

Institute on Human Development and Disability Specialty Clinics

ANNUAL REPORT 2024

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Executive Summary

The Institute on Human Development and Disability (IHDD) at the University of Washington houses a network of twelve specialty clinics serving individuals—primarily children—with developmental, learning, behavioral, and genetic conditions. Eleven clinics are operated in partnership with UW Medical Center (UWMC), while the twelfth—the UW Autism Center (UWAC)—is an IHDD program that incorporates faculty and staff from the UW School of Medicine, the College of Arts & Sciences, and the College of Education. Across this network, interdisciplinary teams provide comprehensive, coordinated diagnostic, assessment, and intervention services tailored to each person and family.

In 2024, the 11 IHDD UWMC specialty clinics served 3,329 patients and conducted 6,307 visits across specialty areas ranging from developmental Follow-up and neurogenetics to pediatric audiology. In addition, the UW Autism Center (UWAC)—an IHDD program that operates outside UWMC—served 520 unduplicated individuals and delivered 10,800 visits. Taken together, IHDD’s clinical programs (UWMC clinics and UWAC) reached roughly 3,849 people and delivered 17,107 visits in 2024.

Clients span the full age spectrum but skew young: roughly half are ages 0–5 and about a third are 6–17; adults 18+ make up the remainder (~10–15%). The combined patient population is about 58% male, 42% female, and less than 1% another sex/gender. Insurance coverage is primarily commercial (52–53%) and Medicaid (~35–40%), with the balance largely Medicare (~10–13%) and a small self-pay/other share (~2–3%). These are directional estimates based on combined UWMC and UWAC data drawn from different reporting systems.

IHDD’s clinical network—including 11 UWMC specialty clinics and the UW Autism Center (UWAC)—provides diagnostic evaluations, ongoing care, and family support through interdisciplinary teams of physicians, nurse practitioners, psychologists, speech-language pathologists, occupational and physical therapists, audiologists, nutritionists, social workers, and genetic counselors. Together, these clinics also serve as essential training sites for UW learners across disciplines and contribute to research, community education, and outreach.

Several clinics experienced notable growth or maintained high levels of service:

- The Adult Autism Clinic recorded its highest annual volume since launching in 2021, with 753 patients and 1,187 visits.
- The LAMBs Clinic more than tripled its service volume over the past five years, reaching 384 patients in 2024.
- The Neurogenetics Clinic served 845 individuals, continuing a steady upward trend since tracking began in 2022.
- The FASD Diagnostic Clinic and PKU Clinic each reported their highest patient volumes in five years.

This report provides both aggregated data and individual summaries for each clinic, offering transparency and insight into the evolving scope and impact of IHDD’s clinical services across Washington State.

Overview IHDD Specialty Clinics

The Institute on Human Development and Disability (IHDD) supports a network of twelve specialty clinics serving individuals with developmental, neurobehavioral, genetic, and metabolic conditions. Eleven clinics are operated in partnership with UW Medical Center (UWMC), and one—the UW Autism Center (UWAC)—operates outside UWMC. Together, these programs deliver coordinated, evidence-based care across the lifespan and provide vital support to families.

IHDD’s specialty clinical programs have evolved over more than five decades. Foundational clinics date to the 1960s–1970s; notable additions include the Fetal Alcohol Spectrum Disorders (FASD) Clinic (1993), Neurogenetics (2006), and, between 2016–2019, the Cardiac Neurodevelopmental Clinic (CNC), Down Syndrome Specialty Clinic, and Late and Moderate Preterm Babies (LAMBs) Follow-up Clinic. In 2021, IHDD launched the Adult Autism Clinic to address growing adult needs.

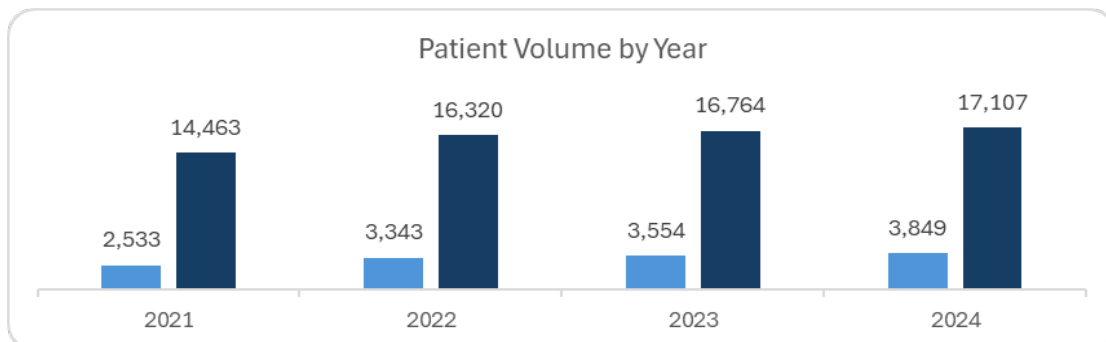
IHDD Specialty Clinics (12):

1. Adult Autism Clinic
2. Biochemical Genetics Clinic
3. Cardiac Neurodevelopmental Clinic (CNC)
4. Child Development Clinic (CDC)
5. Down Syndrome Specialty Clinic
6. Fetal Alcohol Spectrum Disorders (FASD) Diagnostic & Prevention Network Clinic
7. Infant Development Follow-up Clinic (IDFC)
8. Late and Moderate Preterm Babies (LAMBs) Follow-up Clinic
9. Neurogenetics Clinic
10. Pediatric Audiology Clinic
11. Phenylketonuria (PKU) Clinic
12. UW Autism Center (UWAC)

These clinics are located at the IHDD building in Seattle and serve patients from across Washington State and beyond. Each clinic integrates specialists from multiple disciplines to provide coordinated, evidence-based care. Many also contribute to research, workforce training, and systems development.

Patient Volume Trends (2021–2024)

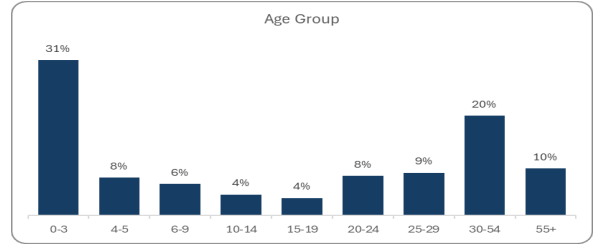
From 2021 to 2024, combined IHDD specialty clinics (UWMC + UWAC) show steady growth in both reach and activity: unique patients rose from 2,533 to 3,849 (+52%), and total visits increased from 14,463 to 17,107 (+18%). The largest jump in unique patients occurred in 2022 (+32%), with continued gains in 2023 (+6%) and 2024 (+8%). Visits also grew each year, though the pace moderated after 2022.



IHDD Specialty Clinics Demographics 2024

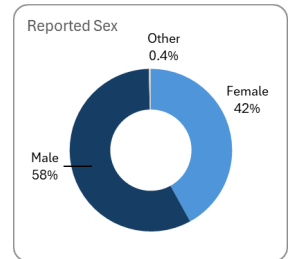
Age

IHDD specialty clinics continue to serve a broad age range, from newborns just 2 days old to elderly clients up to 86 years. This wide span underscores the interdisciplinary scope of our services, spanning pediatric to adult populations.

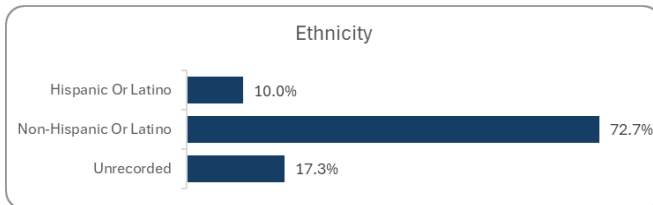
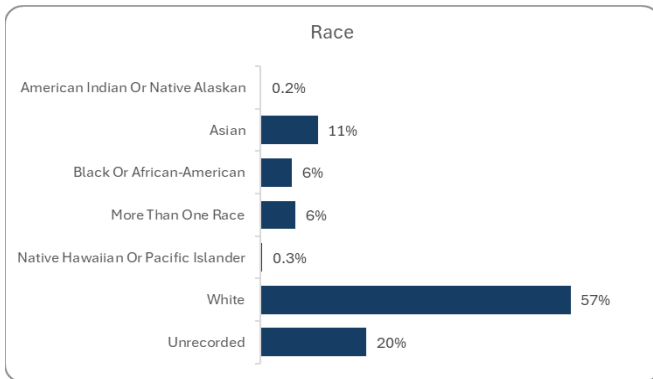


Reported Sex

In 2024, the majority of IHDD clients identified as male, comprising about 58% of the population, while females made up approximately 42%. A small percentage of clients identified as nonbinary or other. This distribution reflects the clinic populations we serve and has remained relatively stable over the past few years.



