# Annual Report

utah department of

# human services

SERVICES FOR PEOPLE WITH DISABILITIES

2019

**For more information, please visit dspd.utah.gov.**

# Director's Message

**Angie Pinna**

In Fiscal Year 2019, DSPD focused its efforts on listening to our constituents. We partnered with the Utah Parent Center to complete a series of focus groups about caregiver compensation, nursing services, technology, integrated community programs, and service design. Self-advocates, parents, family members, and service providers were invited to share their perspectives on each topic. As we move into fiscal year 2020, the information gathered will be considered in a technology workgroup, discussions about transportation improvements, and service design.

The Utah Department of Health and DSPD drafted an application for the Community Transitions Waiver. When approved, this new home and community-based services waiver will support residents of Intermediate Care Facilities who want to move into homes in the community.

Thank you to all of our partners, stakeholders, and constituents who contributed their time, energy, and funding. DSPD's efforts to improve the waiver service system would not be possible without you.

**The mission of the Division of Services for People with Disabilities is to promote opportunities and provide supports for persons with disabilities to lead self-determined lives.**

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# Division Organization

utah department of human services

SERVICES FOR PEOPLE WITH DISABILITIES

DSPD operates four Medicaid 1915(c) Home and Community Based Service Waivers that serve over six thousand people. DSPD completes assessments of strengths and needs that determine eligibility and level of care. Multiple teams orchestrate access to short-term and ongoing services. Employees also help families find community resources to meet their needs. Through person-centered planning, assessment information is used to inform goals and budgeting. Finance teams assist support coordinators, provider agencies, and families with accurate billing and budget management. DSPD tracks and uses data to answer legislative inquiry and meet reporting requirements.

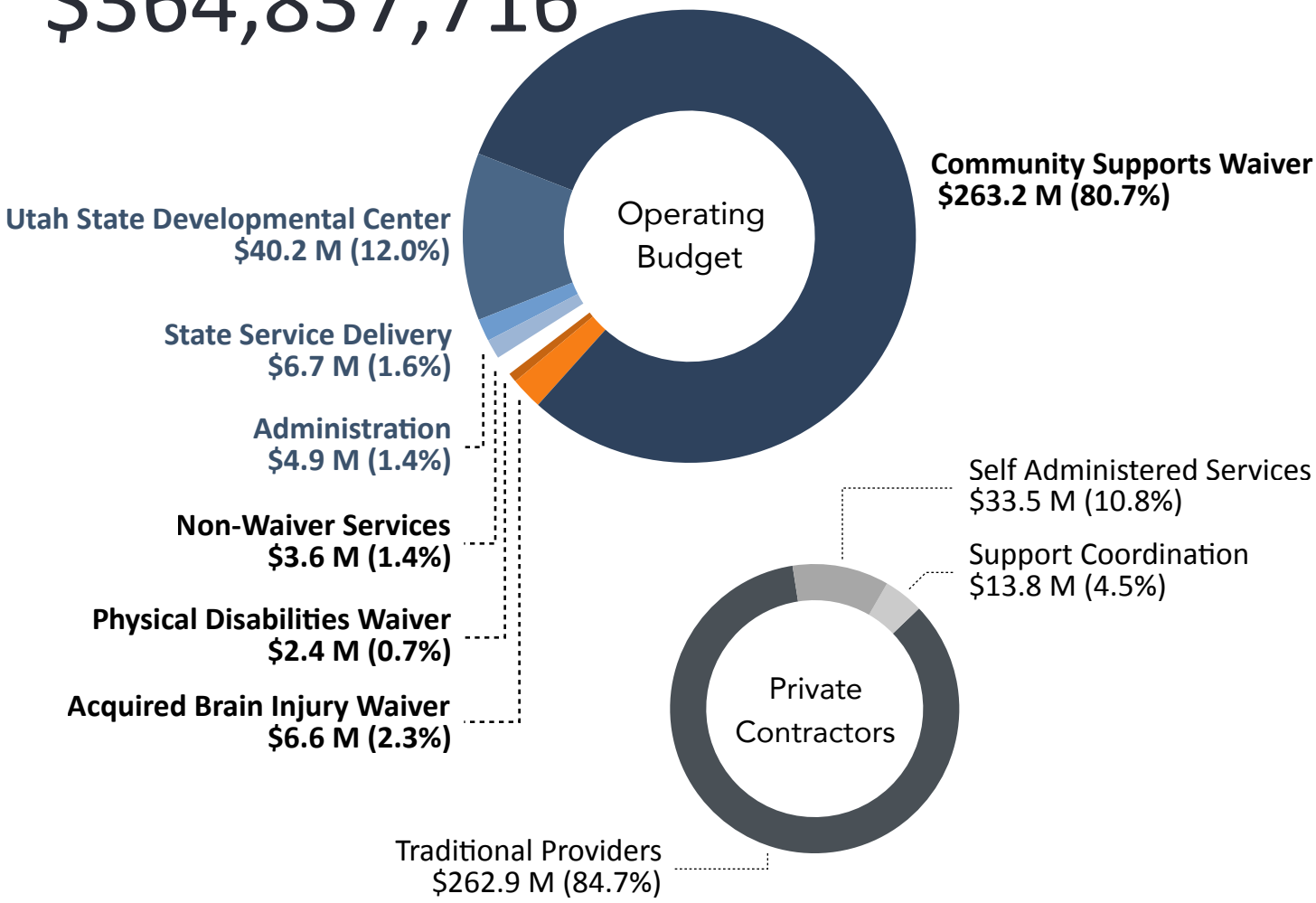
Research teams also conduct stakeholder focus groups and surveys in order to gain community input.

**For more information, visit dspd.utah.gov.**

# Budget Overview

Each year DSPD uses the Federal Medical Assistance Percentage (FMAP) to calculate the percentage of federal matching funds received for every state dollar spent. The FY 2019 FMAP was 30.15%.

$364,837,716




Historical Budgets

| 2014 | 2015 | 2016 | 2017 | 2018 |
|---|---|---|---|---|
| $225,358,786 | $243,774,872 | $270,878,269 | $297,969,073 | $327,725,128 |

# Legislative Appropriations

$7,160,900 Ongoing

**MANDATED ADDITIONAL NEEDS**

As part of the 1915(c) waiver language approved by the Center for Medicare and Medicaid Services, DSPD must provide for changes in health and safety needs of those already enrolled in waiver services. Each request for services (RFS) undergoes a comprehensive review of need by the RFS Committee before approval. This amount includes youth transitioning from DCFS/DJJS service funding.

