

Children & Adults with Developmental Disabilities



Who has a Developmental Disability?

RCW 71.A defines people with developmental disabilities as having mental retardation, cerebral palsy, epilepsy, autism or other neurological conditions similar to mental retardation.

Most importantly people with developmental disabilities are our Family Members...Neighbors...Friends...Classmates...Co-workers

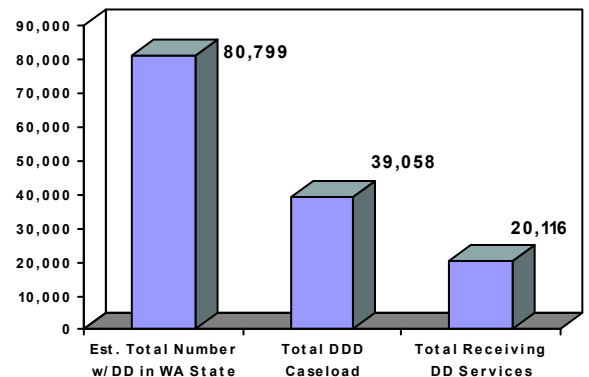
What are the Major Causes?

The majority of causes are unknown. Some identified causes are related to chromosomal abnormalities...damage to the central nervous system...birth trauma...genetics...injuries.

How Many People have a Developmental Disability?

Approximately 1.58% of the general population is estimated to have a developmental disability. In Washington State, this means that about 81,000 children and adults may have this diagnosis.

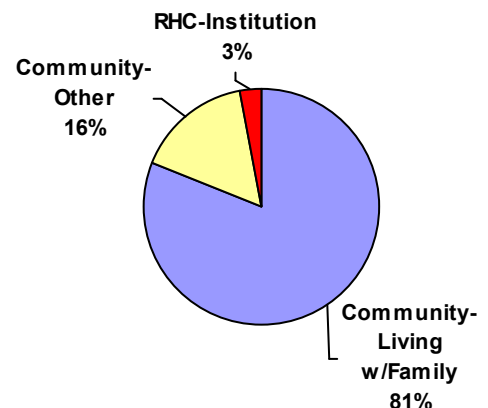
The current caseload of the Division of Developmental Disabilities (DDD) is approximately 39,000, which shows that only half of all people with DD seek services from the state. Of this number, about half are still waiting for services.



Where Do People Live?

The majority of people with developmental disabilities live at home with their parents or other relatives. Some adults live on their own or in a group setting with publicly funded in-home and out-of-home support.

930 individuals on the DDD caseload (3%) live in 5 state-run DD institutions called Residential Habilitation Centers (RHCs). People living in institutions have no greater level of disability than many who are being supported in their own homes by family or community service providers.



What do People Want?

**Employment... Education... Family... Friends... Opportunities...
...a Regular Life**

Developmental Disabilities

Grassroots Advocacy



Community Values

Developmental Disabilities advocacy represents the statewide effort of individuals with developmental disabilities, their family members, service providers and disability organizations.

We are joining together to promote quality community-based services for all people with developmental disabilities.

Times have changed from the days when children and adults with significant disabilities were segregated, moved into institutions, denied education and opportunities to work and participate in our communities.

The majority of people with developmental disabilities now live with their families or in their own homes, with support to be as independent as possible. As a result of changing values, and with the support of state and federal government funding and policies:

Children with developmental disabilities participate in school, adults gain employment, and our communities benefit.

Unlike the old days of defining people by what is wrong with them, community DD advocacy is based on the fundamental belief that having a disability is a normal part of life.