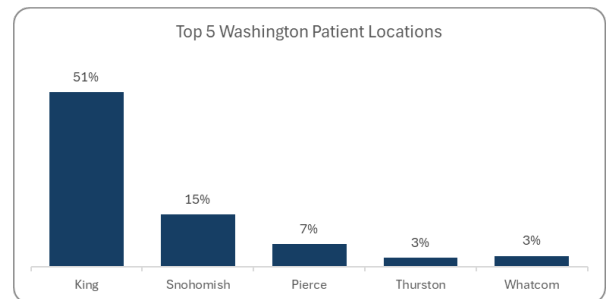
Race & Ethnicity



In 2024, the largest racial group served by IHDD clinics was White, followed by individuals identifying as Asian, Black or African American, and those reporting two or more races. Smaller proportions of clients identified as Native Hawaiian or Other Pacific Islander, and American Indian or Alaska Native. Approximately 10% of clients identified as Hispanic or Latino. Compared to Washington State's general population, the proportion of White clients was somewhat lower, while the percentage of clients identifying as Asian or multiracial was slightly higher. The percentage of Hispanic or Latino clients was similar to the statewide average.

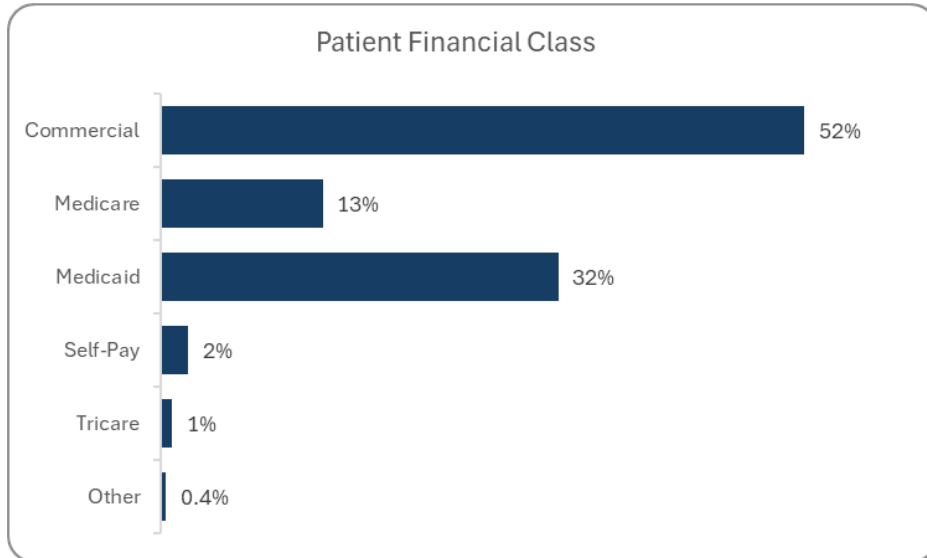
Top 5 Washington Patient Locations

Within Washington, patients came from 37 out of the state's 39 counties. The majority—around 70%—were from King, Snohomish, and Pierce counties, which remain the most populous regions in the state.



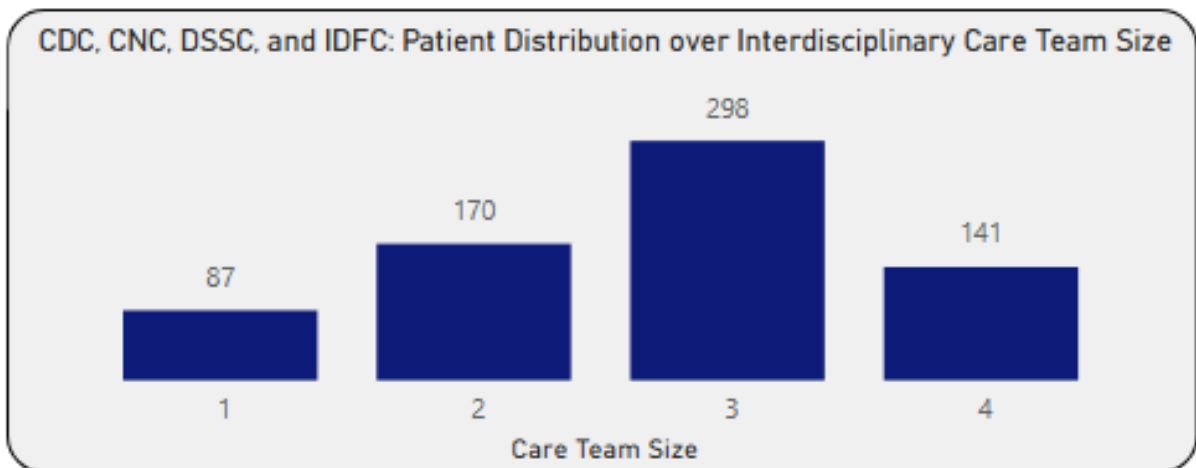
Payor Financial Class

In 2024, 52% were covered by commercial insurance plans, making this the most common coverage type. Medicaid accounted for 32% of the patient population, followed by Medicare at 13%. This estimation excludes patients seen under specific state-funded contracts—such as those in the Biochemical Genetics and PKU clinics—which are billed separately and not reflected in this breakdown. (Payor Financial Class note: percentages reflect any coverage used during 2024. Because some patients change insurance or use different payors for different services, categories can overlap; totals may therefore exceed 100%; rounding also applies.)



Interdisciplinary Care

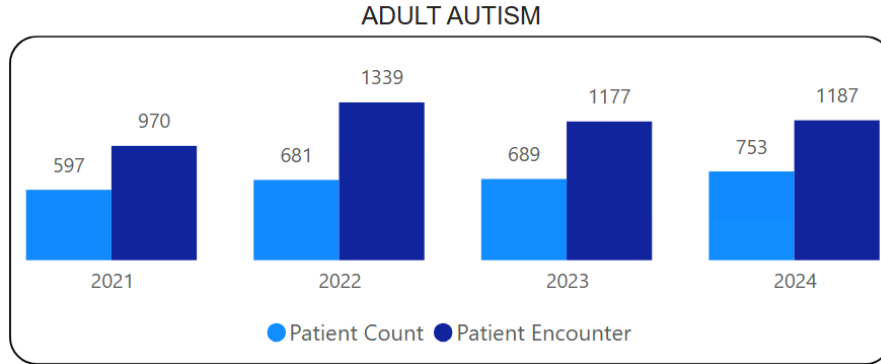
Most IHDD subspecialty clinics operate with an interdisciplinary care model, particularly those focused on diagnostics and developmental Follow-up. Patients are often seen by clinicians from multiple disciplines during a single visit. The chart below illustrates how different clinics integrate various specialties into their care teams. Notably, clinics such as the Child Development Clinic (CDC), Cardiac Neurodevelopmental Clinic (CNC), Down Syndrome Specialty Clinic (DSSC), and Infant Development Follow-up Clinic (IDFC) demonstrate a highly interdisciplinary structure, involving providers from psychology, occupational/physical therapy, speech-language pathology, medical care, and more.



IHDD UWMC Clinics

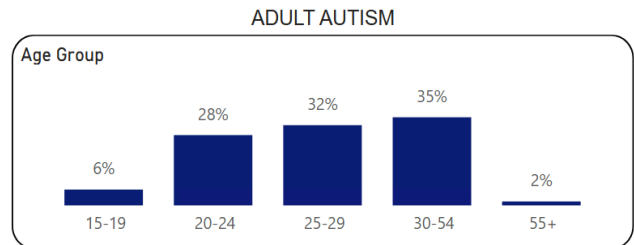
Adult Autism

Established in 2021, the UW Medicine Adult Autism Clinic addresses the complex and evolving needs of individuals over 18 years of age with autism spectrum and related neurodevelopmental disorders. The providers at the Adult Autism Clinic assess the various needs of patients and families and customize care management approaches to assure the best possible patient experience. The clinic provides behavioral medicine services, including medication management and mental health assessments.