$2,000,000 Ongoing

**WAITING LIST TRANSITION FUNDS**

In FY 2019 , DSPD enrolled 469 people from the waiting list into the three available waivers and non-waiver services.

$1,500,000 Ongoing

**DIRECT CARE STAFF SALARY INCREASE**

Beginning in 2015, the legislature funded an initiative to improve recruitment and retention of direct care staff through increased wages. Utah recognizes that adequate and stable staffing is crucial to successful service delivery.

$350,000 Ongoing

**RATE ADJUSTMENTS**

The legislature approved a payment rate increase for Motor Transportation Payment (MTP). Rate adjustments improve access to these valuable services that help people live self-determined lives.

**All dollar amounts are state general fund only.**

# Fiscal Year Highlights

**840**

People received short-term services while waiting for ongoing services

**469**

People from the waiting list enrolled in services through FY19 appropriation and attrition funds

**98%**

of Provider Agencies met contract quality measures

**6,302**

People enrolled in home and community-based services

**113**

Employees dedicated to delivering and improving home and community-based services

# COMMUNITIES SERVED

- Home & Community Based Services
- Eligible Diagnosis
- HCBS Demographics
- New Service Recipients
- Short-Term Services
- Waiting For Services
- Historical Trends

# Home & Community Based Services

Home and community-based services (HCBS), an alternative to institutional care, provide habilitation services to people with disabilities. HCBS support the person's choice to remain in their community.

**COMMUNITY SUPPORTS WAIVER**
A comprehensive, lifespan waiver serving people with an intellectual disability or a related condition, who meet Intermediate Care Facility level of care.

5,853 People

**ACQUIRED BRAIN INJURY WAIVER**
Serves people 18 years or older with a brain injury, who meet Skilled Nursing Facility level of care.

166 People

**PHYSICAL DISABILITIES WAIVER**
Serves people 18 years or older with a physical disability that results in the functional loss of two or more limbs, who meet Skilled Nursing Facility level of care.

105 People

**AUTISM WAIVER**
Provides respite to children up to age seven, who have an Autism Spectrum Disorder (ASD) diagnosis.

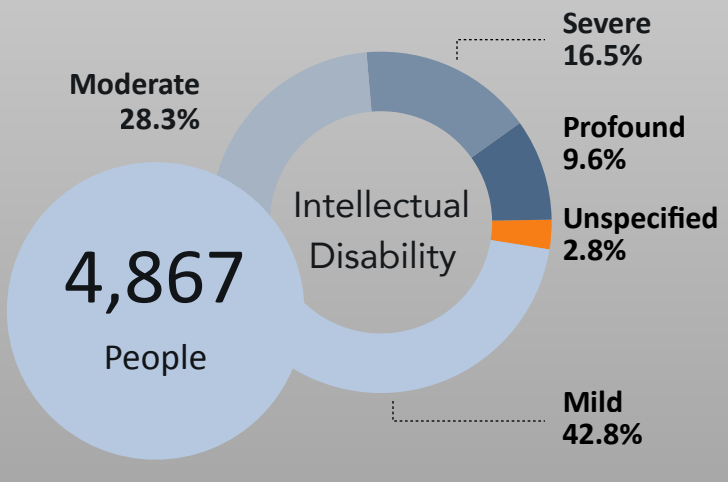
14 People

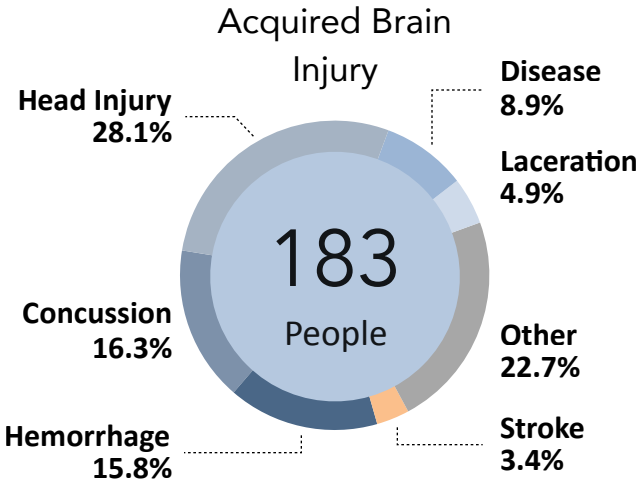
**NON-MEDICAID WAIVER SERVICES**
Lifespan assistance for people who meet DSPD eligibility requirements, but are not eligible for federal Medicaid funding or are transitioning from homelessness.

96 People

* 68 people transitioning into services

# Eligible Diagnosis




## Related Conditions

1,114 People

| Type | Percentage |
|---|---|
| Autism | 61.0% |
| Cerebral Palsy | 14.6% |
| Chromosomal Abnormalities | 10.4% |
| Epilepsy | 3.2% |
| Other | 3.2% |
| Congenital Anomolies | 2.7% |
| Pervasive Developmental Delay | 1.8% |
| Spina Bifida | 1.5% |
| Injury | 1.5% |

## Physical Disability

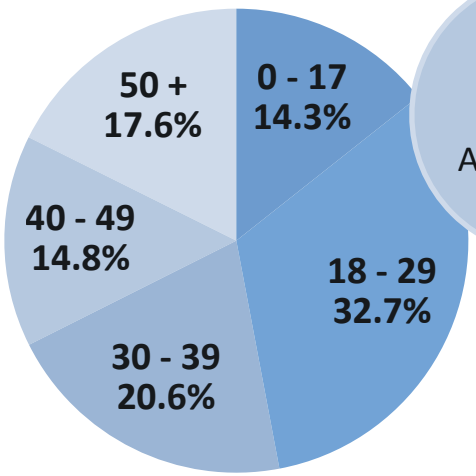
137 People

| Type | Percentage |
|---|---|
| Quadriplegia | 44.4% |
| Other | 23.1% |
| Muscular Dystrophy | 12.8% |
| Cerebral Palsy | 8.5% |
| Multiple Sclerosis | 6.0% |
| Paraplegia | 5.1% |

Eligibility for Division services requires that a person have a minimum of one qualifying diagnosis. A qualifying diagnosis must give rise to mental or physical impairments that cause, at least, three substantial functional limitations in a major life activity, such as: self-care, language, mobility, capacity for independent living, and economic self-sufficiency.

