



I/DD 101

The challenges

WHO ARE INDIVIDUALS WITH I/DD?

- Intellectual or developmental disability
- Lifelong conditions, such as autism, Down syndrome or Cerebral Palsy
- Affect a person's ability to think, learn, and develop skills at the same rate as others.
- Present from birth or early childhood
- Often need support for everyday activities
- Family members, friends, neighbors, classmates and co-workers





WHAT DO INDIVIDUALS AND FAMILIES WANT?

- To live, have access to, and belong in the community
 - The opportunity to learn and grow
 - An affordable, accessible place to live
 - Meaningful things to do, including real jobs for real pay
 - To be healthy and have access to appropriate healthcare
 - Appropriate, adequate supports available when and where they are needed
 - A transparent, easy-to-use service system
 - Economic stability
-The same things that everyone else wants





WHAT KINDS OF SUPPORTS DO PEOPLE NEED?

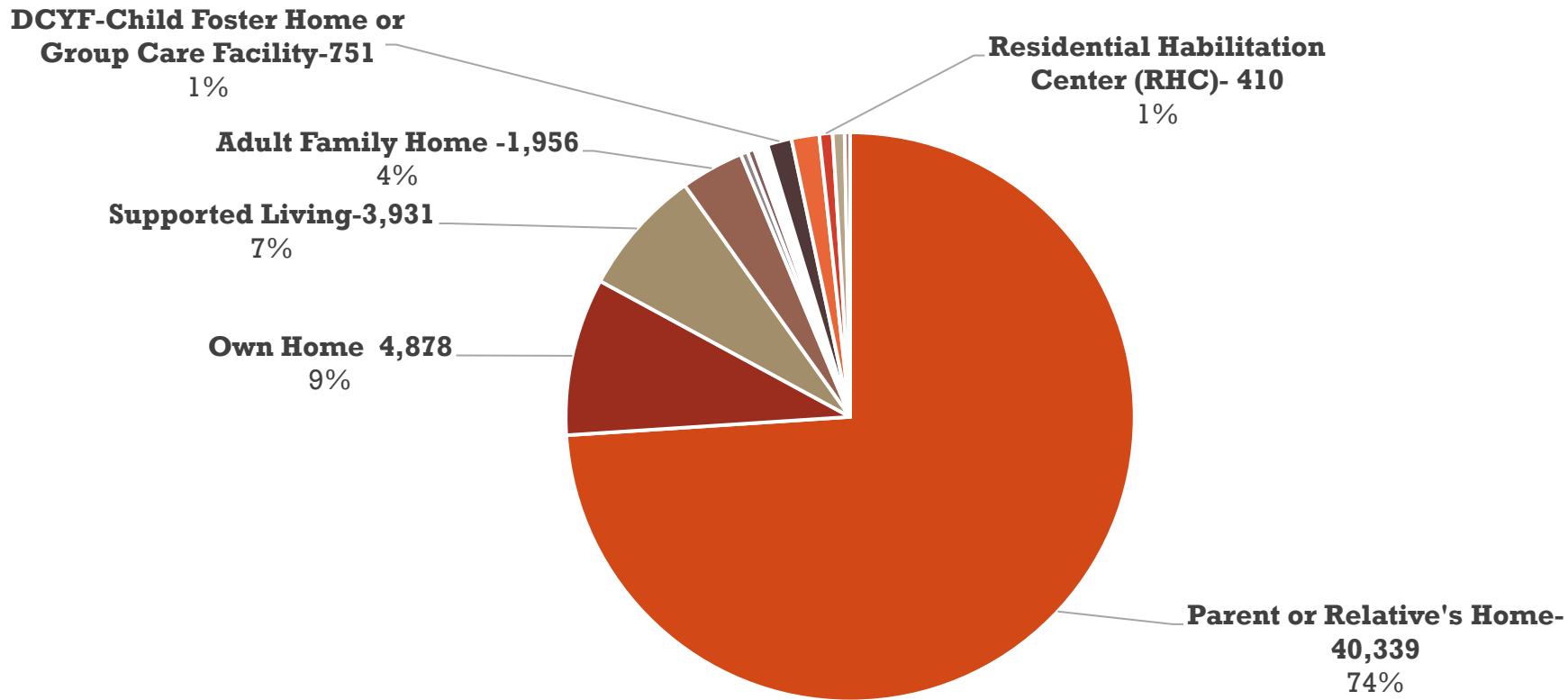
- Personal Care for Activities of daily living (bathing, dressing, eating..)
- Supports to live in their home
- Supports to have a job (finding a job, job coaching)
- Supports making friends and having meaningful things to do
- Supports to access the community (Transportation)