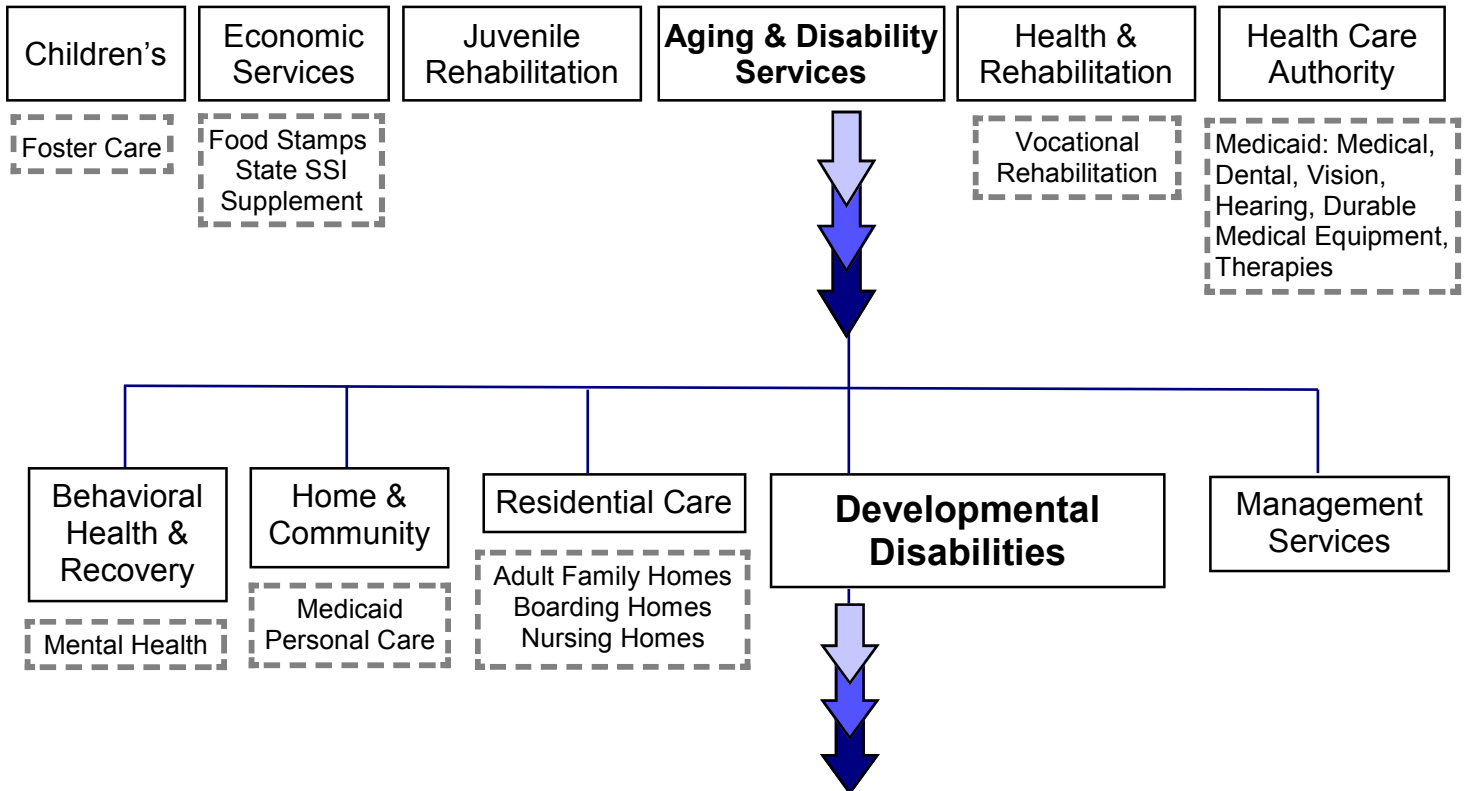
These are not the opinions of a few groups; they are the values of a state and nation moving forward.

Developmental Disabilities: Overview



Department of Social and Health Services

NOTE: Dashed boxes indicate non-DD services accessed by some individuals with developmental disabilities.



DD Services:

- Case management/Intake (provided by the state)
- Early Intervention Services for children age birth-3 (state contracts through counties)
- Individual & Family Services (respite, therapies, home adaptations, etc.)
- Employment/Day (state contracts through the counties)
- Individual & Family Services (respite, therapies, home adaptations, etc.)
- Medicaid Personal Care (assistance in-home with activities of daily living)
- Supported Living/Staffed Residential Services (also known as Community Residential — the community-based alternative to institutional care)

Institutional Care:

- Fircrest—Habilitation Center and Nursing Home
- Rainier—Habilitation Center
- Frances Haddon Morgan Center—Habilitation Center
- Yakima Valley—Nursing Home
- Lakeland Village—Habilitation Center and Nursing Home

Developmental Disabilities: Overview



Funding for DD Services

FEDERAL MATCH

Nearly all DD service dollars are matched with federal Medicaid funding. Under Title XIX, Medicaid is used to match state funding for:

- **Home & Community-Based Waivers.** Services are based on habilitation and support to build and maintain abilities that lead to greater independence.

