

Washington State Department of Social and Health Services

Transforming
Lives

REPORT TO THE LEGISLATURE

Parent(s) with Disabilities Data Study

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Executive Summary

During the 2023 session, the Legislature directed DSHS Developmental Disabilities Administration to study opportunities to enhance data collection on clients in family units with at least one parent having an intellectual or developmental disability. This was done through the 2023-2025 biennial operating budget bill.

This report will identify:

- Opportunities to improve the existing Comprehensive Assessment Reporting Evaluation tool;
- Ways to strengthen data sharing across state departments and school districts;
- Methods to analyze new and existing data; (and)
- An inventory of existing support programs and services for parents with intellectual or developmental disabilities.



As part of this data study, DDA convened an interdepartmental workgroup which included a range of subject matter experts including: representatives from DSHS' Research and Data Analysis Division, DDA Comprehensive Assessment Reporting Evaluation program management staff, DDA's foster youth cross-systems program manager, DDA's educational liaison program manager, the DD Ombuds & stakeholder engagement program manager, and representatives from the Department of Children, Youth, and Family Services.

In addition, DDA solicited input from community partners, including the Supporting Parents with IDD Cohort facilitated by the Arc of Washington. This report will include specific input from individuals with disabilities who have lived experience as parents of minor children.



Background

Parents with IDD face enormous obstacles to successful parenting, both in Washington state and nationally. Some of the key challenges include long standing attitudinal bias against parents with disabilities across systems, a lack of parenting supports and services designed for people with IDD, a lack of awareness of the few tailored supports that do exist and a well justified fear on the part of parents with disabilities to reach out and ask for help.

Historically, DSHS has offered few specialized supports and services designed for parents experiencing intellectual or developmental disabilities. There has been some educational and case management outreach over the years, but this effort has largely been organically driven by case and program management and has lacked formalized policy or service. While there are some services available for parenting education and skill acquisition through DSHS, there is very little tailored for parents with intellectual or developmental disabilities through DCYF and local school districts.

In recent years, some improvements have been made through DDA, DCYF and school districts. Several years ago, DDA added a supported parenting service through a waiver amendment. Some school districts now have specific policies and procedures that address requests for disability accommodations by parents and guardians. DCYF now provides case modifications and community supports for parents who have a cognitive disability. Most of these efforts, however, are still in their infancy with little utilization and a lack of outcome data.

“The system has challenges that need to be addressed. It’s not set up to support parents (with disabilities) who may have personal care or transportation support needs of their own.”

– A parent with a disability and member of “Supporting Parents with Cohort”





Methodology

Quantitative and qualitative data, as well as testimonials, were collected and analyzed for this report.

Data was gathered from DSHS' Research and Data Analysis Unit, DSHS Economic Services Administration, the Department of Health, DCYF and DDA's CARE tool and payment systems. School district data could not be accessed as currently there is not a data sharing agreement in place.

In order to identify parents with disabilities and produce information on their children, the following approaches were used.

- 1. DDA CARE data:** RDA accessed the CARE field which identifies whether a client is a parent of a minor child. This is a new yes/no CARE question added July 1, 2023. It is required for all assessments given to non-Residential Habilitation Center clients age 18 and older. While this approach identifies parents, it does not identify the associated children who may or may not also be enrolled with DDA.
- 2. Birth certificate and child support data:** Birth certificate information was gathered through a partnership with DOH for DDA clients identified as parents. Support enforcement records were also used to identify the associated children and produce measures about the characteristics and needs of those children.
- 3. Economic service assistance unit data:** Economic services assistance units, which are similar to though distinct from household units, where the client is a household head or partner of the household head with related children in the home. This method allowed RDA to identify associated children and produce measures about the characteristics and needs of the children.

Two Supporting Parents with IDD Cohort meetings were attended by DDA staff and input was solicited directly from parents and other cohort members.