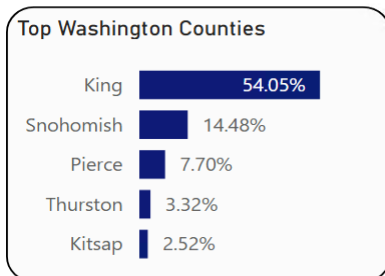
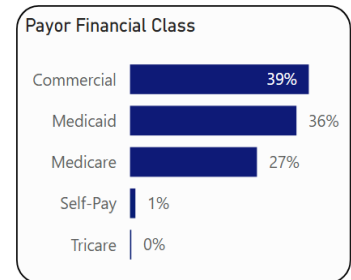
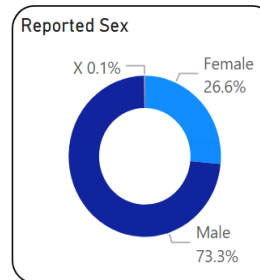


Patient volume at the IHDD clinics has steadily increased since 2021, with both patient counts and encounters rising year over year. In 2024, the clinics served 753 unique patients and recorded 1,187 encounters—the highest in both categories across the four-year span. This upward trend reflects ongoing growing demand for specialized services.

In 2024, the Adult Autism Clinic patients ranged in age from 18 to 69 years. Most patients fell within the 30–54 age group (35%), followed by those aged 25–29 (32%) and 20–24 (28%).



A majority of the patients identified as male (73.3%), while 26.6% identified as female, and 0.1% selected another category. Regarding insurance coverage, the most common coverages were commercial and Medicaid plans, with Medicare also a sizable group; self-pay and Tricare were uncommon. Because coverage can change during the year or differ by service, categories overlap, and the charted totals may exceed 100%.

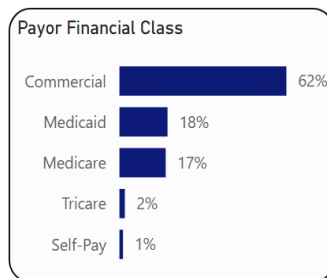
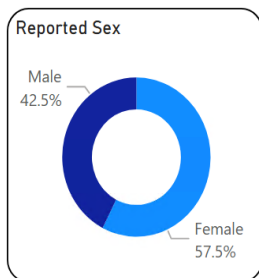
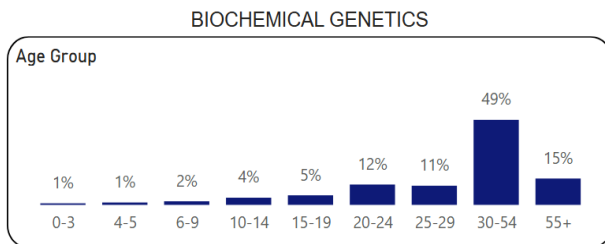
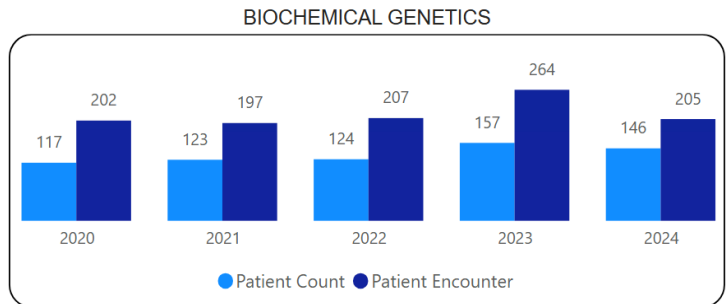


In 2024, over 90% of Adult Autism Clinic patients resided in Washington State, with the majority coming from King (54.05%). The next most represented counties were Snohomish (14.48%), Pierce (7.70%), Thurston (3.32%), and Kitsap (2.52%).

Biochemical Genetics Clinic

The Biochemical Genetics Clinic provides evaluation, consultation, and management services to clients of all ages with a variety of metabolic disorders. Metabolic disorder is a term that encompasses a variety of disorders that result from an inherited inability to produce a particular enzyme necessary for normal metabolism of proteins, fats, or carbohydrates. Because inherited metabolic disorders are rare, many providers are unfamiliar with the complex treatment regimens and other health needs associated with a particular disorder. Consistent and ongoing nutritional therapy to compensate for the missing enzyme is necessary for a person born with one of these disorders. Without therapy, toxic chemicals build up in the blood and tissues and can lead to permanent intellectual disability and other disabilities. Clinics are conducted by an interdisciplinary team that includes a pediatric geneticist, metabolic nutritionist, and genetic counselor. Staff provide counseling about the heritability of disorders and guidance on family planning.

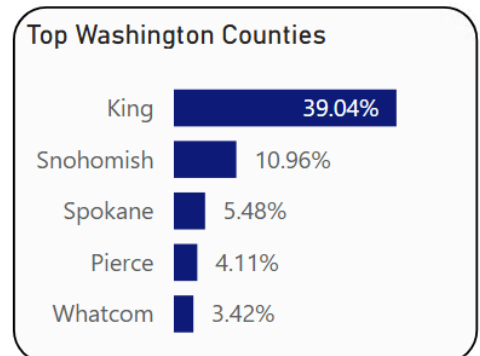
In 2024, the clinic saw 146 unique patients and conducted 205 patient encounters, sustaining the elevated service levels established in 2023 despite a slight decline in visit volume from the previous year.



The clinic served a diverse age range, with patients aged 1 to 78. The majority of clients (49%) fell within the 30–54 age group, followed by 15% aged 55 and older, underscoring the clinic’s role in managing lifelong conditions. Pediatric and adolescent representation was lower, with small proportions across younger age groups, consistent with the rarity of newly diagnosed conditions and the need for sustained care into adulthood. Gender distribution showed 57.5% of patients identifying as female and 42.5% as male, indicating a relatively balanced, yet slightly female majority patient base. Financial class data highlight that 62% of patients were covered under commercial insurance, with Medicaid (18%) and Medicare (17%) also comprising substantial

portions of the population.

In 2024, about 80% of the clinic’s patients were from Washington state, with 39.04% patients resided in King County. However, the clinic also drew substantial patient populations from surrounding counties—Snohomish (10.96%), Spokane (5.48%), Pierce (4.11%), and Whatcom (3.42%)—highlighting its regional reach and importance as a center of expertise for inherited metabolic disorders across Washington State.

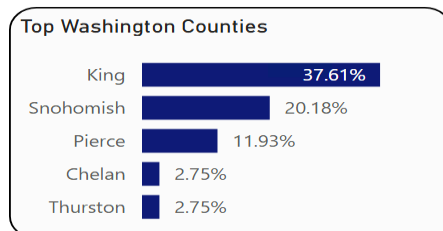
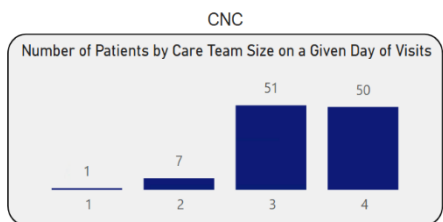
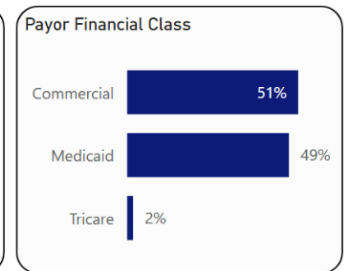
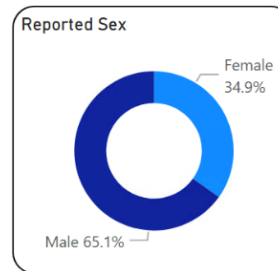
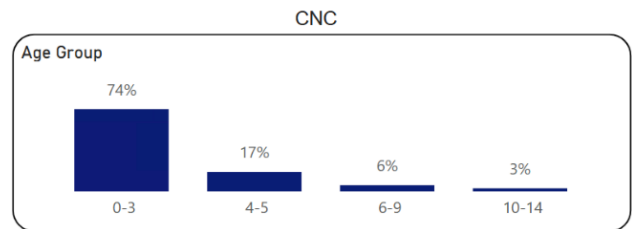
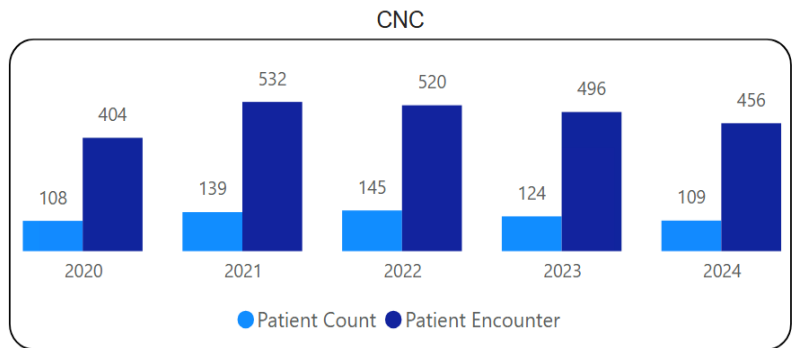


Cardiac Neurodevelopmental Clinic

Children who are born with complex congenital heart disease (CHD) are at risk for problems with growth and development. The Cardiac Neurodevelopmental Clinic (CNC) evaluates and treats infants and children with complex congenital heart defects who had heart surgery before their first birthday. The clinic provides close Follow-up during their first five years of life. A visit to the Cardiac Neurodevelopmental Clinic can provide reassurance that the child is developing as expected. If developmental issues are apparent, the clinic connects patients with appropriate services. The CNC was founded in 2016. Specialists available in the clinic include developmental-behavioral pediatrician, psychologist, physical/occupational therapist, speech therapist, social worker, nutritionist, and audiologist. Clinic staff members work in interdisciplinary teams, combining expertise to evaluate each child and make recommendations for care.