Waiver services include:

- Employment/Day,
- Respite
- Community Residential Services
- Therapies
- Personal care

Service types and amounts vary by waiver (Basic, Basic Plus, Core, Community Protection and Children's Intensive In-home Behavior Supports).

- **Residential Habilitation Centers.** 5 state-run institutions for people with developmental disabilities that provide habilitation and health care services to approximately 930 individuals.
- **Medicaid Personal Care.** In-home care services to assist with activities of daily living, such as bathing and dressing.

Federal Medical Assistance Percentages (FMAP) are the percentage rates used to determine the matching funds rate allocated annually to certain programs.

The American Recovery Reinvestment Act, or the Stimulus Act, which was signed into law on February 17, 2009, included a temporary increase in the FMAP. That increase was extended for 6 months, but at a lower rate.

The FMAP blended rate (July through June) for Fiscal Year 2011 is 40.02% state and 59.98% federal. The FMAP (assumed) for FY 12 is 50.03% state and 49.97% federal.

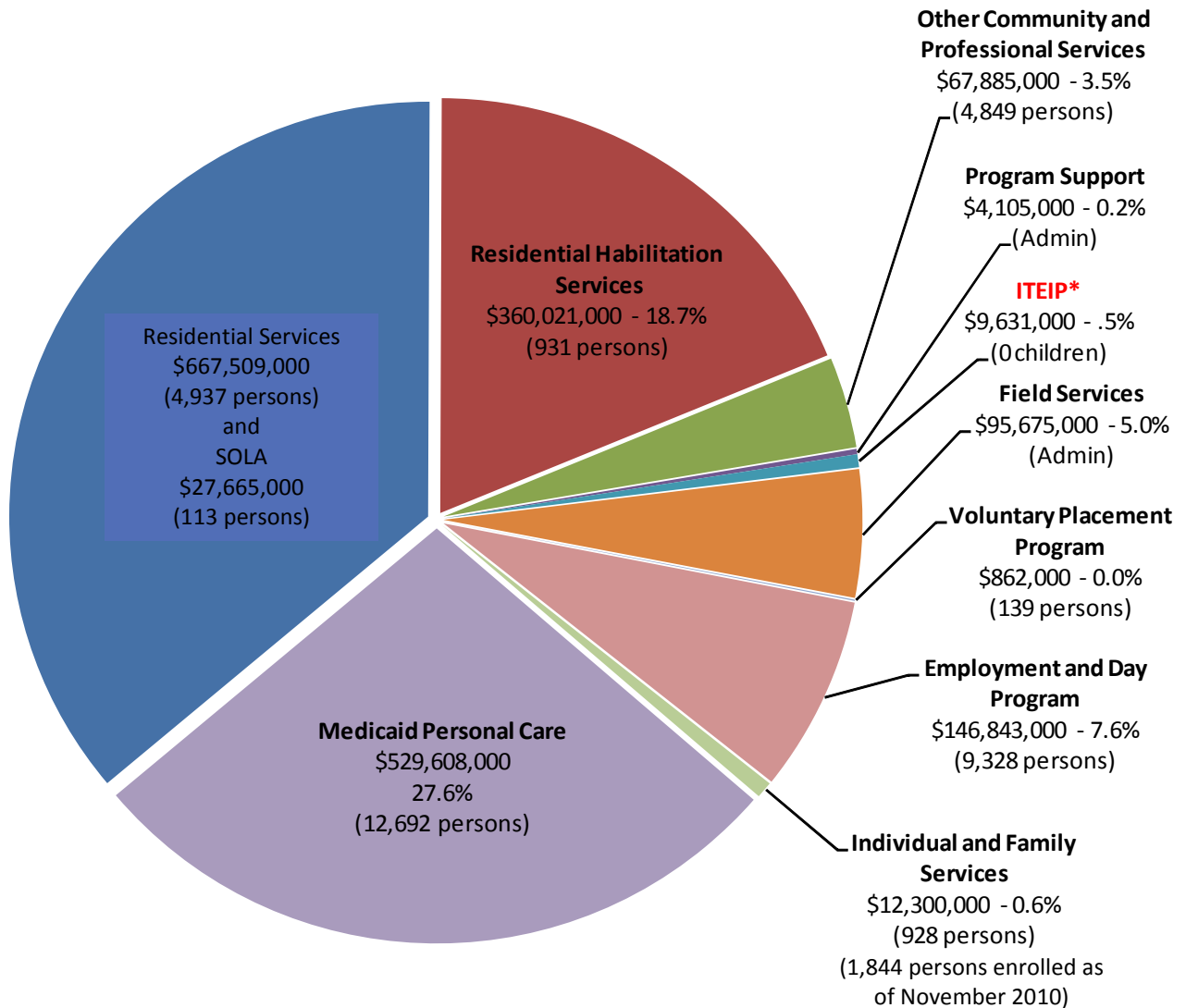
STATE-ONLY FUNDING

Approximately 4,600 clients, or 14% of the total DD caseload, receive state-only funding for:

- Family Support Services
- Employment/Day Services
- State Supplementary Payments (SSP)
- Community Residential

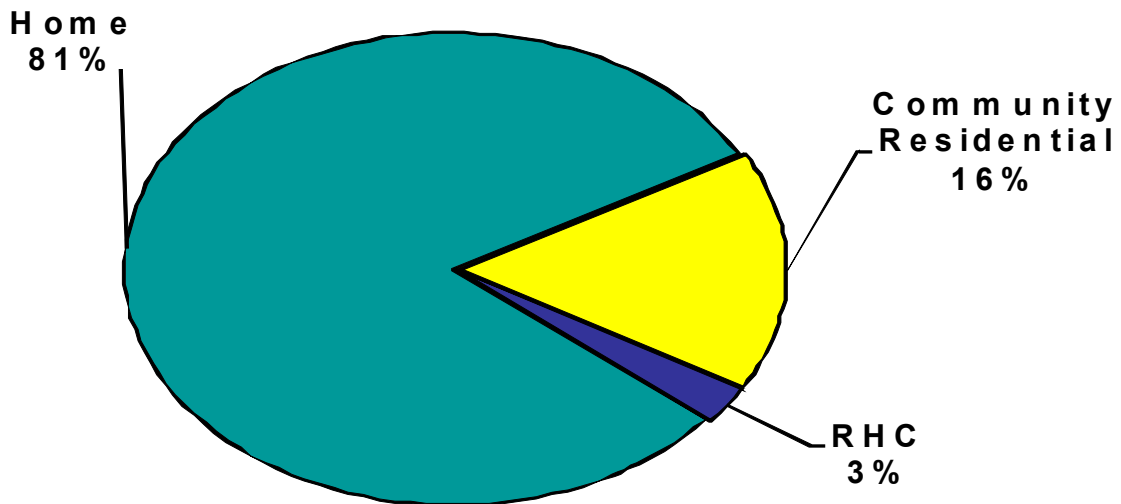
2010—2011 Biennial Base Funding For the Division of Developmental Disabilities

