

2021



Clinical Services Annual Report

A summary of the clients served and services provided between January and December 2020 at the UCEDD clinical service programs

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Introduction

The Center on Human Development and Disability (CHDD) is one of the nation’s largest and most comprehensive interdisciplinary service, research, and training centers focusing on children and adults at risk for or who have established developmental disabilities. Each year, hundreds of University of Washington faculty and staff members as well as numerous doctoral and post-doctoral students make important contributions to the lives of people with developmental disabilities and their families. This is accomplished through a comprehensive array of research, clinical services, training, community outreach, and dissemination activities.

This report presents information about clinical services at the University Center for Excellence in Developmental Disabilities (UCEDD). The UCEDD is a major program of the Center on Human Development and Disability and has been in existence since 1963. It is part of a nationwide network of 67 UCEDDs located in every state and territory of the United States.

The UCEDD clinics and service programs were established to meet the needs of individuals with developmental disabilities, their caregivers, and families with the following vision:

1. Provide comprehensive diagnostic, assessment, and treatment services to individuals with or at risk of developing a developmental disability;
2. Develop innovative and model practices by conducting state-of-the art research and evaluation;
3. Build capacity in the community by serving as a vehicle for training professionals to provide interdisciplinary services.

Each of the clinics is embedded in the eight UCEDD programs in the organizational diagram below.



This annual report gives an overview of the population we serve and the work at UCEDD clinics and service programs within each calendar year. This report addresses audiences who are familiar with the developmental disabilities field at the CHDD and who are interested in gaining a better understanding of UCEDD clinical service programs.

Executive Summary

This annual report presents information about clinical services at the University Center for Excellence in Developmental Disabilities (UCEDD). The University of Washington UCEDD is a part of the Center on Human Development and Disability and has been in existence since 1963. UCEDD has twelve clinics and three service programs to meet the needs of individuals with developmental disabilities, their caregivers, and families through comprehensive, state-of-the-art diagnostic and treatment services.

Along with an overall summary and analysis of aggregated data of all UCEDD clinics and services at the CHDD, we also provide an individual one-page profile for each clinic and service to illustrate their unique areas of clinical work and services in the following order:

- **Subspecialty Clinics:**
 - Autism Center
 - Biochemical Genetics Clinic
 - Cardiac Neurodevelopmental Clinic (CNC)
 - Child Development Clinic (CDC)
 - Down Syndrome Specialty Clinic
 - Fetal Alcohol Spectrum Diagnostic & Prevention Network Clinic
 - Hypothyroidism Clinic
 - Infant Development Follow-up Clinic (IDFC)
 - Late and Moderate Preterm Babies (LAMBS) Follow-up Clinic
 - Neurogenetics Clinic
 - Pediatric Audiology Clinic
 - Phenylketonuria (PKU) Clinic
- **Special Programs:**
 - APEX summer camp program
 - Experimental Education Unit (EEU)
- **Employment Training Program:**
 - University of Washington Employment Program (UWEP)

While the COVID-19 pandemic has caused drastic changes in the general population, our clients with physical and developmental disabilities, who already encounter daily challenges such as barriers to community mobility, reduced access to healthcare services, may face additional challenges during this pandemic. With this in mind, the UCEDD clinics and services are committed to continuing access to safe healthcare to our patients and families. At the beginning of the pandemic, our clinics did have to close briefly but quickly transitioned to telehealth services within three weeks while continuing providing care for urgent cases.

Between January and December 2020, UCEDD clinics and service programs served an estimated total of 2,730 unique clients, accounting for 17,424 visits and 19,472 clinician client interactions, 36% of the reported interactions were via telehealth. While 2020 marked the closure of one of our clinics, the Hypothyroidism Clinic after 40 years serving the community, we also are preparing to expand our services with a new clinic in-house, the Adult Autism Clinic for next year 2021.

Clinical Services *2021* Annual Report

Clinical Services

Background

CHDD operates clinical service programs that serve individuals, primarily children, with or at risk for developmental, learning, and behavioral problems. These programs provide comprehensive and integrated services mainly through the use of interdisciplinary teams of professionals representing a variety of disciplines. A wide range of diagnostic, assessment and intervention clinical services are provided.

