (55%) of individuals 18 years of age and older, served by the Regional Center system, lived at home with a parent or family member. The percent of young adults living at home differs significantly around age 25 as only 12.3% of young adults without disabilities continue to live at home.
- 58% of the family members reported that they and/or their son, daughter, or family member with an IDD, were not able to access all of the authorized services in the Individual Program Plan (IPP) because of the DSP workforce shortage.
- 59% of the family members have had to miss work or limit their personal activities in the last 12 months, with 33% having to do so 26 or more times, because of the DSP workforce shortage.
- There is a growing concern among families, service providers, and regional center service coordinators that there is an increasing number of aging caregivers providing substantial support and care for their son or daughter with complex physical, medical, and/or behavioral needs.

DIRECT SUPPORT PROFESSIONALS

- The majority (79%) of the responding DSPs are women, 68% are non-white, and just over 35% are 55 years and older.
- 32% of the responding DSPs qualify for Medi-Cal and 29% said their children also qualify for Medi-Cal
- There is a serious disconnect between the low wages DSPs get paid, and the high level of skill required to perform the job which is the number one reason DSPs leave the job.
- 46% reported working two or more jobs because they cannot make a living working as a DSP.
- DSPs feel there is a fundamental lack of respect or recognition of the profession, especially in light of the new sector set minimum wages in fast food (\$20.00 per hour) and entry level health care (phase into \$25.00 per hour)

SERVICE PROVIDERS

- Across every service type providers reported significant challenges recruiting and retaining DSPs, with the main reason being low wages.
- The new sector set minimum wages for fast food and health care were implemented after the rate study further complicating recruitment and retention of DSPs.
- 56% of the providers have had to turn down referrals due to the DSP workforce shortage and 35% report having a waiting list.
- An alarming number of providers reported that they are no longer able to accept individuals who require a 1:1 staff person because they cannot hire enough DSPs.
- Providers feel that they are chasing minimum wage for a job that require skill sets that far exceed minimum wage.
- Over half (60%) of the providers who participated in focus groups/interviews reported limiting or eliminating some of their service lines.

SERVICE COORDINATORS

- 76% report that the DSP workforce shortage is one of the main reasons individuals are not receiving the full amount of services authorized in the IPP.
- Day programs and out of home respite were reported as the most requested services and being among the most challenging to find
- DSP workforce shortages contribute significantly to behavioral and mental health challenges for the individuals on their caseloads, and many end up needing crisis levels of support which could have been prevented if they had the proper support.

RECOMMENDATIONS TO INCREASE RECRUITMENT AND RETENTION OF DSP

- **Accelerate development and implementation of the DSP University**, as established in AB 136 (2021), competency based training tied to a tiered wage differential, that is based on a competitive wage rather than minimum wage, and reflective of the skill set required by DSPs.
- **Fully implement and evaluate** the DDS Workforce Initiatives
- **Renew the DSP Training Stipend** and include incentives for service providers who provide additional approved training to DSPs.
- **Create a statewide campaign** highlighting and elevating respect for the profession.
- **Develop a collaboration** with the California Community Colleges and the California Workforce Development Board to develop and implement a workforce development plan specifically for the DSP profession.

INTRODUCTION

Over the last 40 years the demand for DSPs has far outpaced the supply creating an on-going and severe workforce shortage often referred to as the DSP workforce crisis. The shift in demand for DSPs started to become apparent as several laws passed and landmark court decisions were held in favor of individuals with IDD having the right to live in the community. In 1981, the Medicaid Home and Community-Based Services (HCBS) Waiver program was signed into law authorizing states to provide services to people with IDD in their homes instead of institutions resulting in a steady decline in the number of people living in large state-run IDD facilities following implementation of the HCBS Waiver.¹ In 1990 the Americans with Disabilities Act (ADA) was signed into law with a provision known as the Integration Mandate which provided further clarification on the rights of individuals with disabilities to live in the community.² Several years later, the U.S. Supreme Court's 1999 landmark decision in *Olmstead v. L.C.* held that the unjustified segregation of people with disabilities was unlawful discrimination under the ADA significantly strengthening enforcement of federal disability civil rights laws, including the right to live in the community of one's choosing.³

In 1969, 12 years before the enactment of the above-mentioned Medicaid Home and Community-Based Services program, California passed legislation (AB 225) establishing the Lanterman Act and extending the services in the regional center pilot project throughout California. For the next two decades California would pass legislation to ensure alignment with federal civil rights laws guaranteeing

people the right to live of the community, including SB 1383 authored by Senator Dan McCorquodale which expanded the range of services and supports for people served by the regional center system and specifically included the right to make choices about where and with whom they live.

Several lawsuits were filed around the same time legislation was being passed to ensure the rights of people with disabilities to live in the community. Some of the most notable lawsuits filed were:

IN RE HOP(1981)

The California Supreme Court held that adults with IDD placed in the state hospital or developmental center were entitled to judicial review to determine if they should remain institutionalized.

ARC V. DDS (1985)

The California Supreme Court held that the Lanterman Act defines a basic right and corresponding obligation to provide people with IDD the services needed to live in the community, that services in the IPP are an entitlement, regional centers—not DDS—have wide discretion on implementation, and there is a prohibition on cost-saving strategies without changing the law. Regional centers are not permitted to overspend their budgets, if budgets are not sufficient DDS must inform the legislature and increase funding or change the entitlement.

¹President's Committee for People with Intellectual Disabilities, *Advancing Independence and Community Integration for All: Supporting Individuals with Intellectual Disabilities Through High Quality Home and Community-Based Services* (2024) https://acl.gov/sites/default/files/programs/PCPID_Report_508%20compliant.pdf

²Americans with Disabilities Act, *Integration Mandate*, <https://www.ada.gov/topics/community-integration/>

³U.S. Health and Human Services, *Community Living and Olmstead* <https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html#:~:text=The%20U.S.%20Supreme%20Court's%201999,More%20on%20Olmstead%5D>

COFFELT V. DDS (1993)

A class action lawsuit was ultimately settled out of court and required the state to downsize developmental centers by 2,000 individuals within 5 years, suspended admissions, and required establishment of a quality assurance program.

CAPITOL PEOPLE FIRST V. DDS (2009)

A class action lawsuit that was ultimately settled out of court and required, among other things, the state to inform people living in state institutions and large facilities about the right to choose where they want to live and to help them implement their rights.

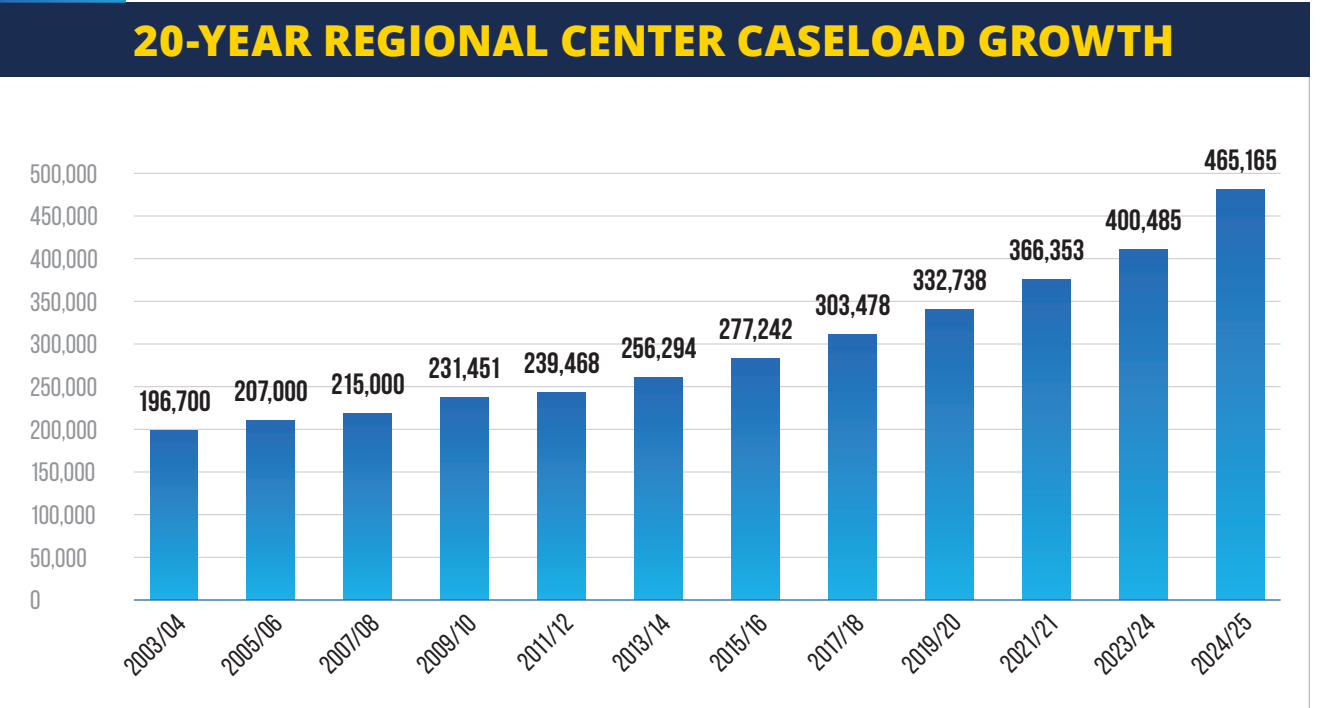
Later, California would enact two other pieces of legislation that reaffirmed the state's commitment to the deinstitutionalization of people with IDD. The legislation enacted in 2012 (AB 1472) imposed a moratorium on new admissions to Developmental Centers (exceptions included those involved with the criminal justice system of in need of short-term crisis stabilization), and SB 82 (2015) required DDS to submit a plan to close the Developmental Centers.

Together, the national and state efforts significantly reduced the number of people with IDD living in large institutions in California. The reduction of people living in institutional settings along with steady regional center caseload growth drove up the demand for DSPs as more people were living and obtaining a range of services and support in the community. [SEE TABLE 1]

Funds such as the Coffelt Fund, which later became the Community Placement Plan (CPP) fund, and the Community Resource Development Plan (CRDP) fund, were established to cover costs related to the transitions from institutional settings to community-based setting, enhancing capacity of services, and developing new resources to support people in the community. However, these funds were only available to support initial costs for transitions and expanding capacity but did not cover labor costs, as those were built into the rates paid to service providers.

A series of state budget deficits and spending reductions beginning in the early 1990's led to rate cuts, rate freezes, caps on spending, and unpredictable funding for community-based

TABLE 1.



disability service providers that lasted for almost two decades.^{4,5} From 2003–2015 the majority of increases were either restoration of previous cuts or to account for statewide minimum wage increases and federal overtime rules. [SEE TABLE 2]

After years of unpredictable funding the legislature passed ABX2-1 in 2016 which, among other things, provided for rate increases with the primary focus being on increasing wages and enhancing benefits

for direct support workers who spend 75% or more of their time providing direct support. In addition, ABX2-1 also required DDS to submit a rate study to the legislature addressing sustainability, quality and transparency, in the community-based service system.⁷ The rate study was submitted to the legislature in March 2019 with an overall finding that the Developmental Services system was systemically underfunded by \$1.8 billion. The state began efforts toward rate reform as specified

in the Budget Act of 2021 with a phased-in rate adjustment timeline and specified requirements for wage and benefit enhancements for DSPs who spend 75% or more of their time providing direct support.⁸ The requirement for DSP specific funding came in 2022 with the acceleration of the rate model implementation.

The supply of DSPs has not kept pace with the demand for several reasons with the main reason being the historically low wages paid to DSPs in relation to the expectations and responsibilities of the job. The concerns of under-development, under-investment, and the sustainability of the DSP workforce have been documented for years. In 2006 the U.S. Department of Health and Human Services, Planning and Evaluation Office of Disability, Aging and Long-Term Care produced a report to Congress in response to serious concerns about the DSP workforce shortage.⁹ The report, *The Supply of Direct Support Professionals Serving Individuals with Intellectual and Developmental Disabilities*, raised concern about the already growing and alarming shortage of DSPs. An important finding in the report centered on a 1999 California State Auditor’s report that discussed the impact of high turnover rates, and the lengthy process of replacing DSPs, on individuals with IDD. The historic lack of a clear understanding of the role and responsibilities of the DSP has long contributed to the low wages and inadequate rate setting methodology.

For the last two decades national advocacy organizations have been leading an effort to establish a standard occupational code (SOC), through the Bureau of Labor and Statistics (BLS), for DSPs which would create an official federal

recognition of the DSP profession. A SOC is a system used at the federal level to classify workers and jobs into occupational categories for the purpose of collecting, calculating, analyzing or disseminating data. These occupational codes are used for a wide range of purposes including but not limited to standardizing comparison of job data across sectors, analyzing labor market trends, identifying training needs, and setting salary ranges. It is important to note that all state and local government agencies area strongly encouraged to use this national system to promote continuity, as such California uses the SOC to classify occupations.^{10,11} Specifically for HCBS funded services, it allows for a standardized way to classify jobs such as Personal Assistants (PA), Certified Nursing Assistants (CNA), and Home Health Aides (HHA), collect accurate data on those classifications, and enable data-driven policy decisions regarding rate setting, staffing levels, compensation, and identification of important workforce trends.

It has been widely acknowledged that there are significant gaps data, knowledge and understanding of the DSP workforce as a subset of the larger HCBS workforce. One of the main gaps of knowledge comes from the lack of a standard definition of DSP and the duties that they perform. The Home and Community-Based Services Federal Opportunities Regarding Workforce and Research Data (HCBS FORWARD) workgroup, established under the U.S. Department of Health and Human Services and the U.S. Department of Labor, found that federal data on HCBS workers are insufficient to address many of the most pressing research and policy questions and further suggested development of a standard definition for DSP duties that is sufficiently

TABLE 2.

DDS RATE CHANGES, 2013–2015⁶

Fiscal Year	Adjustment
FY 2003–04	↓ Rate freezes for a number of services, including day programs, in-home respite, supported living, and respite
FY 2004–05	↓ Rate freezes for work activity programs
FY 2006–07	<ul style="list-style-type: none"> ↑ Rate increase to account for state minimum wage increase ↑ 3% increase for a number of services with rates set by DDS or negotiated rates with Regional Centers ↑ Targeted 3.86% wage enhancement for certain services provided in integrated settings ↑ 24% increase for supported employment
FY 2006–07	↑ Rate increase to account for state minimum wage increase
FY 2008–09	<ul style="list-style-type: none"> ↓ Rate freezes for all services with negotiated rates ↓ Implementation of statewide median rates that limited negotiated rates for new providers ↓ 10% rate reduction for supported employment
FY 2009–10	↓ 3% reduction for all services except supported employment and usual and customary rates
FY 2011–12	↑ Institution of updated statewide median rates
FY 2012–13	↑ Restoration of 3% reduction
FY 2013–14	↑ Restoration of 1.25% reduction
FY 2014–15	<ul style="list-style-type: none"> ↑ Rate increase to account for state minimum wage increase ↑ 5.82% increase for in-home respite, supported living, and personal assistance due to change in federal overtime rules

⁴ Association of Regional Center Agencies, *On the Brink of Collapse, The Consequences of Underfunding California’s Developmental Services System* (2015), <https://arcanet.org/wp-content/uploads/2015/02/on-the-brink-of-collapse.pdf>

⁵ DDS, *Rate Action History July 2003—June 2015* https://www.dds.ca.gov/wp-content/uploads/2019/02/DSTF_RateAction_20190212.pdf

⁶ Burns & Associates, *DDS Vendor Rate Study* (March 2019) <https://www.healthmanagement.com/wp-content/uploads/DDS-Vendor-Rate-Study-Report.pdf>

⁷ Association of Regional Center Agencies, *Analysis of ABX2-1* <https://www.arcanet.org/docs/abx2-1.pdf>

⁸ Department of Developmental Services, *May 11, 2023 Rate Reform Directive*, <https://www.dds.ca.gov/wp-content/uploads/2023/05/PERCENTAGE-OF-RATE-ADJUSTMENT-USED-FOR-WAGES-AND-BENEFITS-FOR-DIRECT-CARE-STAFF.pdf>

⁹ U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy, *The Supply of Direct Support Professionals Serving Individuals with Intellectual and Developmental Disabilities, Report to Congress* (2006).

¹⁰ Standard Occupational Classification Manual (2018), https://www.bls.gov/soc/2018/soc_2018_manual.pdf

¹¹ California Employment Development Department, Labor Market Information Division, <https://labormarketinfo.edd.ca.gov>

detailed and distinct from other HCBS workforce occupational categories.¹² The workgroup further suggests that a standardized definition could improve data collection, workforce development, program planning, classification, and ultimately inform the state Medicaid agency rate setting methodology.

Some of impacts of the DSP workforce shortage are measurable such as turnover, vacancy rates, unused authorized services, and provider waitlist. However, there are other impacts that are immeasurable

as it is difficult to quantify the more intangible or hidden losses related to a person's (or family's) independence, emotional well-being, quality of life, and ability to have and make choices when they don't have the support they need. Surveys, focus groups and 1:1 interviews were conducted with individuals served by the regional center system, their family members, DSPs, service providers, and regional center service coordinators to gain a better understanding of the real day to day impacts the DSP workforce shortage has on the lives of people with IDD and their families. ■

IMPACT OF THE DSP WORKFORCE SHORTAGE ON INDIVIDUALS SERVED BY THE REGIONAL CENTER SYSTEM

Children and adults with intellectual and developmental disabilities (IDD) rely on direct support professionals (DSP) to assist them with a wide range of supports and services they need to live full lives in the community. Necessary supports and services can range anywhere from total care which is defined as comprehensive support across all aspects of life including personal care, medical needs, activities of daily living, education, social interactions, and community integration, to coaching individuals on maintaining employment, housing, relationships, and other important life decisions.

Individuals served by the regional center system participated in surveys, focus groups, and 1:1 interviews. Surveys were sent to service providers, families, advocacy organizations, and the Association of Regional Center Agencies (ARCA)

who then shared the surveys with individuals with IDD. Surveys were also conducted in-person at the May 2024 Supported Life Conference and a March 2024 advocacy rally held at the state capitol. Focus groups and 1:1 interviews were also held in-person at several different locations throughout the state as well as virtually via zoom. There were 113 respondents to the survey and 70 individuals that participated in focus groups or 1:1 interviews with representation from all 21 regional centers.

The majority (79%) of individuals surveyed receive traditional services from a regional center, 12% are in the Self-Determination Program, and 10% were unsure of the type of services they receive. All of the respondents and participants are 18 years of age or older, the majority are White (68%) and 93% speak English as their primary language.

Over half (61%) of the respondents and focus group participants report the daytime activity as being a Day Program, followed by 15% who reported working part-time (not in supported employment), 10% are in supported employment, and 12% said they do not have a day time activity. The remaining 2% were distributed among work activity programs, being retired, school, and volunteering.

Focus group and interview participants were not asked about their living situation so the following figures are representative of the survey respondents only:

I live at home with my parent or family member	30.91%	34
I live in a group home	8.18%	9
I live in a home/ apartment and receive supported living services	36.36%	40
I live in a home/ apartment and receive independent living services	15.45%	17
Other	9.09%	10

Just under two-thirds (64%) of the survey respondents and focus group/interview participants reported having one or more new staff within the last 12 months. Although many of the individuals were not sure how many new staff they have had, over 75% said that it was at least two or more, 20% reported they have had 6 or more new staff, and at least two individuals reported they have had 10 or more new staff within the last 12 months.

The individuals that participated in the focus groups and interviews have a wide range of support needs which influences their perspective on how, or what, type of support they feel the need from the DSPs that support them. Individuals were

asked what some of the specific ways are in which their staff support them. Based on the individual's responses their answers were categorized into four different types of support—physical, behavioral, independence, and relationship.

PHYSICAL SUPPORTS

Several people had physical disabilities or mobility challenges that required various levels of physical support. The physical supports needed range from standing next to a person and offering light physical support to someone who may be unsteady on their feet to full physical support including lifting, transfers, and providing all aspects of personal care. Many of the individuals who require higher levels of physical support talked about the reality of their lives without DSPs, and the fear that they would have to live in an institution or hospital setting if they didn't have enough people to support them. People who had previously experienced living in more restrictive settings were particularly concerned about losing their independence and not being able to live in their homes, and with the people they want, many of whom were their roommates or life partners. A few of the comments made by people with higher levels of physical support needs include:

“What does my staff do for me? You don't understand, they do everything for me...it means the difference of whether I get to get out of bed that day or not.”