The Cardiac Neurodevelopmental Clinic (CNC) has shown consistent service delivery over the past five years, with both patient counts and encounters peaking in 2021. While the number of encounters gradually declined in subsequent years—to 456 in 2024—the clinic maintained a relatively steady patient count, ending with 109 patients in 2024, slightly above the 2020 figure of 108.

In 2024, the CNC primarily served very young children, with 74% of patients aged 0 to 3 years, aligning with the clinic’s mission to follow children with complex congenital heart defects during their early developmental years. Smaller portions of the patient population fell into the 4–5 (17%), 6–9 (6%), and 10–14 (3%) age brackets. The sex distribution was 60.2% male and 39.8% female. Financially, the clinic served a diverse mix of patients, with almost half covered by Medicaid.

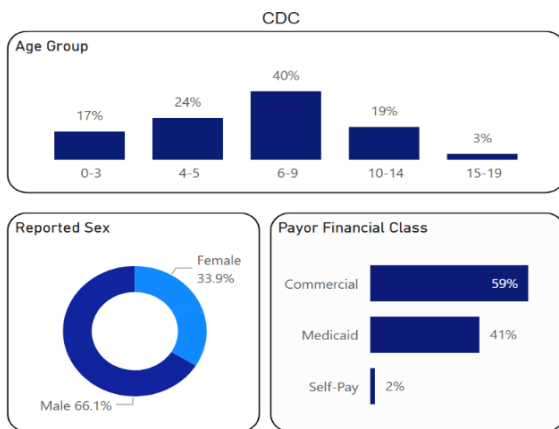
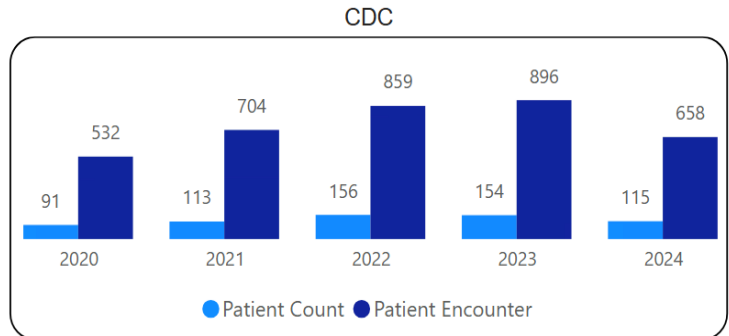


CNC emphasizes interdisciplinary care, and this is evident in the staffing pattern observed on clinic days. The majority of patients (101) were seen by teams of three or four providers, with smaller numbers seen by teams of one- or two-member teams. Geographically, CNC patients predominantly came from King County (37.61%), followed by Snohomish (20.18%), Pierce (11.93%), Chelan (2.75%), and Thurston (2.75%) counties.

Child Development Clinic

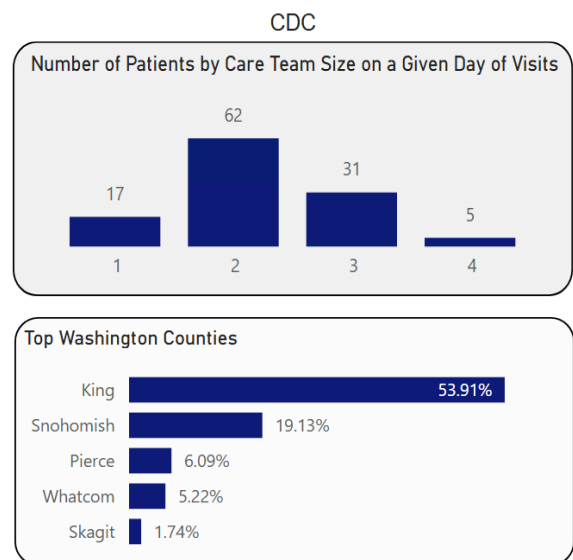
The Child Development Clinic (CDC) provides diagnosis, assessment, and management plans for children from early childhood to adolescence with or at risk for neurodevelopmental disabilities. Clinic staff members work in interdisciplinary teams, combining expertise to evaluate each child and make recommendations for care. Staff members include professionals such as audiologist, developmental-behavioral pediatrician, nurse, nutritionist, occupational/physical therapist, psychologist, social worker, and speech and language pathologist. The clinic is the primary venue at the IHDD for interdisciplinary clinical training under the auspices of the Leadership Education in Neurodevelopmental Disabilities training grant awarded by the Maternal and Child Health Bureau.

From 2020 to 2024, both patient count and encounter volume reflected steady engagement, with notable annual fluctuations. Peak service delivery occurred in 2023 with 154 patients and 896 encounters. In 2024, the clinic served 115 unique patients with a total of 658 encounters, demonstrating sustained service capacity even with a slight decline from the prior year.



The 2024 demographic breakdown highlights that the largest age group served was 6–9 years old (40%), followed by children aged 4–5 (24%), and 0–3 (17%). Adolescents aged 15–19 represented the smallest proportion at just 3%. The patient population skewed male, with 66.1% identifying as male and 33.9% as female. Regarding insurance coverage, Coverage was split between commercial and Medicaid plans, with a very small self-pay share. Families may change coverage or use more than one payor across visits, so categories overlap and the charted totals may exceed 100%.

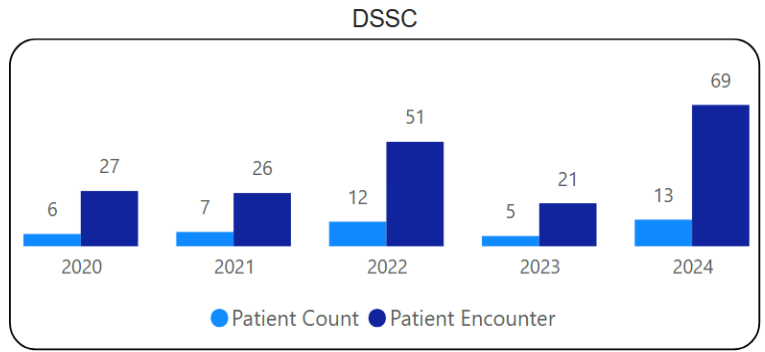
Operationally, the CDC functions as a fully interdisciplinary clinic, where each patient visit involves a team of specialists selected based on the child's specific and often complex developmental needs. Team composition varies, with most visits involving two or more clinicians from different disciplines, reflecting the clinic's commitment to providing comprehensive, collaborative care tailored to each patient. Geographically, over half of the patients came from King County (53.91%), with additional representation from Snohomish (19.13%), Pierce (6.09%), Whatcom (5.22%), and Skagit (1.74%) counties—highlighting a broad but locally concentrated reach within Washington State.



Down Syndrome Specialty Clinic

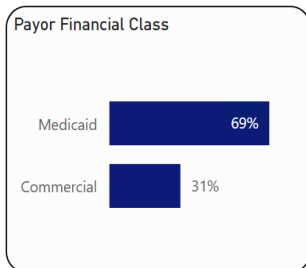
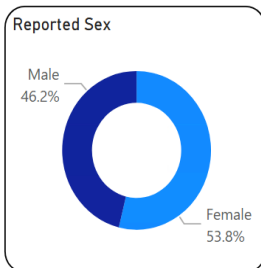
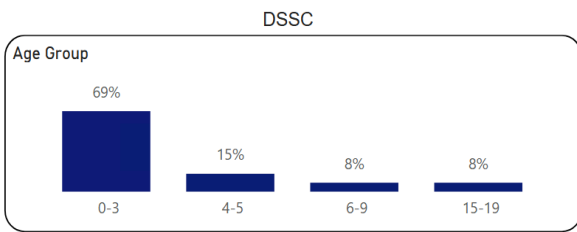
The Down Syndrome Specialty Clinic was founded in September 2016. The clinic focuses on providing formal developmental assessments, consultation for behavioral concerns, and assessment for common medical problems that can contribute to behavioral or developmental concerns. The clinic also collaborates with schools and early intervention programs to help provide the best environment for success. In addition, the co-existence of other diagnoses such as ADHD or Autism Spectrum Disorder are assessed as needed.