Key Data Points

The data we accessed through DSHS' Integrated Client Databases with the help of DSHS' Research and Data Analysis Division indicates there are approximately **850** known parents of minor children with a diagnosis of intellectual or developmental disabilities in Washington state today. For the purposes of this report, we were largely limited to DDA and Medicaid clients with a formal diagnosis of an intellectual or developmental disability, in accordance with current Washington state rules and standards. Please note DDA is currently in the process of redefining eligibility requirements, without regard to IQ. These new eligibility standards will greatly increase access for people with cognitive disabilities in our state. The new eligibility rules will take effect no later than July 1, 2025. We know that many more parents in Washington state who experience cognitive disabilities meet the broader federal definition. These parents also depend on and are impacted by our healthcare and child welfare systems in Washington state. In preparation for this report DSHS, DCYF and other partnering organizations felt strongly that the need for more supports and services is not limited to those parents involved with DCYF, DDA or Medicaid.



	DDA Clients who are Mothers	DDA or Medicaid Clients with a DD Diagnosis who are Mothers	DDA Clients who are Fathers	DDA or Medicaid Clients with a DD Diagnosis who are Fathers	Children with a Parent who is a DDA Client	Children with a Parent who is a DDA or Medicaid Client with a DD diagnosis
Total	343	606	155	236	491	833
High Medical Risk Flag	76	193	21	37	--	--
Mental Health Diagnosis	97	294	28	80	73	144
Medicaid Coverage	305	568	121	202	440	753
Child Protective Services	63	118	26	43	77	137
DDA Case Management	97	97	57	57	34	58
Basic Food Assistance	245	440	96	157	273	492
Employed	103	213	77	119	---	---

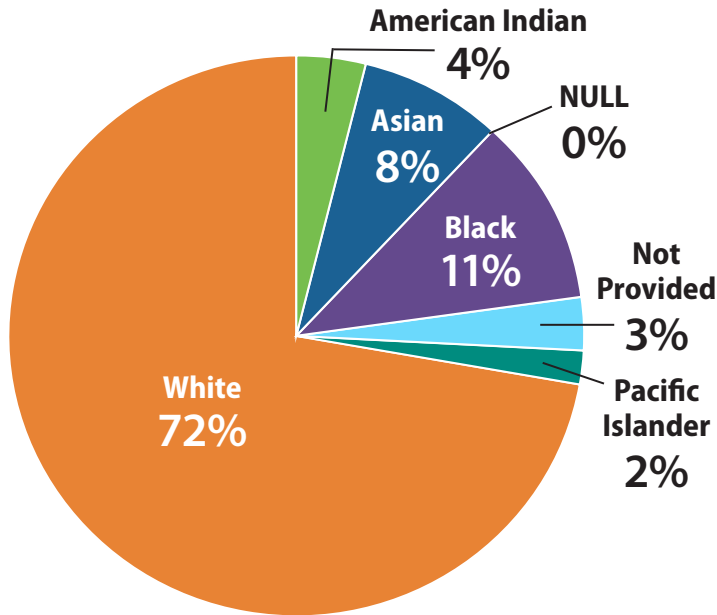
More detailed information on health conditions, mental health conditions, and social service use is available in the [Appendix](#).

A full report from RDA will be available in fall 2024 at this [link](#).