“I depend on my staff for everything because I have CP and cannot move my body like other people can, I need them to help me with everything I do. I need help to do even basic things that other people just do like eat, get dressed, shower, go to the bathroom... everything.”

“I love my job. D makes sure I can get to work, and get there on time, he gets me ready for work every morning and he is better than most because he is always on time so I can be on time.”

¹² Administration on Community Living, Improving Data on the Workforce Delivering Home and Community-Based Services (2024), <https://acl.gov/sites/default/files/Direct%20Care%20Workforce/improving-hcbs-workforce-data-issue-brief.pdf>

“I am blind so she is my eyes in the community, I couldn’t go out and do stuff without her.”

“They help me keep my dignity, just because I am disabled doesn’t mean I don’t care. It can be very difficult, especially if you have had bad experiences, to trust someone to do that kinds of personal care.”

“My job coach is getting ready to leave me and I am very sad because we have a really special bond.”

BEHAVIOR SUPPORTS

Research shows that DSPs play a significant and meaningful role in providing emotional support to people with IDD who have complex behaviors, and that the relationship is one built on trust. The trusting relationship provides a sense of connectedness that allows the DSP to gain insight into, and respond to, the needs of the individual they are supporting.¹³

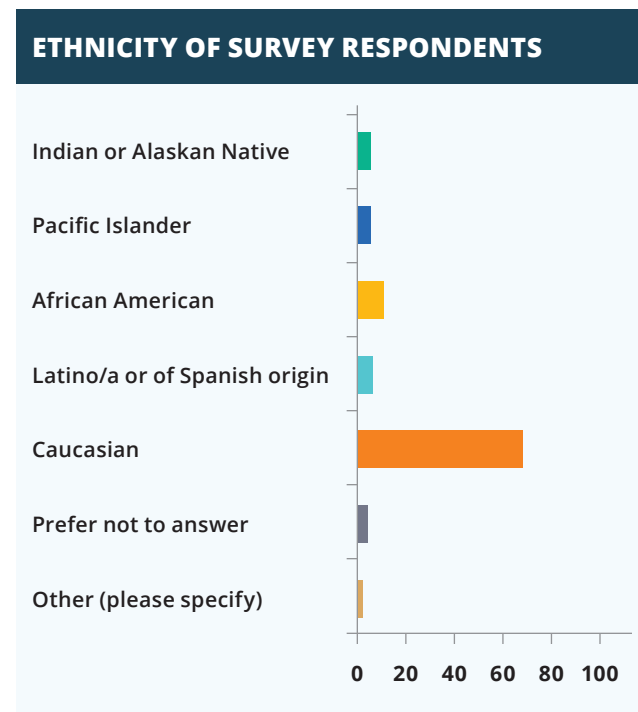
Many of the individuals who participated in the focus groups acknowledged that they often feel frustrated and sometimes have a hard time managing their emotions. Consistent with research, a deep appreciation was expressed by several individuals who said they are grateful to their staff because their staff don’t just get mad and leave, and they trust them to help them calm down. A few people talked about the importance of their behavioral goals and how their coaches/staff help them meet their goals.

“It is so important to me to know I have a coach I can trust because I don’t deal well with change, I have always been resistant to change but even more so after COVID.”

“They help me with my mental health appointments which is so important because I really need to keep those appointments and understand the information the doctor gives me so I can make person-centered choices. They especially help me remember the questions I wanted to ask my doctor or remind me to tell them something that is important for them to know.”

“I have a lot of anxiety about a lot of things and I need someone to tell me I can get through it and calm me down and that is what my staff does for me every single day.”

“My staff helps me learn and remember how to respect others which is a goal I have.”



INDEPENDENCE

Supporting individuals to achieve or maintain independence was something DSPs were credited with frequently during the focus group discussions. The desire to be independent, whether individuals perceived themselves as independent or working towards independence, was central to the role they believe DSPs have in their life. Although there were notable differences in what independence meant to each person, they all attributed their ability to be independent to the DSPs that support them. For example, some of the individuals thought of independence at being able to decide where they wanted to go have lunch on certain days, while others saw independence at working toward getting jobs and living in their own apartment. Some of the comments specific to how DSPs support independence or developing independence include:

“They help me get groceries and all my errands done.”

“I love to garden and cook and my DSP does that with me, they help me get everything so I can use the food I grow and cook healthy meals with it.”

“I am blind so she helps me do sighted guide, she goes to classes with me, and really makes me feel comfortable, especially in the community.”

“She helps me go in the community which I love, I love shopping, going to lunch, and getting manicures.”

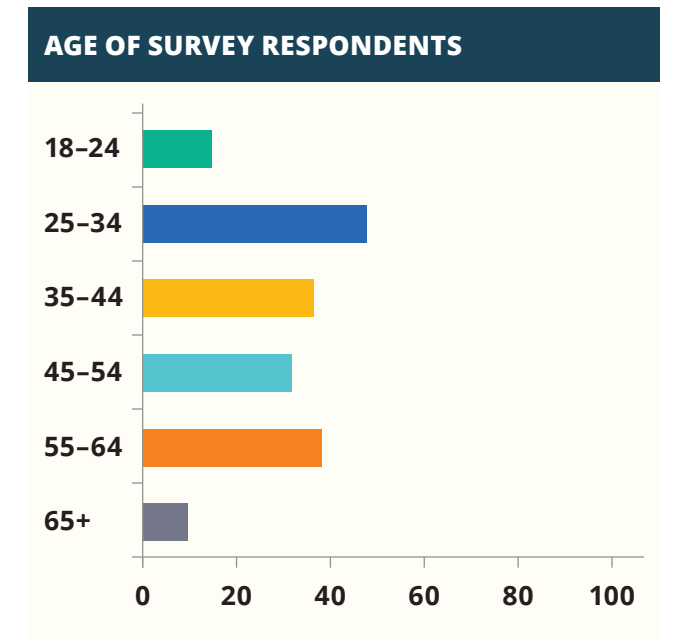
“My staff helps me fill out job applications and how to pay attention to detail when I am filling them out, it is important to pay attention to all the details so people can see that you really want a job.”

“I get to live my own life and make my own decisions.”

“Money, they really helped me a lot to learn about how to manage my money so I don’t spend it all at one time and then don’t have any money later when I need it.”

“They help me go in the community and make sure I am safe.”

“I want to be a coach someday and my staff are helping me learn how to do that.”



¹³ Journal on Intellectual Disabilities, (2022) Connectedness Between People with Intellectual Disabilities and Challenging Behavior and Support Staff: Perceptions of Psychologists and Support Staff, <https://pmc.ncbi.nlm.nih.gov/articles/PMC9941799/>



“They help us learn how to work with others.”

“A DSP is not just there to be your personal helper, they are there to give you confidence and support, and guide you and encourage you, especially in times when you need it the most.”

“When you work in a kitchen sometimes you have to do other people’s jobs too and I need my job coach to show me how to do those other jobs when I have to.”

DSPs often have a vital role in ensuring the health and wellness of the individuals they support. It is very common for DSPs to accompany the individuals they support to health care appointments; help facilitate clear communications between the individual and their health care provider, explain the information shared, and provide support to the individual during medical tests or exams. Several individuals talked about the importance of being healthy and making healthy choices as part of being independent, they also acknowledged the important role their DSPs play in supporting them

to understand and manage some very complex and chronic health conditions. Some of the comments related to health, healthy choices, and the role of the DSP include:

“I would be a hot mess and probably not able to live independently, I would probably be stuck in a board and care somewhere if they didn’t help me understand my medication and remind me if I forget to take it.”

“They help me learn how to stay healthy—like setting reminders to my medication and to drink a lot of water especially when it is very hot outside.”

“Cooking, doctor’s appointments, and all kinds of stuff that keeps me healthy.”

“It’s real important to me that I have someone to talk to and ask questions when I don’t exactly know what I am doing.”

“I have diabetes and high blood pressure so it is really important to me to meet my health goals, my staff helps me do that, we go to the farmers market and she shows me how to cook healthy meals.”

SOCIAL LIFE AND RELATIONSHIPS

It is not uncommon for people with IDD to experience challenges understanding social or personal boundaries. DSPs are instrumental in supporting individuals in developing and maintaining relationships with their peers, as well as understanding the nuances of social and personal boundaries. Many of the individuals talked about the ways in which their DSPs supported them in developing friendships, engaging in appropriate social interactions, and participating in social activities. In addition to supporting the development of other relationships, a majority felt very connected to the DSPs that have been consistent in their lives and felt that their relationship was more of a friendship. Some of the comments related to building relationships include:

“They help me so I can participate in the social events that I like.”

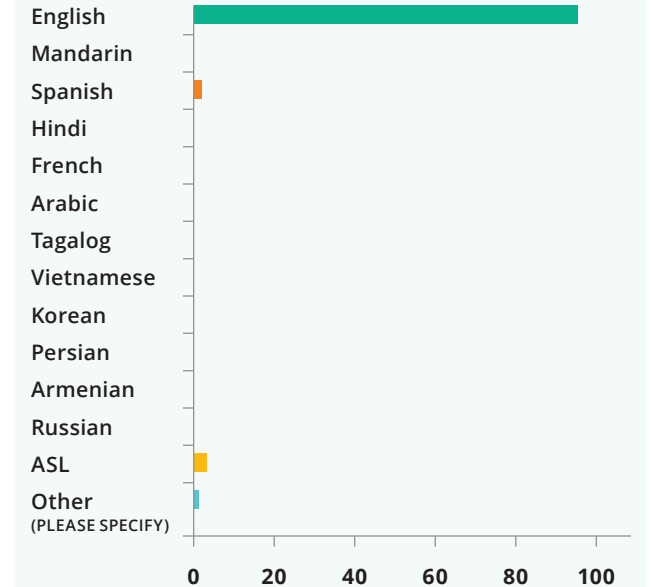
“We do so much together that I feel like we are close friends, we have a very good friendship.”

“I love my staff because they help me build friendships and have a social life.”

“I get to see my girlfriend at the movies and other places and call her because J helps me do that and it makes me happy.”

“I have a lot of friends now and I missed them when I didn’t see them.”

PRIMARY LANGUAGE OF SURVEY RESPONDENTS



STAFF TURNOVER

The impact of staff turnover on people with IDD cannot be understated as changes, especially frequent changes, in DSPs can have a dramatic effect on the quality of life for individuals who rely on their support. Research shows that DSP turnover has a direct, and detrimental, impact on the health and safety of people with IDD, as one study found that people who experience staff turnover had higher rates of emergency room visits, more instances of abuse and neglect, and more injuries than people who did not experience DSP turnover.¹⁴ Additional research found that continuity and security in staffing significantly increased quality of life for individuals with IDD in several different areas, including but not limited to, health, satisfaction with relationships, and community.¹⁵

The majority of individuals that participated in the focus groups/interviews reported feelings of sadness, anxiety, anger, and disruption related to

¹⁴ *The Impact of Direct Support Professional Turnover on the Health and Safety of People with Intellectual and Developmental Disabilities, Inclusion* (2021) Vol. 9, No. 1, 63–73

¹⁵ *The Impact of Continuity and Security, Intellectual and Developmental Disabilities* (2022) Vol. 60, No. 2, 101-112

staff changes, however, two individuals said they didn't mind because it was exciting and a chance to meet new people. As mentioned above nearly two-thirds of the individuals surveyed or interviewed reported at least one or more staff changes in the last 12 months with some experiencing significant turnover in the staff that support them. Some of the comments shared by the individuals include:

"Yes, at least 3 people have left, and that is so difficult because it feels like a death to me. I never get to see them again, I have a very good friendship and love them with all my heart and when they leave it is so, so difficult because I lost a friend who I can no longer talk to."

"It feels like a death to me. I feel like I mourn a death because I know I never get to see them again. It makes me very sad."

"It makes me feel upset and that is a heavy feeling for me—I wish I could go back to them."

"It is very difficult for me when my staff leave or are gone because I have to train new people on how to help me, it is very hard and it makes very nervous. I get so nervous when I have to retrain someone because I need total care/ personal care and I am physically fragile, my hips get dislocated very easily and it is very painful."

"It affects every part of my life because everything changes and it makes me sad."

"I don't know how many have left but I know it's a lot."

DSP turnover and vacancies often mean that individuals have to miss doing things that are important to them such as work, social engagements, routine errands, church, and other activities that are necessary for, or improve, quality of life. During the focus group discussions and interviews many people talked about the disruption that happens to them when their staff leave and how they often feel like it is a setback for them. For example, one individual said he had to quit a job he really loved when his job coach left because all the other job coaches were busy so they could not support him at work. He went on to discuss how bad that made him feel because he worked so hard to get that job.

Several of the individuals also talked about always being afraid of their staff leaving them because so many have left in the past. The fears they talked about were related to losing the relationships but also losing out on the activities in their lives that they like to do, and that are important to them. Two women, both who have cerebral palsy and use power wheelchairs, talked about how fragile their independence really is because they know how much they rely on their DSPs for nearly every physical aspect of their lives. Some of the comments that individuals shared during this part of the discussion include:

"My independence is very important to me and I don't take it for granted. I could be warehoused in a very restrictive facility and just sitting there being depressed."

"I went from going out all the time to not being able to go out and do stuff, it was very depressing and isolating, I had a lot of anger issues and then I was worried that I would be in the hospital and 5150."

"Sometimes I have to stay home because I live in a group home and there is no one to take me out, it is really frustrating."

"I miss going to church and seeing my friends because there is no staff to take me on the weekends."

"I saved money for a long, long, long, time to go to a concert, I bought a ticket and everything, and then couldn't go because there was no one to take me. I was really upset."

Throughout the focus groups/interviews the individuals all talked about how important their DSP(s) were to them, and for most, how hard it is on them when their DSPs leave. The final question posed during the focus groups/interviews was whether there was anything else they wanted policymakers to know about how the DSP workforce shortage impacts people with IDD. While many individuals reiterated the importance they place on the relationship and their independence, several said they understood that their DSPs had to leave to make more money for their family. The individuals who talked about DSP wages all said they wish DSP could get paid enough to stay with them. Some of the comments related to what individuals want policymakers to know include:

"When I was in ILS a lot of people left because they said they were not making enough money to live on."

"It is important that they know I like where I am and I came from a bad place that I don't want to go back to because they were mean."

"If DSPs actually had a living wage there would be less turnover."

"It is very hard when you just get assigned new people and they don't even know you and you don't know them, it takes a long time to get to trust them because you just don't know them and they are just put in your life."

"The state has to do something, they have to do something because otherwise what will happen to all of us."

"I am scared of not having people to help me."

LIMITATIONS

Limitations to consider in interpreting the findings from this report include the small sample size and common characteristics of the participants as they all were able to communicate verbally and all but three did so in English. Given the small sample size, common characteristics, and voluntary participation there may be selection bias meaning that the sample may not be representative of the larger population of individuals served by the regional center system in California.

CONCLUSION

It is important to understand the unique relationship between DSPs and the individuals they support as that relationship directly affects the quality of life for individuals with IDD. DSPs provide a wide range of supports and services to individuals, much of which can be very personal in nature, require deep levels of trust, and a commitment to person-centered supports. Over time a rapport is built and these relationships become very important to both the DSP and the individual they support, however, when there is frequent turnover it can be very hard to build and maintain a trusting relationship.

Individuals with IDD in California are feeling the stress and strain of the DSP workforce shortage as many experience persistent turnover in the DSPs that support them. The emotional and mental health impacts include feelings of sadness, anxiety, and fear associated with the frequent turnover of DSPs in their lives. Moreover, as the system continues to experience significant challenges recruiting and retaining DSPs, many individuals continue to lose opportunities for employment, social inclusion, and the ability to fully access their communities. The DSP workforce crisis has evolved to be more than a shortage but rather has become a systemic problem that directly impacts the quality of life for people with IDD in California. ■



IMPACT OF THE DSP WORKFORCE SHORTAGE ON FAMILIES

Families provide a substantial amount of care for their adult family members with intellectual and developmental disabilities (IDD). Nationally, families make up an informal residential care system that is five times larger than the out of home residential care system.¹⁶ In California just over 80% of the children and adults served by the Regional Center system reside with a family member, or in the family home, so it is essential to engage parents and other family members to gain a better understanding of the impact of the DSP

workforce shortage on their family member, as well as themselves.¹⁷ In order to learn more about the support families provide, and the impact of the DSP workforce shortage, surveys, focus groups, and 1:1 interviews were conducted with families throughout the state. The surveys, focus groups, and interviews were available in English and Spanish. A total of 221 family members responded to the survey, and 43 parents and/or family members participated in focus groups and 1:1 interviews.

¹⁶ Family Support of Older Caregivers: Factors Influencing Change in Quality of Life, American Journal on Intellectual and Developmental Disabilities (2024) Vol. 129, No. 4 308-325

¹⁷ Department of Developmental Services, 4th Quarter Consumer Characteristic Report (December 2023) <https://www.dds.ca.gov/transparency/facts-stats/>

FAMILY DEMOGRAPHICS

The first set of questions on the survey were related to demographic information including ethnicity, age, and primary language spoken. The responding family members were predominately Caucasian, over 56 years old, and English speaking.

ETHNICITY

- American Indian/ Native Alaskan 1% |
- Asian 1% |
- Black or African American 3% |
- Hispanic/Latino 14% |
- Native Hawaiian 5% |
- White 74% |

AGE

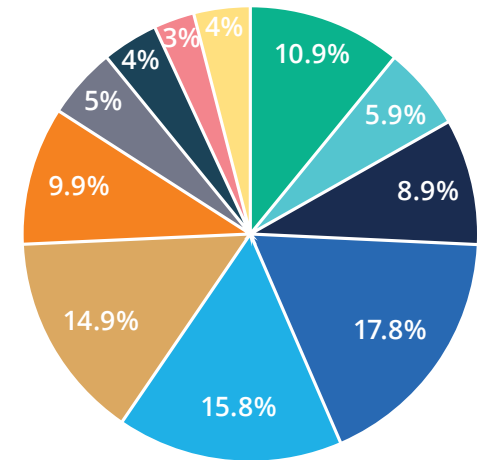
- Under 35 3% |
- 36-45 10% |
- 46-55 18% |
- 56-65 35% |
- 66-75 24% |
- 75 and older 10% |

PRIMARY LANGUAGE

- English 90% |
- Spanish 7% |
- Persian, Hindi, ASL 3% |

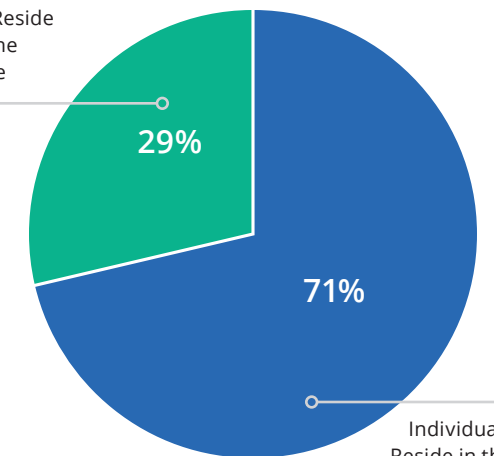
AGE OF CHILD OR FAMILY MEMBER

- 0-10
- 11-15
- 16-20
- 21-25
- 26-30
- 31-35
- 36-40
- 41-45
- 46-50
- 51-55
- 56 and older



RESIDENCE

Individuals Reside Outside of the Family Home



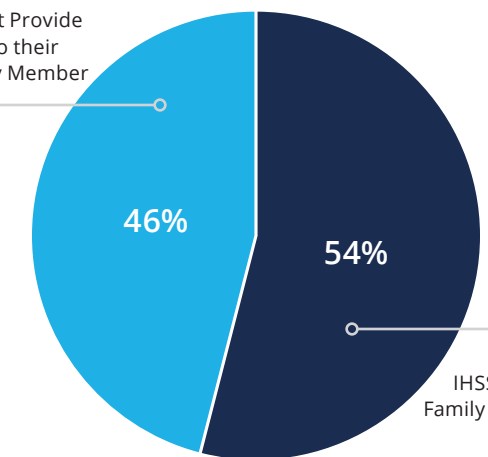
Individuals Reside in the Family Home

HOUSEHOLD INFORMATION

The next set of survey questions focused on household information including the age of their family member, whether the individuals lives with them or outside the family home, and if they provide In-Home Support Services for their family member. Families reported that 71% of their families members with disabilities live in the same household as they do, with almost half (49%) being between the ages of 21 and 35 years old and 54% of the respondents (or another family member) provide the In-Home Support Services hours for their family member. It is also worth noting that approximately 14% of the families have more than one family member with an IDD.