STATISTICS

- 1-3% of the population has an intellectual or developmental disability (170,000)
- **54,533 DDA clients**
 - 26,358 children
 - 28,175 adults
- Of those **adults**, **16,062 (55.3%)** live with and receive care from a **parent** or a **relative**.





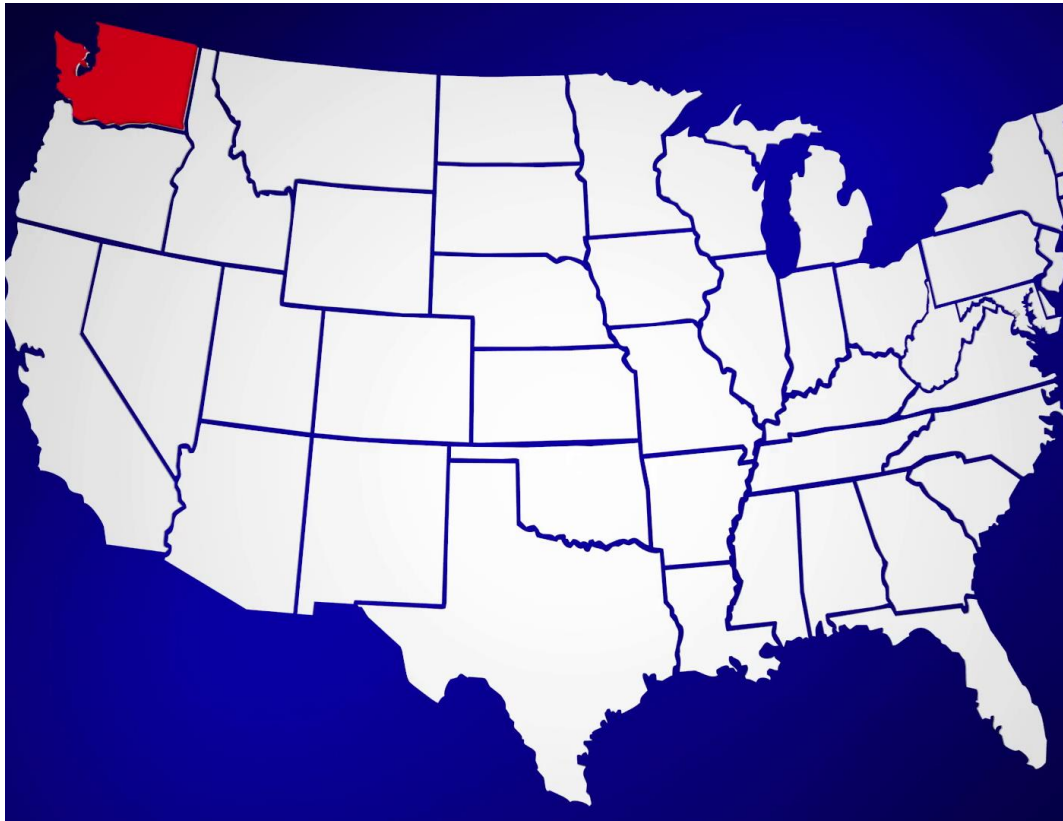
WHERE DO PEOPLE LIVE?