The majority of CHDD clinical service programs were established in the 1960s and 1970s along with the construction of CHDD's four buildings and development of foundational training, community outreach, and research programs. The Fetal Alcohol Spectrum Disorder Clinic was established in 1993, the Autism Clinic in 2000, the Neurogenetics Clinic in 2006. Over the course of 2016-2019, the Cardiac Neurodevelopmental Clinic, Down Syndrome Specialty Clinic, and Late and Moderate Preterm Babies Follow-up Clinic were established and are now included in this report.

Data Sources

Data sources for this report include:

- UW Medical Center EPIC electronic health records
- CHDD Clinical Databases
- EEU demographic data
- UW Employment Program Annual Report

Interdisciplinary Approach:

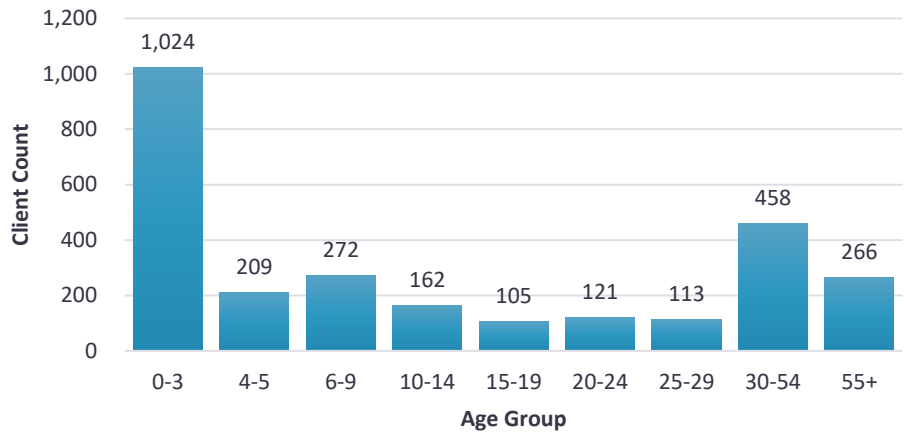
- Audiology
- Applied Behavior Analysis
- Developmental Pediatrics
- Employment Services
- Genetics Counseling
- Medical Genetics
- Neurology
- Nursing
- Nutrition
- Occupational Therapy
- Physical Therapy
- Psychology
- Social Work
- Special Education
- Speech and Language Pathology

Overview of CHDD client demographic data 2020

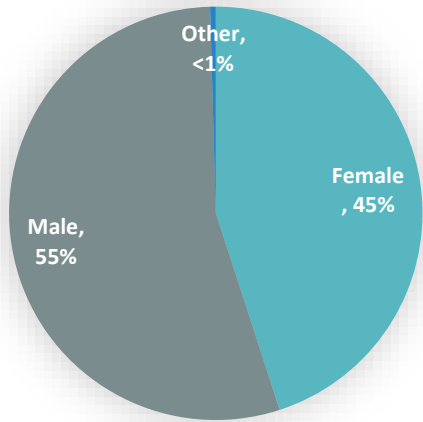
Age

While CHDD clinics and services aim to serve all age groups during 2020, 65% (1,772) of our clients were 19 or younger; half of whom were from the 0-3 age group. The youngest client served was about 7 days old and our oldest was 93 years old.