IN-HOME SUPPORTIVE SERVICES (IHSS)

Do not Provide IHSS to their Family Member



Provide IHSS to their Family Member

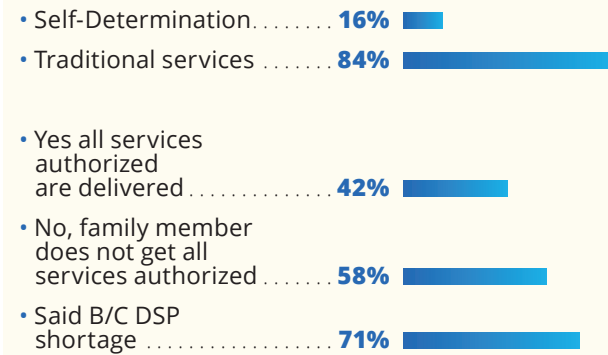


REGIONAL CENTER SERVICES

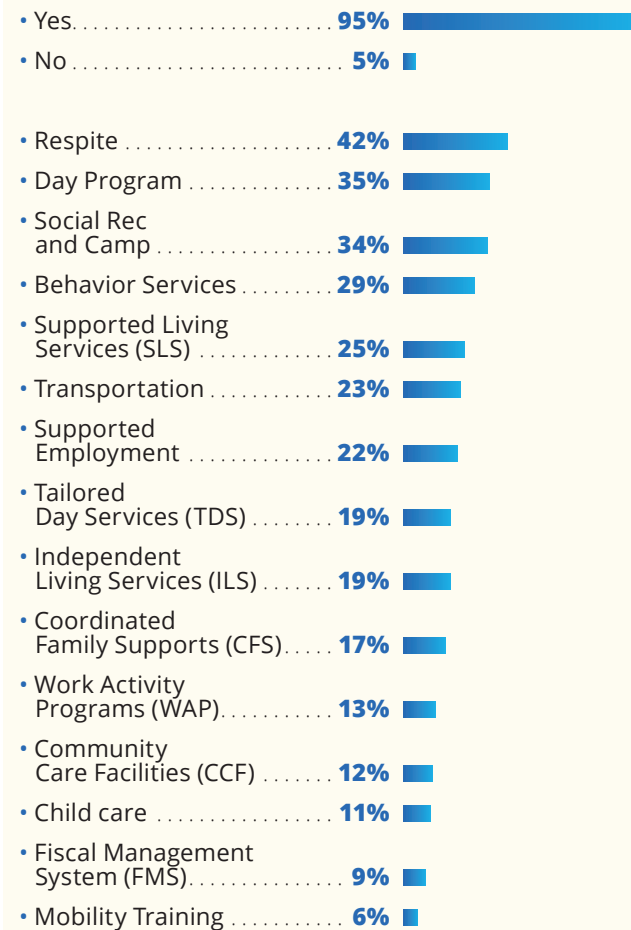
Family members were asked what type of services their family member receives (traditional or self-determination), whether they receive all of their regional center authorized services, and the services they find most challenging to find. They were also asked if they believe the challenges finding services is a result of the DSP workforce shortage. In addition, families were asked if their Service Coordinator speaks the same primary language as the individual and family does. The majority (84%) of families participating in this study reported that their family member receives traditional services from the regional center, 58%

FAMILIES FOUND THAT RESPITE, DAY PROGRAM, SOCIAL RECREATION AND CAMP, BEHAVIOR SERVICES, AND SUPPORTED LIVING SERVICES WERE THE TOP 5 HARDEST SERVICES TO FIND.

said that their family member does not receive all of the regional center authorized services, and of those that do not receive all of their authorized services, 71% believe it is because of the DSP workforce shortage. Families also reported that 95% of the Service Coordinators speak the primary language of their family member. Families found that respite, day program, social recreation and camp, behavior services, and supported living services were the top 5 hardest services to find.



Service Coordinator Speak Primary Language



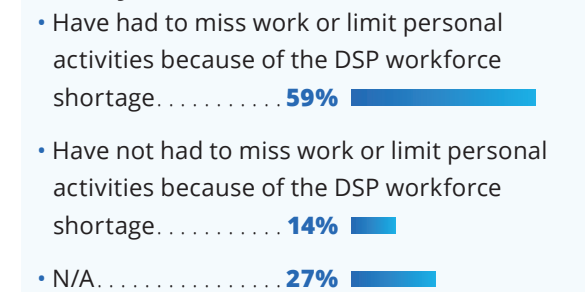
IMPACT OF THE DSP WORKFORCE SHORTAGE

The final series of questions on the family survey are related to the impact of the DSP workforce shortage on their employment and personal activities, the number of staff changes, and whether the DSPs that support their family members speak their primary language. Over half (59%) of family members have

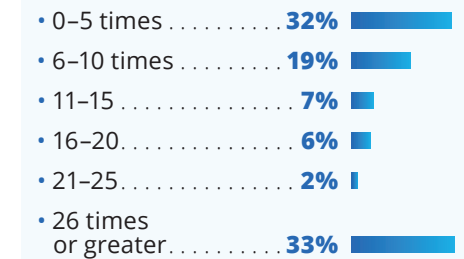
had to miss work or limit their personal activities, with one-third (33%) reporting an occurrence of five or less times, and one-third (33%) being 26 or more times in the last 12 months. More than half (52%) of families reported changes in the DSPs that support their family member with 25% having 1 change, and 20% having 5 or more changes in DSPs. The majority (84%) of individuals are always supported by DSPs who speak their primary language.



Family members:



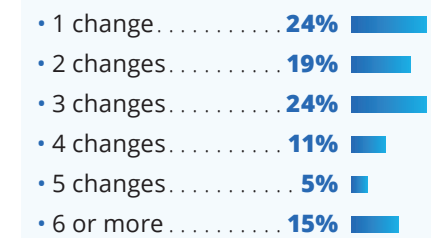
Last 12 months had to miss work/personal activity



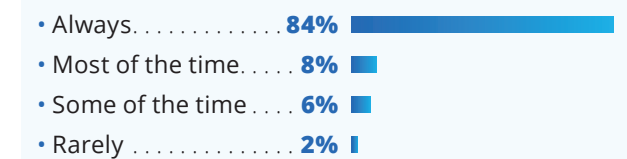
Changes in DSP over last 12 months



How many staff changes?



DSP speak primary language



According to the American Association on Intellectual and Developmental Disabilities (AAIDD), and The Arc of the United States in their joint position statement, the vast majority of people with IDD live in the family home and families are overwhelming the primary source of support for their family member with IDD.¹⁸ In 2023 DDS reported that approximately 81% (288,854) of individuals with IDD resided in the family home with 55% (195,286) of those individuals being 18 years of age and older.¹⁹ National Census data shows that in 2023, 54.6% of young adults without an IDD (18–24 years old) live at home with their parents which is similar to young adults with IDD. A notable change occurs for young adults without an IDD between 25–34 as the percent living at home drops to 12.3%.²⁰ However, that does not hold true for young adults, age 25–34, as the percent living at home remains over 50%. The DSP workforce shortage has reached crisis levels, exacerbating the reliance on families to provide care to their family members with IDD.²¹ To gain a better understanding of the reliance on families focus groups and 1:1 interviews were conducted both virtually and in-person with 43 families throughout the state. The majority of focus group participants were parents except for two siblings, and just over half of the parents (24) were 65 years of age or older, with the oldest parent being 79 years old.

CHALLENGES ACCESSING OR MAINTAINING SERVICES AND SUPPORTS

During the focus groups/interviews families were asked if they or their family member have, or have had, challenges accessing or maintaining supports

THE DSP WORKFORCE SHORTAGE HAS REACHED CRISIS LEVELS, EXACERBATING THE RELIANCE ON FAMILIES TO PROVIDE CARE TO THEIR FAMILY MEMBERS WITH IDD.

and services as a result of the DSP workforce shortage. All of the family members reported providing varying levels of support to their family member with some providing extensive levels of either, or both, physical and behavioral support. When asked to elaborate on the reason they are providing support they all said it was because they could not find someone to provide the services, especially if the level of support their family member needs requires 1:1 support.

Generally speaking, regional centers authorize services based on the individual needs of the person who is eligible to receive services. The authorized services are outlined in an Individual Program Plan (IPP) and once authorized, the regional center service coordinator works with the individual and/or their family to find a service provider (vendor) in their area who can provide the services. Services authorized by regional centers can include respite, day program, behavior services, independent living services, supported living services, supported employment, personal

assistance, group homes, as well as many other services to support the needs of the individual to live in the community.

The challenge for many individuals and families is that even though the services are authorized in their IPP they are often unable to receive the full amount of authorized services because of a severe shortage of DSPs who can provide the services. Exact data on the severity of the shortage in California is not available however, a recent national survey reported that 95% of the service providers reported a moderate to severe staffing shortage in the last year.²² California service providers reflect that trend as they overwhelmingly reported moderate to severe DSP shortages in the surveys, focus groups, and 1:1 interviews conducted for this report. To better understand the connection between the DSP shortage and service delivery, families were asked about their experiences and whether they and/or their family member are receiving all their authorized services.²³ All of the family members said they, and their family member, experience challenges when it comes to accessing the full amount of authorized services. While a couple of the parents reported feeling like they (meaning their child) do not have any services at all, the majority of the families said the biggest challenge was finding someone to come consistently to provide the services and supports their son or daughter.

Of the 43 family members that participated in the focus groups and 1:1 interviews, just over two-thirds said they have struggled to find respite workers, especially behavioral respite, so they rarely use the full amount authorized respite. Two parents reported that their child is authorized for day program services but can only attend two or three days a week because the program does not

have enough staff. Several families said they are on waitlists for various services, especially for day programs and behavior support services. One family in particular reported being on a waitlist for a behavioral day program for over three years because there are very limited programs that provide the level of support her son requires. There were two families that reported they believe their family members were receiving all of the services that are authorized in their IPPs.

IMPACT OF THE DSP WORKFORCE SHORTAGE ON FAMILIES

Recognizing the severity of the DSP workforce shortage, families were asked specifically how the DSP workforce shortage impacts them and their families. Although each family's experience is unique there were several commonalities that ran throughout the family experiences. The common experiences centered on the financial, physical, and emotional stress, as well as the fear of what will happen to their son, daughter, or sibling when they are no longer able to care for them.

Several studies have found that households that include a person with a disability are more likely to experience financial strain because of limitations on employment opportunities, and one study found that family incomes on average are 30% lower for families that include individuals with disabilities.²⁴ Consistent with the research, parents shared the realities of their financial circumstances and the financial sacrifices they have to continually make, and attributed it to the DSP workforce shortage. It was widely acknowledged among the parents with both minor and adult children, in both single parent and two parent households, that they struggle to balance the needs of their child with the demands

¹⁸ American Association on Intellectual and Developmental Disabilities, Family Support Position Statement (2020), <https://www.aaidd.org/news-policy/policy/position-statements/family-support>

¹⁹ Department of Developmental Services, 4th Quarter Consumer Characteristic Report (December 2023) <https://www.dds.ca.gov/transparency/facts-stats/>

²⁰ United States Census Bureau, Historical Living Arrangements of Young Adults, <https://www.census.gov/data/tables/time-series/demo/families/adults.html>

²¹ California's Care Workforce, Public Policy Institute of California (April 2024) <https://www.ppic.org/publication/californias-care-workforce/>

²² ANCOR, The State of America's Direct Support Workforce Crisis 2023, https://www.ancor.org/wp-content/uploads/2023/12/2023-State-of-Americas-Direct-Support-Workforce-Crisis_Final.pdf

²³ Respite is the service referenced in this report for parents or family members, all other services referenced are specific to the individual served by the regional center system.

²⁴ A Research Agenda to Support Families of People with Intellectual and Developmental Disabilities with Intersectional Identities, Intellectual and Developmental Disabilities (2024), Vol. 64 No. 3 162-173

of their jobs. Approximately half of the parents were in two parent households, and they all reported that one parent either completely stopped working or seriously limited the hours and times they could work. The majority of the single parent households, as well as several of the two parent households reported relying on being their child's IHHS provider as their source of income.

For parents that were working many reported forgoing or being passed over for career advancement or promotions because they needed to focus their attention at home. Further discussions about their financial situations included fears related to not having enough retirement, housing instability, food insecurity, and the inability to continue to provide long-term support as they themselves age. Some of the comments shared by parents related to their financial stress include:

"We have very little money in our household and sometimes I don't even have enough money to buy food so there is no way I can pay someone more money to come to my house and help with my son. I really need help."

"It took a long time to transition to this program and I rely on the program so I can work, when his coach calls out I have to call out from my work too."

"I am a single mom and I had to stop working when my daughter went to adult services because it was too hard, I had to call in all the time, I was late so much because transportation was a joke, there was always something."

"You lose certain services when your kids get to a certain age...like daycare that ends at 12 because kids supposedly can be on their own at that age, but not our kids, they can't be on their own. That is why people have to quit work when their kids get to a certain age because daycare is hard to find for kids, especially older kids, with disabilities."

"I know I will be on public benefits if I outlive my child because I have no retirement since I had to stop working and as her IHSS worker I cannot contribute to that retirement plan since she lives with me. It is really a no win situation for us."

This physical and emotional toll of supporting children with disabilities was also discussed at length during the focus groups and 1:1 interviews. Several of the parents reported physical challenges including managing aggressive behavior, lifting, changing, bathing, and often lifting heavy mobility or durable medical equipment which they all said becomes a lot harder as they get older. A particularly alarming concern for several parents centered on the reality that they are struggling to manage their child's aggressive behavior and often getting seriously injured in the process. One mother spoke tearfully about balancing the fear for her own safety against the fear of her son being taken out of her home if she sought medical help for injuries sustained during an attempt to manage his behavior.

Several parents shared very emotional and personal experiences about the challenges they face every day because they don't have consistent, or in some

cases any, support as a result of the DSP workforce shortage. It is worth noting that all of the parents who shared the following personal stories said their child was authorized for the services and they are on waitlists, some are on multiple waitlists, for day programs that accept 1:1 supervision, behavioral respite, or in home behavior supports.

"Our son graduated from high school during COVID so transitioning to adult services was all but impossible. He is a big kid with a lot of intense behaviors, he is non-verbal, he is on the severe end of the autism spectrum, intellectual disability as well as epilepsy, he is also a runner. He really needs a day program that takes 1:1 for behaviors but any that could possibly work have huge waiting lists. The 24/7 for the last 4 years has been very hard on our family for many reasons but last year I was diagnosed with cancer and had to go through cancer treatment which was horrible. It is hard for both of us to physically manage our son, and we have limited family support at this time because our other kids are all spread out. It has been hard on our son too, he has been without structured activity for so long that putting that back in his life will require a lot of work on everyone's part. He gets very frustrated and breaks things, we have gone through close to 20 televisions in the last year because he gets mad and breaks them. He is constantly hurting himself and we often get hurt in the process too."

"We are the forgotten ones, us parents that have kids with profound disabilities, they are not going to go to work, they are not going to live independently, or cook or shop for themselves, they have different needs and I think we have gone way too far with a lot of the HCBS stuff. My daughter stay home with me right now because I can't find a program that can support her level of need—she needs to be changed and fed, she likes to watch cartoons and yeah I know she is an adult but so what... she likes it! Why should she be punished because someone else decided she is too old to like cartoons. What about her, what about what she likes?"

"I am in my 70s and I don't know how much longer I can do this. I can't remember the last time I slept the entire night or even in my own bed. Most of the time I sleep a few hours at a time on the couch in case my son tries to leave the house for some unknown reason. Good luck finding someone to come in overnight. Honestly, I worry every day about what will happen to him when I am gone, who will take care of him. It is scary to think about that."

"I haven't been on vacation with my husband in years, and I mean years! I would love to go away with him even for a weekend but we cannot trust that everything will be okay. Oh what I would give for an out of home behavioral respite!"

"We don't have any regular in-home care right now and we haven't had since COVID but recently we have been able to get a couple people once in a while, but the challenge is when we do get someone we are competing with other families who are supplementing DSPs hourly rate sometimes \$5.00 or \$6.00 more per hour but we don't have that kind of money."

"Families who have members with complex medical needs feel that they are at an even greater disadvantage because not only do they struggle to find DSPs who can support their child or family member but they report that nursing care is even harder to find. One mother participated in a focus group from her son's bedside while he was hospitalized explaining that "this is where we end up when we can't get proper level of care and support at home".

She further explained that her son has very complex needs as he is non-verbal, has autism, uses a wheelchair, and requires IV medication and nutrition so he needs a lot of support at a high level. This mother has particular insight into the DSP workforce because she was a DSP for many years and she said she feels very disheartened by how hard it has been to find people who can support her son at the level he needs. She has taken on all

"I had a really good job with really good retirement but I had to give it up because my son has a lot of needs. My wife had a good job with better benefits so she worked and I stayed home with our son. It really changed the income we have for our retirement."

of his care needs, often at the expense of her own physical health, and fears that no one will be able to take care of him if something happens to her.

There was a wide range of responses from parents who reported that they and/or their child receives some or most of the services they are authorized for. Several of the parents said they were unaware of whether their son or daughter was receiving all of their services because they were in supported living, or a group home, and were only notified if there were permanent changes in staff. Four of the parents whose children were also in supported living said that they were “on-call” as back up if staff call out which two parents said was frequent and the other two said was occasional.

Other parents reflected on the impact of the DSP workforce shortage on their children and the disruption it causes for them. The main thing parents said was that sudden changes in staff, schedules, or routines are very hard on their children and tend to cause an increase in aggressive behavior, anxiety, and overall unhappiness. For example, several parents said it was not uncommon for the staff to call out and in some cases that means that their child does not go to program that day which can be very upsetting, especially for the individuals who are very routine oriented. There were two parents who reported that these changes were so upsetting for their child that it would result in aggressive behavior toward the parents.

AGING CAREGIVERS

There is no universal definition of caregiver or a set age at which someone becomes an aging caregiver, however for the purpose of this report a person who is 65 years of age or older and providing care for their adult child with IDD will be considered an aging caregiver. As mentioned over half of the parents that participated in the focus groups/interviews were 65 years of age or older and providing care to a family member with an IDD. The focus groups and interviews with family members, service providers, and regional center service coordinators elevated a concern that many aging caregivers are in the position of having to provide



high levels of complex care to their sons and daughters because of the DSP workforce shortage.

There is a growing concern that aging caregivers of adult children with IDD, who have complex behavioral and/or physical needs, are being disproportionately impacted by the DSP workforce shortage. The reason given is that many of the adult service providers have had to limit the number of individuals they can serve, especially individuals with complex or high support needs that would require a 1:1, because they simply do not have the DSPs to provide the services. Since the majority of adults with disabilities live at home it stands to reason that individuals who are waiting for services would be waiting at home with their parents, thus increasing the reliance on family, and in many cases, aging caregivers.

All of the aging caregivers who participated in the focus groups and interviews reported that their son or daughter has very complex needs either physically, behaviorally, or both. In addition, several parents said they also provide care to other family members including, more than one child with an IDD, elderly parents, or spouses with health conditions. Recent research on compound caregiving—providing care for more than one family

member at a time—highlights the specific subset of aging caregivers that care for adults with IDD and the unique circumstances that set them apart from the more general caregiver population. The research shows that almost 70% of family caregivers of individuals with IDD are at some point compound caregivers which further amplifies the need for formal supports.²⁵ Some parents discussed the painful feelings associated with an unnatural desire that their child pass away before they do because they can't bear to think about what will happen to their child when they are gone. The following are some of the comments and experiences shared by parents who are aging caregivers as they discussed the demands of caregiving:

“People, including our own family, are afraid to come to our house because sometimes he is just so hard to manage. It gets really hard and I feel so lonely sometimes. I would love to have friends over to play cards again.”