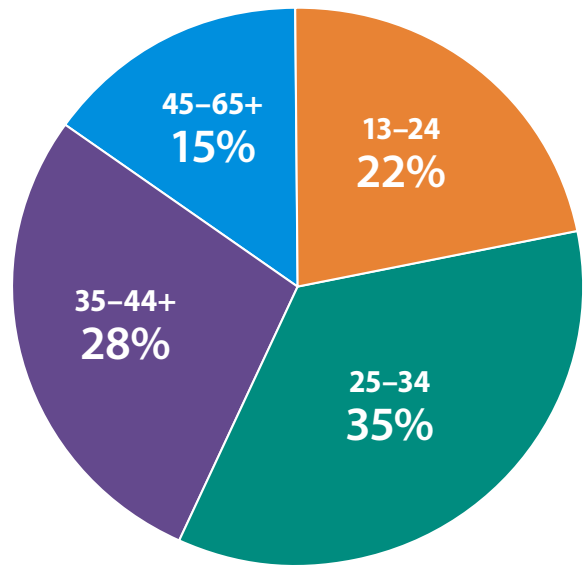


DDA CARE Data

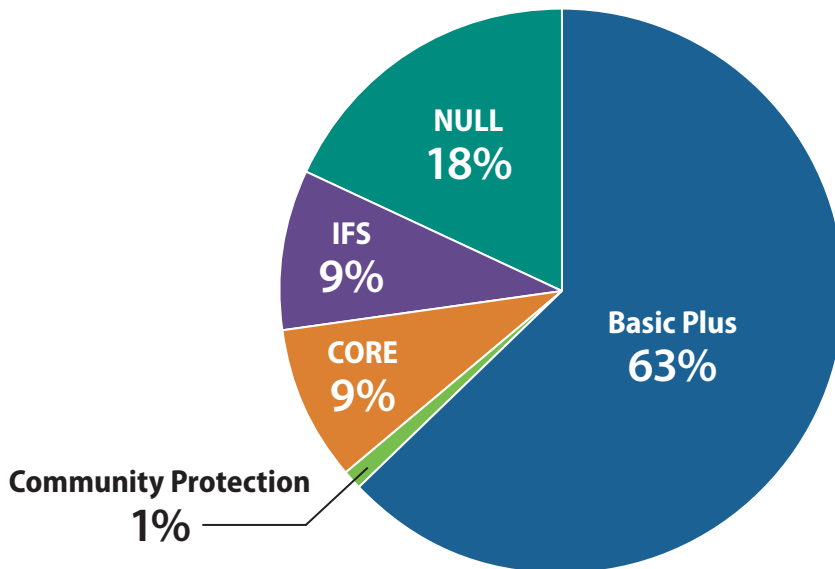
**DDA Clients
Who Are Parents by Race**
(primary identified race)



**DDA Clients
Who Are Parents
by Age Range**



**DDA Clients
Who Are Parents by Waiver**





Key Findings and Analysis

Parents with IDD account for about 0.3 percent of all Medicaid parents in Washington state. There are nearly 500 individuals served through DDA who are parents of minor children. Approximately 350 additional parents who receive Medicaid services but are not DDA clients, have been identified as having a DD diagnosis.

Fear and stigma may be a factor for parents with intellectual and developmental disabilities. People we spoke to in the Supporting Parents with IDD Cohort, for example, expressed concerns that if they shared their stories, they feared child welfare would come into their lives, scrutinize, and jeopardize their custody of their child. This fear is supported by past studies on the topic which have also found, “adults with intellectual and developmental disabilities, in particular, have expressed reluctance to parent due to fear of Child Protective Services involvement.”

As mentioned in the introduction, there are a number of support services available through DSHS, DCYF, the school districts and other sources for parent education and support, in general. Resources specifically targeting parents with IDD, however, are limited. In recent years there has been increased awareness of the need and some tailored supports have been developed or evolved to better support people with IDD. DCYF now provides case modifications and community supports for parents who have a cognitive disability. There are also examples of best practices across the state where DSHS, DDA and DCYF case management work collaboratively to support families with a parent with IDD. Such partnerships have been more formalized in some areas. There is also improvement within school districts in terms of awareness and accommodation for parents with IDD. Most of these efforts, however, are still in their infancy and the tailored services which have been developed have been under-used. Fear and stigma associated with parenting by people with IDD also creates barriers to awareness and access.

There are several services offered through DDA that may serve to support parents with IDD, and families as a whole, such as: respite, stabilization services, peer mentoring, person centered plan facilitation, assistive technology, and staff and family consultation.

There is one service specifically developed for and intended to support parents with IDD. The service is called Supported Parenting. Supported Parenting was added to the CORE and Individual & Family Services waivers several years ago. It has hardly been used at all since it was developed. Just one client has taken advantage of this service in recent years. Supported Parenting is intended to support DDA clients who have children of their own (or are expecting) and are enrolled in the IFS or CORE waivers. Services may include teaching, parent coaching and other supportive strategies in areas critical to parenting which are designed to build parental skills around the child’s developmental domains.