AGE GROUP DISTRIBUTION



GENDER



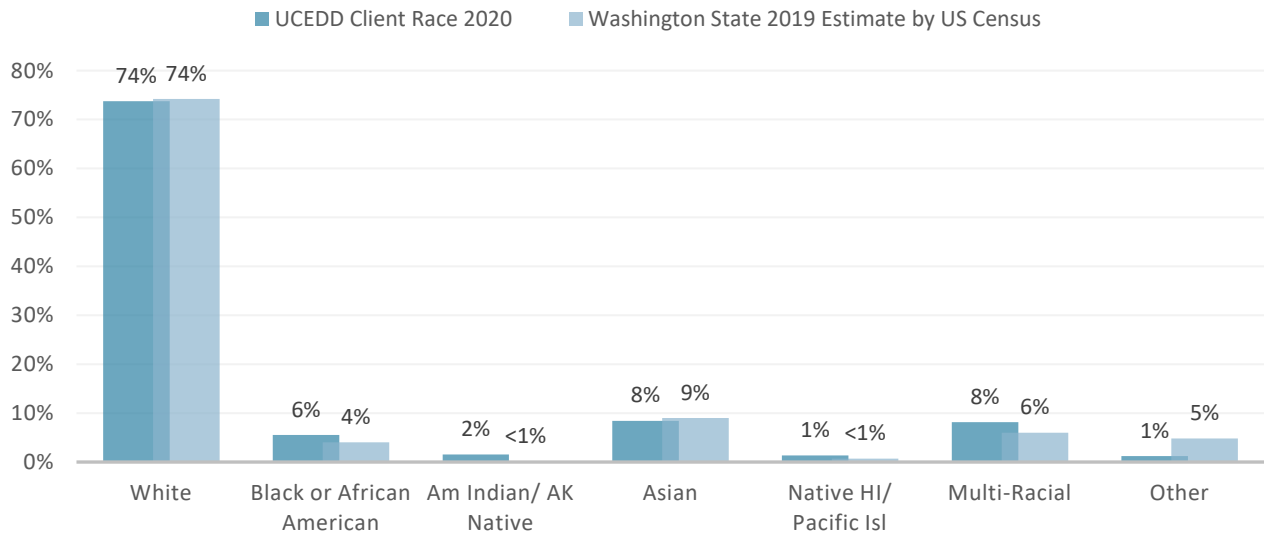
Gender

In 2020, of the estimated 2,730 clients, about 55% identified as male, 45% female, and less than 1% identified as other. This gender ratio has been consistent over the years with more male-identified clients in the population we serve.

Race

Our client population racial make-up in 2020 was similar to that of the estimated Washington State racial demographic data from the US Census. Of those who reported (77%, 2,090) their racial data, the majority of the clients (74%, 1,542) identified as white or Caucasian. The next largest group was Asian (9%, 178).

RACE



Home Locations

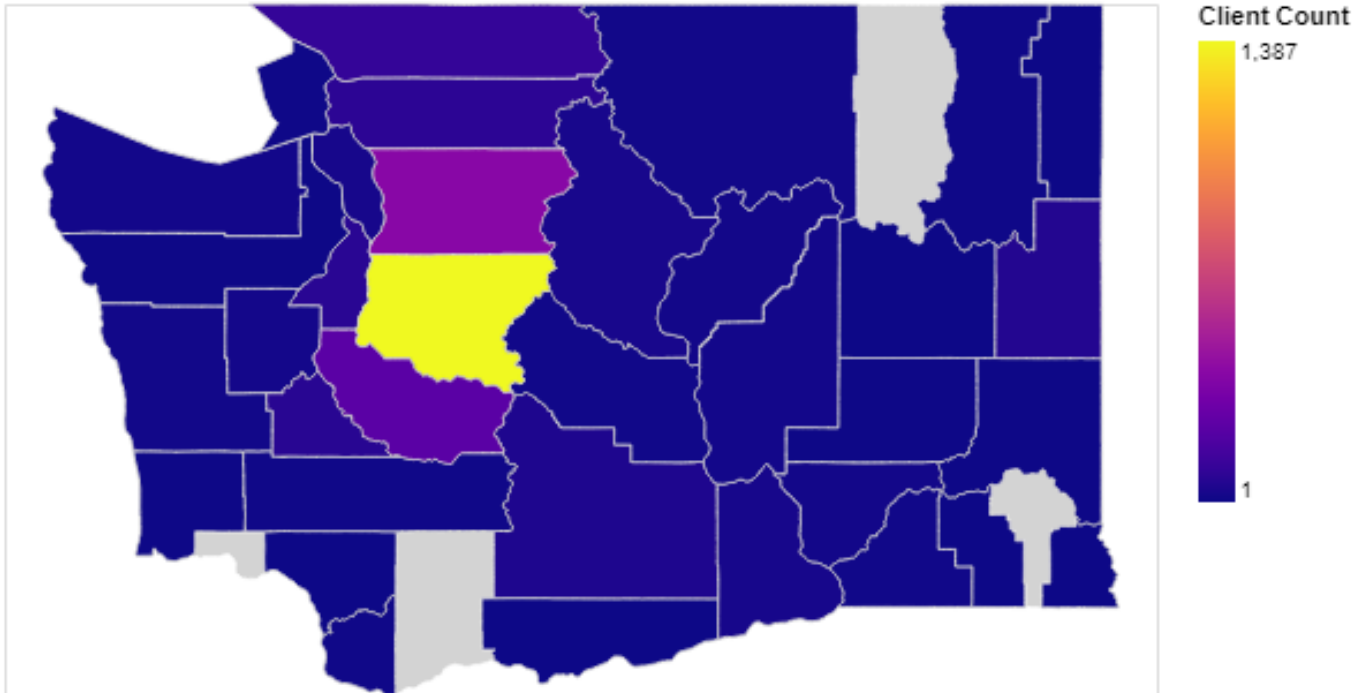
Top 5 US States	Number of Clients
WA	2,605
ID	29
AK	19
OR	11
CA	4

In 2020, all clients were from the United States; 98% of our clients lived in Washington State. The next top states were Idaho, Alaska, Oregon and California, accounting for about 2% (62) of our clients.