“I am in my 70s and in pretty good shape, I do all the lifting because it is too hard on my wife to lift our daughter in and out of the bathtub, in an out of her chair, to and from her bed. She really does her best to help us though, she relaxes her body to make it easier to lift her. Eventually we are going to need someone to help lift her though.”

“I have had many health problems myself but I don't go to all my doctor appointments because more often than not I don't have someone who can stay with my son and I can't take him with me.”

“I am taking care of my mother who is in her 90s and my son and that can get very stressful. He does have a day program which is really important to all of us but we have a very hard time getting people to come to the house so if I need to take care of something for my mom I have to take my son with me and that is very difficult.”

“As hard as it can be I still worry everyday about what will happen to my child when I am gone, I have taken care of her for so long, I just know what she needs sometimes even before she knows. I can understand her, no one else can, but I can.”

“We have services but it is ridiculous how many people come and go, it is easier just not to have any one because all these people coming and going, I don't know them, my son doesn't know them, it's not worth it.”

A couple of the parents said they felt like they had pretty good support, their son or daughter had something to do during the day, and they know the staff well, which made the parents feel a lot better about what will happen when they are gone or no longer able to care for their child. Those parents also said they have other children who will take over their son or daughter's care and they know they will do a good job, but they still want to make sure all their services and supports are in place.

STAFF TURNOVER AND FAMILY RECOMMENDATIONS FOR INCREASING RECRUITMENT AND RETENTION OF DSPS

Every family member that participated in the focus groups/interviews reported at least one change in staff within the last 12 months. However, the vast majority reported more than one staff change with some being upwards of more than two a month within the last 12 months. Parents and family members were asked for their thoughts on why it was so difficult to recruit and retain DSPs, to which the number one answer was wages. The families unanimously agreed that low wages were the biggest barrier to recruiting and retaining DSPs. It was widely acknowledged that the job can be very complex and that it is often a hard job. Some of the comments, suggestions, and recommendations from family members included:

²⁵ *Compound Caregiving: Toward a Research Agenda*, Journal of Intellectual and Developmental Disabilities, 2022, Vol. 60, No. 1, 66–79



“We need to a way to level the playing field— pay a livable wage so families don’t have to compete against each other by paying additional money out of their pocket to try to keeps DSPs from leaving.”

“This is very challenging work and people do not get paid enough to do it.”

“If this was such an easy job we wouldn’t need so much support just to manage our own kids, people need to get paid what they are worth, we need people to get paid what they are worth.”

Another suggestion made by families was to increase awareness about the profession and show people how great it can be. Many family members said they feel a lot more should be done to raise awareness and respect for this job. Nearly every family member shared something special about their loved one and said anyone who gets the chance to work with them would be lucky. Some of the comments from families about how great the DSP profession are included:

“We don’t hear enough good things about these amazing people, our kids are amazing people and people who work with them are so lucky... we have to show people that.

“My son is an amazing person, he loves music and he wants to learn and be independent. It is sad though because he gets X’d out before he even gets a chance because he can’t get the proper support to be able to do those things.”

“You have to start raising awareness about this awesome profession in high school, you have to make it an attractive and desirable profession—think about things like paid training, internships, livable wages and benefits so people can stay in the jobs they grow to love.”

The final question family members were asked was if there was anything else they felt policymakers should know about the impact of the DSP shortage on families and individuals served by the regional center system. The family members shared several thoughts beginning with saying that everything should be considered when thinking about ways to incentivize this workforce and increase the number of people who want to be DSPs. The family members also felt very strongly that policymakers need to be educated about the importance of this workforce, that they need to understand that these supports are essential to life for so many people. Some of the comments included:

“This system has been so underfunded for so long and it is just going to get worse now that policymakers have passed a law for fast food workers to get \$20 an hour, unless they do something like that for DSPs it will get harder and harder for people like our sons and daughters to live their lives because there will be no one to help them do it...the state just has to do better by our families.”

“What about the Lanterman Act? Is it just going to be a set of empty promises?”

“Think about what it costs to not invest in this workforce—parents can’t work so you lose there, people have to seek higher levels of care when it becomes a crisis so you lose there, people with disabilities lose their independence which is the greatest loss of all.”

“The workforce is not professionalized but it needs to be. This isn’t that hard to do... we have done it before... I mean think about the trades, there are lots of ways to get there, we just have to do it.”

“We need to change the narrative about this workforce and make it a priority, funding these services should not be discretionary.”

LIMITATIONS

Limitations to consider in interpreting the findings from this report include the small sample size, and self-selection of the survey respondents and focus group/interview participants. Given the small sample size and voluntary participation there may be selection bias meaning that the sample may not be representative of the larger population of parents or family members of individuals served by the regional center system in California.

CONCLUSION

The ripple effect of the DSP workforce shortage can be felt in so many different areas of life for families that include people with IDD. In California, the majority of people with an IDD live at home at disproportionate rates when compared to the general public. They continue to live with their parents, or another family member, well into their adult years and many of the families struggle to fill the gaps in services and supports created by the DSP workforce shortage. For some the gap in services has become so unmanageable that parents have had to quit their jobs, or limit the hours they work, so they can take on the care that DSPs would otherwise be providing. Many families are struggling to meet the needs of their family members with IDD, especially the individuals who have complex behavioral, medical, and/or physical needs, as a result of severe staffing shortages. Parents and family members of individuals served by the regional center system urge policy makers to prioritize the DSP workforce shortage and understand that DSP services are essential to life for so many individuals with IDD. ■

IMPACT OF THE DSP WORKFORCE SHORTAGE ON DIRECT SUPPORT PROFESSIONALS

IMPACT OF THE DSP WORKFORCE SHORTAGE ON DSPS

A Direct Support Professional (DSP) is someone who works directly with individuals with intellectual and developmental disabilities (IDD) to support them in becoming as independent as possible and live meaningful lives in the community. DSPs provide a wide range of supports and services based on the individual needs of the person they are supporting. The supports and services DSPs provide include things like assisting individuals to meet their basic personal care needs, teaching and ensuring health and safety, support in developing and maintaining relationships, finding and maintaining employment, navigating the community, maintaining health and wellness, managing complex medical conditions, behavioral supports, and nearly anything else the individual needs to live a full life in the community.

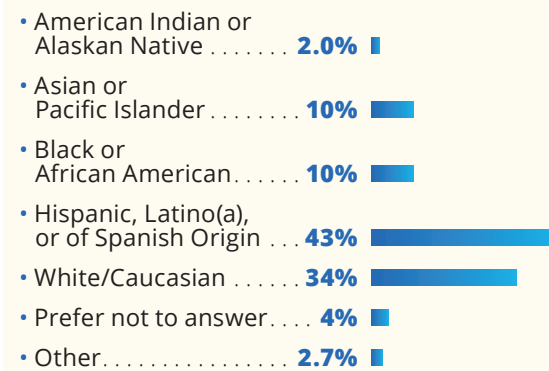
The focus of this report is to take an in-depth look at the DSP workforce crisis in California, and the impact it is having on individuals with IDD and their families. The DSP section of the report will focus on the significant challenges associated with recruiting and retaining DSPs for from their perspective. To gain further insight into the challenges surveys, focus groups, and 1:1 interviews were conducted with approximately 2,300 DSPs. The DSP surveys were conducted in Spanish and English for a total of 2, 287 survey respondents and 61 focus group/1:1 interview participants.

DEMOGRAPHICS OF THE DSP WORKFORCE IN CALIFORNIA

Based on findings from the survey, the DSP workforce is predominately made up of women (79%) with 66% being non-white or non-Caucasian. Over one-third (35.5%) of the respondents reported

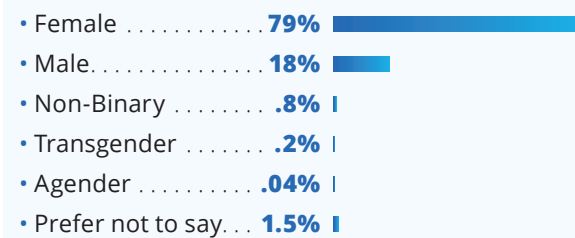
being age 55 and over, the majority of DSPs (40%) are between 35 and 54 years old, while 23.5% are under 34 years old. The primary language spoken by most (75%) of the DSPs is English, with Spanish following at 16%.

ETHNICITY

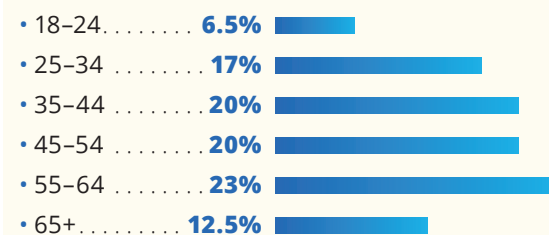


NOTE: PERCENTAGES MAY NOT EQUAL 100% BECAUSE IT WAS A "CHECK ALL THAT APPLY" QUESTION SO SOME MAY HAVE MORE THAN ONE ANSWER

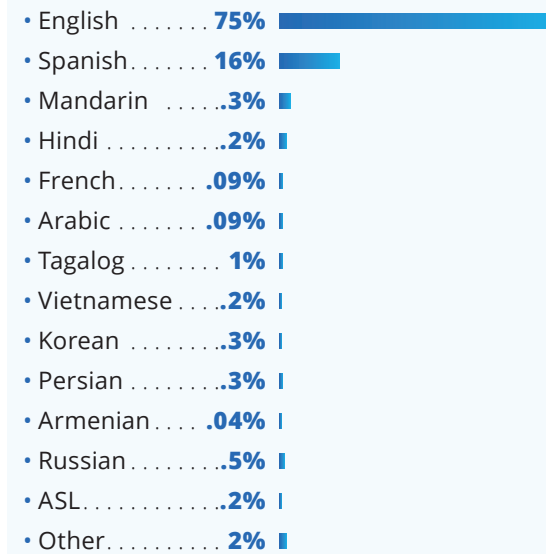
GENDER



AGE



PRIMARY LANGUAGE



In comparison, a recent national survey found that the DSP workforce is 69.8% women, with an average age of 43 years old, and predominately non-white with 43.6% being Black or African American, 4.9% Hispanic or Latinx, and 2.3% being Asian.²⁶

FAMILIAL RELATIONSHIPS TO INDIVIDUALS WITH IDD

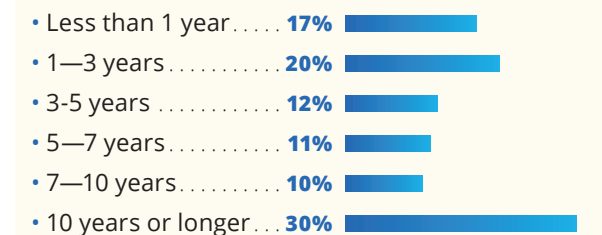
Very little, if any, data exists related to how many DSPs have a family member with an IDD. However, this could be an important data point to consider for further research and understanding different factors that may motivate someone to become a DSP. Fifty percent (50%) of the respondents reported having a family member with a disability. Caution should be used when interpreting this data point as "disability" was not defined or limited to an intellectual or developmental disability. Future research on familial relationships and motivation to work as a DSP should be considered.

LENGTH OF TIME AS A DSP

DSP tenure is an important metric for measuring workforce stability as it can provide, among other things, insights on emerging trends, employee satisfaction, retention strategies, and the level of experience of a workforce. For example, assuming the percentages from the survey are a reliable representation of the DSP workforce, the data shows a notable decrease in retention of DSPs after 3 years. Several of the DSPs that participated in the focus groups/interviews talked about the disconnect between getting raises associated with minimum wage increases and merit based or regular pay increases. They felt that the wage increases associated with increases in state minimum wage should not be considered in lieu of the raises they should get as employees, but several of the DSPs reported increases to minimum wage were the only increases they have received.

The increase in retention associated with transparency in pay increases is well-documented in workforce research. Though many factors go into deciding how much and how often to increase employee wages it is fairly standard for employees to get at least a cost of living increase annually. The drop in DSP retention after 3 years could very likely reflect a corollary relationship between DSP's expectation of an increase in wages associated with their level of experience and the service providers inability to increase wages based on their current rate reimbursement. This data could be used to support the development of retention strategies such as a tiered system of reimbursement that accounts for experience of DSPs in the workforce.

LENGTH OF TIME AS DSP

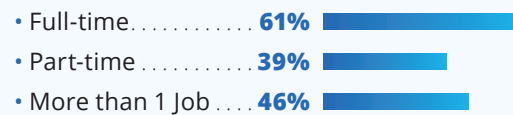


²⁶ National Core Indicators, State of the Workforce 2022, https://idd.nationalcoreindicators.org/wp-content/uploads/2024/02/ACCESSIBLE_2022NCI-IDDStateoftheWorkforceReport.pdf

EMPLOYMENT STATUS

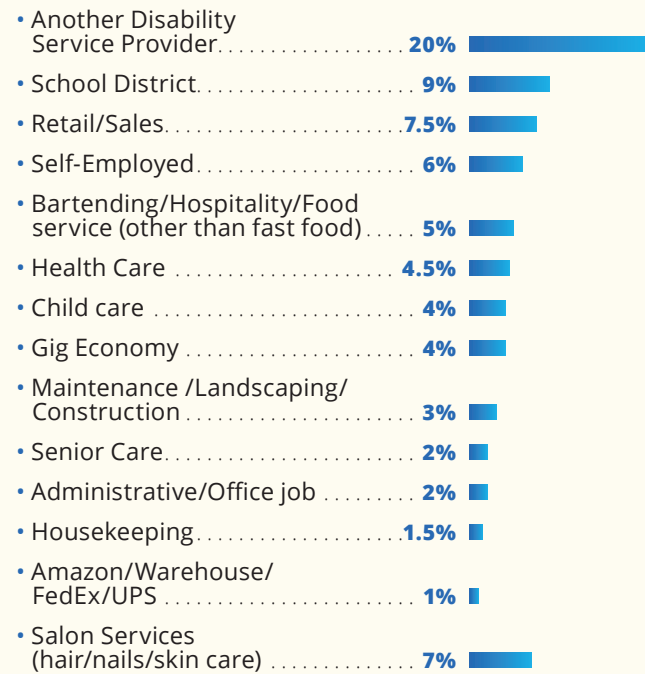
Due to the low wages DSPs get paid many have to work more than one job, or overtime, to support themselves and their families. National estimates suggest that nearly half of the DSPs in the workforce work more than one job, and in fact many work two or three jobs.

The majority (61%) of the DSPs surveyed reported working full-time, 39% reported working part-time, and 46% reported having more than one job.²⁷



DSPs who work more than one job were asked to provide information on what type of other employment they have. The answer choices on the survey included In-home Support Services (IHSS), Fast Food, and Other. For the purposes of this report IHSS workers were categorized separately from DSPs because, even though there may be some overlap in services delivered, they are separate and distinct jobs. Fast food was also specified given the potential impact on the DSP workforce as a result of the recently passed legislation that established a minimum wage of \$20.00 per hour for fast food workers.²⁸ It should be noted that at the time the survey was created the agreement to increase the minimum wage for health care workers to \$25.00 had not been finalized, however, as of October 2024 an agreement was reached and the provisions set forth in Senate Bill 525 will be implemented.²⁹

Of the DSPs who work more than one job, 35% reported working as an IHSS worker, 4% reported working in the fast food industry, and 61% report under the “other” category. The “other” category included:



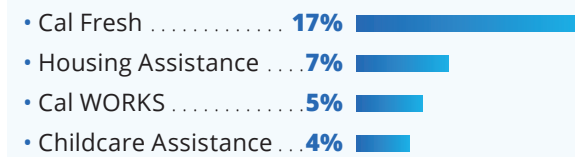
NOTE: THE PERCENTAGES IN THE “OTHER CATEGORY” EXCEED 61% BECAUSE SOME OF THE RESPONDING DSPS REPORTED WORKING SEVERAL JOBS.

HOUSEHOLD INFORMATION

The final series of questions on the DSP workforce survey were aimed at developing a better understanding of household information such as the percent of single parent households and households that qualify for one or more types of public benefit. Public benefits are government

funded programs that provide assistance to people with low or no income.³⁰ Information about public benefit utilization of a workforce is critical to understanding what is referred to as the Benefits Cliff as it can significantly impact lower-wage workers and their families.³¹

Approximately 25% of the responding DSPs reported being single parents and of that number just over 50% have more than one child. Nearly one-third (32%) of the responding DSPs qualify for Medi-Cal themselves and 29% reported that their children qualify for Medi-Cal as well. Medi-Cal is the state’s public health insurance and to qualify an individual’s Modified Adjusted Gross Income (MAGI) cannot exceed 138% of the federal poverty level (FPL) which amounts to \$20,783.00 annually.³² In addition to Medi-Cal other public benefit utilization included:



Several studies, both national and state, have found that 42% to over 50% of the DSP workforce relies on some type of public assistance.³³ A recent report from the California Health Care Foundation found that nearly half (47%) of California’s direct care workforce receives one or more types of public assistance.³⁴

DSP FOCUS GROUP DISCUSSION

One of the main considerations in DSP workforce development is how the profession can be made more attractive to people who may, or may not, know about the profession. To understand what makes the profession attractive it was important to find out why current DSPs wanted to become a DSP in the first place. The majority of DSPs who participated in the focus groups/interviews reported developing an interest in the position after learning about it from a family member or friend who was currently working as a DSP or previously worked as a DSP. Some of the other reasons given included wanting to help people, a desire to have a job that makes a difference, a religious calling to serve people, previous experience in a summer camp for kids with disabilities and just needing a job.

Recent research related to DSP recruitment and retention found that those who found deep meaning in their work may be more likely to stay at that job even when other offers were presented.³⁵ To gain a sense of the meaningfulness or value the DSPs attached to their job they were asked what they valued most about being a DSP. The relationships and connections they built with the individuals they support tended to be what they valued the most. Many found the job to be very rewarding because they enjoyed supporting individuals to live their lives and teach them skills that they will have forever. In addition to

³⁰ CA Department of Social Services, Benefits and Services <https://www.cdss.ca.gov/benefits-services>

³¹ U.S. Chamber of Commerce Foundation, Benefits Cliff: Effects on Workers and the Role of Employers, <https://www.uschamberfoundation.org/workforce/benefits-cliffs-effects-on-workers-and-the-role-of-employers>

³² Department of Health Care Services, Medi-Cal Eligibility <https://www.dhcs.ca.gov/services/medi-cal/Pages/DoYouQualifyForMedi-Cal.aspx>

³³ American Association on Intellectual and Developmental Disabilities, Joint Statement with National Association of Direct Support Professionals, DSP Workforce [https://www.aaid.org/news-policy/policy/position-statements/direct-support-professionals-\(dsp\)-workforce](https://www.aaid.org/news-policy/policy/position-statements/direct-support-professionals-(dsp)-workforce)

³⁴ California Health Care Foundation, California’s Direct Care Workforce (January 2023), <https://www.chcf.org/wp-content/uploads/2022/12/CaliforniaDirectCareWorkforce.pdf>

³⁵ Inclusion, 2024, Vol. 12, No. 3, 186-200

²⁷ American Association on Intellectual and Developmental Disabilities, Direct Support Professional Workforce, Joint Statement AAIDD and NADSP [https://www.aaid.org/news-policy/policy/position-statements/direct-support-professionals-\(dsp\)-workforce#:~:text=Wages%20paid%20to%20direct%20support,Wages%20need%20to%20be%20increased](https://www.aaid.org/news-policy/policy/position-statements/direct-support-professionals-(dsp)-workforce#:~:text=Wages%20paid%20to%20direct%20support,Wages%20need%20to%20be%20increased)

²⁸ Assembly Bill 1228 (2023), Fast Food Restaurant Industry https://leginfo.ca.gov/faces/billNavClient.xhtml?bill_id=202320240AB1228

²⁹ Senate Bill 525 (2023), Minimum Wage, Health Care Workers https://leginfo.ca.gov/faces/billTextClient.xhtml?bill_id=202320240SB525

the relationships with the individuals many DSPs also felt a deep sense of connection to the team [coworkers] they work with so much so that they feel bad if they have to call out due to illness or family responsibilities. Some DSPs even referred to the individuals they support and their team as their family.