# HCBS Demographics

## Age




**34.1**
Average Age

**6,302**
People Served

**38.3%**
Female

**61.7%**
Male

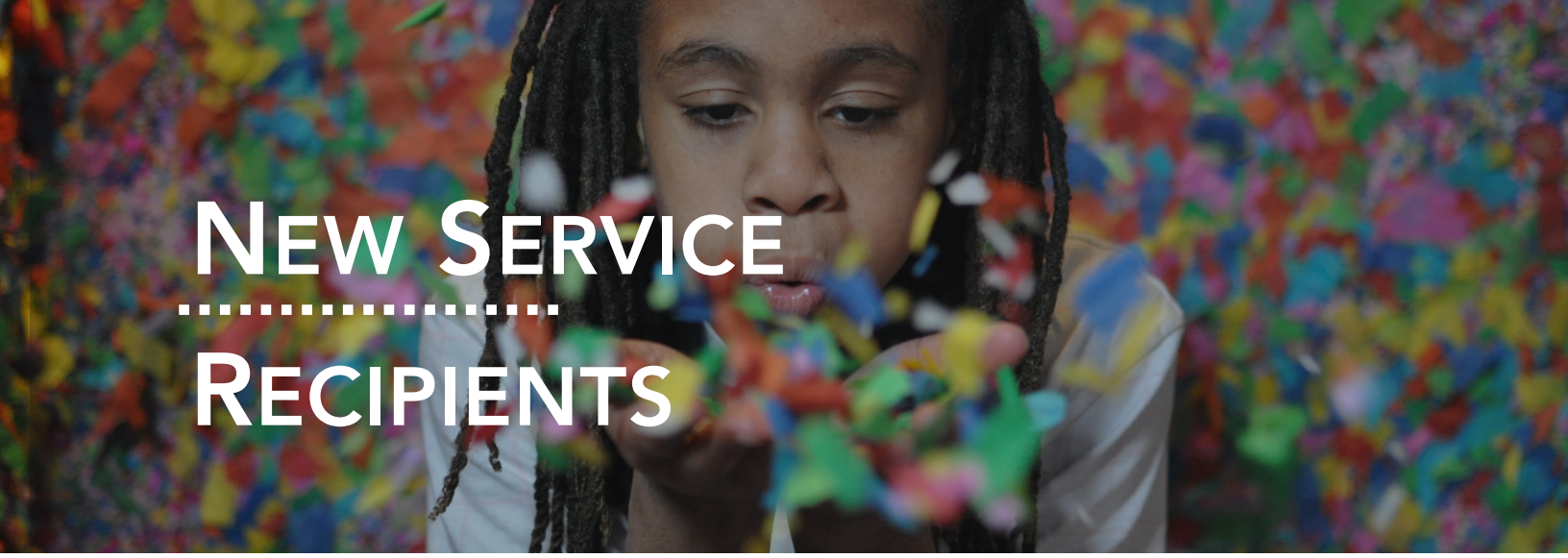
## Disability

| Type | Percentage |
|---|---|
| **Intellectual Disability** | 77.2% |
| **Related Conditions** | 17.7% |
| **Acquired Brain Injury** | 2.9% |
| **Physical Disability** | 2.2% |

## Race & Ethnicity

| Type | Percentage |
|---|---|
| **White** | 83.0% |
| **Hispanic/Latino** | 9.7% |
| **Asian/Pacific Islander** | 1.9% |
| **American Indian** | 1.9% |
| **Black/African American** | 1.9% |
| **Other** | 1.6% |

**For more information, visit our dashboard.**



# New Service Recipients

## Appropriation Funding

| | Most Critical | Respite Only |
|---|---|---|
| Number of People | 218 | 97 |
| Average State Budget | $13,367 | $4,920 |
| Average Total Budget | $44,332 | $16,318 |

568
People Enrolled

## Attrition Funding

| | Crisis | Court Order |
|---|---|---|
| Number of People | 150 | 4 |
| Average State Budget | $22,139 | $34,289 |
| Average Total Budget | $73,423 | $113,719 |

## Transfer Funding

| | DCFS | Transition |
|---|---|---|
| Number of People | 49 | 50 |
| Average State Budget | $27,649 | $27,327 |
| Average Total Budget | $91,698 | $90,629 |

# Short-Term Services

While waiting for ongoing supports, DSPD can provide some short-term services. Available services include: Supported Work Independence (SWI), Respite Services, and Community Service Brokering (CSB). Funding comes from a combination of ongoing and one-time appropriated general fund dollars allocated each fiscal year. People may be eligible to receive one or more of the limited short-term services available while waiting. In FY 2019, each service enrolled the following number of people:

**SUPPORTED WORK INDEPENDENCE**

SWI is designed to assist eligible persons, who are waiting for ongoing services, obtain and maintain competitive employment in an integrated setting, earning at least minimum wage.

232 People

**RESPITE SERVICE**

In an effort to address caregiver burnout, DSPD can offer a person's caregiver relief through limited, one-time respite services.

544 People

**COMMUNITY SERVICE BROKERING**

CSB connects eligible persons waiting for ongoing services to a skilled advisor who expertly links the person to available community resources.

64 People

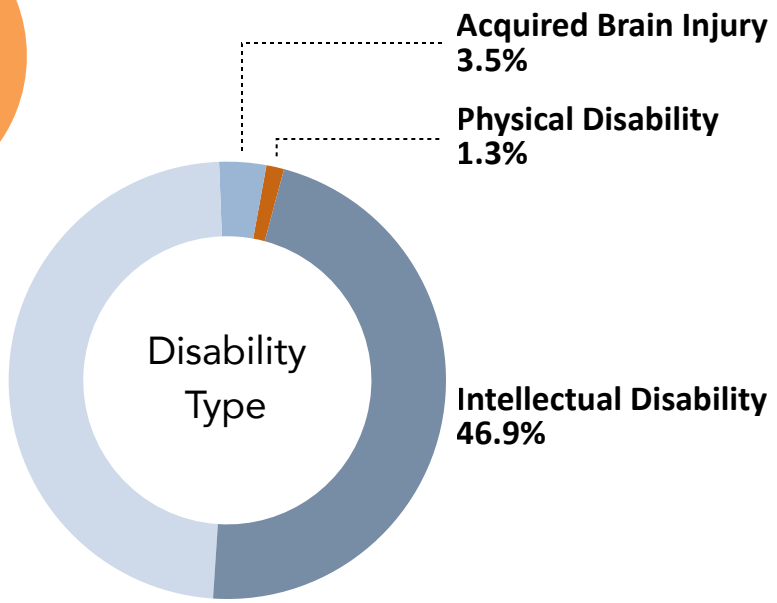
# Waiting for Services

DSPD uses all available funds to provide services to as many eligible persons as possible. At the end of FY 2019 there were 3,286 people waiting for services. As funds become available, DSPD enrolls people with the most critical needs into services.