Within Washington State, clients came from 35 out of 39 counties. The majority of whom (92%) came from the three most populous counties, according to census.gov, King, Snohomish, and Pierce. The map below displays which counties clients came from within the state of Washington. Gradient colors correspond with the estimated number of clients that came from each Washington State county during 2020. Grey colors indicate four counties with no UCEDD clients.

Top 10 WA Counties	Number of Clients
King	1,387
Snohomish	385
Pierce	223
Whatcom	98
Skagit	73
Kitsap	65
Thurston	63
Spokane	47
Yakima	37
Chelan	25

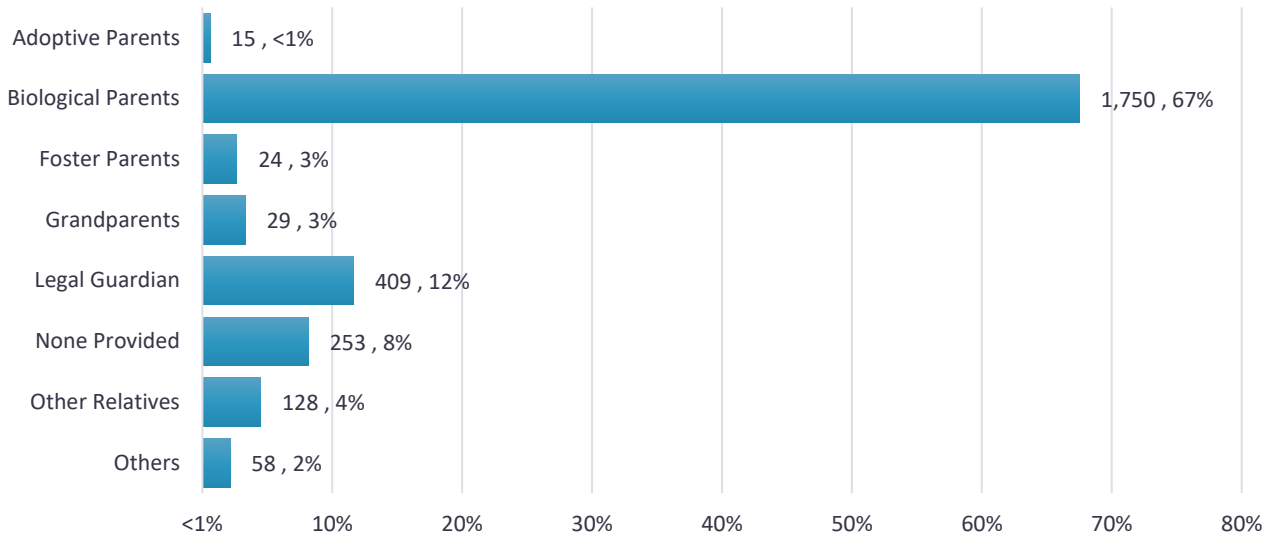
UCEDD Clients by Washington State Counties 2020



Caregivers

About 68% of CHDD clients are cared for by a biological parent (n = 1,750). 'None' means that the individual does not have a caregiver or declined to report this data point.