A sense of belonging, being good at their job, and always being able to learn something new were also qualities of their job that they attached significant meaning. Several DSPs spoke about the experience of being a DSP during the Covid-19 pandemic and for some, how their bonds became even stronger because they went through a very uncertain time together. One comment, “It is amazing how you can grow into a position, I didn’t understand it until I saw growth in the clients I support”, evoked an in-depth discussion not just about the personal value that they felt but also about the value of what they are contributing to other people’s lives. Some said they were scared when they first started as a DSP because they didn’t know how to support people, what to do when behaviors occurred, how to communicate with individuals who use non-verbal communication, or how to deal with new situations, but as their confidence grew they were able to “grow into the position.”

Another comment that elevated excitement and conversation among the focus group participants was from a DSP who said “I support a 76 year old man who is still excited every day to learn new things. He also teaches me and shows me new things like listening to his old music. I never thought I would be listening to, and like, 60s music.” Several of the DSPs spoke about the reciprocal nature of the relationship they have with the people they support and the uniqueness of the job as a result. DSPs who have supported the same person (or people) for many years felt that the DSP profession is so unique because they could not think of any other job where you play so many roles in a person’s life, and sometimes for many years. Part of the conversation centered on a discussion about the interesting balance DSPs must find when they are “so deep” in the lives of another person because of how easy it is to internalize their (the people they support) successes and failures. Some of the DSPs said it is

just too hard to explain the connection between DSPs and the people they support, unless you have done it before, because it can be everything at once—success, failure, happiness, sadness, pride—sometimes it can be very complex.

CHALLENGES OF THE DSP PROFESSION

While all of the DSPs who participated in the focus groups/interviews reported feeling a sense of value and meaning in their work, they also shared that they experience immense challenges that can make it very difficult to be a DSP. The emotional connection that develops between DSPs and the individuals they support can be just as challenging as it can be rewarding. For example, one DSP said the biggest challenge for her was losing the person she supported for years as she mourned for that person the same she did for her own family. She said she is still not the same and not sure when she will be. However, most of the challenges they expressed can be categorized into four different areas which include low wages, lack of respect and recognition for the positions, burnout from workload, and unrealistic expectations.

LACK OF RESPECT OR RECOGNITION FOR THE PROFESSION

The majority of DSPs said they feel undervalued and unappreciated because there is a fundamental lack of respect or recognition for the DSP profession. Several DSPs said they have always felt this way but now more than ever it is apparent because the state has officially recognized, and even further devalued the DSP profession, by setting a new \$20.00 per hour minimum wage for fast food workers, while doing nothing for DSPs. The consensus among all of the DSP focus group participants was that it would be great if people just knew what they did and they didn’t have to explain what they do or why they do it. Some of the comments DSPs made specific to feeling undervalued and underappreciated were:

“You tell people what you do and how much you get paid to do it and they are like oh hell no!”

“Nobody knows what we do—if you tell someone you are a childcare provider they know what you do, if you tell them you are a teacher they know what you do, a CNA they know what you do...but tell them you are a DSP, and they are like...a what?”.

“It is sad to me because what would happen if we didn’t do this job—the clients would all be locked up somewhere or sitting in a room with 10 other people? That’s not right, they like to live their life just like we do.”

“It is sad the fast food is prioritized over people.”

“In my family everyone is a nurse, it is just what you do. They don’t understand why I do this job instead because I make so much less money. I really like this job and it is what I want to do.”

LOW WAGES

The historically low wages paid to DSPs have hindered the recruitment and retention of DSPs for decades. Currently the vast majority of DSPs start their career earning minimum wage or just slightly

above and, according to the survey conducted for this report, approximately 40% do not get annual cost of living or merit-based increases on a regular basis. Many of the DSPs in the focus groups said the raises they have been given are because of the state increases in minimum wage, so they are still making minimum wage. Further, the majority of DSPs said they work a second job and/or know several of their co-workers that work a second and sometimes third job just to make a living. Nearly half (46%) of the DSPs who took the survey reported working more than one job.

The focus group participants expressed a wide range of emotion when it came to the wages they earn. Many were simultaneously sad and angry because they felt earning a livable wage should not be considered a privilege. A livable wage is the minimum hourly wage that allows a full-time employee to cover the cost of their families basic needs without needing financial assistance.³⁶ Further, they felt it is unfair to have to sacrifice and sometimes work a second job they don’t even like so they can continue to do the job (DSP) that they love. Some of the DSP comments related to low wages include:

“The hourly wage is so bad especially when you consider the complexities of the job and that we are responsible for people’s lives. For some people we provide total care which means 24/7 care, things like g-tubes, traches, suctioning, making sure they get their meds on time, and these are all a matter of life and death.”

“It is hard to give your 100% when you are so tired from working all the time.”

“It is very sad to me that fast food is prioritized over people...it is just sad.”

³⁶ What is a Livable Wage and How is it Calculated? Living Wage Calculator <https://livingwage.mit.edu/pages/methodology>



“It is so frustrating that you can love a job so much, a job that is so important but not get paid what you are worth—I can’t believe we can’t even get paid what fast food workers are making.”

“It is hard to work so much, I am so tired, and I miss my family.”

STAFF BURNOUT/TURNOVER

The high turnover rate within the DSP profession has prompted research on occupational stress and burnout experienced by DSPs.³⁷ While some DSPs are more resilient than others in managing stress

and burnout it often takes a toll on their physical and mental well-being, especially when they are working in chronically understaffed and under resourced circumstances. Research shows that the stress and burnout DSPs experience can have a significant negative impact on service delivery.³⁸ DSPs expressed feelings of guilt, inadequacy, anxiety, frustration, and exhaustion when discussing the impact of the workforce shortage not just in relation to themselves but also for the individuals they serve.

The majority of DSPs reported feeling stressed about the workforce shortage because they know it is inevitable that they will have to take on the responsibilities of someone else in addition to their own. The additional responsibilities are often the cause of higher stress levels because it can mean supporting additional individuals they don’t know, higher ratios that are out of compliance, change in routine for the individuals they already support, long hours, conflicts with family life, and strained relationships with individuals they support as well as co-workers. Some of the comments about burnout and stress shared by DSPs during the focus group discussions include:

“When there are not enough DSPs it puts us all in the position having to take on a lot more risk.”

“Things change on a moment’s notice when someone calls out and that puts a lot of stress on those of us who are there.”

“When we are overworked we don’t take care of ourselves like we should which leads to a lot of other problems, health problems, mental health issues, it’s not healthy for anyone.”

UNREALISTIC EXPECTATIONS

Several of the DSPs talked about the stress of being short staffed in the community and the constant anxiety that goes along with keeping everyone safe. Most of the DSPs said they felt very confident and competent supporting individuals in any environment but that it becomes a “numbers game” when they have too many people to support at one time. This issue becomes particularly important in the context of inclusion as staffing limitations significantly reduce the ability for DSPs to support individuals in fully accessing the community, developing meaningful connections, and ensuring the safety of the individuals in the community.³⁹ Some of the comments shared by DSPs specific to being short staffed in the community include:

“The community can be a very dangerous place to be depending where you are. Sometimes it is hard to find safe things to do especially when we don’t have money and everything we do has to be free. It’s even harder to find things to do when you have too many people with you because we don’t have enough staff.”

“We are a fully community-based program, we meet at a public place in the morning and are out all day—it can be very challenging when you are by yourself because someone called out especially when you think about everyone’s personal needs. Like where we can find a clean and accessible bathroom that everyone can go in at the same time since I can’t just leave someone outside.”

“Sometimes it is so hot outside that it is not safe for us to be out all day so we have to find a place to cool down and that can really agitate the clients we support. Some staff just don’t want to work in those conditions...you can’t blame them, no one want to walk around all day in 100+ degree weather, I mean we should have some consideration for those kind of days.”

“People can be so rude to us when we take our groups out in public, often we don’t feel very welcome and it’s even worse when you walk in to a place with 4 or 5 people with you—it would be nice to have enough staff to have smaller groups.”

“We have to encounter so much in the community—homeless people that harass us, people fighting at the bus stop, it just doesn’t feel safe for us.”

Feelings of guilt and inadequacy were also discussed in the context of calling out sick and the impact it has on others that they work with or support. Many of the DSPs reported working even when they are sick because they worry about leaving their co-workers even more understaffed than they already are. They also report worrying about the individuals they serve not getting adequate support when they are not there as well as when they are shorted staffed overall. Several of the DSPs spoke to the concern about the individuals not getting the quality of services that they should get as a result of always having to juggle schedules and people when they are so short staffed. Some comments related to feeling guilty and inadequate include:

“When we are short staffed the individuals we love, and support suffer because they don’t get what they need”

“People come and go all the time, and it is really hard, it is especially on the individuals we support because it is so disruptive. They need consistency...consistency is what helps them meet their goals.”

“I feel so bad if I call out because you never know who will get sent in and sometimes if you send the wrong person it can be even worse that being short staffed.”

³⁷ Who Thrives as a Direct Support Professional? Personal Motivation and Resilience in Direct Support, Research in Developmental Disabilities, Volume 106, Nov. 2020

³⁸ They Care for Others, but What About Themselves? Understanding Self-Care Among DSPs and It’s Relationship to Quality of Life, John M. Kessler, Jess Troxel https://www.aidd.org/docs/default-source/default-document-library/keesler.pdf?sfvrsn=398f3621_0

³⁹ Inclusion, 2023, Vol. 11, Living in Localities: Factors that Influence the Social Inclusion in Neighborhoods of Adults with Intellectual and Developmental Disabilities: A Systematic Scoping Review

“It’s just hard to watch the clients get the short end of the stick, I mean everything changes when someone calls out, and sometimes there are a lot of people out at the same time. I feel so bad when I have been promising that we can do something and then the day comes to do it, and we can’t because we have had to add more individuals to our group for the day or sometimes longer.”

DSPs also said they frequently feel frustrated and exhausted and while some of those feelings were related to the stress of being short staffed, they acknowledged that the job itself can be just as challenging as it is rewarding. In part, the feelings of frustration were often things that are out of their control, like transportation being unpredictable, jobsites closing without notice, people leaving without notice, and inconsistencies with management. Their feelings of exhaustion were related to being tired, often from having to pick up the slack of others, from doing the job of two people, and sometimes just from the emotional toll the job takes out of them. Some comments that were shared related to feeling frustrated and exhausted include:

“It feels like we spend more time trying to figure out transportation than we do actually supporting the clients, it is the worst part of our day.”

“Transportation is impossible, it literally ruins our day more often than not.”

“It affects their trust when people are always coming and going. Who knows, they might have a wall up because of past experiences. Then you see more behaviors and even disengagement.”

“We are total care, so I support people who have significant physical disabilities as well as IDD, we are so short staffed that I have to manage changing 6 people by myself and still try to help them meet their daily goals... it just feels impossible and that makes me feel very bad. Just imagine that—each individual needs to be changed 3 time a day and I have 6 people—I know they are trying to hire more people, but it is so hard because a lot of people will not do this job for the amount we get paid.”

DSP FACTORS IN DECIDING WHICH SERVICE PROVIDER TO WORK FOR

Although there is a substantial body of research on the DSP workforce shortage and factors that contribute, there are relatively few studies that explore the perspectives, lived experience and support needs of DSP.⁴⁰ While low wages are consistently held to be the main challenge for retaining DSPs there are other factors such as staff burnout, lack of support from management, and poor hiring practices that contribute to higher turnover rates.⁴¹ The factors that contribute to turnover also play an important role in DSPs deciding which service providers to work for. Several of the DSPs said they currently work for two different service providers and the deciding factor of which one they work more hours for was related to pay. If one provider was paying even slightly more than the other and they could work more hours for the one that paid more, they were more likely to be full-time or work more for that provider. Other DSPs said they left one provider for another because they didn’t feel respected, supported, or appreciated

by their supervisors. A few DSPs said they moved from one provider to another because they moved (relocation). There were also a few DSPs who said they left one provider for another because they didn’t like what was going on with the provider they were working for (i.e. they felt the provider “didn’t care” about anything but the bottom line.)

The type of benefits an employer can offer is also an important consideration in deciding which organization to work for. The majority of the DSPs who work 32 hours a week or more said their employer does offer, at a minimum, medical benefits and some employers offer a more extensive range of benefits to choose from such as medical, dental, vision, life, wellness, and flexible spending accounts. The majority of DSPs said they do participate in the benefits plan while others said they were still too expensive, and they could not afford the employee contribution required to get the benefits. One DSP who does not participate in the employer offered plan said, “when you make as little as we make every penny counts so I cannot afford to participate in the benefits.”

DSPs in the focus groups unanimously agreed that increasing wages to reflect the real work of DSPs is the number one thing that could be done to increase recruitment and retention of DSPs. However, taking that into consideration, they were asked what are some other things that are important to consider when it comes to job satisfaction and retention. The suggestions tended to fall within three main categories which include the relationship with management, training, and being valued.

RELATIONSHIP WITH MANAGEMENT

There tended to be greater job satisfaction among DSPs that felt they had a good relationship with their supervisor and with the management team as a whole. A key takeaway from this conversation centered on the importance DSPs place on being able to get support from their direct supervisors as well as the management of the organization . They wanted to know they could count on their supervisor if they needed something or had

questions about how to handle a situation. Further, DSPs stressed that the most strained relationships between management and the frontline (DSPs) occur when management knows they are struggling and does nothing to help, especially when they are short staffed, and everybody is working hard to meet the needs of the individuals.

TRAINING

Nearly all of the DSPs in the focus groups said that providing meaningful training is something that could be done to help increase retention. They made a very clear distinction between training and meaningful training however because they want training on more than just what is required such as first aid and CPR. Many wanted training that got deeper into the skills they need to provide high quality care, person-centered supports, and supporting individuals with complex needs. Several of the DSPs said they know for a fact that people leave all the time because they don’t feel prepared to do the job.

BEING VALUED

The discussion about feeling, or not, valued by their employers brought up a lot of emotion for many of the DSPs with responses falling into three different categories which were feeling valued, feeling like a “cog in the wheel”, or not feeling valued at all. Those that feel valued said they knew that their employer was doing everything they could do to pay better, recognize their contributions and hard work, and respect the job they do. Others reported feeling that they were just “a cog in the wheel” and often felt taken for granted. The rest of the DSPs said they didn’t feel valued at all and felt it was an “us against them” [DSPs against management] type of work environment.

The DSPs that felt valued were asked if they could give examples of what made them feel, or know, that they were valued. Of the DSPs that reported feeling valued they said honest and regular communication from management was a big part of it because it makes them feel like part of the team,

⁴⁰ Direct Support Professionals’ Perspectives on Workplace Support: Underappreciated, Overworked, Stressed Out, and Stretched Thin, Intellectual and Developmental Disabilities (2021) Vol. 59, No. 3, 204-216

⁴¹ The Self-Perpetuating Turnover Cycle: Front Line Supervisors and Direct Support Professionals Reflect on it Causes and Impacts, Inclusion (2024) Vo. 12, No. 3, 172-185



they feel respected and even though they may not always agree with what is going on they at least feel that their opinion matters. These DSPs tended to feel like there was a good company culture and a sense of connectedness.

Those that felt they were just “a cog in the wheel” summed up their feelings by saying they just do their job and don’t really care if there is a good company culture or not because they just want to focus on the individuals they support. Within this context, however, some said it would be nice to be shown they are valued and appreciated by their employer but that as long as it wasn’t a bad place to work they were fine.

The more emotional responses came from DSPs who did not feel valued at all. There were several tearful responses that could be summarized as DSPs feeling like “what about us?” They feel forgotten and unappreciated for the hard work that they do. For example, a few DSPs were very upset that their employer was giving sign-on bonuses to new DSPs when they have been there, and they have “been through it”. The main thing they meant by the statement that they had “been through

it” was that they stayed through COVID and took the responsibility of being essential workers very seriously. They expressed feelings of hurt and anger that they have been there the entire time and someone new comes in and gets, in some cases, a \$1,000.00 sign-on bonus. An even deeper resentment came at the fact that they would also have to train the new person who may or may not be making more than they are. DSPs who fell into this category reported that even though they love the people they support they are always keeping their eye open for other opportunities because it is hard to keep working somewhere when they don’t feel valued.

It is important to note that the feedback from DSPs about job satisfaction and retention mirrors findings in recent research. For example, one study found that DSPs want access to better, higher quality, and relevant competency-based training. Some of the areas DSPs suggested for training included information specifically tailored to IDD, dealing with families and conflict, how to support people who are dual-diagnosed, mental health, behavioral health, and communication.⁴² Another study found that while trauma informed practices

have historically been associated with supporting individuals with disabilities, organizations that use trauma informed organizational practices could have better outcomes and higher levels of employee (DSP) satisfaction.⁴³ Some of the most recent research related to turnover found that positive environments that foster respect and dignity for employees can significantly reduce turnover and overall quality of support for people with IDD.⁴⁴

Another factor DSPs consider in deciding where to work is whether there are opportunities for advancement within the provider organization that they work for. There were a few DSPs who reported having a lot of opportunity for promotion or advancement but generally speaking, DSPs who worked for larger providers [100 or more employees] said they tended to have more openings, and some were lead positions but not necessarily in management, though occasionally management positions do open. The majority of the DSPs that work for the larger provider said that when management positions do open the Directors were really good about moving people up from within the organization. DSPs that work for employers with less than 100 employees said they had a harder time moving up because when people get to that level they tended to stay longer. The chances of moving into a leadership position for DSPs that worked for employers with 25 or fewer employees were even less as few opportunities were available.

Though a fair number of DSPs expressed a desire to move into a management position, the majority said they would rather not be in a management position because they really love the work they do as a DSP. However, they did say they would really appreciate the opportunity to advance their career as a DSP. Workforce stability research consistently finds that motivation factors are drivers of job satisfaction, and those factors include opportunities for growth,

recognition, advancement, and direct engagement with the work itself.⁴⁵

The last question asked during the focus group discussion was what three things employers could do to increase recruitment and retention of DSPs. The top three answers were increase wages, create flexibilities to allow for professional judgment, and demonstrate value and respect for DSPs.

WAGES

The focus groups had a mix of DSPs, some who had been working as a DSP for many years and others who were new to the position. All of the DSPs, regardless of how long they had been a DSP said they believe that providers could increase recruitment and retention if they could pay DSPs commensurate with their education, experience, and skill. The more experienced DSPs said it is so hard to get someone to do this job for such little pay, especially if they have experience.

CREATE A CLEAR PATH FOR ADVANCEMENT AND PROFESSIONAL DEVELOPMENT

The second suggestion DSPs had to increase recruitment and retention was the creation of a clear path for advancement and professional development. DSPs shared a very clear message that no one wants to work a dead-end job, or one with such low, or no, expectations especially when you are working with people who rely on you. They felt very strongly about being recognized as trusted professionals that support the growth and development of another human being and compared the responsibility to that of a teacher or counselor.

⁴² *Direct Support Professionals’ Perspectives on Workplace Support: Underappreciated, Overworked, Stressed Out, and Stretched Thin*, Intellectual and Developmental Disabilities (2021) Vol. 59, No. 3, 204–216

⁴³ *From the DSP Perspective: Exploring the Use of Practices that Align with Trauma Informed Care in Organizations Serving People with Intellectual and Developmental Disabilities*, Intellectual and Developmental Disabilities (2020), Vol. 58, No. 3, 208–220

⁴⁴ *Treating Employees with Dignity, Respect and Fairness: The Impact of the Quality of Life for People with Intellectual and Developmental Disabilities*, (2024) Inclusion, Vol. 12, No. 3, 156–171

⁴⁵ *Workforce Stability: Motivation Factors Impacting Satisfaction in the IDD Field* (2022) Vol. 10, No. 4, 285–296

A few of the DSPs talked about the embarrassment and pain of the “warm body” mentality associated with being a DSP because there is such desperation to hire people. They said they hear it all the time...“Are they breathing? Hire them!”, “We just need a warm body at this point.”, “Can they string a sentence together? Hire them!” and its wrong, it’s hurtful, and it further marginalizes and devalues the people they support. Further, there was a very strong belief that DSPs who do the job because they love it, and are good at it, want higher expectations for those who are or want to be DSPs.