Clinics run on the 4th Tuesday morning of each month. Specialists available include developmental-behavioral pediatrician, psychologist, physical/occupational therapist, speech therapist, social worker, nutritionist, genetic counselor, and audiologist. Clinic staff members work in interdisciplinary teams, combining expertise to evaluate each child and make recommendations for care.

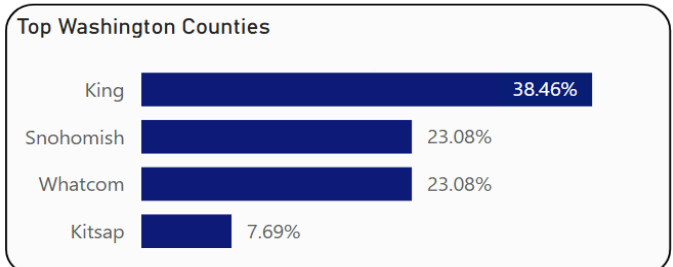
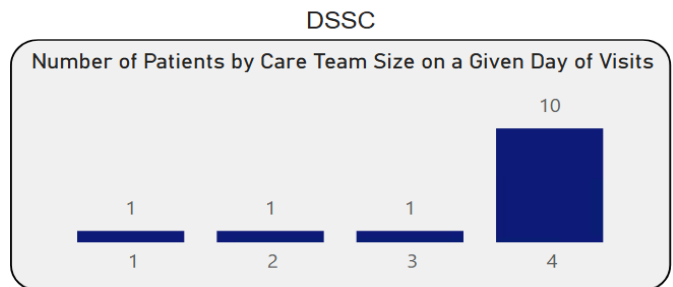


In 2024, the Down Syndrome Specialty Clinic (DSSC) experienced a notable increase in patient activity, recording 13 unique patients and a total of 69 encounters—the highest in the past five years.

Demographic data for 2024 reveals that the majority of DSSC patients (69%) were infants and toddlers aged 0–3 years. Slightly more patients identified as female (53.8%) than male (46.2%). In terms of insurance coverage, a significant majority (69%) were covered by Medicaid, indicating the clinic’s role in serving publicly insured families, while 31% had commercial insurance.

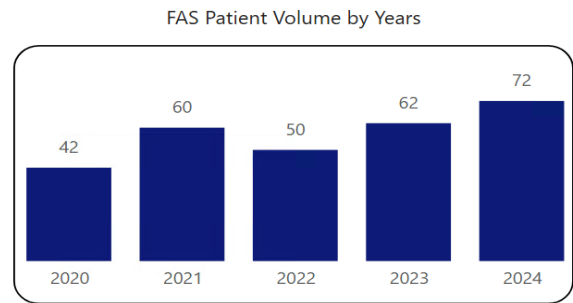


In 2024, the Down Syndrome Specialty Clinic (DSSC) primarily operated with interdisciplinary care teams, with most patients (10 out of 13) being seen by a team of four providers during their visit. Geographically, the majority of DSSC patients came from King County (38%), followed by Snohomish and Whatcom Counties, each contributing 23% of the patient population. Kitsap County accounted for almost 8%. This distribution indicates that while DSSC serves families from across the region, a significant portion of its patient base resides in the greater Seattle metropolitan area.



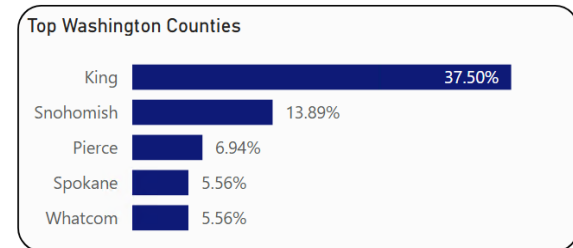
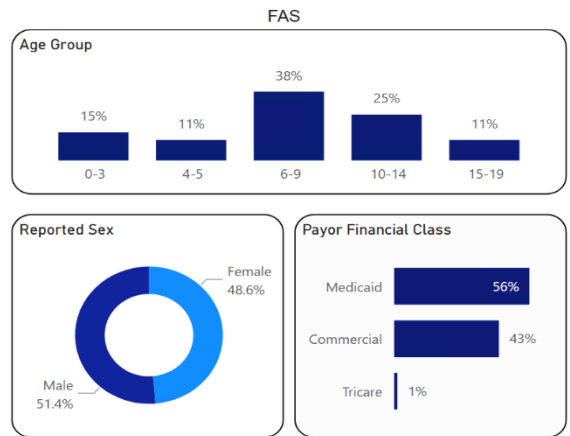
Fetal Alcohol Spectrum Diagnostic & Prevention Network Clinic

The Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network (FAS DPN) is a network of Washington State community-based clinics and the core clinical/research/training FAS DPN clinic at IHDD. The core clinic at the IHDD was first established in 1993 through support from the Centers for Disease Control. The goals of the FAS DPN are primary and secondary prevention of FASD through screening, diagnosis, research, and training. The network seeks to 1) demonstrate the value of interdisciplinary diagnostic clinics that accurately identify FASD in persons of all ages, 2) provide comprehensive treatment planning (medical, mental health, educational/vocational, and social service) to reduce secondary disabilities, and 3) locate and intervene with the birth mothers of these individuals to prevent recurrent births of affected children. Each clinic in the network uses the same interdisciplinary approach and systematic diagnostic method, the 4-Digit Diagnostic Code and FAS facial recognition software developed by FAS DPN faculty. The FAS DPN has diagnosed over 3000 patients to date. The FAS DPN has expanded both nationally and internationally through the training of interdisciplinary teams. IHDD faculty members have trained over 210 interdisciplinary teams worldwide. On average, a client had one visit to the FAS clinic. At each visit, a client often saw a team of interdisciplinary clinicians including a developmental pediatrician, a speech-language pathologist, a social worker, a psychologist, and/or an occupational therapist.



In 2024, the FAS DPN Clinic saw a notable increase in patient volume, reaching 72 individuals—up from 62 in 2023 and marking the highest annual volume over the five-year span since 2020. This upward trend reflects a growing demand for diagnostic and prevention services related to FASD.

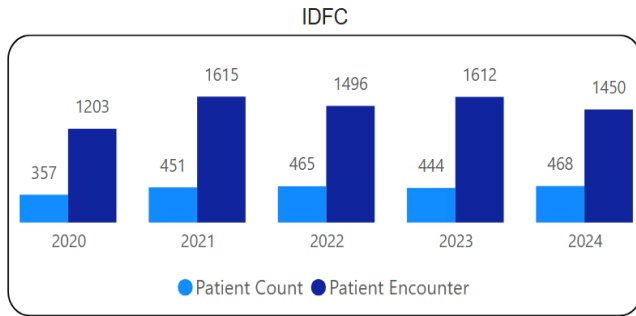
Among the 2024 patient population, children aged 6–9 represented the largest age group at 38%. The youngest groups (ages 0–3 and 4–5) and older adolescents (15–19) each comprised 11–15% of the caseload. Gender distribution was relatively balanced, with 51.4% male and 48.6% female. In terms of insurance coverage, Medicaid was the most common payor at 56%, followed by commercial insurance at 43%, and Tricare at just 1%.



Geographically, the majority of patients came from King County (37.05%), Snohomish (13.89%), Pierce (6.94%), Spokane (5.56%), and Whatcom (5.56%) counties. This reflects a strong regional concentration in central Puget Sound, but also suggests outreach and service to more rural or eastern parts of the state.

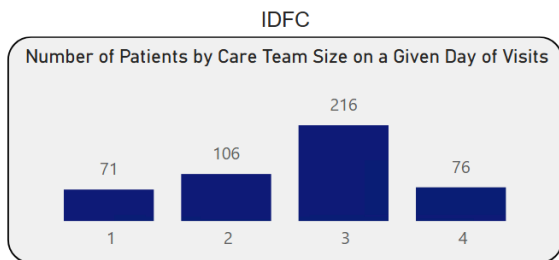
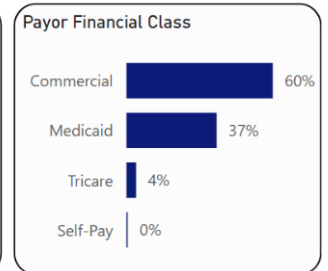
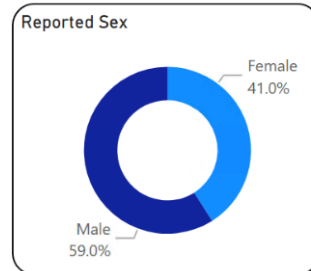
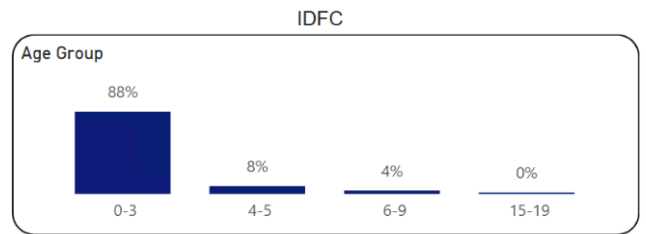
Infant Development Follow-up Clinic

The Infant Development Follow-up Clinic (IDFC) was established in 1977 to provide developmental Follow-up of children from birth to age eight who are designated as high risk due to prematurity and/or low birth weight or prenatal exposure to drugs. The goal of the clinic is to provide early identification and referral for early intervention for the neurodevelopmental and neurobehavioral problems. Each year about 350 clients visit the IDFC to receive diagnostic and treatment services. The majority are referred to IHDD by the University of Washington Medical Center. The clinic also conducts long-term Follow-up clinical research concerning neonatal outcomes, complications, and treatment.