- Parent or Relative's Home- 40,339
- Supported Living-3,931
- DDA Group Home- 220
- DDA Out of Home Services- 114
- Alternative Living-79
- Companion Home-74
- Other or Unknown-860
- Other Facility-368

- Own Home 4,878
- Adult Family Home -1,956
- State Operated Living Alternatives (SOLA)- 218
- Adult Residential Care (ARC)-95
- Assisted Living Facility (Non-ARC)-70
- DCYF-Child Foster Home or Group Care Facility-751
- Residential Habilitation Center (RHC)- 410
- Homeless-170



WASHINGTON STATE RANKS 38TH IN PER CAPITA SPENDING FOR I/DD SERVICES

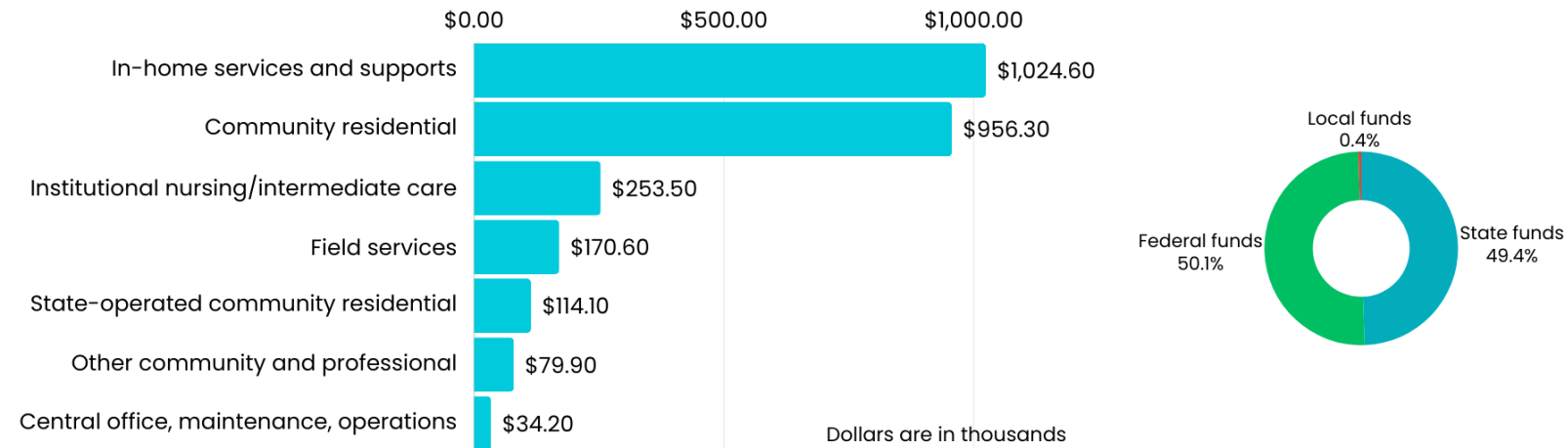


- 14,982 DDA clients receive NO paid services

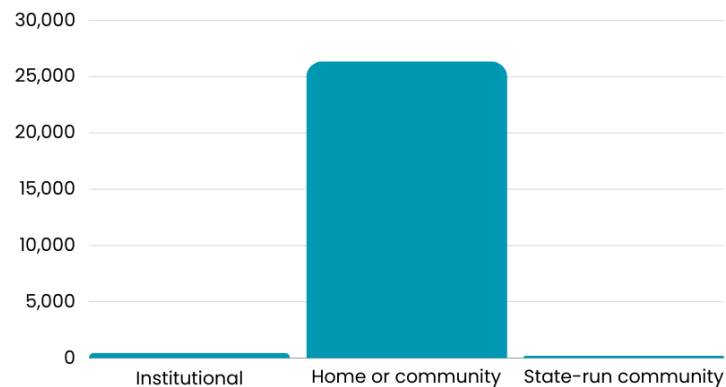


DDA 2023-25 operating budget

Most DDA services are Medicaid long-term services and supports, which are funded by a mix of state and federal funds. These services can be provided in either an institutional setting, or through home and community based services.



Where people are supported



98% of participants use home and community-based services.

1.5% are supported in institutional nursing facilities or intermediate care facilities (“Residential Habilitation Centers”)

Less than 1% are supported in small-group state-run community residential



WHAT'S A WAIVER?

WHAT ARE YOU WAIVING?