**3,286**
People Waiting

**5.5**
Average Years Waiting

**22.9**
Average Age

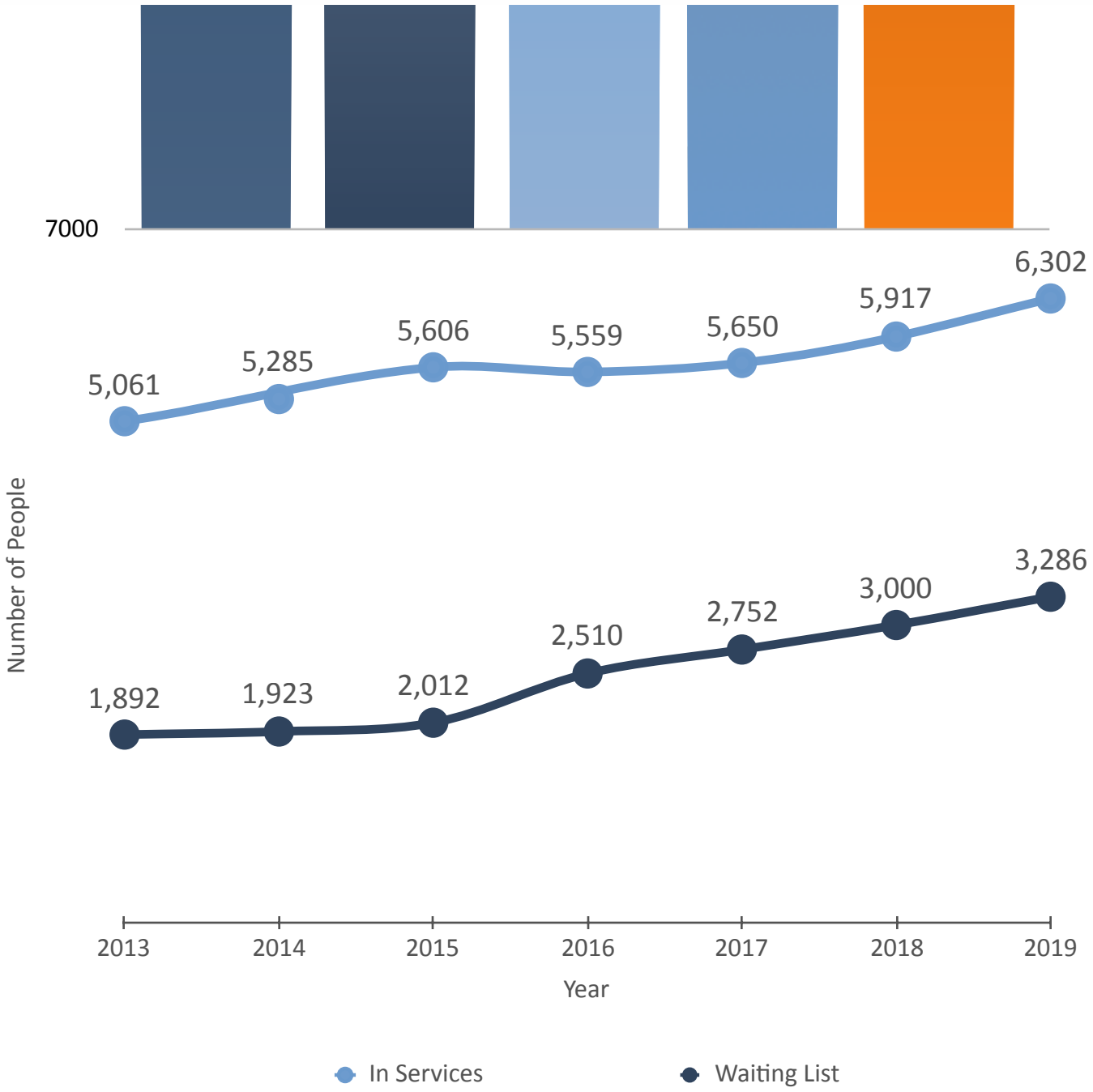



Requested Services*

| Type | Percentage |
|---|---|
| **Personal Assistance & Supported Living** | 41.3% |
| **In-Home Supports & Respite** | 50.8% |
| **Residential Services** | 6.1% |
| **Host Home & Professional Parent Services** | 1.9% |
| **Day Supports** | 23.7% |
| **Supported Employment** | 19.0% |