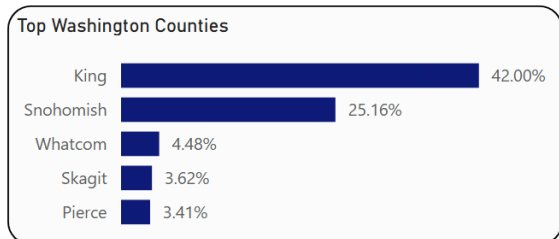


The IDFC has shown consistent activity over the past five years. While the patient count has remained relatively steady from 2022 to 2024, there was a modest decline in total encounters from the peak in 2021 to 1,450 in 2024. This suggests a slight decrease in visit frequency per patient or changes in service delivery, such as fewer multidisciplinary visits per encounter.

In 2024, the clinic's patient population was predominantly infants, with 88% under age 3, and very few patients aged 4-9, reflecting IDFC's mission to focus on early developmental monitoring. The gender distribution skewed slightly toward males (59%), which aligns with historical trends across IHDD clinics. Financial coverage for these visits leaned heavily on commercial insurance (60%), followed by Medicaid (37%), with minimal Tricare (4%) and no self-pay clients reported.



Regarding clinic operations, the most common care team size on a visit day was three providers, serving 216 patients, suggesting a preference or need for interdisciplinary collaboration.

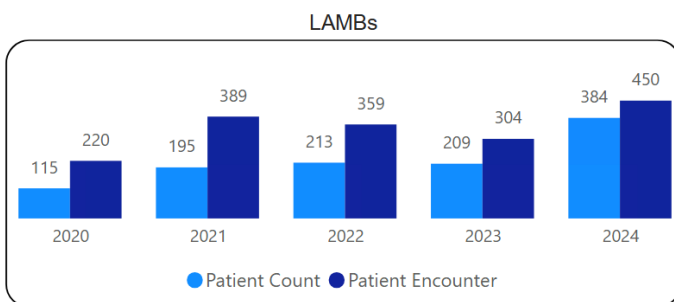


Geographically, about 40% of IDFC's patients came from King County, with significant representation also from Snohomish (25.16%). Smaller percentages came from surrounding counties such as Whatcom, Skagit, and Pierce, indicating a broad regional draw centered around the Seattle area.

Late and Moderate Preterm Babies (LAMBs) Follow-up Clinic

The Late and Moderate Preterm Babies (LAMBs) Follow-up Clinic at the IHDD works with children who were born between 32 weeks to 36 weeks and six days gestation: that is, four to eight weeks early. The clinic provides developmental assessment and ongoing monitoring. Knowing that these children are at higher risk for developmental differences, the goal is to identify any problems early and help the family to support the child to grow, learn, and thrive. A LAMBs clinic evaluation includes:

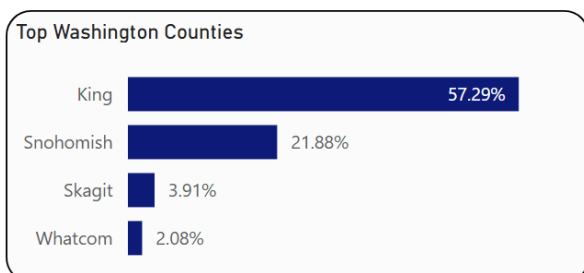
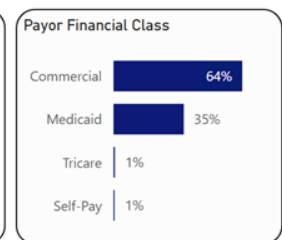
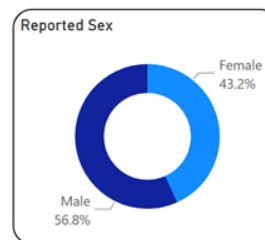
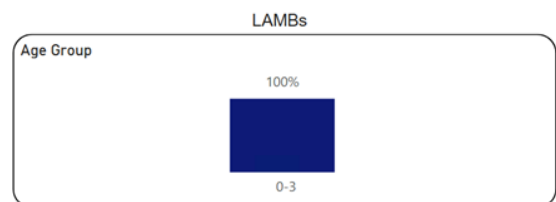
- A comprehensive medical history, neuromotor exam, and a Level 2 norm-referenced screening and assessment tool such as the Capute Scales Cognitive Adaptive Test Clinical Linguistic & Auditory Milestone Scales (CLAMS).
- A detailed report on findings with recommendations for services, medical evaluations, laboratory studies, or imaging if pertinent which is sent to the primary care provider.
- An audiology evaluation at one year-old, autism screening at one and two years old of age, and an oral health screening at one year.



From 2020 to 2024, the Late and Moderate Preterm Babies (LAMBs) Follow-up Clinic at IHDD experienced significant growth in both patient count and encounters. In 2020, the clinic served 115 unique patients with 220 total encounters. By 2024, those numbers had more than tripled, reaching 384 patients and 450 encounters. This upward trend reflects

expanding services and outreach, with a particularly notable jump between 2023 and 2024, indicating increased demand and possibly broader referral or access mechanisms.

For 2024, detailed demographics provide a clearer picture of the population served. All patients in the LAMBs Clinic fell within the 0–3 years age group, consistent with the clinic's mission to support development in children born moderately preterm. Males represented 56.8% of the patient population, while females accounted for 43.2%, maintaining the clinic's typical gender ratio. In terms of financial coverage, the majority of families (64%) had commercial insurance, followed by Medicaid at 35%, with Tricare and self-pay options each covering 1%.

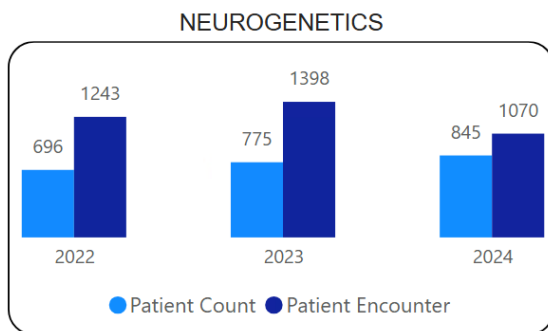


Geographically, most patients in 2024 resided in Washington State, particularly in King County, which accounted for 57.29% of the clinic's patients, followed by Snohomish (21.88%), Skagit (3.91%), and Whatcom (2.08%). This regional distribution underscores the clinic's role as a central provider of specialized Follow-up care for late and moderate preterm infants in the greater Seattle area and surrounding counties.