VALUE AND RESPECT

Overall, the DSPs agreed that there are many non-wage related ways their employers can show they value and respect the work that DSPs are doing. It should be noted that many of the DSPs said their employers were doing a lot to show they value and respect the DSPs and they are appreciated for that. Some of the things they feel show respect and value include:

Employee Recognition Programs, developed with the input of the DSPs because they want to be heard about what is important to them and how they want to be recognized.

Opportunities to Learn, the DSPs said they feel respected and valued when they are offered the opportunities to go to a conference or some type of meaningful training because it feels like their employer is investing in them.

Bonuses, even though bonuses are a financial contribution they are not wage related and sometimes if someone has really gone above and beyond, like may did through COVID, it makes sense that employers would recognize them with a bonus.

Investing in Company Culture, several of the DSPs said they really value, or would really value, feeling like they are part of something bigger and that happens when everyone is together at things like potlucks, holiday parties, and summer barbeques and company hosted events are an important part of that.

Create Opportunities to Be Heard, all of the DSPs said that one of the best ways to show they are respected and valued is to listen to them, they have good ideas, or constructive feedback that when acted on makes them feel that they are part of a team and their opinion matters, as one DSP said, “it doesn’t have to be anything monumental or big, it could be as easy as an open door policy.”

LIMITATIONS

Limitations to consider in interpreting the findings from the DSP section of this report include self-selection of the survey respondents and focus group/interview participants. While the survey sample size (2,287) and number of focus group/interview participants are likely an adequate representation of the workforce the method of recruitment may have limited the types of services the DSPs were recruited from. For example, very few DSPs were represented from participant-directed services or the Self-Determination Program.

CONCLUSION

The majority of DSPs enjoy their job and the people they support but they often experience high levels of burnout because of the workforce shortage. For many the intrinsic value of the work keeps them in the field but often they must work at least one other job to make a living. The low wages and high responsibility associated with the job creates a disconnect for DSPs with nearly a third of the workforce leaving within the first 3 years. DSPs in California fear it is only going to get worse as other industry sectors such as fast food and entry level health care set sector based minimum wages that are substantially higher than what DSPs get paid. DSPs want their workforce to be professionalized as they believe it will bring value and respect to the profession. Finally, they want to get paid wages that reflect the work that they do and the importance of their job. ■



IMPACT OF THE DSP WORKFORCE SHORTAGE ON DISABILITY SERVICE PROVIDERS

Disability service providers, also referred to as regional center vendors, provide a wide range of supports and services to over 458,000 people with intellectual and developmental disabilities (IDD) in California. Service providers must be vendored by a regional center before they can provide and be reimbursed for services. Once vendored, service providers contract with one or more of the 21 regional centers in California to deliver services authorized in the persons Individual Program Plan (IPP).

To gain a better understanding of the impact of the on-going Direct Support Professional (DSP) workforce shortage on individuals served by the regional center system surveys, focus groups, and 1:1 interviews were conducted with service providers throughout the state. Service providers ranged in size from serving 1 individual to 3,810 individuals. There was representation from a wide variety of service lines including, but not limited to:

- Residential Services [Community Care Facilities/ Group Homes]
- Independent Living Services [ILS]
- Supported Living Services [SLS]
- Coordinated Family Supports [CFS]
- Family Home Agency [FHA]
- Specialized Residential Facility [SRF]
- Adult Residential Facility for Persons with Special Health Care Needs [ARFPSNHN]
- Respite
- Behavior and Safety Net Services
- Childcare
- Creative Art Program
- Day Program
- Early Intervention
- Financial Management Services [FMS]
- Job Training
- Mobility Training
- Non-Residential Afterschool Program
- Personal Assistant
- Social Recreation and Camp

- Supported Employment Services
- Tailored Day Services
- Transportation
- Work Activity Program

Additional information gathered through the surveys includes, but is not limited to, regional center catchment areas served, number of regional center clients served, number of direct support professionals each service provider employs (both full and part-time), number of bilingual employees, whether they have had to limit services or decline referrals due to the DSP workforce shortage, if they have a waitlist, turnover rate, open positions, as well as DSP wage and benefit information.

A total of 70 service providers took the survey which represents a total of 28,667 individuals served by 20 of the 21 regional centers and 19,915 DSPs. In addition to the surveys, six focus groups and three 1:1 interviews were held for a total of 42 service providers.

EMPLOYMENT OF DIRECT SUPPORT PROFESSIONALS

Just as there was a wide range of services provided, there was great variance when it came to the size of the service providers and how many DSPs they employed. The size of the service provider organizations ranged anywhere from employing one DSP to employing 3,895 DSPs in a single organization. The majority of respondents had a mix of part-time and full-time DSPs however a few employed only part-time or only full-time DSPs.

[SEE TABLE 1]

Full-time	6,425
Part-time	13,490

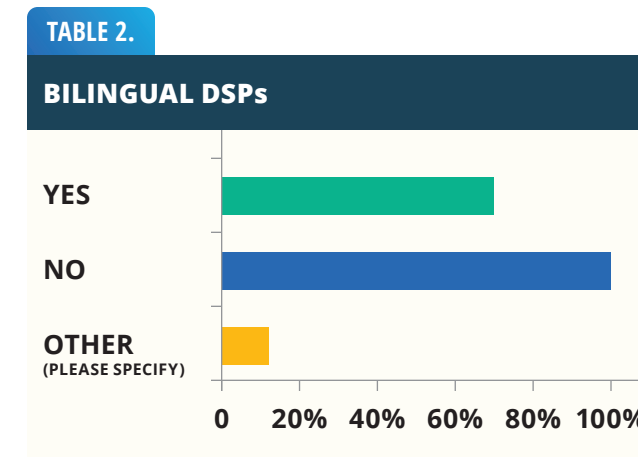
EMPLOYMENT OF BILINGUAL DSPS

The Georgetown University National Center for Cultural Competence and Mission Analytics Group (NCCC-MA) conducted an independent evaluation of the California Department of Developmental Services (DDS) efforts to reduce disparities and advance equity through the Service Access and Equity (SAE) Grant Program.⁴⁶ The SAE grants are funded through an annual budget allocation for the purpose of providing funding to community-based organizations and regional centers to increase equity in access to services for people with IDD and their families. The NCCC-MA Team used the NCCC Disabilities Disparity Framework to examine a wide range of disparities experienced by people with intellectual and developmental disabilities (IDD). The framework identified availability, accessibility, acceptability, quality, and utilization as the areas of focus for the purpose of evaluating disparities within the DDS System. For the purpose of this report and understanding the relevance of the survey question as it relates to the bilingual and/or multilingual DSPs workforce, the focus will be on accessibility and utilization.

A significant finding highlighted in the Georgetown report was related to workforce capacity, and centers on the challenges associated with the ability of service providers to attract and retain knowledgeable and skilled DSPs due to the low wages DSPs get paid. Further, the NCCC-MA Team

found that the workforce shortage is further exacerbated by the need for personnel who can provide culturally and linguistically competent supports and services and work within under-resourced communities. In the context of the DSP workforce and the capacity to support individuals who speak a language other than English it is important to understand how accessible the services and supports are, as well as the utilization rates.⁴⁷ It is well understood that access to supports and services in the language a person speaks or uses is essential to reducing disparities and increasing utilization of the service(s).

It is important to note that the NCCC-MA Team acknowledged that the SAE grants alone are not enough to address the system wide disparities, but that DDS has invested in numerous other initiatives aimed at reducing disparities and advancing equity. One of the DDS initiatives aimed at reducing disparities in accessibility and utilization is the pay differential for bilingual or multilingual DSPs.⁴⁸ Service providers were asked whether the percentage of bilingual or multilingual DSPs they employ was adequate to support the language needs of the individuals they serve. [SEE TABLE 2]



Of the 70 providers that responded to the survey 68% said yes, they felt the percentage was in fact adequate, 20% said no they do not have enough bilingual/multilingual staff to meet the needs of individuals served, and 12% provided another answer. Some of the “other” responses included reasons such as “all of the people they support speak English”, “we do not track this information”, and “current needs are met but can always use more”.

LIMITATION OF SERVICES DUE TO THE DSP WORKFORCE SHORTAGE

Service providers of all types and sizes unanimously agreed that DSPs are the backbone of the system and without a sufficient DSP workforce people go underserved, and in many cases even unserved. One of the focus group questions centered on how the DSP shortage has impacted the service provider organization. The comments made during the discussion can be categorized into the following three areas: staff burnout, inability to serve existing clients or expand services, and realities of the labor market.

REALITIES OF THE LABOR MARKET

Across every service type, service providers reported significant challenges attracting and retaining DSPs, citing low wages as the number one reason. In California low wage workers are defined as those who earn less than two-thirds of the median full-time wage, or less than \$19.69 per hour.⁴⁹ Several of the service providers reported that starting wages for DSPs in their organizations fell within the range of \$16.00 to \$18.00 per hour so they would be considered low wage workers.

⁴⁶ Independent Evaluation of the Service, Access, and Equity Grant Program, Georgetown University Center for Cultural Competence, https://www.dds.ca.gov/wp-content/uploads/2024/05/GeorgetownUniversitySAE_EvaluationFullReport_Nov2023.pdf

⁴⁷ NCCC Disabilities Disparity Framework queried accessibility of supports and services such as geographic distribution, hours of delivery, technology, language access, accommodations, and universal design, as well as utilization rates across culturally and linguistically diverse populations including types of supports and services.

⁴⁸ Department of Developmental Services, Workforce Initiatives, <https://www.dds.ca.gov/initiatives/workforce-initiatives/>

⁴⁹ UC Berkeley Labor Center, Low Wage Work in California Data Explorer 2024 <https://laborcenter.berkeley.edu/low-wage-work-in-california-data-explorer-2024/>



Nearly all of the service providers voiced serious frustration related to “having to constantly chase minimum wage” and not being able to pay a competitive wage. There was a consensus among service providers that there is a real disconnect between what DSPs are expected to do, the skill sets they need to have, and the low wage that they get paid to do the job. Service providers also agreed that they have very little flexibility in the rate they can pay DSPs because the base rate model assumptions, developed in the rate study were built by “cobbling” the DSP position together from four other Standard Occupational Codes (SOC) from the U.S. Bureau of Labor Statistics—personal aide, home health aide, psychiatric aide, and recreation worker—with adjustments being tied to minimum wage and inflation.⁵⁰

It was widely recognized that in many cases the skills needed to support individuals with IDD in the

community far exceed the expectations set forth in the occupations that were used to develop the base rate model. Service providers report that while there is some overlap in the duties associated with the current base rate model, the model and the rates do not fully reflect the complexity of the DSP job. Further, the rates are not tiered to reflect level experience or complexity of the individual served (unless they are in an enhanced behavior support program), which therefore serves to seriously limit their ability to compete in the labor market.

Recent legislation (AB 1228 and SB 525) passed establishing new industry set minimum wage of \$20.00 per hour for fast food workers, and a phased-in minimum wage of \$25.00 per hour for certain non-licensed health care workers (medical assistance, nursing assistants, janitors, etc.). There are over 40 different local minimum wage ordinances in California, many of which further complicate a service providers ability to compete in a tight labor market. For example, service providers operating in areas without a higher local minimum wage ordinance report frequently losing staff to a commutable provider who does have a higher local minimum wage. The rate study acknowledges that they did not specifically consider local minimum wage ordinances but wage adjustment factors, with the exception of the City of Los Angeles, exceeded the local ordinances.

Sector-set minimum wage in fast food and health care were not factored into the rate models because the rate model assumptions were built before the new sector set minimum wages were established. The majority of service providers voiced serious concern about the deepening divide between what they can pay and what people can make working in fast food, health care, and the gig economy. As this divide grows service providers report experiencing an ever-shrinking applicant pool, especially applicants that can meet the needs of the people they serve.

STAFF BURN OUT

A majority of the directors and managers reported being very concerned because they can see the burn out at every level. DSPs are often doing the job of two people because of chronic understaffing, and managers are routinely providing direct support, often at the expense of their other responsibilities as managers. Without question, the majority of service providers felt that DSPs do this job because they love the job and the people they support. They also widely acknowledged it is a sacrifice for some DSPs because the low wages mean that well over half of the DSPs they employ have to work a second and third job just to make it.

Some of the challenges associated with DSP shortages include:

- Unhappy or stressed DSP because of increased workload
- Being out of compliance with ratios
- Having to limit or change the activities for individuals we serve
- Increase injuries to both DSPs and individuals served—which results in increased Worker’s Comp claims
- Retaining staff that we would otherwise let go
- Increase turnover and vacancy rates
- Inability to provide consistent person-centered supports
- Quality of services suffer

INABILITY TO SERVE EXISTING CLIENTS OR EXPAND SERVICES

The DSP workforce shortage has a direct impact on the service providers ability to meet the needs of the individuals they serve and drastically reduces the likelihood of expanding or developing programs for new service lines. Several service providers reported that they are currently not operating at capacity because they don’t have the DSP workforce to support the individuals they currently serve let alone any that may be on the waitlist. Nearly all of the service providers in the focus groups said they have a waitlist, some with very long waitlists of 300+, and others who said they do not even take waitlist referrals anymore because they do not see being able to serve them in the foreseeable future.

Some providers also said they have completely stopped accepting anyone who requires a 1:1 because they simply cannot afford it. Those that have stopped serving individuals who require a 1:1 sadly acknowledged that it tends to be the more complex individuals, who often need the support the most, that are going without the services.

“We are almost back to the 1950s, they stay at home if you can’t serve them.”

Many service providers said they would like to expand their services to some of the more innovative models like tailored day services (TDS) and coordinated family supports (CFS), but those are 1:1 services for which they do not have the workforce. Approximately 50% of the service providers reported having to reduce or eliminate certain services, including for individuals they currently serve, because they do not have enough DSPs to even fill the immediate need. The limitation of services could include shortened days, fewer days, changes in programing, or reduction of certain program services.

The next question centered on whether service providers have had to supplant the services of other providers that also serve the same individual(s). Approximately 40% of the service providers reported that they have had to supplant the services of other providers because of the other provider having to limit services. Examples of supplanting services included residential providers needing to staff up for the days and times during the week that the individual cannot go to their day program, day programs and residential programs covering and/or coordinating transportation, and some reported that they just “pick up the slack” when and where they need to.

The third question related to limitations on services was specific to the number of authorized hours that go unfilled. While the majority of respondents

⁵⁰ DDS Vendor Rate Study and Rate Models (March 2019), <https://www.healthmanagement.com/wp-content/uploads/DDS-Vendor-Rate-Study-Report.pdf>

answered this question with a specific number of hours that ranged from 0 unfilled hours to 11,520 unfilled hours, some other respondents provided a percentage-based response that ranged from 15–70%. A significant limitation related to interpreting data from this question exists because the unfilled hours are reported in the aggregate, so it was not possible to distinguish which service types had the highest number of unfilled hours. In addition, there is no way to determine total number of unfilled hours among the respondents because of the mix of numerical data and percentages. Even so, it is worth noting that the provider who reported the highest number of unfilled hours (11,520) provides day program and transportation services.

SERVICE PROVIDER WAITING LISTS AND INABILITY TO ACCEPT REFERRALS

It is important to understand what is meant by waiting lists in the context of the disability service system in California. The DDS system is funded by a combination of state and federal dollars. A substantial amount of the federal dollars come from Medicaid Waivers, primarily the Home and Community Based Services (HCBS) Waiver. The Medicaid Home HCBS Waiver(s), authorized under section 1915(c) of the Social Security Act, allows states to provide home and community based services to individuals who would otherwise require a level of institutional care.⁵¹ Approved HCBS waivers—most notably the Home and Community Based Services for Developmentally Disabled, Home and Community Based Alternative, and Self-Determination Program for the DDS system—specify how many people can be served under

each waiver in any given year. When the demand for these services exceed the capacity (also referred to as waiver slots) states are allowed to create waiting lists. While many states do have formal waiting lists for their HCBS-DD Medicaid services, California is not one of those states as the state does not limit or restrict access to waiver services for individuals served through the Regional Center System.⁵² The current California HCBS-DD Waiver seeks to enroll (provide slots for) up to 179,000 individuals by December 31, 2027 which means that the state can draw federal dollars to support reimbursement of those HCBS services.

In addition, California supports thousands of individuals with IDD through the 1915(i) State Plan Home and Community-Based Service and the 1915(c) Self-Determination Program Waiver, which are not capped. The 1915(i) allows states to offer HCBS to Medicaid-eligible individuals who meet the state-defined minimum needs-based criteria that are less stringent than the institutional deeming criteria of the federal HCBS waiver. The Self-Determination Program waiver allows the state to provide a voluntary, alternative option for the delivery of HCBS services and supports, selected and directed by the participant.⁵³

The most recent caseload data (April 2024) for DDS finds that there are 478,570 individuals that have an active status with a regional center, or receive, or have received, at least one purchase of service within the last 12 months.⁵⁴ The total number of individuals served includes approximately 60,000 children in the Early Start Program, many of whom will be ineligible for waiver services after they exit the Early Start Program. The reported

number of individuals receiving regional center services, or with an active status, is more than twice the available HCBS-DD waiver slots which clearly demonstrates that California’s demand is much greater than the available slots. If California relied solely on the HCBS-DD waiver to provide services it is clear that there would be a substantial waiting list. However, through the Lanterman Act, California accepts a responsibility for persons with developmental disabilities and an obligation to them which it must discharge.⁵⁵ The state’s acceptance of this responsibility creates a duty to provide services to individuals who meet eligibility criteria for regional center services which basically eliminates the existence of a formal waiting list for HCBS-DD waiver services.

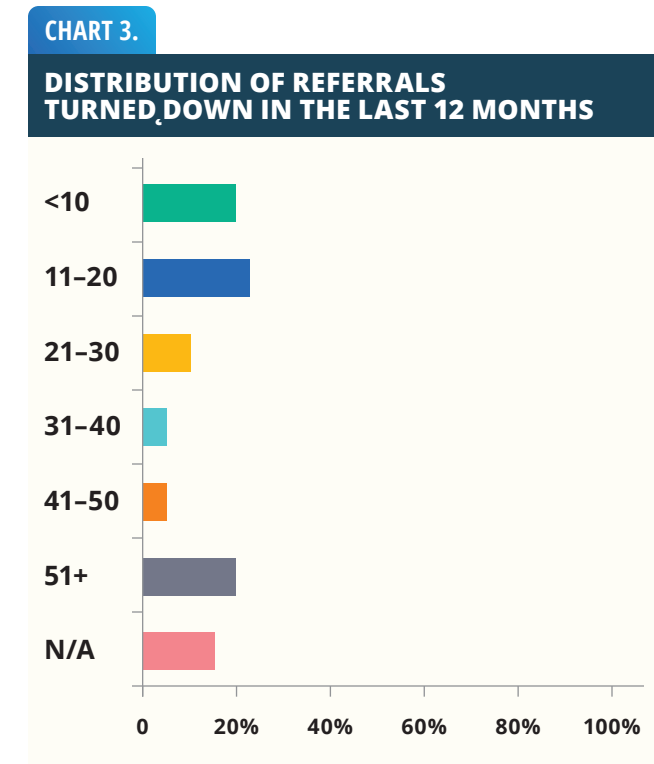
While formal state waitlists do not exist in California, service providers (as well as family members and service coordinators) consistently reported having waitlists, and in some cases very long waitlists. Approximately 35% of service provider survey respondents reported having waitlists that ranged from under five individuals on the list to over 300 individuals on their waitlists. Just under half of the service providers provided an average number of days an individual remains on the waiting list which ranged from 30 days to several years. In addition, all of the service providers who participated in focus groups and 1:1 interviews reported having waitlists with some being well into the hundreds. Especially noteworthy is that all of the service providers who reported having waitlists attributed it to the DSP workforce shortage.

To avoid confusion about the difference between declining a referral and a contingent acceptance of a referral based on availability of a DSP (placing the individual on a waitlist pending the ability to hire a DSP) separate questions were asked related to referrals and waitlists. Of the service providers surveyed, just over half (56%) reported having to turn down referrals within the last 12 months.