A Waiver is a set of Medicaid Services that are available for a specific population of people

Waives services in an institution to receive services in the community

Children: Waives the parental income to become Medicaid qualified

WA currently has 5 DDA Medicaid Waivers

Waivers are state specific

DDA Waivers are capped

Waivers are federally matched 50/50



Housing Options By Waiver

Individual and Family Services (IFS)
6179

Living at Home

Children's Intensive In-Home Support (CIIBS)
199

Living at Home

Basic Plus
11,659

Living at Home

Adult Family Home
1877**

Shared Living

Core
4578

Living at Home

Supported Living
3879

SOLA/202

Companion Home/72

Alternative Living/85

Group Training Home/217

Shared Living

Community Protection
369

Community Protection Home

BASIC PLUS WAIVER SERVICES

Respite

Set by assessment
minimum 20 hours a
month

Not available when
you move out of
family home

Aggregate Services

up to \$6219 per
year

Community
Engagement
Specialized
Habilitation
Therapeutic
Adaptations
Environmental
Adaptations

Employment & Day Programs

Individual
Employment

Community
Inclusion

Other Services

Up to \$6000 per
year

Staff and Family
Consultation
Transportation
Wellness Education
Extermination of
Bedbugs
Risk Assessment
Stabilization
Services

Non-Waiver Service: Personal Care by Assessment



CHALLENGES



A SYSTEM THAT DOESN'T WORK

- Difficult to understand
- Difficult to access
- Difficult to navigate
- Services that are not timely
- Inflexible
- Antiquated



LACK OF CAPACITY



LACK OF CAPACITY LEADS TO CRISIS



- **Individuals**
 - don't get the care they need
 - end up isolated
 - end up in the hospital or jail
- **Families**
 - have to quit work
 - go into financial crisis
 - are separated
- **Agencies**
 - can't adequately serve new people
 - go out of business
- **Students**
 - don't get an appropriate education
 - Are isolated and/or restrained
 - get sent out of state



WORKFORCE





**LACK OF APPROPRIATELY AND
ADEQUATELY TRAINED, CULTURALLY
COMPETENT, PROFESSIONALS**



LOW WAGES/RATES



ACROSS ALL SERVICES

- Healthcare
- Mental Health
- Behavioral Health
- Employment
- Local Community Programs
- Homecare
- Residential Services
- Childcare
- Education