Supported Parenting services may be provided by the following licensed, registered or certified professionals contracted with the Developmental Disabilities Administration to provide Supported Parenting.

- Audiologist
- Licensed practical nurse
- Marriage and family therapist
- Mental health counselor
- Occupational therapist
- Physical therapist
- Registered nurse or licensed practical nurse
- Speech/language pathologist
- Social worker
- Psychologist
- Certified ASL instructor
- Nutritionist
- Counselors registered or certified in accordance with the requirements of chapter 18.19 RCW
- Certified dietitian
- Recreation therapist registered in Washington and certified by the National Council for Therapeutic Recreation
- Psychiatrist
- Professional advocacy organization

More information and evaluation are needed to better understand the discrepancy between the unmet needs of parents with IDD and the use of DDA's supported parenting service. We do know that supported parenting hours through IFS are limited to funds available from within the IFS waiver's annual allocation. Supported parenting is just one of many services a client may choose from within their annual IFS waiver budget. The vast majority choose other IFS service from the menu, most notably respite service. Core waiver participant service hours (for supported parenting) are limited to the hours identified in their person-centered service plan based on need. Other barriers to the use of supported parenting may be a need for provider recruitment, fear and stigma, and the need for more education and outreach about the service. DDA is currently undertaking a waiver restructuring project which may also present an opportunity to better promote the supported parenting service. Some input we received for this report did suggest that many DDA case resource managers and DCYF social workers may not be aware of the supported parenting service. Finally, parents with IDD have advocated for more supports to be included in the supported parenting services and specifically to "allow for hands on support" for parents and how providers can assist with tasks to help their children. It was also suggested that the supported parenting service should be reviewed with stakeholder input.

¹Parenting Focus Group held by DDC at the SeaTac Conference Center on April 29, 2015. Supporting Parents w IDD Cohort, March 26, 2024



Data Elements & Limitations:

As illustrated in the data section above, a substantial amount of data was collected on the prevalence and characteristics of parents with intellectual and developmental disabilities in Washington state. This was possible with the help of DSHS' Research and Data Analysis Division (link again here to the RDA data report), and through partnerships and data sharing agreements with other state departments and administrations. Information on client demographics, Medicaid eligibility, risk scores, emergency department utilization, economic services and behavioral health medical history come from the DSHS Integrated Client Databases which integrate administrative data from multiple Washington state agencies. Client assessment scores come from DDA's CARE database. Birth data comes from the Department of Health. DDA also recently added a question to the CARE tool, adding a new required question which asks whether the individual being assessed has a child under 18 years old.

There were some limitations to data collection. For example, OSPI is not currently a part of DSHS' Integrated Client Databases. There is not a current general data sharing agreement in place between DSHS' RDA and OSPI. This prevented RDA and DDA from being able to cross DSHS client data with student data from school districts. CARE data was also limited. For example, CARE questions and associated data reports do not include characteristics about the children of parents enrolled and assessed through DDA. For example, we could not easily determine the nature of the current relationship between the parent and child or whether the child was also eligible, enrolled or receiving services through DDA. It was also suggested that richer exchanges of data between DCYF and DDA may be helpful.

Improvement to these data areas should be considered. The parents and stakeholders we spoke to in preparation for this report expressed concerns for which richer data may be helpful. One theme shared by stakeholders was the idea that the system needs to do a better job at serving the family as a whole. The Supporting Parents with IDD Cohort workgroup, for example, believed the system was not set up to support the entire family and that Medicaid services, in particular, were not set up this way and served to create barriers to supporting both the parent and the child, together. Support with activities of daily living needs for both the parent and child, including transportation (i.e. to grocery store/grocery shopping) were included in the examples given. Improving data sharing between DSHS and OSPI as well as richer data collection by DSHS on the nature of the relationship between the parent with IDD and their minor child may provide more context and could help to better gauge the scope of the needs of parents with intellectual and developmental disabilities. Such data may also serve to reinforce the idea that there is a need for systemic change and to implement a more holistic approach to supporting these families.

[Appendix](#)