***The numbers do not add to 100%, because people can be waiting for multiple services.**

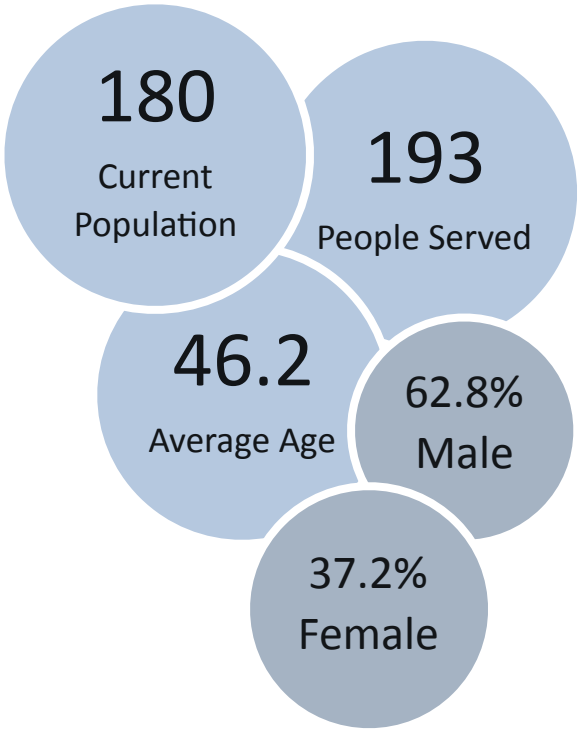
# Historical Trends



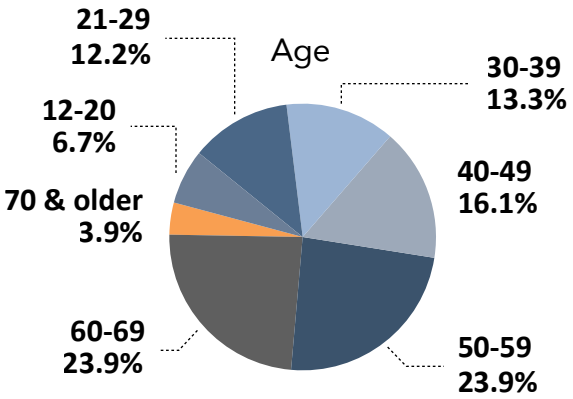
# USDC Demographics

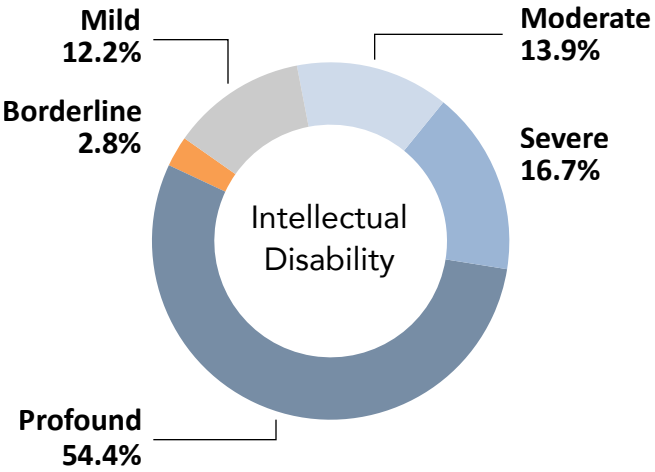
utah department of human services

UTAH STATE DEVELOPMENTAL CENTER




USDC serves all ages in a comprehensive residential setting. On-site services include: habilitation, medical, dental, employment and recreation. Dormitory style living matches four to six people as roommates who share common areas. Staff assist with grocery shopping, cooking, and cleaning. USDC also offers respite support for people enrolled in DSPD services. Families report that this valuable service supports continued caregiving at home.