HOUSING

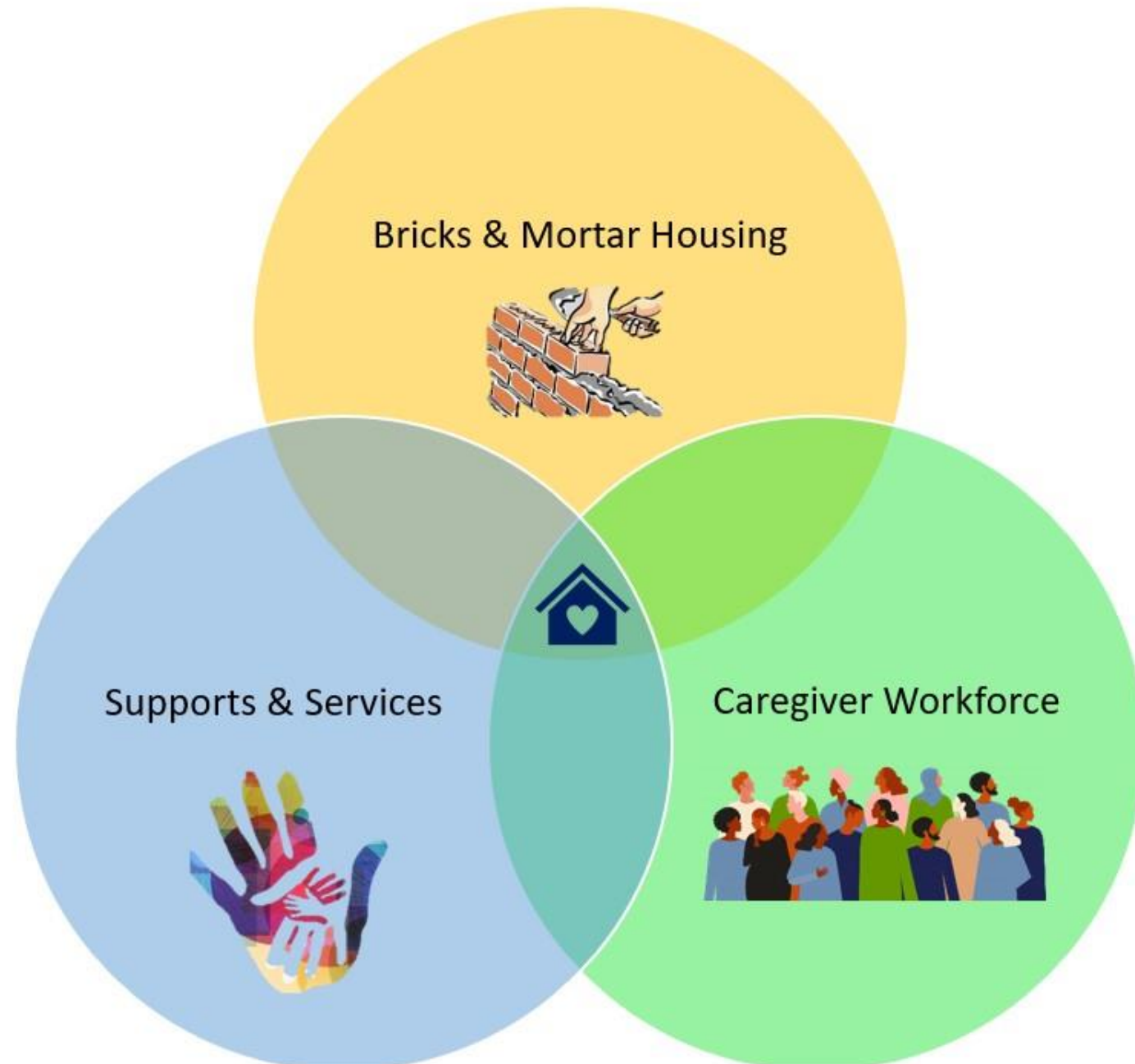


OUR POPULATION



- Extremely low-income SSI= \$943 a month
- \$2000 asset limit SSI
- 30-40% of people with IDD have a concurrent mental health diagnosis –
- About 15% of people with IDD served in Supported Living need to live alone/have 1 person in the home





