

Children & Adults with Intellectual/Developmental Disabilities



Who has an Intellectual/Developmental Disability?

RCW 71.A defines people with developmental disabilities as having mental retardation (intellectual disability), 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

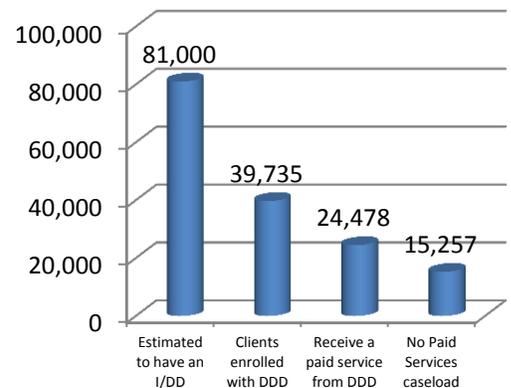
What are the Major Causes?

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 Intellectual/Developmental Disability?

Approximately 1.58% of the general population is estimated to have an Intellectual and/or developmental disability (I/DD). In Washington State, this means that about 81,000 children and adults may have this diagnosis.

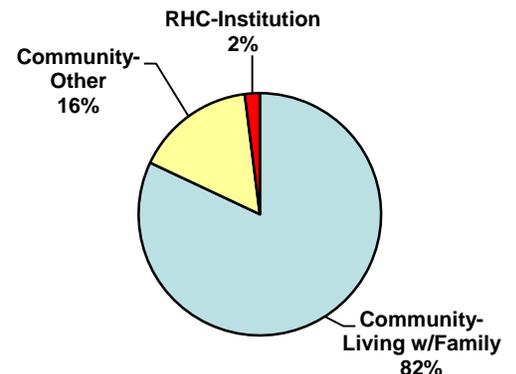
The current caseload of the Division of Developmental Disabilities (DDD) is approximately 40,000, which shows that only half of all people with I/DD seek services from the state. Of this number, more than 15,000 are still waiting for services.



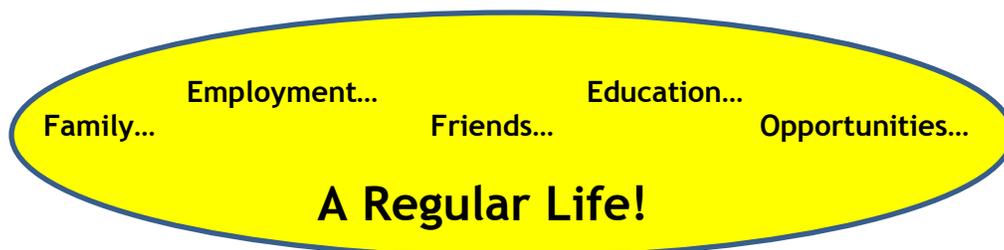
Where Do People Live?

The majority of people with I/DD 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.

About 825 individuals on the DDD caseload (2%) live in 4 state-run DD Intermediate Care Facilities (ICF) (known as Residential Habilitation Centers or RHCs). People living in these state-run 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?



No Paid Services Caseload – There are 15,257 individuals with Intellectual/Developmental Disabilities (I/DD) who are clients of the Division of Developmental Disabilities (DDD) and are eligible for paid services, yet receive nothing because there is no funding allocated. This is known as the NO PAID SERVICES caseload. There are 21,211 people who do receive at least one paid service from DDD. The level of need for those not receiving services is the same as those who are getting something. A survey of the NPS caseload shows the #1 need is respite, which can be provided at low cost through the Individual and Family Services program.

Medicaid Services – Medicaid Personal Care is an entitlement service for those who qualify. It provides in-home support for people with I/DD who need assistance with activities of daily living such as bathing, toileting, feeding, etc. About 30% of the NO PAID SERVICES caseload qualify for MPC services, but are unaware they do. DDD does not notify people that they may be eligible.

“Optional” Medicaid services - Pharmacy, vision, hearing and therapy services are considered “optional”, meaning the state is not required to provide them, but has done so for those in need in our state. People with I/DD often have severe health issues that require medication for their survival. People with I/DD who live on social security and don't have extra money to pay for costly medications.

Individual and Family Services (IFS) - The IFS program partners with families caring for their loved one in the family home. It is one of the most cost-effective programs in DDD. It is centered on the needs of the person with I/DD and their family. They can use their allocation to pay for services identified in their DDD Assessment. Most families use their funding for respite. This program is state-only; it receives no matching Federal funds.

HCBS Waiver Services - Home and Community Based Services (HCBS) waivers were created in the Medicaid program as an option for people who are assessed as eligible for care in an Intermediate Care Facility (ICF), but “waive” that entitlement and choose instead to receive their services in a community setting. This is a huge fiscal savings for the state, as the more costly ICF placement is an entitlement for those who qualify.

Abuse and Neglect Investigations – Disability Rights Washington released a report detailing poor responses from DSHS to allegations of abuse and neglect in supported living and in State Operated Living Alternatives (SOLA). They recommended mandating prompt investigations, having sufficient investigators for timely investigations, specific requirements for providers, enhancing state regulatory authority and establishing an interdisciplinary committee to review client deaths. *(Community advocates also recommend that when a person with I/DD is sexually assaulted, the perpetrator should be arrested and prosecuted; have a monetary fine on mandatory reporters who fail to report; hire state investigators who specialize in investigations involving people with I/DD and create a DD ombudsman. DSHS should ensure that people in community residential services also receive an employment or day program as a way to reduce isolation and increase community involvement.)*

Behavioral Services – The prevalence of autism has increased to 1 in 110 children; many parents struggle to understand how to meet the challenges this means for their family. Behavioral services are provided to about 75 families through the Children's Intensive In-home Behavior Supports (CIIBS) waiver program. Families want to keep their child in the family home, but without the availability of state funded community services they are faced with no alternative but out-of-home placement.

Case Managers for NO PAID SERVICES – In 2010 the legislature cut all funding for case managers for the NO PAID SERVICES caseload. Families have no one to connect with to find out if they might be eligible for some other service such as MPC. Community organizations have tried to fill the gap but struggle with funding and have no access to the database to connect with those families.

Supported Living Provider Wages - Funding for direct support wages for supported living providers has been cut to the point that wages no longer reflect the increased responsibility and complexity of supports. In fact, Supported Living provides exactly the same level of support to clients on the same waiver as those in the State Operated residential settings (SOLA), who are paid 35% higher.

Transition Services for Graduates – Each year there are a specified number of students with I/DD who graduate from high school. It is important to provide employment or day services for them allowing them to participate in their communities and have the chance to be tax-paying citizens.

Office of the Education Ombudsman – The Governor's Office of the Education Ombudsman (OEO) is an independent agency not controlled by the state education agency (OSPI). The OEO has resolved thousands of complaints. In 94% of the cases the issues were completely resolved and the parents dropped potential lawsuits against the district.

Office of Public Guardianship (OPG) - The OPG provides guardians for people who are incapable of caring for themselves and protecting their own interests. We need to maintain the current OPG caseload (100 persons) to ensure that the vulnerable adults facing significant risks continue to be protected.

Housing Trust Fund (HTF) - In 1993, the Legislature created the DD set-aside within the State Housing Trust Fund in the Capitol budget. The HTF DD Set-Aside ensures that tenants with I/DD living primarily on SSI only pay 30% of their income for rent and utilities, the owner commits to 40-years of this affordability, units are reserved for people with I/DD and that all units include a level of accessibility to ensure health and safety.