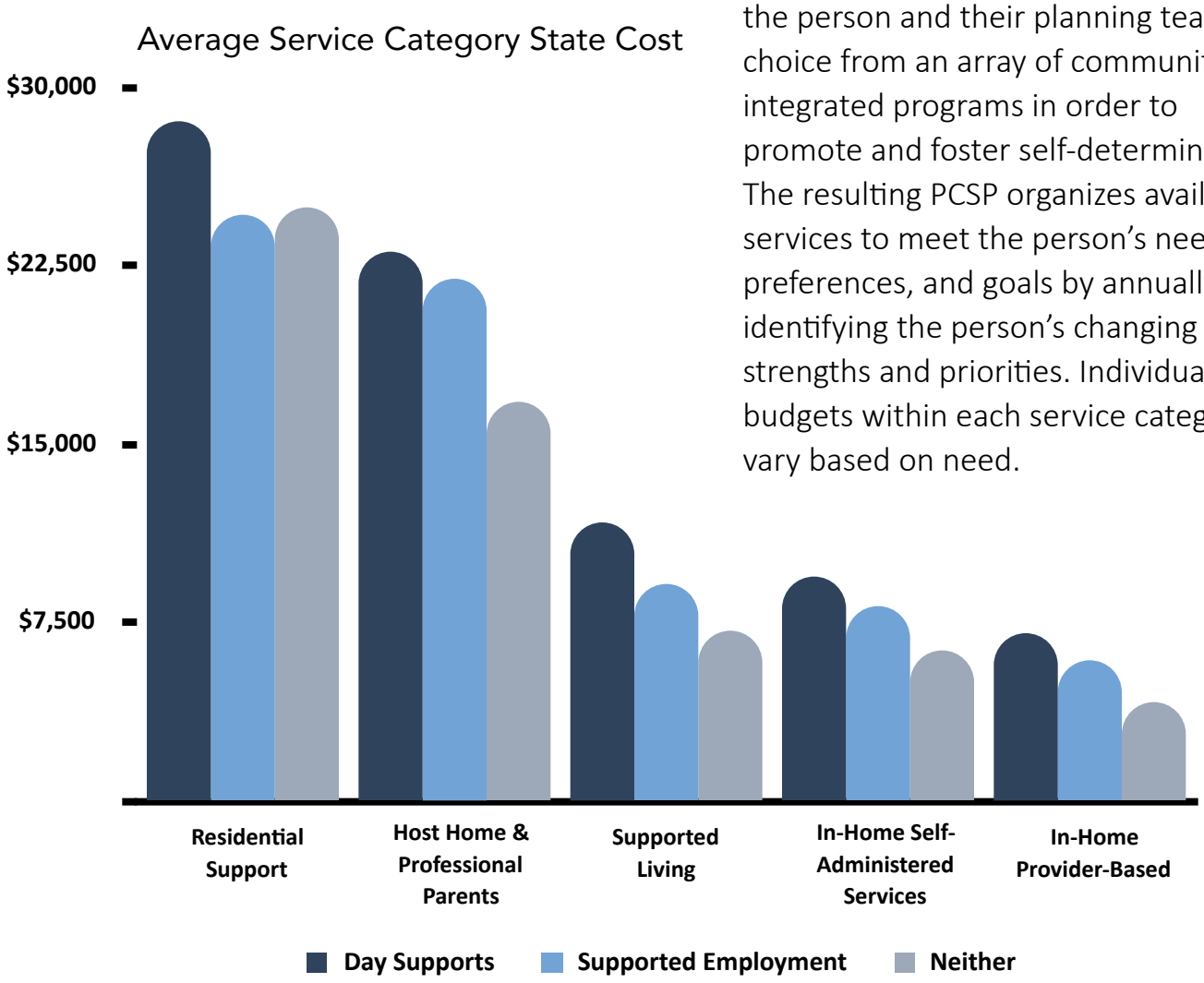

**For more information, visit usdc.utah.gov.**

# SERVICE CATEGORIES

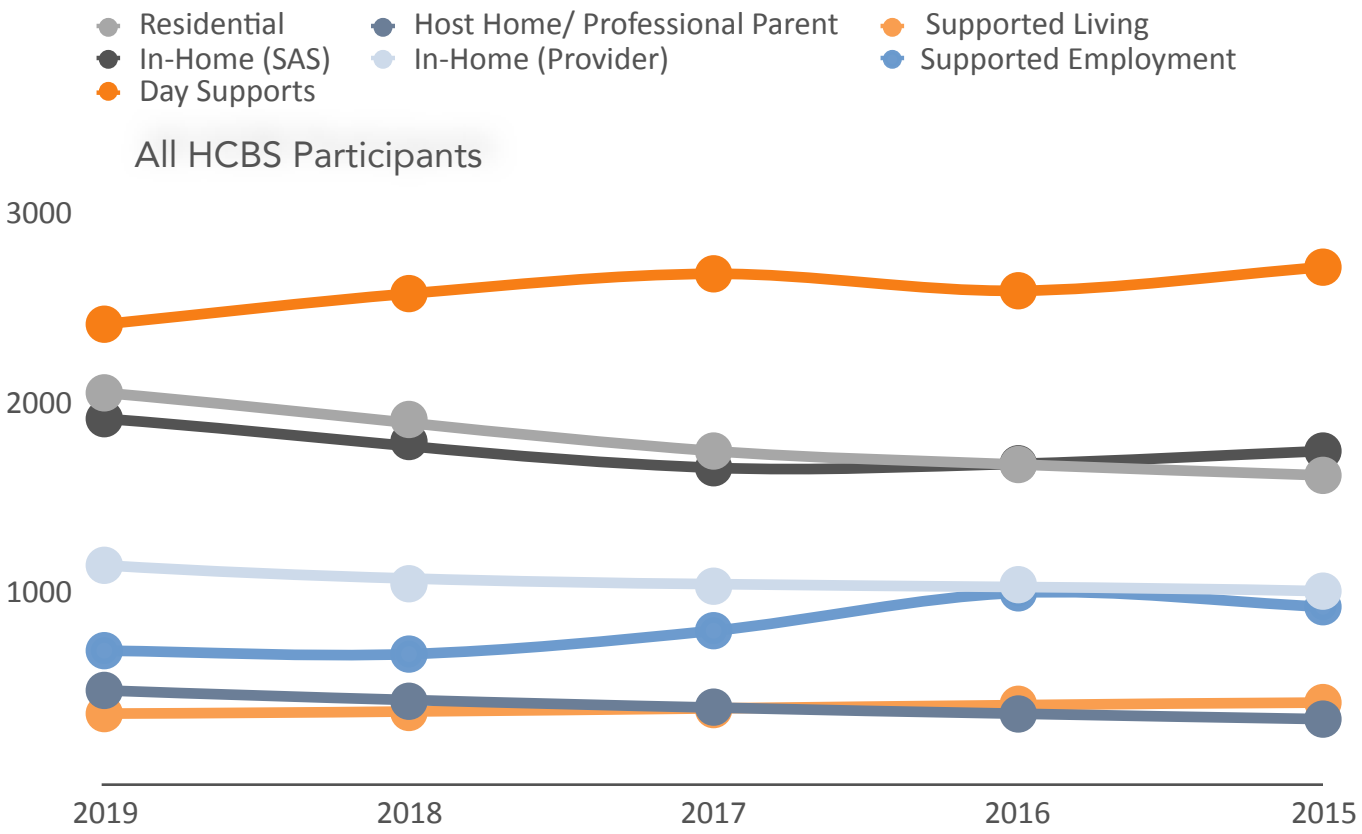
- Residential Support
- Host Home & Professional Parents
- Supported Living
- In-Home Self-Administered Services
- In-Home Provider-Based

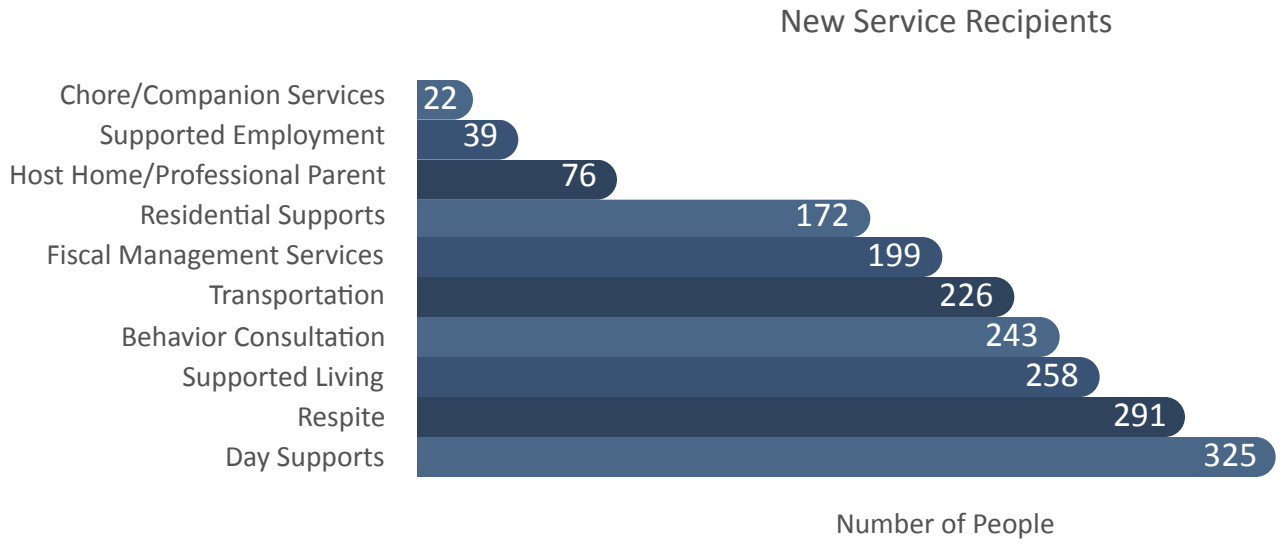
# Spending Overview

DSPD uses validated assessments, self-report, and provider experience to tailor a person-centered service plan (PCSP). Person-centered planning offers the person and their planning team choice from an array of community integrated programs in order to promote and foster self-determination. The resulting PCSP organizes available services to meet the person's needs, preferences, and goals by annually identifying the person's changing strengths and priorities. Individual budgets within each service category vary based on need.



# Service Utilization



# Residential Support

Residential habilitation offers 24-hour support in supervised apartments and group homes as an alternative to institutional settings. Individualized assistance helps the person obtain and maintain independent living skills in their chosen community. Services that often accompany RHS, include: prescription monitoring, behavior consultation, employment, and day support.

## RHS Spending

| | |
|---|---|
| **Average Annual Total Cost** | $91,454 |
| **Average Annual State Cost** | $27,576 |
| **Total Cost** | $188.6 M |
| **Total State Cost** | $56.8 M |

2,063 People

40.9 Average Age

73.9% Day Supports

17.6% Supported Employment

8.4% Neither

# Host Home & Professional Parent

Host family residential services offer a shared living experience for youth and adults, with exceptional care needs, who want a family environment, but cannot live with immediate family members. The host family provides assistance with independent living skills and supervision that helps the person engage in their community and avoid isolation.