Neurogenetics Clinic

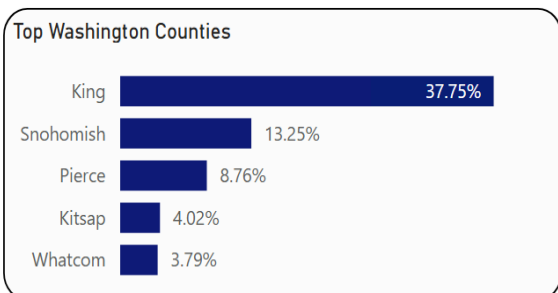
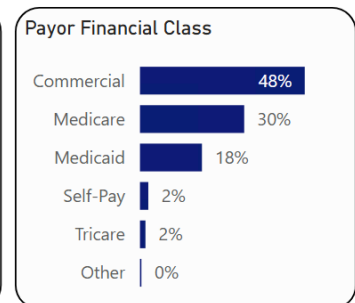
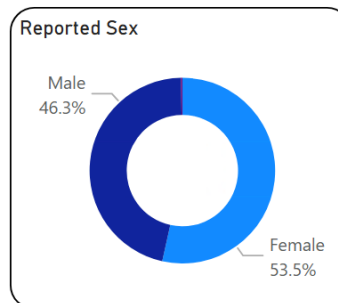
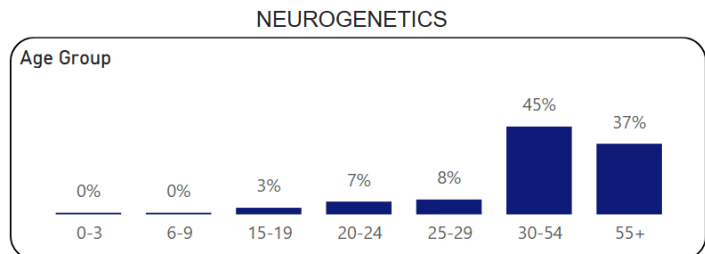
The Neurogenetics Clinic is co-sponsored by the Departments of Neurology and Medicine (Medical Genetics). The clinic's purpose is to evaluate, diagnose and provide genetic counseling and long-term management for patients and families with a wide variety of genetic diseases of the nervous system. The clinic is also a clinical training site for medical students, residents, and fellows. The Neurogenetics Clinic is a full-day clinic that meets three times each month. Each year the clinic serves those who have an array of neurogenetic disorders including Huntington's disease, Charcot-Marie-Tooth disease, autism hereditary neuropathy, hereditary ataxias, muscular dystrophies, familial dementia, familial movement disorders, leukodystrophies, Neimann-Pick type C, and others.

This clinic uses an interdisciplinary team approach that includes a neurologist, a neurogenetic nurse specialist, a genetic counselor and a medical social service worker. Patients receive an examination, diagnostic testing, genetic counseling, attention to their social service needs and longitudinal Follow-up. This represents a unique clinical resource in the state of Washington and includes an annual outreach clinic in Spokane and Yakima.



Trend data for Neurogenetics began separate tracking in 2022. Since then, the clinic has shown a steady increase in patient engagement. Patient count rose from 696 in 2022 to 775 in 2023 and further to 845 in 2024.

The 2024 demographic data reveals that the clinic predominantly serves adults, with 82% of patients aged 30 and older—45% between 30–54 years and 37% aged 55 and above. The sex distribution is relatively balanced, with 53.5% female and 46.3% male. Financially, nearly half of the patients (48%) have commercial insurance, followed by Medicare (30%) and Medicaid (18%), with small portions self-paying (2%), using Tricare (2%), or categorized as other (0%).



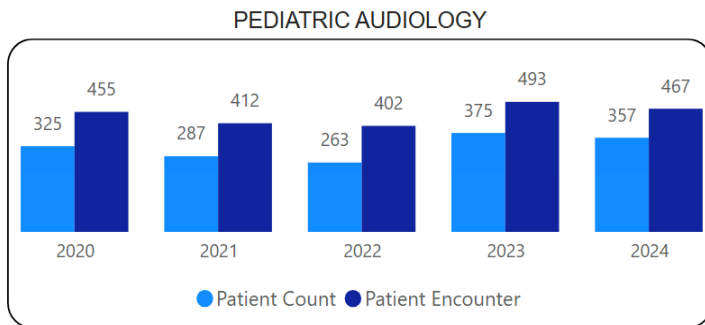
Geographically, most patients reside in Washington State's most populous counties. King County accounts for 37.75% of the clinic's patients, followed by Snohomish (13.25%) and Pierce (8.76%), with smaller proportions from Kitsap and Whatcom counties. This distribution reflects the clinic's accessibility and regional importance as a specialized resource within the state.

Pediatric Audiology Clinic

The Pediatric Audiology Clinic has three primary goals:

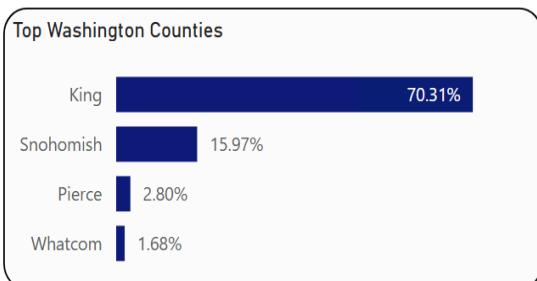
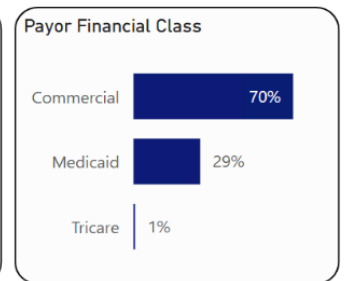
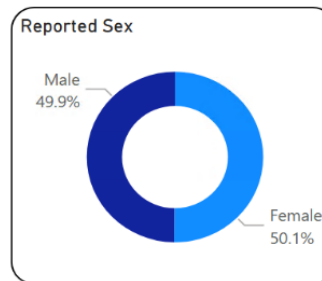
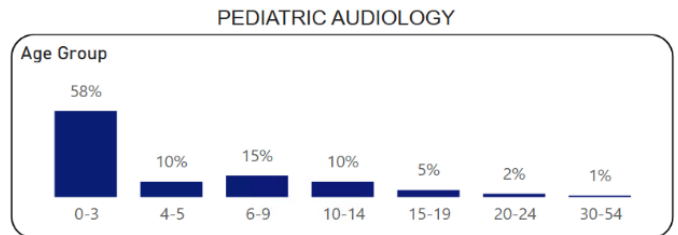
1. To identify hearing loss as early in life as possible;
2. To provide access to hearing technology; and
3. To coordinate Follow-up services for intervention, monitoring, and ongoing evaluation.

Activities of this clinic include newborn hearing screening at the University of Washington Medical Center (UWMC), diagnosis of hearing loss in the IHDD clinic, dispensing hearing technology (hearing aids, hearing assistance devices) to families of infants requiring them, and ongoing Follow-up with clients served. Universal newborn hearing screening was implemented at UWMC in 2004. This program is a collaborative effort between the Pediatric Audiology Clinic and the Department of Otolaryngology/Head and Neck Surgery. Data from this program are sent to the Washington State Early Hearing Detection, Diagnosis, and Intervention database for both neonatal screening outcomes and Follow-up diagnostic testing.



The Pediatric Audiology Clinic continues to fulfill its mission of early hearing loss identification, access to hearing technology, and coordinated Follow-up services. Trend data from 2020 to 2024 show fluctuations in patient volume and encounters. While 2023 marked the highest service year, 2024 volumes remained robust and above pre-2022 levels, indicating ongoing high demand for services.

In 2024, demographic data reveal that the clinic primarily served very young children, with 58% of patients aged 0–3. The next largest age groups were 6–9 and 10–14 years (both at 15%), while older age groups constituted a much smaller portion of the population. The gender distribution was nearly equal, with 50.1% identifying as female and 49.9% as male. Regarding financial coverage, the majority of patients (70%) had commercial insurance, while 29% were covered by Medicaid and 1% by Tricare.



Geographically, the clinic served patients from various counties, though the majority were concentrated in King County (70.31%), followed by Snohomish (15.97%) and Pierce (2.80%). Smaller numbers came from Whatcom and Thurston counties. This concentration in more populous counties reflects both the clinic’s central location and the distribution of pediatric audiology needs across the state.

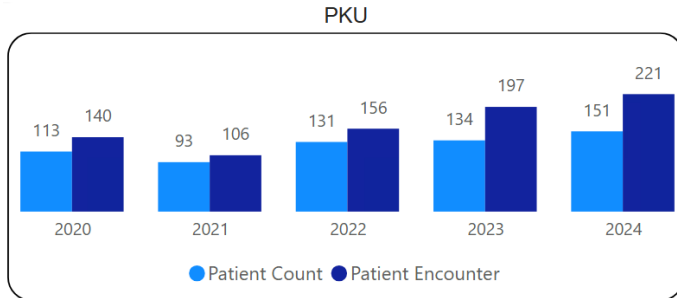
Phenylketonuria (PKU) Clinic

The Phenylketonuria (PKU) Clinic provides diagnosis, assessment, medical nutrition therapy, genetic counseling, and consultation for ongoing dietary management and health supervision, as well as evaluation of treatment outcomes to all children with PKU and their families.

Phenylketonuria is a genetic disorder in which the child is born without the ability to break down the amino acid Phenylalanine (Phe). This causes higher than normal levels of Phe in the blood which results in damage to the brain and intellectual disability if left untreated.