[\[SEE TABLE 3 FOR DISTRIBUTION\]](#)

HEALTH AND SAFETY WAIVER UTILIZATION DUE TO THE DSP WORKFORCE SHORTAGE

Welfare & Institutions Code sections 4681.6, 4648.4(b), 4681.5, 4684.55, 4689.8, 4691.6 and 4691.9 authorize the Department of Developmental Services to approve exemptions to rate freezes for the purpose of mitigating risks to consumer health and safety.⁵⁶ To obtain a Health and Safety Waiver (H&S Waiver) the vendor and the regional center must complete a H&S Waiver worksheet and provide supporting documentation to the DDS requesting a rate adjustment. Supporting documentation includes, but is not limited to, at least three months of payroll reports, operating costs, administrative costs, a monthly budget detailing current and proposed costs, and other justifications that demonstrate why the current rate is insufficient to maintain the health and safety of the individual served. H&S Waivers are not guaranteed and can be denied or rescinded.



⁵¹ Centers for Medicare & Medicaid Services, HCBS TA, <https://www.hcbs-ta.org/taxonomy/term/8>

⁵² California Approved 1915(c) Home and Community Based Services Waiver, Section 6(D) Access to Services <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/81051>

⁵³ State Council on Developmental Disabilities, Self-Determination Program, Informational Meeting (2015) <https://scdd.ca.gov/wp-content/uploads/sites/33/2016/08/Handout-1.DDSWaiverTrainingPckt.Part-1-Aug-28-2017.pdf>

⁵⁴ CA Department of Developmental Services, Comprehensive Dashboard, Facts and Stats, <https://www.dds.ca.gov/transparency/facts-stats/dds-comprehensive-dashboard/>

⁵⁵ The Lanterman Developmental Disabilities Services Act and Related Laws, https://www.dds.ca.gov/wp-content/uploads/2024/02/Lanterman_2024_Pub.pdf

⁵⁶ CA Department of Developmental Services, Health & Safety Waiver Process, <https://www.dds.ca.gov/rc/health-safety-waiver-process/>



Survey responses for DSP vacancies ranged from 0 vacancies to 100 while the DSP turnover rate ranged from 1% to 77%.

The September 13, 2018 Regional Center Directive, Instructions for Requesting a Health and Safety Waiver Exemptions, identified common circumstances under which a H&S Waiver could be approved.⁵⁷ Examples of circumstances that may require a H&S Waiver include, but are not limited to, transition from an institutional setting to the community, transition from out of state back to California, risk of admission to a state operated acute setting, risk of out of state placement, or situations in which a vendor cannot safely serve an individual absent a rate increase. Approximately 10% of the providers surveyed reported having a H&S Waiver for one or more of the individuals they serve because they were unable to hire DSPs, at their current rate, with the required level of experience necessary to meet the complex needs of the individuals.

DSP VACANCIES AND SERVICE PROVIDER TURNOVER RATES

Service providers were asked about both their DSP vacancy rates (number of unfilled positions) and their DSP turnover rates (number of DSPs that leave the company). Survey responses for DSP vacancies ranged from 0 vacancies to 100 while the DSP turnover rate ranged from 1% to 77%. Given the relatively small sample size of responding service providers (38 out of 70 respondents answered this question) calculating an unweighted average is highly likely to result in skewed data that does not accurately represent the turnover rate for service providers throughout the state. While a weighted average would typically produce a more representative turnover rate for service providers throughout the state, the sample size and data

limitations associated with the data collected in this survey are insufficient to produce a representative statistic with an acceptable level of confidence.

The DSP workforce shortage has strained service providers' ability to hire DSPs for decades. However recent research suggests the shortage has reached crisis levels with the COVID-19 Pandemic.⁵⁸ According to the National Core Indicators (NCI) 2021 State of the Workforce Report the weighted average turnover rate, across states, was 43.3% with the range being 28.5% to 87.5%. In 2021, the CA DDS began collecting workforce data to establish a baseline and evaluate challenges, existing initiatives and shape future policies for enhanced workforce stability. The first year the data was available was 2021 with 2,095 service providers responding. In 2021, the weighted average annual turnover rate was 34% and the weighted average vacancy rate for full-time DSPs was 20%. In 2022, 1,714 service providers responded to the survey and the weighted average annual turnover rate was 32% with the vacancy rate for full-time DSPs being 14%.⁵⁹ It is important to note that DDS urges caution related to interpreting the data as there are some notable limitations.

During focus group discussions several service providers also urged caution related to interpreting turnover and vacancy rates as performance measures, or as quality indicators, for several reasons. First, based on sample size and self-selection of responding service providers the turnover and vacancy rates may not be representative of the wide size range of providers. Some service providers voiced concern that smaller providers (those that employ under 20 DSPs) may have a higher response rate than large providers as a result of the \$8,000 incentive to take the survey.

Second, although turnover and vacancy rates are used to measure performance and quality in many sectors it would be unjust to use those as indicators or performance measures because so many factors that influence those rates are out of their control. Some of the factors they mentioned include a well-documented DSP workforce shortage, on-going challenges recruiting and retaining DSPs due to low wages, even \$1.00 per hour can incentivize DSPs to jump from one provider to another, changes in local and state minimum wage, new \$20.00 per hour minimum wage for fast food, and the new \$25 minimum wage phase-in for certain health care workers (nursing aides, medical assistants, clinic workers, janitors, etc.). In addition to factors that are out of their control, there was concern that using turnover and/or vacancy rates as a quality indicators or performance measure could have unintended consequences such as incentivizing a provider to keep a DSP who they would otherwise terminate for poor performance.

The last series of survey questions were related to hourly wages and overtime costs. Service providers were asked what the beginning hourly wage is for entry level DSPs, the average hourly wage for DSPs with at least 3 years of experience, and the hourly wage for the highest paid DSP in their organization. The hourly wage for entry level DSPs ranged from \$16.00 per hour to \$23.00 with the average being \$18.82 per hour. The hourly wage for DSPs with at least 3 years of experience ranged from \$16.00 per hour to \$28.00 per hour with the average hourly wage being \$20.24 per hour. The hourly wage for the highest DSP ranged from \$16.00 to \$32.00 per hour with the average being \$23.67.⁶⁰

In addition to hourly wages, service providers were asked if they were able to provide annual

⁵⁸ Inclusion (2022) Vol. 10 NO. 4, 285-296

⁵⁹ CA Dept. of Developmental Services, DSP Workforce Survey, Interactive Dashboard, <https://www.dds.ca.gov/rc/vendor-provider/dsp-workforce-survey/>

⁶⁰ **NOTE:** One service provider report \$50.00 per hour creating a range of \$16.00–\$50.00; however, given that it was found to be 4.77 standard deviations from the mean, any data point greater than 3 standard deviations from the mean is considered an outlier and therefore eliminated from the data set. [50–24.28/5.39 = 4.77] Standard Deviation, s: 5.39, N=43, Sum, $\Sigma x = 1044.46$, Mean, $\bar{x} = 24.29$, Variance, $s^2 = 29.10$

⁵⁷ DDS Regional Center Directive, https://www.dds.ca.gov/wp-content/uploads/2019/03/HS_DDSLetter_20190305.pdf

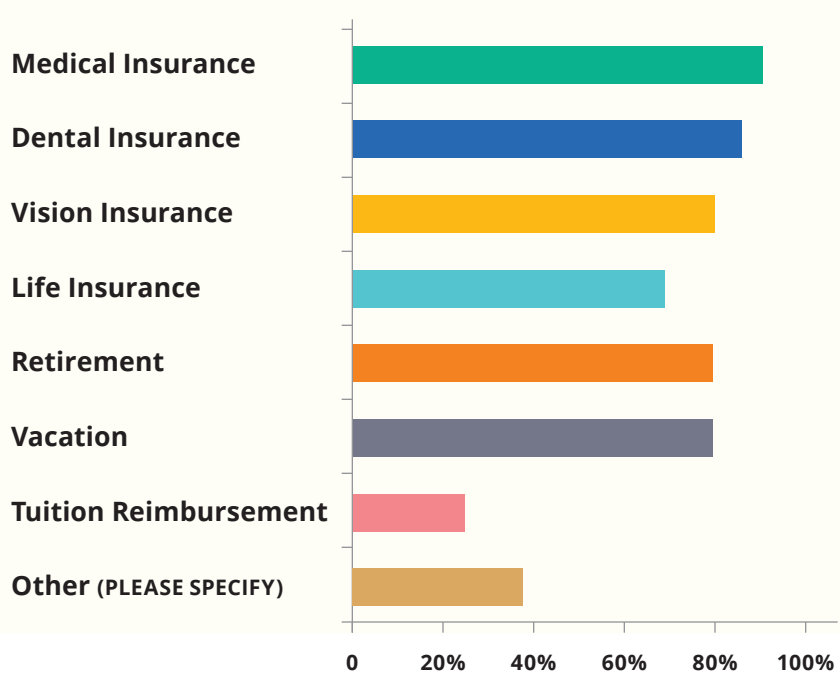
increases, as well as the type of benefits they can offer to the DSPs they employ. Of the responding service providers 60% said yes, they are able to give annual increases, however, the question did not include details on the amount or percentage of the increases they were able to provide.

Of the responding service providers nearly all reported being able to offer a range of benefits to their employees [SEE CHART 4].

Some of the benefits that fell under the “other” category include flexible spending accounts (FSA) mileage, on-site fitness room or gym membership reimbursement, pet insurance, pre-paid legal services, childcare reimbursement, financial counseling, wellness benefits, paid time off, employee assistance program, transportation [BART] reimbursement, paid job related training, and health incentives. A notable limitation of the survey question is that it did not specifically ask whether or what percentage of the benefit was paid by the employer and what percentage was the employee contribution.

CHART 4.

DO YOU OFFER ANY OF THE FOLLOWING BENEFITS TO DSPs YOU EMPLOY? (CHECK ALL THAT APPLY)



MAIN COST DRIVERS THAT AFFECT SERVICE PROVIDERS ABILITY TO RECRUIT AND RETAIN DSPS

Service providers identified several cost drivers that affect their ability to recruit and retain a high-quality DSP workforce. Some of the cost drivers identified include, but are not limited to, recruitment expenses, hiring bonuses, background checks, onboarding costs, training costs, and management time.

Recruitment expenses included things like advertising, posting on services like Indeed and ZipRecruiter, as well as referral bonuses for employees who referred someone that was hired. The majority of providers reported the costs associated with recruitment are basically out-of-pocket costs because even though the rate models factor in 12% of the overall rate for administrative costs, those costs tend to be associated with administrative staff salaries, benefits, facility costs, insurance(s), equipment and supplies, professional services, and licensing/accreditation fees which

exceed the 12%. One of the larger service providers reported incurring out-of-pocket costs of \$300,000 in the last year just on job board (Indeed/ZipRecruiter) postings alone.

Hiring bonuses, background checks, and onboarding costs were also cost drivers that impacted their ability to recruit and retain DSPs. Hiring bonuses, whether for a new hire or to a DSP who referred the person, are an added expense that is not covered in the rate models. When asked if they saw that as a business decision many said yes, but it is still the cost of doing business because they struggle so badly to compete in the labor market given the low wages that they can pay based on the rates they receive for delivering services.

TRAINING COSTS AND MANAGEMENT TIME

The DDS Rate Study rate model assumptions include a fixed amount, .67 cents for training and .90 or .91 cents for supervision, per billable hour for vendors to provide training and supervision of DSPs.^{61,62} All of the service providers acknowledged the value and benefit of building workforce capacity and stability through on-going training, but they also said they face many challenges in being able to do so because the amount built into the rate models is not sufficient to cover the cost of training. The majority of service providers reported that the amount they receive to provide training does not even cover the cost of the mandated trainings as required by Title 17 and Title 22, California Code of Regulations, and other mandated trainings, let alone any additional training.

In addition to training costs, providers reported the following as significant cost drivers, not covered in the rate models, related to training:

- Additional staff cost for another DSP to cover for the DSP who is in training
- Additional hours, could go into overtime, if the DSP is asked to do training outside of their regular work hours
- Conference registrations, travel, and lodging costs can be very expensive and not attainable given the current rate
- Hiring an expert in certain subject matter areas such as person-centered planning, community navigation, or supported employment are typically cost prohibitive
- Managers who would be providing training are often doing direct support because of being so short staffed so not only are the DSPs not getting trained, but managers are not able to keep up with their own job responsibilities

Another concern about the strain on management time was raised in relation to managers having to devote excessive amounts of time to dealing with a “revolving door” of DSPs. The rate study factors in 1 supervisor per every 10 DSPs, however, providers report that their manager are often required to supervise more than 10 DSPs, and in many instances, they are also juggling providing direct support along with performing their supervisory duties. Further, depending on the size of the organization managers are often having to carve out time to review applications, conduct interviews, follow-up with potential hires, and do the onboarding, which creates additional strain on their role as a supervisor or manager.

UNACCOUNTED FOR COSTS

All of the service providers that participated in the focus groups reported feeling the impact of unaccounted for costs, the main ones being Private Attorneys General Act (PAGA), drastic increases in insurance, and individual absences from program.

PAGA AND OTHER COMPLEX LABOR LAWS

The PAGA (Private Attorney General Act) is a California Labor Code that allows aggrieved employees to bring a civil action on behalf of themselves and other current or former employees to enforce a violation(s) of any provision in the Labor Code that provides for a civil penalty.⁶³ Service providers all said they live in fear of PAGA because a single PAGA claim can cost hundreds of thousands of dollars. Many providers said they have in fact been subject to PAGA claims and have had to pay substantial amounts to settle such claims. The main cause of action, according to the service

⁶¹ Rate Models for Alta California Regional Center, Burns and Associates (2024) https://www.dds.ca.gov/wp-content/uploads/2023/12/Alta-California-Regional-Center_Accessible-January-2024.pdf

⁶² Rate Models for San Diego California Regional Center, Burns and Associates (2024) https://www.dds.ca.gov/wp-content/uploads/2023/12/San-Diego-Regional-Center_Accessible-January-2024.pdf

⁶³ Private Attorneys General Act, <https://www.dir.ca.gov/Private-Attorneys-General-Act/Private-Attorneys-General-Act.html>



providers, revolves around timely 10 minute rest breaks and on-duty lunch for the DSPs. All of the service providers reported having a plan in place for breaks, but 100% compliance is nearly impossible especially given the critical DSP workforce shortage, the shift to more community-based programming, ratio compliance, and transportation issues, that make giving a 10-minute break after 4 hours to all employees nearly impossible. That said, all of the service providers reported giving DSPs a 10-minute break but not always within the 4th and 5th hour of the workday.

California does have an on-duty lunch waiver that employees can sign agreeing to an on-duty meal period for which they get paid.⁶⁴ However, there is no waiver for the 10-minute breaks, and they must be given a break for every 4 hours of work. As mentioned above, service providers acknowledge there are times that it is impossible to provide a 10-minute break at the 4th hour of work because it would be endangering the individual(s) being supported. Some examples that were shared include:

“Taking public transit to and from a job site with a 1:3 ratio. It takes about 15 minutes to get to the bus stop, for a 45 minute bus ride, with 3 hours at the job site, and another 45 minute ride back, with another 15 minute walk back from the bus stop, which amounts to 5 hours.”

“Three staff called out leaving us very short staffed and out of compliance in our ratios, we tried to juggle staff but even with managers doing direct support we still didn’t have the staff to give timely breaks, and we can’t just leave the clients we serve because we are a behavior support program.”

“We are a community based program so we have individuals and their staff out many different places. We do our best to make sure DSPs schedule with one another to meet up at different places in the community so they can give each other a break but that can change on a moment’s notice if someone gets sick, someone’s transportation is late, someone needs extra time in the restroom...there are a

million reasons why they may not be able to give each other timely breaks, but we really do try.”

The above are just a few of the examples that service providers offered in explaining why 100% compliance with the 10-minute break rule is just not a reality given the nature of the work. The service providers expressed great frustration with, and fear of, PAGA because they are continuously at risk for things they cannot control. Current law requires employers to pay an additional one-hour premium for missed rest breaks but paying the premium pay does not eliminate or limit liability for the missed breaks. Further, if providers are found even 1% liable they not only have to pay for all their own incurred costs, but also attorney fees for the aggrieved, and the majority (if not all) of the insurance carriers exclude PAGA from coverage. Therefore, any losses or settlements attributable to PAGA claims, including the premium pay, are out-of-pocket, and unaccounted for, costs for service providers.

INSURANCE INCREASES

Insurance rates for auto, property (home and commercial), health care, and workers compensation have all seen significant increases in the last few years. While insurance reform efforts are among the leading public policy conversations occurring at the state level many service providers are still heavily burdened by their ever-increasing insurance rates. For example, one service provider reported an annual increase of \$750,000 for fire insurance. Another service provider said their rates tripled last year which ultimately put them in the red (running at a deficit).

Service providers also report a 9% to 27% increase in the cost of health insurance and while many said they could absorb the cost, others said they had to pass on a portion of the cost to their staff. Auto

SEVERAL OF THE SERVICE PROVIDERS SAID GIVEN THE LOW WAGES DSPS MAKE, REQUIRING THEM TO PAY EVEN HIGHER INSURANCE COST IS YET ANOTHER BARRIER TO RECRUITING AND RETAINING THEM.

insurance rates are also rising sharply as estimated increases range anywhere from 30%–50% depending on the location of the insured. Aside from covering the cost of increases to their vehicles, service providers are also grappling with the expectation of DSPs to transport individuals in their personal vehicles because they too will face steep increases in auto insurance. Further complicating the auto insurance issue is the requirement by most carriers to insure anyone who uses their vehicle for work under a commercial plan which costs more. Several of the service providers said given the low wages DSPs make, requiring them to pay even higher insurance cost is yet another barrier to recruiting and retaining them.

INDIVIDUAL ABSENCES

The rate models are built on assumptions that include a range of factors including wages, benefits, productivity, program operations, administrative costs, staffing ratios, staffing levels, absences, travel costs, facility costs, and program supplies.⁶⁵ However, service providers said it is unclear how the attendance/absence factor was determined, and that it does not accurately account for the impact of planned or unplanned absences as evident by

⁶⁴ Department of Industrial Relations, https://www.dir.ca.gov/dlse/FAQ_MealPeriods.html

⁶⁵ DDS Vendor Rate Study and Rate Models (2019) Burns and Associates, <https://www.healthmanagement.com/wp-content/uploads/DDS-Vendor-Rate-Study-Report.pdf>

the fact that they are a significant contributor to unaccounted for costs.

Though there was discussion about planned versus unplanned absences the majority of providers said that even planned absences can have a significant impact because they still have to staff accordingly. For example, if they have a 1:3 ratio and one individual is out for a planned reason (i.e. medical appointment, family vacation, etc.) they still have to staff for the other two individuals. The exception was that if it was a 1:1 ratio then the provider could usually move the DSP to support another person or team.

All of the providers said the same is true for unplanned absences because they have staffed according to their mandated ratios and they still have to pay their staff for that day, Regardless of whether the absence was planned or unplanned, the majority of providers said they hire DSPs for a certain amount of hours per week and sending them home for the day without pay is simply not an option, especially in light of the low wages they already get paid. Some of the comments related to attendance/absences include:

“If one of our participants is out for a few days it is not like we can just have two-thirds of a DSP, or move the other two participants to other teams—that’s just not right, they have individual plans they work.”

“Again...TRANSPORTATION is a major factor in when, sometimes if, our participants get here on time or not. Sometimes they are several hours late or leave several hours early, but we still have to have staff here in case they arrive.”

“We already have a hard enough time getting DSPs, can you imagine if we told them they had to go home for the day without pay because the person, or people, they support was out for some reason... that would do nothing but make it even harder to keep people.”

“This is not how business works; tell me what other business works like this. I could see not paying us if you pay us for a service and we don’t show up to provide it, but we are here, we are showing up.”

CONCLUSION

Service providers across the state have had to limit, reduce, or eliminate the services they provide to people served by the regional centers as a result of the DSP workforce shortage. The low wages combined with the complexities and responsibilities of the job have led to serious challenges for service providers in recruiting and retaining DSPs to provide services and supports to people with IDD. The vast majority of service providers report turning down referrals or having a waitlist for people seeking their services because they do not have enough DSPs to meet the need.