## HHS & PPS Spending

| | |
|---|---|
| **Average Annual Total Cost** | $71,782 |
| **Average Annual State Cost** | $21,644 |
| **Total Cost** | $35.7 M |
| **Total State Cost** | $10.7 M |

498 People

30.6 Average Age

62.0% Day Supports

18.7% Supported Employment

19.3% Neither

# Supported Living

## SL Spending

| | |
|---|---|
| **Average Annual Total Cost** | $29,053 |
| **Average Annual State Cost** | $8,760 |
| **Total Cost** | $10.9 M |
| **Total State Cost** | $3.2 M |

Multiple supported living options offer hourly, intermittent care for people who live in their own home. Services designed to maintain health and safety, and avoid isolation include: transportation, personal care, homemaking, chores, medication monitoring, advocacy, communication assistance, and other activities of daily living.

16.2% Day Supports

43.9% Supported Employment

39.9% Neither

47.6 Average Age

376 People

# In-Home Provider-Based

## In-Home Spending

| | |
|---|---|
| **Average Annual Total Cost** | $20,194 |
| **Average Annual State Cost** | $6,089 |
| **Total Cost** | $23.3 M |
| **Total State Cost** | $7.0 M |

An enrolled person and their family can access respite, companion, homemaker, chore, and personal assistance through a contracted provider agency. The person and provider agency collaborate to design a service plan that maintains health and safety, and avoids isolation.

55.9% Day Supports

16.6% Supported Employment

27.5% Neither

32.2 Average Age

1,156 People

# In-Home Self-Administered

Engagement in waiver service through SAS allows a person and their family to become an employer of their own direct service staff. SAS includes access to a fiscal management agent that provides payroll and budget management services. Waiver services offered under SAS include: respite, companion, homemaker, chore, and personal assistance.

## SAS Spending

| | |
|---|---|
| **Average Annual Total Cost** | $24,592 |
| **Average Annual State Cost** | $7,415 |
| **Total Cost** | $47.3 M |
| **Total State Cost** | $14.2 M |

1,927
People

26.8
Average Age

31.6%
Day Supports

7.0%
Supported Employment

61.4%
Neither

# TATE

Tate, a post-high student from Murray School District, participated in the Utah School to Work Project. Through School to Work, Tate accessed a team of supports from multiple agencies including: his para-educator from the post-high program, a VR counselor, WIOA Youth Counselor and employment specialist provider. The team coordinated a full range of services for Tate as he explored community integrated employment.

Because School to Work focuses on student with significant disabilities, using a Customized Employment model provides the best outcomes. Tate's VR Counselor connected him to RISE Employment Services for Discovery. During Discovery, Tate identified an interest in animal care. After completing Discovery, the WIOA Youth Service Coordinator and CRP coordinated an internship opportunity at a reptile shop called Mark's Arc. The supervisor at Mark's Arc and Tate tried different job tasks until they identified job tasks that matched Tate's abilities and interests.

Tate did remarkably well at work. Employment coaching significantly phased out during the internship. The employer was so pleased with the care and good work he was doing that they offered Tate permanent employment. Tate's employment specialist assisted in the negotiations for permanent employment.

Tate continues to work successfully at Mark's Arc. Some of his responsibilities include handling the animals when they need to be removed from their cages for cleaning, the cleaning of the cages feeding the animals, and assisting with snake molting. Now that Tate is employed, he chooses to spend more time working and less time at the post-high program. He attends post high activities that interest him, and is developing a full life beyond school.

Customized Employment helped Tate find work meaningful to him with an employer who values his contributions to the workplace. Tate completes tasks more and more independently and continues to exceed everyone's expectations.

# Day Activities

Assistance for adults who want to obtain, maintain, and advance in competitive integrated employment and entrepreneurship paying at least minimum wage, or in self-contained business locations. The service provides a job coach or co-worker support to either an individual or group. Employment support offers the flexibility to customize work hours and setting in order to follow the person's interests and achieve the Person's goals.

## Supported Employment

| | |
|---|---|
| **Number of People** | 948 |
| **Average Age** | 39.2 |
| **Average Annual Total Cost** | $51,572 |
| **Average Annual State Cost** | $15,550 |
| **Total Cost** | $48,890,225 |
| **Total State Cost** | $14,741,625 |

Daytime supervision and support, in either an individual or group setting, designed to help develop and maintain habilitation skills, including: self-help, community living, and communication skills. Structured programs provide socialization, skill building, and leisure activities.

## Day Support

| | |
|---|---|
| **Number of People** | 3,150 |
| **Average Age** | 36.1 |
| **Average Annual Total Cost** | $65,021 |
| **Average Annual State Cost** | $19,605 |
| **Total Cost** | $204,814,921 |
| **Total State Cost** | $61,756,819 |

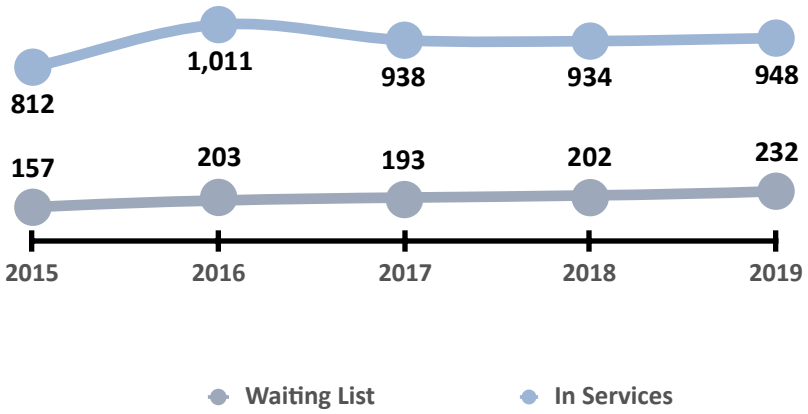
# Employment

Committed to the Employment First initiative, DSPD recognizes the benefits of prioritizing meaningful, competitive employment opportunities for people enrolled in services.

## Supported Employment Spending

| Fiscal Year | State Dollars | Total Dollars |
|---|---|---|
| 2019 | $2,804,035 | $7,991,393 |
| 2018 | $2,689,892 | $7,762,199 |
| 2017 | $2,563,830 | $7,372,080 |
| 2016 | $2,469,305 | $6,883,596 |
| 2015 | $1,948,971 | $5,496,916 |

Historic Counts




### SWI

Supported Work Independence provides skill development and job coaching to adults waiting for waiver services.

**59%**
Employed

**$8.32**
Average Wage

**13.8**
Average Hours Worked

177

**Traditional Provider Companies**

Operate statewide to provide direct support staff and structured programming designed to maintain health and safety in integrated, educational, and self-determined settings.

57

**Support Coordination Companies**

A statewide network of Qualified Intellectual Disability Professionals who assist people and their families coordinate care through Medicaid waiver services and other community resources.