Bricks & Mortar Housing



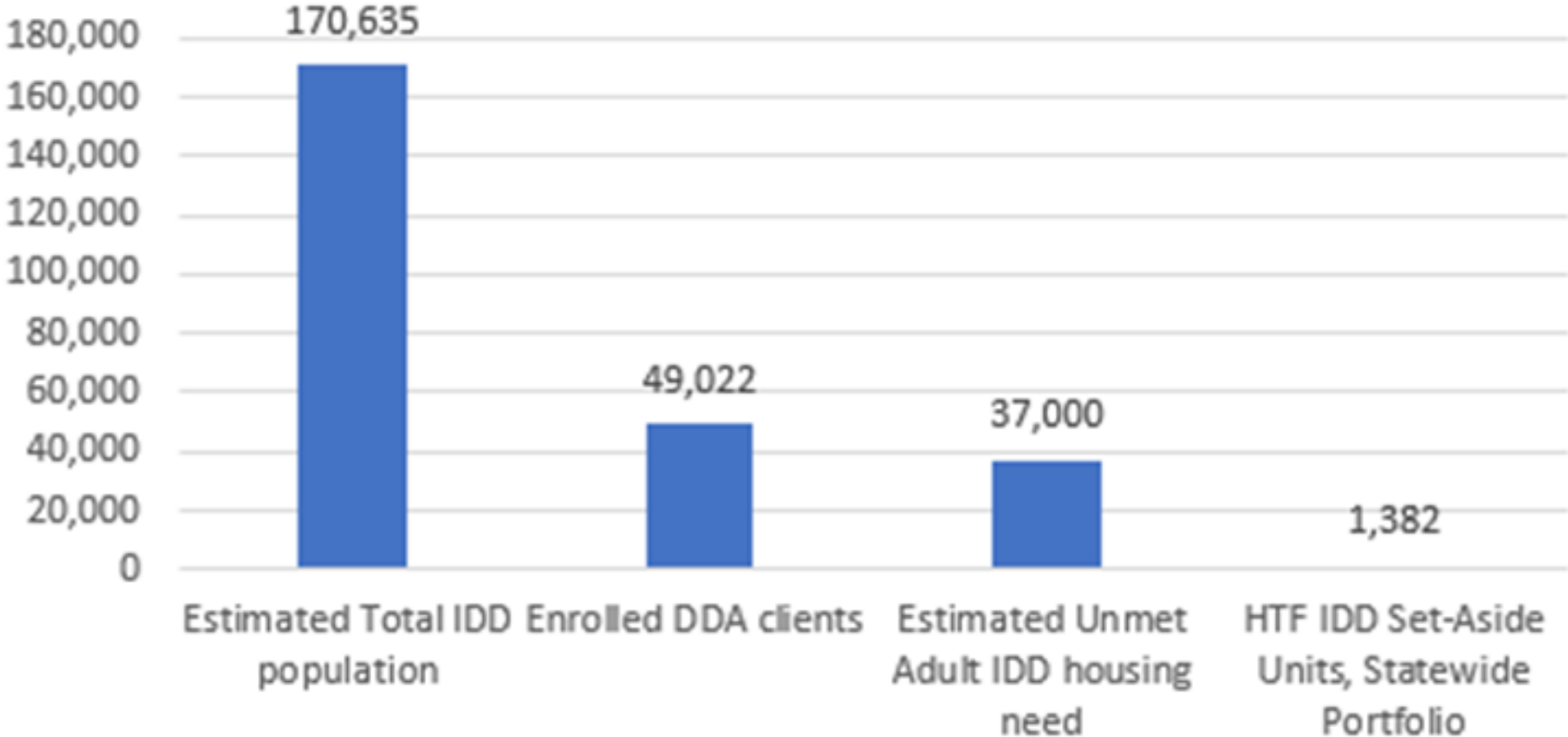
Supports & Services



Caregiver Workforce



2021 Washington State IDD Population and Housing at a Glance





PRICED OUT

- There is no United States housing market in which a person living solely on Supplemental Security Income can afford a safe, decent apartment without rental assistance.

**Technical Assistance Collaborative, 2024 Priced Out report*



WHAT IS NEEDED?

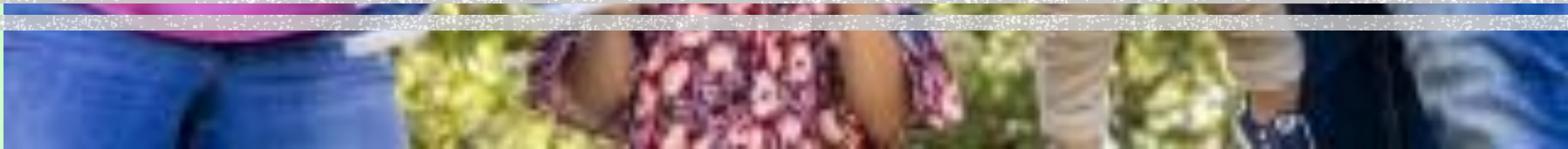


- Affordable
- Accessible
- Integrated





FAMILY SUPPORTS





- Families are the long-term care system for individuals with I/DD
- **16,062 (55.3%) Adult DDA clients** live with and receive care from a **parent** or a **relative**
- It is estimated that more than 2000 individuals over the age of 40 are living with parent

FAMILIES NEED

- Affordable, Accessible Reliable Childcare and after-school programs
- Adequate funding for supports that give individuals meaningful things to do while family members work
- An occasional break from caregiving (respite)
- A reliable network of well trained, care providers
- Timely and easy to use services
- Information & Support
- Assistance navigating systems



AGING FAMILY CAREGIVERS NEED

- Support to plan for the future
- Assurance there will be things in place when they are no longer able to provide care





EDUCATION REFORM IS NEEDED

- Washington is 44th in the nation in use of inclusive practices
- Washington continues to send many of our high acuity students with I/DD out of state.
- Washington continues to restrain and isolate students with disabilities disproportionately
- Washington continues to place a funding “cap” on school districts





TRANSPORTATION

- Accessible
- Reliable
- Affordable





CAN YOU HELP?