Service providers are eager to provide some of the newer, person-centered, services such as Coordinated Family Supports and Tailored Day Services, however they consistently feel limited in their ability to expand their services as they continue to struggle to meet current demand. Moreover, the service providers believe that DSP workforce must be prioritized as that is the only way they can expand their services to ensure people with IDD can live full, rich lives in the community. ■

IMPACT OF THE DSP WORKFORCE SHORTAGE ON REGIONAL CENTER SERVICE COORDINATORS

Individuals who qualify for regional center services are assigned a service coordinator who is responsible for overseeing and implementing that person's Individual Program Plan (IPP) by coordinating services, monitoring progress, and advocating for their needs. Service coordinators assist individuals in the IPP planning process, identifying appropriate services and providers, maintaining updated information about the person, coordinating and adjusting services as needed. Service Coordinators are key to gaining a better understanding of the impact of the Direct Support Professional (DSP) workforce shortage because they know who on their caseload is receiving the services in their IPPs, who is not receiving all of the services in the IPP, and the reason they may, or may not, be receiving those services.

- Regional Center of Orange County
- San Andreas Regional Center
- San Diego Regional Center
- Tri Counties Regional Center

CASELOAD INFORMATION

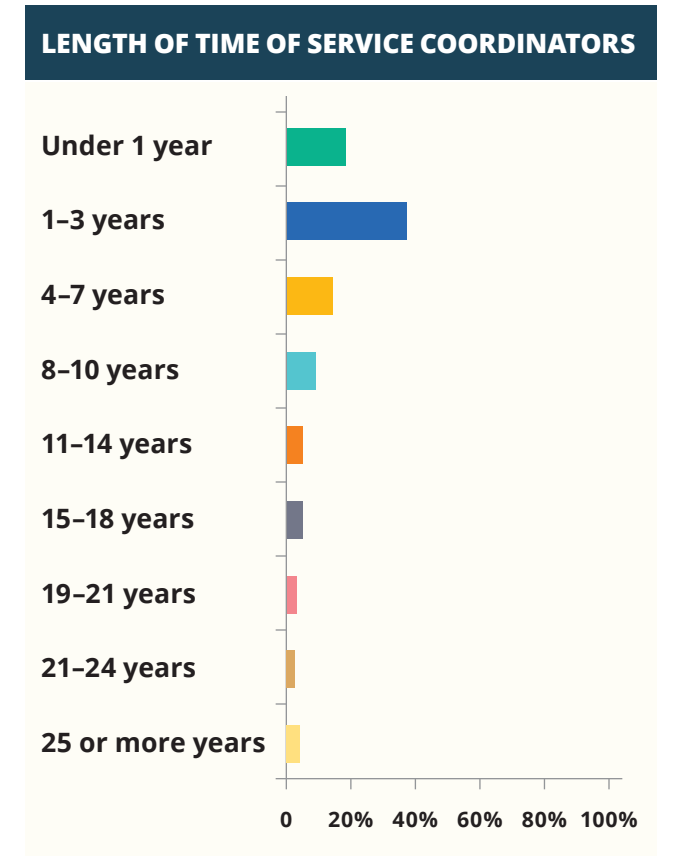
Service Coordinator caseload information specific to type of caseload and number of individuals on the caseload was collected to ensure representation from a range of ages and service needs across the DDS system. The majority of responding service coordinators (50.57%) have an adult caseload, followed by children three and older (39.20%),

DEMOGRAPHIC INFORMATION OF SERVICE COORDINATORS

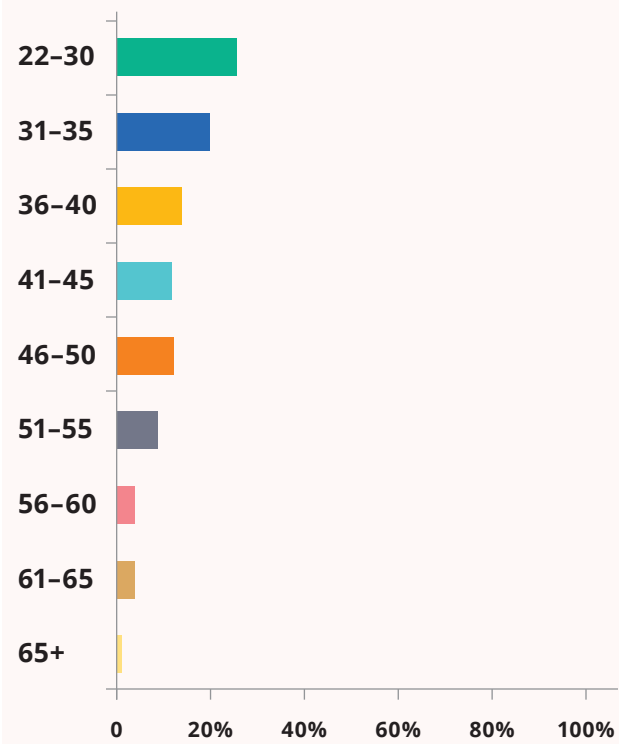
The Service Coordinator survey and focus group invitations were sent to all 21 Regional Centers in California. A total of 611 Service Coordinators responded to the survey and 2 focus groups were conducted with 8 Service Coordinators. Basic demographic information related to age, ethnicity, primary language, regional center, and length of time as a service coordinator, was also collected.

Survey respondents included Service Coordinators from the following Regional Centers:

- Alta California Regional Center
- Eastern Los Angeles Regional Center
- Golden Gate Regional Center
- Harbor Regional Center
- Kern Regional Center



AGE RANGE OF SERVICE COORDINATORS



PRIMARY LANGUAGE SPOKEN BY SERVICE COORDINATORS



ETHNICITY OF SERVICE COORDINATORS

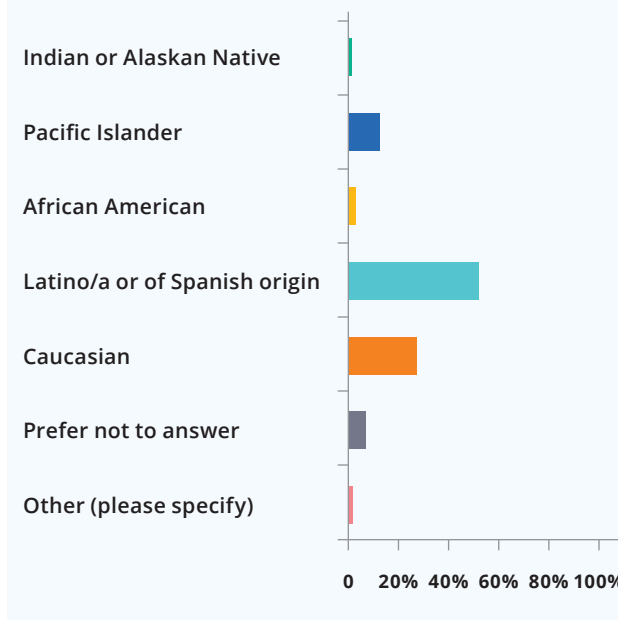
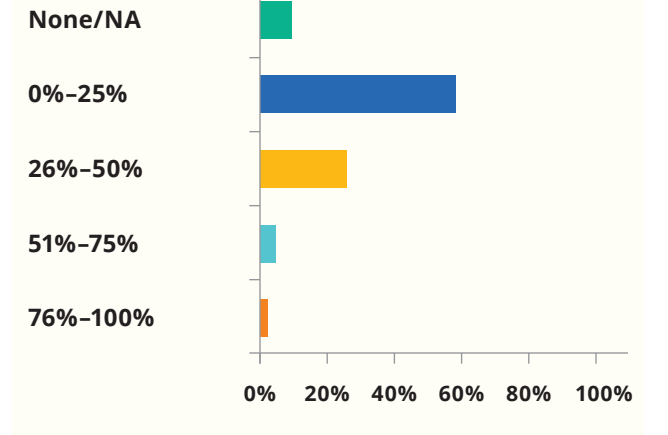


TABLE 5.



on their caseload that are unable to access, or do not receive, the full amount of authorized services [SEE TABLE 5]

Further, 76% reported that the DSP workforce shortage is one of the main reasons individuals are not receiving the full amount of authorized services.

The number of Service Coordinator referrals and provider waitlists are another important factor to consider in understanding purchase of services and utilization as it could be an indication that an individual is authorized for, but unable to access, services in their IPP. Service Coordinators were asked how many referrals they made within the last 12 months that service providers were unable to accept. The responses ranged anywhere from 0 to over 100 unaccepted referrals with many Service Coordinators saying, “too many to count”, “lost count”, “don’t even keep track anymore”, and “you just have to keep trying until you find someone.” A notable exception to the reported range came from one Service Coordinator who reported 850 unaccepted referrals in the last 12 months with the

Early Start (19.32%), the “other” category (18.18%), forensic (2.65%) and enhanced behavioral (1.70%). Some of the caseload types in “other” included employment specialist, transition, specialized cases from Fairview, foster youth, self-determination, Deaf specialist, end of life, and intake.

Caseload ratios measure the number of clients assigned to a service coordinator. The caseload ratios for the responding service coordinators ranged from 18 to 100 clients. Current caseload ratio requirements as set for the in Welfare and Institutions Code⁶⁶ are:

- **General ratio** » 1:62 for most clients enrolled on the Home and Community-Based Services Waiver
- **Community-Placed Consumers** » 1:45 for individuals who have moved from a developmental center to the community within the last 12 months
- **Complex Needs** » 1:25
- **Children under 6 years old** » 1:40
- **Low to No Purchase of Service** » 1:40
- **All other caseloads** » 1:66

It should be noted that recently enacted statutory changes have resulted in a reduction of caseload ratios for children under 6, the low to no purchase of service populations, and individuals with complex needs.^{67,68} Almost two-thirds (63%) of the responding service coordinators had caseload ratios greater than 1:66 individuals, however, caution should be used in interpreting that data point as it is a raw percentage that does not account for any variables such as caseload mix, time caseload exceeds 1:66, temporary assignment of uncovered cases, and other factors that influence caseload ratios.

PURCHASE OF SERVICE AND UTILIZATION

Regional Centers purchase services outlined in a person’s Individual Program Plan (IPP), or Individual Family Service Plan (IFSP) for a child under three, which is known as a Purchase of Service (POS). Generally speaking, the POS Standards guide the types of services and supports a regional center

may purchase for the individual they serve. Each regional center develops their own POS standards that are intended to be unique and meet the needs of the community it serves. However, there are some statutory requirements that all regional centers must adhere to, and all POS policies must be approved by the DDS.⁶⁹

POS utilization is an important indicator of whether the individuals served are actually accessing all the services and supports they are entitled to in the IPP or IFSP. Service Coordinators were asked if they had individuals on their caseload that are not receiving the full amount of regional center authorized services. Approximately 83% of the responding Service Coordinators reported that individuals on their caseload were not receiving the full amount authorized in their IPP or IFSP. Service Coordinators were also asked about the percentage of individuals

⁶⁶ Welfare and Institutions Code, Article 2, Section 4640 – 4659.2]

⁶⁷ June 2022 Trailer Bill, Senate Bill 188 (Chapter 49, Statutes of 2022)

<https://www.dds.ca.gov/wp-content/uploads/2022/10/June-2022-Trailer-Bill-Language-Affecting-Regional-Centers.pdf>

⁶⁸ June 2019 Trailer Bill, Senate Bill 81 (Chapter 28, Statutes of 2019)

https://www.dds.ca.gov/wp-content/uploads/2019/08/trailerBill_SB81August2019.pdf

⁶⁹ Welfare and Institutions Code § 4519.5, 4620.3, 46204.4, 4620.5, 4629.5, 4644, & 4646.4

biggest challenges occurring in day program, group home placement, and respite referrals.

Finally, Service Coordinators were asked what specific services are the most challenging to find for the individuals on their caseloads. Service Coordinators report the most challenges services to find include day programs (especially programs that will accept a person who requires 1:1 support), in-home and out of home respite, nearly all behavioral support services, nursing care, and transportation.

FOCUS GROUP DISCUSSION

Two focus groups were held with Service Coordinators to gain a better understanding of the impact of the DSP workforce shortage on their ability to coordinate services for the individuals on their caseload, as well as the impact on the individuals they coordinate service for. All of the Service Coordinators that participated in the focus groups reported challenges finding services for at least some, and often many, of the individuals on their caseloads. In many cases, individuals are at home waiting for services and Service Coordinators report that the more complex the needs of the individual are, the harder it is to find services. There is a growing frustration, often straining the relationship between Service Coordinators, families and the individuals they serve, as service provider waitlists continue to grow, and individuals wait longer and longer for services.

Service Coordinators report seeing the consequences of the DSP workforce shortage every day and in all aspects of their job, particularly in the way it impacts the individuals they serve. One Service Coordinator said in the “21 years I have been a Service Coordinator I have never seen the workforces shortage so bad—it’s frightening”. Others discussed what they referred to as the “empty promise” of the Lanterman Act and the Home and Community Based Services (HCBS) rule because without DSPs to provide the services

individuals have limited choices and live in more restrictive environments than they need, making it almost impossible to live full lives in the community.

IMPACT OF THE DSP WORKFORCE SHORTAGE ON INDIVIDUALS SERVED

The mental health and well-being of individuals on their caseloads was also raised as a concern because Service Coordinators have noticed a marked increase in the number of individuals experiencing isolation, depression, and anxiety. DSP staffing shortages were cited as one of the main reasons for some of the mental health challenges as it has caused significant disruptions in routines, feelings of loss, and limitations on social opportunities. Several of the Service Coordinators said they fear it is only going to get worse as we start to see the ripple effect of the new sector set minimum wages such as those in fast food and health care.

In some areas long waitlists and limited vendors (or limited vendor capacity) mean that individuals seeking services can wait months or even sometimes years to get the services they want or need to live successfully in the community. Among the issues raised by Service Coordinators was the reality, and consequences, of individuals being placed in inappropriate placements, or not receiving adequate services, while they wait for the services they want. For example, one Service Coordinator said that day programs are very difficult to find in his area and even more so if the individual requires a 1:1 for behavior and parents hit a crisis point when they are the sole support for their adult children with complex behaviors. When the crisis point happens it can have terrible consequences, people get hurt, hospitalizations increase, and sometimes it can even get so bad it becomes a forensics case.⁷⁰

Another unfortunate reality is that often it is aging caregivers who are trying to manage the needs of their adult children who may have complex

needs. Several of the Service Coordinators with adult caseloads said that approximately 30–33% of the individuals they serve are living with an aging caregiver (a person 65 or older) and of that number approximately 50% do not get the full amount of services authorized in their IPP. The Service Coordinators reported that many of these families are taking on the majority of the care because there are simply not enough DSPs to support their needs.

Cultural sensitivity and language barriers were also cited as challenge related to the DSP workforce as some Service Coordinators acknowledged how difficult it is to find DSPs who understand the culture and speak the language of the individuals and families they are seeking services for. One Service Coordinator expresses his frustration saying “It’s not about the money or the authorization of services because we have the money and the services are authorized. It’s about finding the people who actually understand the culture and speak the same language as the individual or family to deliver the services”.

SUGGESTIONS FOR ADDRESSING THE DSP WORKFORCE SHORTAGE

Service Coordinators were asked what they thought could be done to address the DSP workforce shortage. The number one response was increase the wages of DSPs, followed by increasing awareness about the DSP profession, and the need to create a clear career ladder that incentivizes DSPs to want to develop their skills and stay in the profession. A significant part of the discussion centered on changing the narrative of what DSPs do and moving from the pervasive belief that DSPs are “doing God’s work” or “helping the helpless” to one of it being a skilled and valued workforce with a level of sophistication that is required to support individuals with disabilities to live full lives in the community.

There was consensus that the rates have simply not kept up with the cost of living so low wages is the number one barrier to developing even an adequate, let alone robust, DSP workforce.

However, many of the Service Coordinators also recognized the need for the DSP workforce to be valued and respected at every level from the service providers (employers), regional centers, DDS, and society as whole. One Service Coordinator said “DSPs have people’s lives in their hands, that is an immense responsibility. They are expected to manage complex medical conditions, complex behaviors, teach people how to make and keep friends, support people in attaining and keeping employment, develop independence...this list goes on. And we pay them what?”

Many Service Coordinators also felt that creating a clear career ladder for DSPs, that includes increases in pay at each step, would help grow the workforce. Similar to steps within the regional centers, they felt it may incentivize DSPs to stay in the field if they know they can make a livable wage and continue to grow in their jobs.

CONCLUSION

Regional Center service coordinators have an essential role in the lives of people with IDD and their families in California as they help identify, access, and manage the services that individuals need to live full lives in the community.

As such, they are in a unique position not only to understand the personal impacts of the DSP workforce shortage, but also the broader implications as they continue to see more and more individuals on their caseloads waiting for services.

Service coordinators are an underutilized source of information when it comes to understanding the larger impact of the DSP workforce shortage as they have ready access to how many people on their caseload are waiting for services, how many are able to fully access and utilize services they are authorized for, how many referrals they have made, what the most challenging services are to find, and whether or not under-utilization of services and waitlists are a result of the DSP workforce shortage. ■

⁷⁰ Forensic Case, an individual served by a regional center that is also involved in the criminal justice system.

CONCLUSION

The impact of the DSP workforce shortage on the lives of people with IDD and their families cannot be overstated as the harmful effects are evident in so many different areas of their lives. The DSP workforce shortage is the single greatest barrier to inclusion for people with IDD as it serves to limit opportunities to further independence in social settings, employment, relationships, personal development, and preferred living options.

Advocates, the legislature, and the administration have worked for several decades to ensure that

the civil rights of people with IDD are not only protected, but advanced, by upholding and enforcing laws guaranteeing people with IDD the right to live in the community.

The recent investments made as a result of the DDS Rate Study are an important step toward funding a chronically under-funded system, however, without significant effort to address the workforce shortage, the DDS system will continue to lack the workforce infrastructure necessary to support people with IDD and their ability to live full, rich lives in the community. ■

ACKNOWLEDGMENT

On behalf of the California Policy Center for Intellectual and Developmental Disabilities, I want to thank everyone who contributed to this report. We are so very honored and humbled by all of the people that placed their trust in us and shared some of their most personal experiences. This report would not have been possible without the open, honest, and sometimes painful accounts of the challenges people experience because of the DSP workforce shortage. It is with immense gratitude that we thank everyone who participated in the focus groups, interviews, and surveys in an effort to bring light to the critical importance of the DSP workforce.

On a personal note, I want to thank all of the editors and the team at CPCIDD for your thoughtful input and contributions, as well as the countless hours you spent reading, rereading, and proof reading this report. Your time and dedication shows and is much appreciated.

Thank you for taking the time to read this report.

Respectfully,



Teresa Anderson
Executive Director—California Policy Center
for Intellectual and Developmental Disabilities

RECOMMENDATIONS

Recommendations to strengthen the DSP workforce were made by all who participated in the focus groups and 1:1 interviews, which included individuals served by the regional centers, family members, DSPs, service providers, and regional center service coordinators. There was significant overlap in some of the recommendations, however, there were two recommendations that were common to all of the participants which include:

- Pay DSPs a competitive wage based on the skill set required for the job.
- Professionalize the DSP Workforce by elevating the standards and providing comprehensive training, a clear career ladder, competitive compensation, and recognition as a skilled profession.

OTHER RECOMMENDATIONS INCLUDED:

- Engage the Community Colleges, Workforce and Economic Development Division, and the Workforce Development Board to create a workforce development plan specifically for the DSP profession.
- Create a Statewide Awareness Campaign about the importance and value of the DSP Profession.
- Create a standard definition of the DSP job and update the rate models to reflect accurate assumptions that are based on a competitive wage.
- Expand the types of competency-based training opportunities for DSPs to include entry level through advanced training with a focus on individuals with complex needs.
- Accelerate implementation of the DDS Workforce Initiatives that are already authorized and funded. Current DDS Workforce Initiatives specific to the DSP workforce include:
 - Bilingual/Multi-lingual Pay Differential
 - DSP Training Stipend Program
 - DSP Internship Program
 - DSP University & Associated Wage Differentials
 - Technology Pilot Program
- DDS could engage provider associations, the legislature, the administration, and the Department of Labor to find a solution or compromise to the PAGA claims created when a conflict between the health and safety of individuals with IDD and Labor Code 226.7 as it relates to the 10 minute break.



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