3

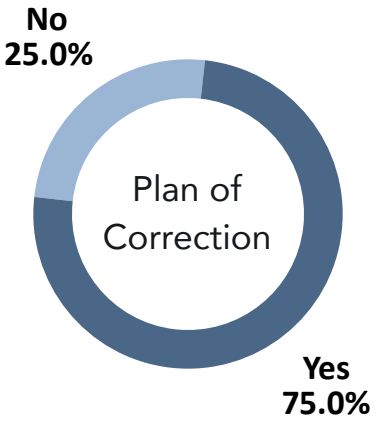
**Fiscal Agent Providers**

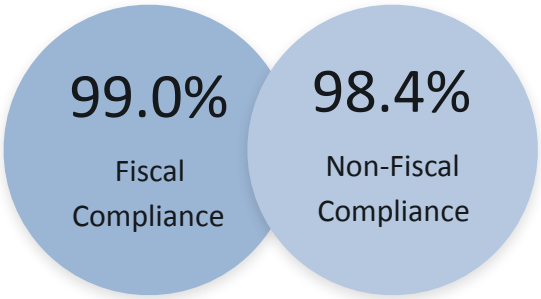
As part of the self-administered service model, fiscal agents assist people and their support team with fulfilling employer requirements, including: hiring, payroll, and taxes.

# Provider Reviews

The Office of Quality and Design's (OQD) provider contract audits measure compliance with fiscal and non-fiscal contract standards, and number/severity of plans of correction needed. All practices found in violation of contractual requirements must be remediated according to the OQD corrective action process:

1. Provider may become compliant by the end of the review cycle, or
2. Develop a remediation plan that designates timeframes for progress toward compliance.




97.7%

**MINOR**
Issues do not negatively impact a Person's well-being or jeopardize funding requirements.

2.3%

**SIGNIFICANT**
Non-compliance with Division Directives, contract requirements, or other rules that results in inadequate treatment; or has the potential to jeopardize a Person's well-being.

0.0%

**MAJOR**
Issue results in imminent danger to a Person's health and safety, or an imminent risk to one or more people.

# Settings Rule Update

Medicaid requires that all states be complaint with the Home and Community Based Services final settings rule by March 19, 2022. The Centers for Medicare and Medicaid Services granted final approval of Utah's State Transition Plan. FY 2019 system change efforts include:

- All providers had approved remediation plans to help them come into compliance with the Settings Rule
- In person visits were made to all day support settings and any site that had not completed remediation
  - A stakeholders workgroup approved the observation and interview tools that were used on the visits
  - The workgroup is reviewing summaries of all visits to validate the recommended compliance status
- The Utah State University Employment and Community Integration Technical Assistance and Training Center is supporting 13 providers to receive expert technical assistance in their efforts to transform their services to be Settings Rule compliant. The USU TA center has also hosted several webinars and trainings on community integration and employment.
- Working with the National Center for Advancing Person Centered Planning and Systems to reinvigorate our person-centered support plans process. Our main objectives are improving stakeholder engagement in the system change efforts with person centered thinking; and making needed changes and advancements to the PCSP software.

**For more information, visit dspd.utah.gov/setting.**

# Sandra Asbury Employment Opportunity Award

The Sandra Asbury Award recognizes provider agencies or support coordinators who demonstrate innovation in employment opportunities for people with disabilities.

**AMBER MARSH EMPLOYMENT DIRECTOR - NORTH EASTERN SERVICES**

Amber Marsh, of North Eastern Services, champions changes to employment support services that increase community jobs for real pay for all people with disabilities. She is leading the development of an Utah APSE (Association for People Supporting Employment-First) chapter and NES's provider transformation efforts. Amber helped NES grow their employment services while completely restructuring their organization to make it more employment centered. Now over 66 individuals supported by NES are currently employed in the community. Amber and NES also work with ODEP and the Employment and Community Integration Technical Assistance Center through Utah State University to continue to learn how to provide more inclusive, individualized services that include employment.

Amber and the employment team at NES in cooperation with Utah State Office of Rehabilitation are part of a hiring initiative and training program. NES has created multiple partnerships with businesses in the community to help employ individuals with disabilities. These businesses now strive to hire individuals with disabilities due to the positive impact that the individuals had on the business.

# Ila Marie Goodey Award

Named for the late Dr. Ila Marie Goodey, a former psychologist at the University of Utah, the award honors direct care professionals who respect individuality, promote independence, and honor self-determination. Dr. Goodey, nationally and locally recognized as a passionate advocate for people with disabilities, has been described as representing "the ideal of selfless service to others with an uncompromising insistence on the right of all people to experience a high quality of life, especially those who are unable to fully represent themselves."

**DAWN PERRY HOST HOME PARENT - CHRYSALIS**

Dawn has been a professional parent for more than 11 years. The DSPD emergency services team needed a home for a young woman who had been isolated for many years without any opportunities to access the community or build friendships. Dawn lovingly invited the teen into her home, determined to give this young woman the life she deserves. Dawn set up her room with all the things we knew were important to her and treated her like family from the moment she walked in the door. Integrating a new child into a family is never easy. Dawn followed her behavior plan perfectly and stayed consistent through all the up's and down's.Dawn demonstrated her skill as a professional parent by navigating stressful incidents that impacted her employment and family with love and compassion.

She regularly sought help from the support team and helped craft a meaningful person centered plan. Now this young woman meets all of her

goals.  She feels like she found a mother and family; and is moving toward new goals, finding new friendships, and starting a new job. Dawn's unconditional love, wealth of patience, and use of her own skills and support network undoubtedly laid the foundation for this young woman to find her balance and come into her own.

**CHRIS LARSON - IMBER SERVICES**

Imber Services provides quality, creative, inclusive and community focused services to my 23 year old son with autism who has significant assistance needs, so that he has the opportunity to live and learn in his community. He anxiously waits for his staff to pick him up and is happy when he returns home. Imber provides him with a variety of age appropriate individual and group activities under the direct supervision of well trained and caring staff. The groups are small, so I trust that my son's support staff can focus on his needs and help him choose the activities he wants to participate in. These activities include volunteering at the food bank, shopping, physical activities, or just enjoying the beautiful outdoors at the parks and canyons in the area. My son has friends, both staff and other clients who participate in the program.

Chris Larson is developing a program that is more than I could have expected.  The program builds a sense of trust and support between the individuals, the staff, and the families, which leaves me with a feeling of success for both of us.  Chris is building a strong foundation with local organizations and businesses that will be sustainable for the future. I am so fortunate that my son is going to be a part of that future. Imber Services "reaches for the heavens"; Chris is living his dream, so that our young adults can live theirs.