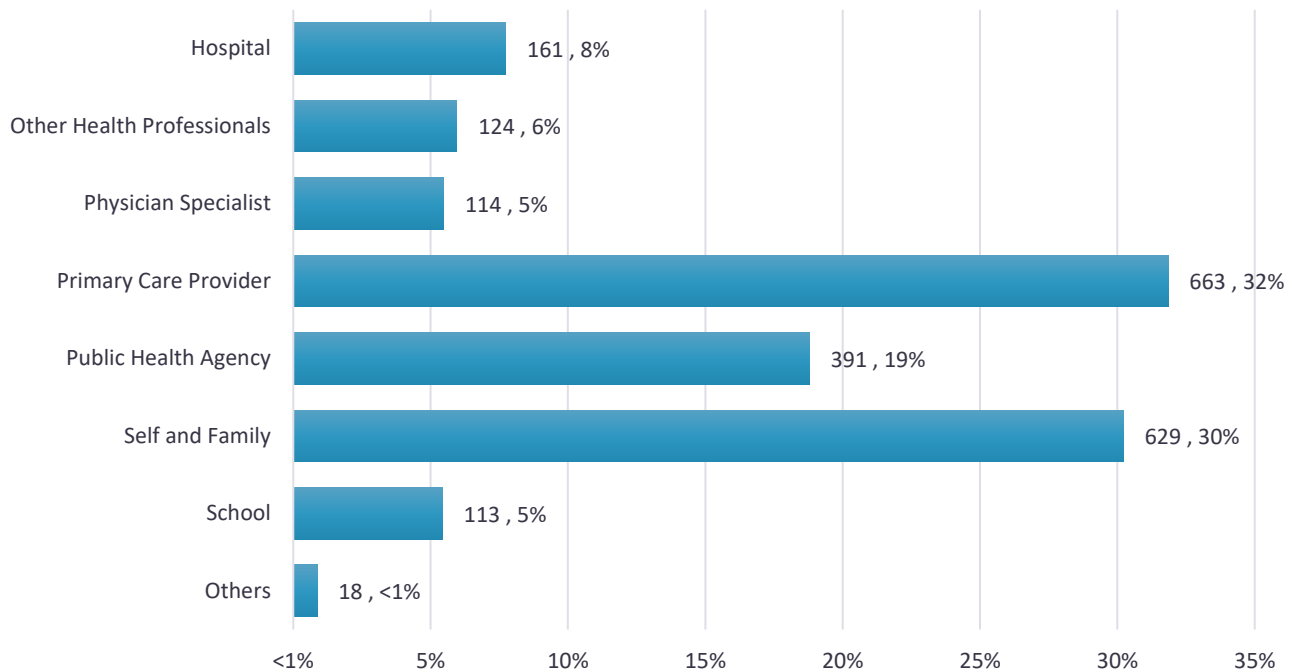
CLIENT'S CAREGIVERS



Referrals

Of the reported referrals (76%, 2,082), most clients were referred by a primary care provider (n=663) or from Self and Family (n=629). The next most common referrals came from Public Health Agencies (n=391), Hospital (n=161), and Other Health Professional (n=124).