Biennial Budget: \$1.9 Billion (Total Funds)



*As of July 2010, the budget allotment for (ITEIP) was transferred to Department of Early Learning
Client counts are unduplicated for paid service month July 2010
Source: DSHS/Aging & Disability Services Administration

Where Do People with Developmental Disabilities Live?



IN-HOME (for persons in their family or own home)

Medicaid and Waiver Personal Care	10,524
Not Receiving In-Home Services	20,657
	31,181

Community Residential

Supported Living	3,422
Personal Care Residential	1,853
Group Homes	303
Alternative Living	214
Companion Home	57
Community ICF/MR	54
Voluntary Placement Program (children)	139
State Operated Living Facility (SOLA)	119
Total with a Community Service	6,161

Residential Habilitation Center (RHC)

Fircrest	200
Rainier	366
Lakeland	220
Yakima Valley	92
Frances Haddon Morgan	53
Total RHC Residents as of July 2010	931

80,799 people estimated in Washington State with a developmental disability
 39,058 clients enrolled with the Division of Developmental Disabilities
 20,116 of those clients receive at least one paid service from DDD
 18,892 of those clients received no paid service from DDD in July 2010*
 13,617 of those clients receive no paid services from DDD at all

* Received no paid service in this service month, but may receive a service in other months of the year) Note: Includes Waiver, Medicaid Personal Care and State Only fund sources. Source: DSHS/Aging and Disability Services Administration as of July 2010