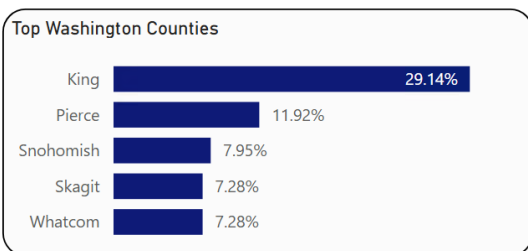
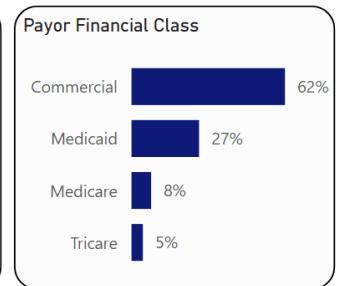
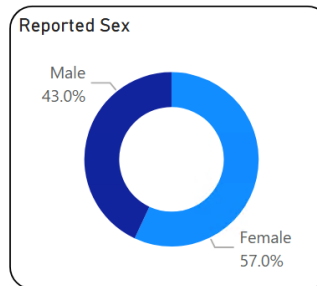
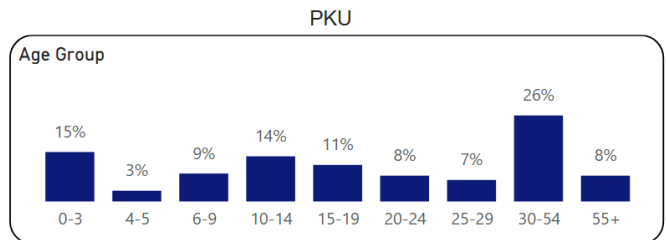
Fortunately, if a child is identified by Newborn Screening, diagnosed in early infancy, and receives appropriate treatment, typical physical and cognitive development can be expected. The treatment of PKU requires lifelong management of Phe levels regulated through the client's diet. Clinicians at the PKU clinic work with families and clients to ensure that the child is receiving adequate nutrients for normal development while limiting intake of foods high in Phe.

The PKU Clinic is comprised of a team of trained health care professionals that represent multiple disciplines. Long-term interdisciplinary planning and Follow-up services are provided.



The PKU Clinic has experienced steady growth in both patient count and encounters over the past five years. From 2020 to 2024, the number of unique patients rose from 113 to 151, while patient encounters increased from 140 to 221, reflecting a growing demand for the clinic's specialized services and sustained Follow-up care.

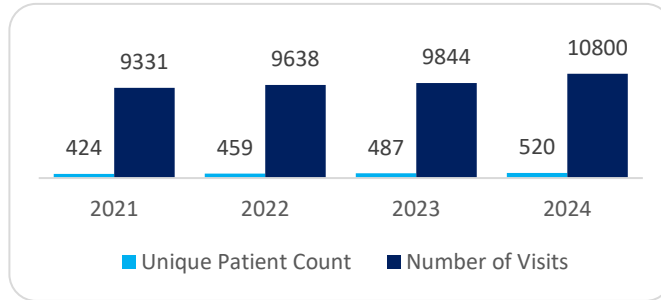
In 2024, demographic data reveals that the largest portion of PKU patients were adults aged 30–54, representing 26% of the population, followed by infants aged 0–3 years at 15% and children aged 10–14 years at 14%. Females made up a greater share of the patient population (57%) compared to males (43%). This data highlights the clinic's important role in ongoing PKU management across the lifespan and demonstrates its reach in serving patients across a broad geographic and demographic spectrum. From a financial perspective, the majority of patients (62%) were covered by commercial insurance, with Medicaid covering 27%, Medicare 8%, and Tricare 5%.



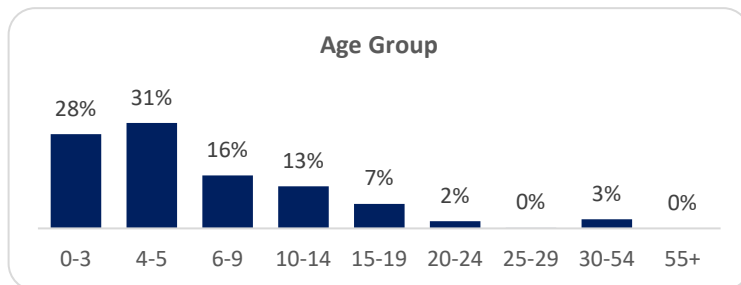
Geographically, the clinic primarily serves patients from King County, which accounted for 29.14% of the PKU patient population. Other top counties included Pierce (11.92%), Snohomish (7.95%), Skagit (7.28%), and Whatcom (7.28%), indicating strong regional representation from Western Washington.

UW Autism Center

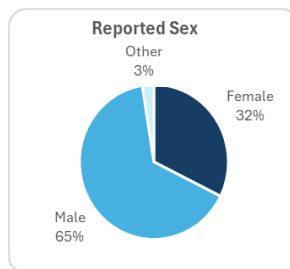
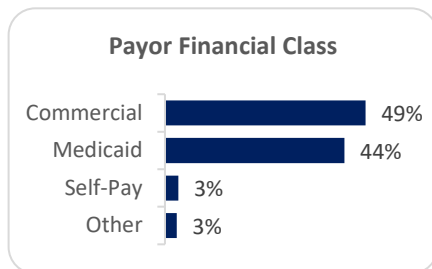
The UW Autism Center provides clinical services across the lifespan, offering diagnostic evaluations and individualized interventions tailored to each person and family. Services include comprehensive diagnostic evaluations, therapy and parent coaching, feeding services, occupational and speech-language therapy, and social groups—delivered by a coordinated team that centers family goals and evidence-based care. The team collaborates closely with caregivers and community partners to translate recommendations into daily routines, and emphasizes strengths-based, practical strategies that support communication, learning, and participation at home, in school, and in the community.



From 2021 to 2024, the number of unique patients rose from 424 to 520, an increase of 23%, and total visits grew from 9,331 to 10,800, a 16% gain. Both measures increased steadily year over year. The largest single-year increase in visits occurred in 2024 (about 9.7%), while the unique patient count has expanded by roughly 6–8% annually since 2022.



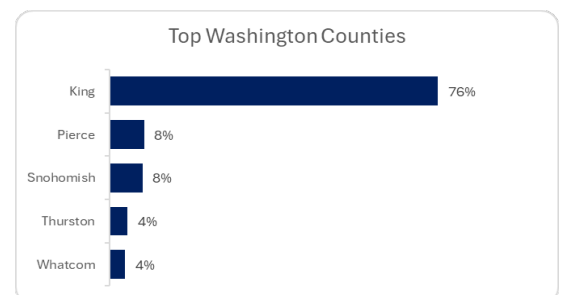
In calendar year 2024, UWAC Clinical Services served 520 unduplicated individuals and delivered 10,800 total visits. Nearly all—97.3% (n=506)—were children and youth with special health care needs ages 1–25. The population skews young: children ages 0–5 alone make up nearly six in ten clients, with most of the remaining clients in the school-age range and comparatively smaller shares among adolescents and adults.



Most clients' reported sex were male (65%), followed by female (32%), with 3% identifying as other sex.

The payor mix was 49% commercial, 44% Medicaid, 3% self-pay, and 3% other.

Geographically, King County accounted for 76% of clients, followed by Pierce and Snohomish at 8% each, and Thurston and Whatcom at 4%.



Thank You to Our Partners

Our work is made possible through generous support and collaborative partnerships. We are especially grateful to the following entities:

Funding and Institutional Partners

- Centers for Disease Control and Prevention (CDC)
- Maternal and Child Health Bureau (MCHB)
- University of Washington Medical Center (UWMC)
- UW Medicine
- UW College of Arts and Sciences
- UW College of Education
- Washington State Department of Health
- Washington State Health Care Authority

Community & Philanthropic Support

- Individual donors and family foundations
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Philanthropic giving plays a critical role in:

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- Training the next generation of interdisciplinary providers
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Data Sources

Data sources for this report include:

- UW Medical Center EPIC electronic health records
- UW Autism Center

Contact Information

- Adult Autism Clinic 206-598-3100
- Biochemical Genetics Clinic 206-598-1800
- Cardiac Neurodevelopmental Clinic 206-598-6710
- Child Development Clinic 206-598-3327
- Down Syndrome Specialty Clinic 206-598-3327
- Fetal Alcohol Syndrome Diagnostic & Prevention Network (FAS DPN) 206-598-9666
- Infant Development Follow-up Clinic 206-598-9348
- Late and Moderate Preterm Babies (LAMBS) Follow-up Clinic 206-598-9348
- Neurogenetics Clinic 206-598-4030
- Pediatric Audiology Clinic 206-598-9347
- PKU (Phenylketonuria) Clinic 206-598-1800
- UW Autism Center 206-598-3100