Developmental Disabilities Unmet Need

County	Individual & Family Services Wait List	Employment for High School Graduates for 2010-11 Biennium	Employment for Age 21-62 not in a day program	Senior Families Persons age 40 + living with parents
Adams	13	7	16	10
Asotin/Garfield	14	2	30	6
Benton/Franklin	365	60	481	70
Chelan/Douglas	78	16	118	20
Clallam	50	29	223	26
Clark	471	78	687	121
Cowlitz	53	31	201	33
Ferry	7	2	16	4
Grant	89	22	189	27
Grays Harbor	91	21	166	22
Island	50	6	67	13
Jefferson	19	2	59	11
King	1977	250	2,453	400
Kitsap	201	45	300	68
Kittitas	18	3	40	6
Klickitat	15	3	52	9
Lewis	57	18	168	26
Lincoln	13	3	10	5
Mason	52	8	89	26
Okanogan	28	12	84	8
Pacific/Wahkiakum	22	7	50	9
Pend Oreille	13	2	28	12
Pierce	570	147	1,333	208
San Juan	2	0	13	1
Skagit	66	23	142	32
Skamania	10	1	22	3
Snohomish	368	100	723	123
Spokane	564	136	958	145
Stevens	56	6	100	10
Thurston	172	58	390	67
Unknown	1	0	7	2
Walla Walla/Columbia	66	16	133	18
Whatcom	111	27	240	33
Whitman	15	6	18	4
Yakima	216	50	611	97
Total	5,913	1,197	10,217	1,675

Data from Aging and Disability Services Administration as of October 2010

Help the Unserved: Increase Waiver Capacity

Issue

The Medicaid Program continues to provide the majority of DD funding for both institutional and community services. Home and Community Based Services (Waivers) provide an alternative to institutional care. This year a new waiver (Children's Intensive In-home Behavior Supports) was implemented to reduce the number of children entering state institutional care.

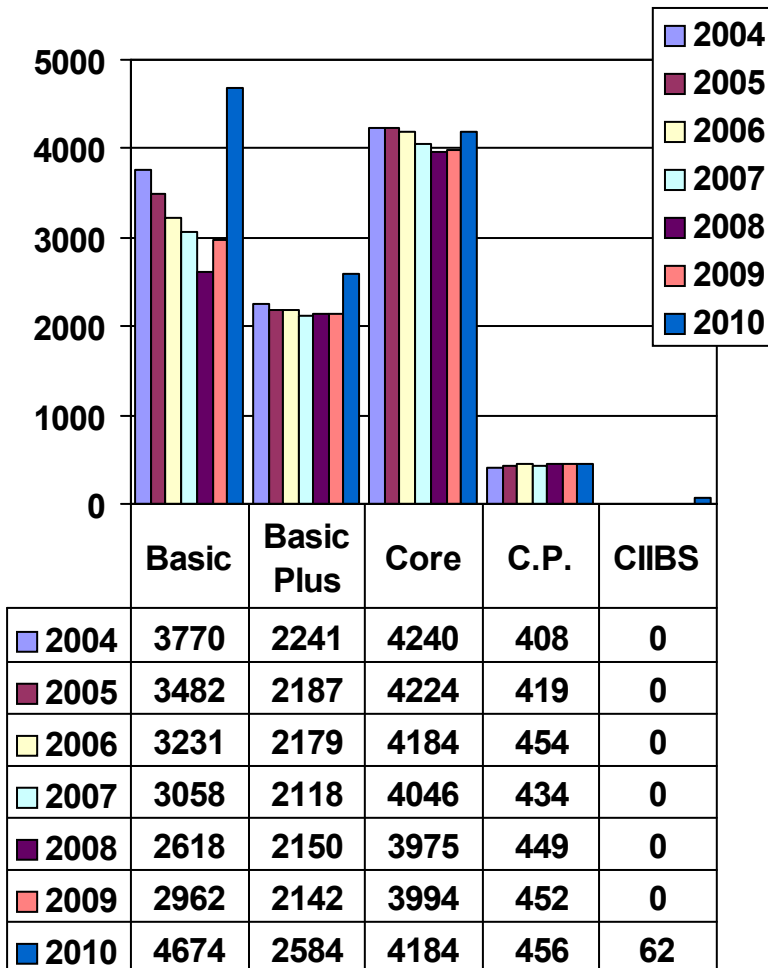
Total Waiver Capacity:

2004: 10,659
2005: 10,312
2006: 10,048
2007: 9,656
2008: 9,048
2009: 9,550
2010: 11,944

Overall Caseload Growth:

(Unduplicated numbers)

2004: 34,804
2005: 36,532
2006: 38,527
2007: 40,059
2008: 41,110
2009: 42,294
2010: 39,058



There are currently 893 individuals approved, but waiting for waiver services.

(Data received from DSHS/Aging and Disabilities Services Administration) July 2010

Key Waiver Elements

Basic	Meets ICF/MR level of care guidelines, but has a strong natural support system (family). Does not need out-of home residential services. Includes: employment/day services, respite, therapies, personal care.
Basic Plus	Meets ICF/MR level of care guidelines, but is at high risk of out-of-home placement or loss of current living situation. Includes: Basic Waiver service coverage, skilled nursing, additional employment/day funding.
Core	Meets ICF/MR level of care guidelines. Requires residential habilitation services or lives at home, but is at immediate risk of out-of-home placement. Includes all Basic and Basic Plus waiver services, in addition to supportive living services (up to 24 hour supervision and support).
Community Protection	Meets ICF/MR level of care and requires 24 hour, on-site, staff supervision to ensure safety of others ; requires therapies and/or other habilitation services; meets the criteria for "community protection."
CIIBS	The Children's Intensive In-home Behavior Supports waiver meets ICF/MR level of care and provides in-home positive behavior supports from qualified from PhD or MA level therapists with intense case management and collaboration with family, school & other service providers.

Families of People with Developmental Disabilities Want to Save the State Dollars!

The National Alliance for Caregiving (NAC) released a report in November 2009 focusing on the caregiving of children with special needs. There are an estimated 65.7 million unpaid caregivers who provide care for a child or adult with special needs. This study was done on a group of 1,757 caregivers.

- Half of caregivers of children are providing care to their own son or daughter (55%). Child care recipients are also commonly a grandchild (18%), another relative such as a niece or nephew (13%), a friend (8%), or some other non-relative (5%). The remaining 1% provide care to a younger sibling.
- A large majority of caregivers of children help by monitoring the child's condition (85%), by ensuring that others know how to deal with him/her (84%), and by advocating on his/her behalf with schools, government agencies, or care providers (72%). Six in ten perform treatments or therapies for learning, emotional or behavioral issues (65%), give medicines or injections (64%), or deal with financial issues (63%). Four in ten are involved in giving physical or medical therapies (44%), preparing a special diet (40%), or arranging/supervising outside services (39%).
- Caregivers of children are more likely to be the sole unpaid caregivers than are caregivers of adults. While 54% of caregivers of children report someone else has also provided unpaid care to the child within the past 12 months, significantly more caregivers of adults report having this assistance (68%).
- Seven in ten caregivers of children perceive themselves to be the primary caregiver (72%), including 44% who are sole caregivers and 28% who report that there are other unpaid caregivers but that they provide the most care to the child. Caregivers of children are more likely to be the primary unpaid caregiver than are caregivers of adults (53%).
- Three out of four caregivers of children report making changes to their work situation. Those caring for a child are three times as likely as those caring for an adult to have had some of the more severe impacts on their employment situation.
- Of those caring for a child:
 - 74% go in late, leave early, or take time off.
 - 32% take a leave of absence.
 - 30% reduce work hours or take a less demanding job
 - 21% give up working entirely
 - 15% lose job benefits
 - 11% turn down a promotion
 - 5% choose early retirement
- Of those caring for an adult:
 - 65% go in late, leave early, or take time off.
 - 18% take a leave of absence.
 - 9% reduce work hours or take a less demanding job
 - 7% give up working entirely
 - 4% lose job benefits
 - 5% turn down a promotion
 - 3% choose early retirement

Family care providers endure a lot in expenses, health problems, emotional stress and lost personal time committed to caring for their loved one with a developmental disability. Many of these individuals would be eligible for admittance into a Residential Habilitation Center (state institution). Families want to keep their loved one at home, but need a little extra help from Medicaid Personal Care hours, Individual and Family Services (respite) or services that are provided through Home and Community Based Services Waivers.

\$15,208 per month for RHC

\$6,500 per month for Community Supported Living

\$6,177 per month for CORE Waiver

\$2,229 per month for Basic Plus Waiver

\$1,739 per month for Medicaid Personal Care

\$296 per month for Individual and Family Services

Every option in the community is LESS THAN HALF the cost of an RHC!