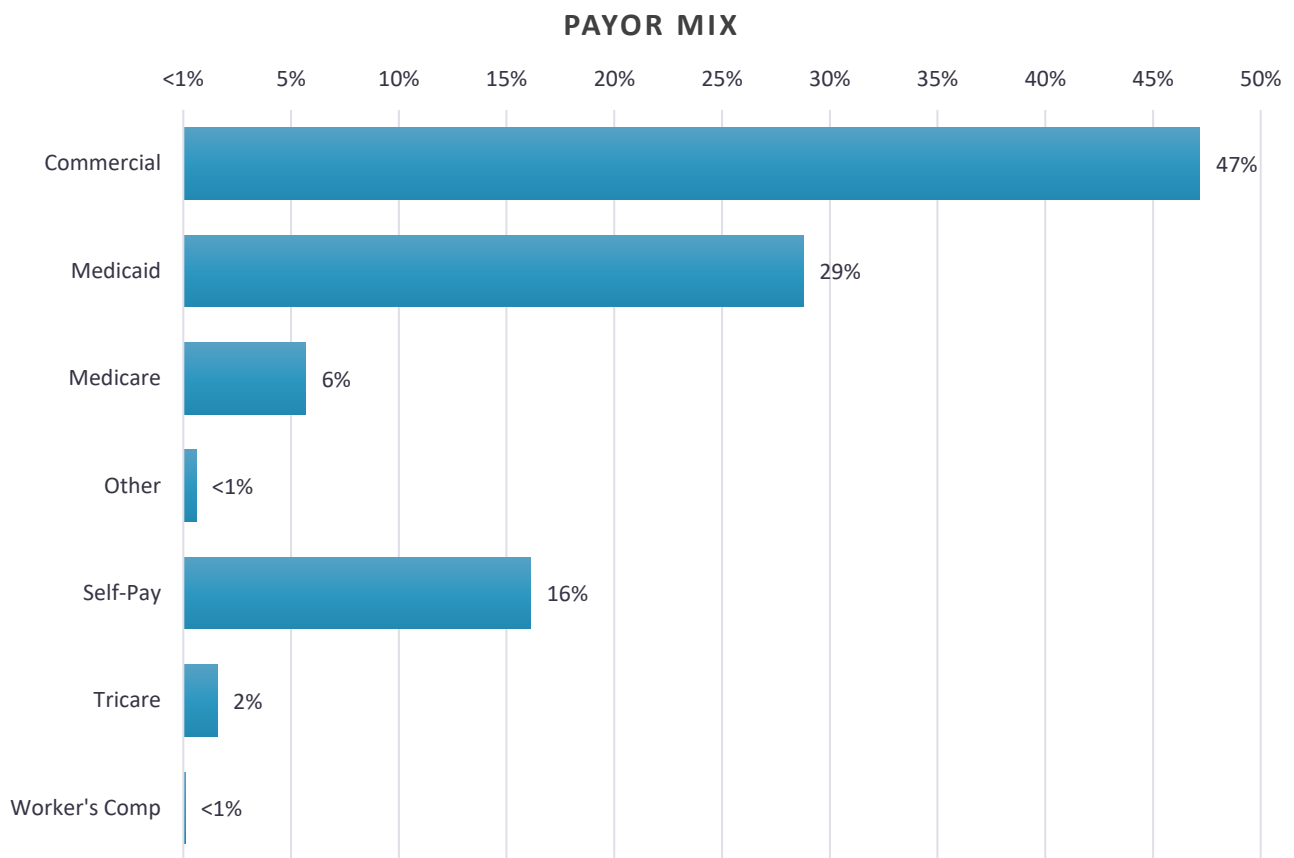
REFERRAL SOURCE



Payor Mix

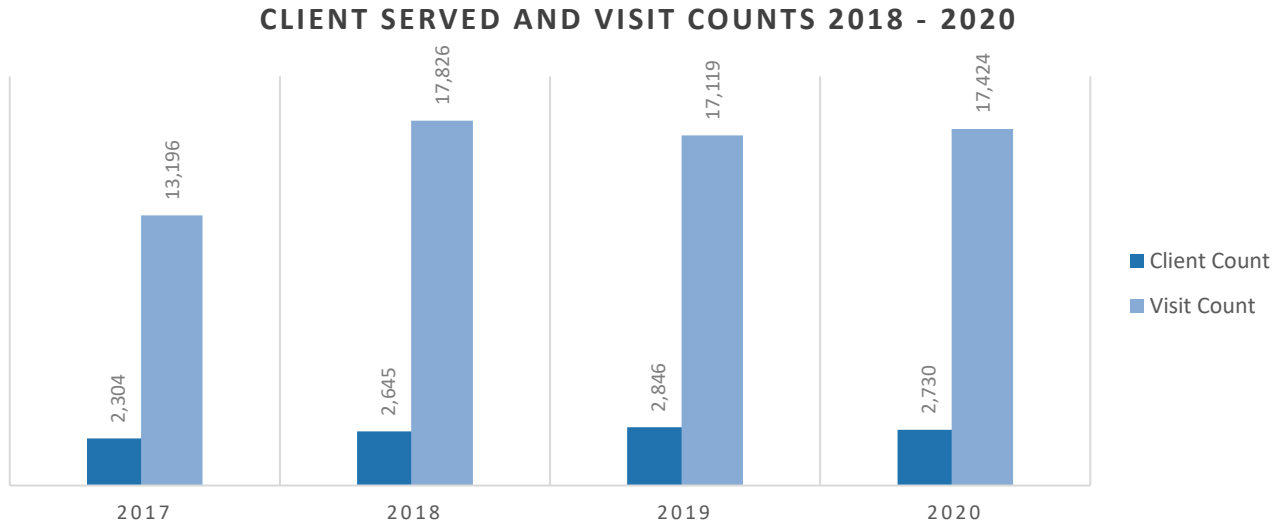
While many health centers include payor mix analysis along with revenue as indicators of financial health, the payor mix analysis in this case is an attempt to illustrate the financial demographic of our clients. This payor mix data only includes subspecialty clinics and/or services with a clinical treatment component since insurance data does not apply to non-clinical service programs such as the EEU classes and the UW Employment Program. In addition, part of Biochemical Genetics or the PKU clinics have contracts with state and/or other agencies to provide their specialty services; these contract services are not included in this payor mix data.

Of all CHDD subspecialty clients with insurance data in 2020 (n=2,482), 47% had commercial insurance. The next most common insurance category was Medicaid (29%). Self-Pay was 16% and Medicare 6%.

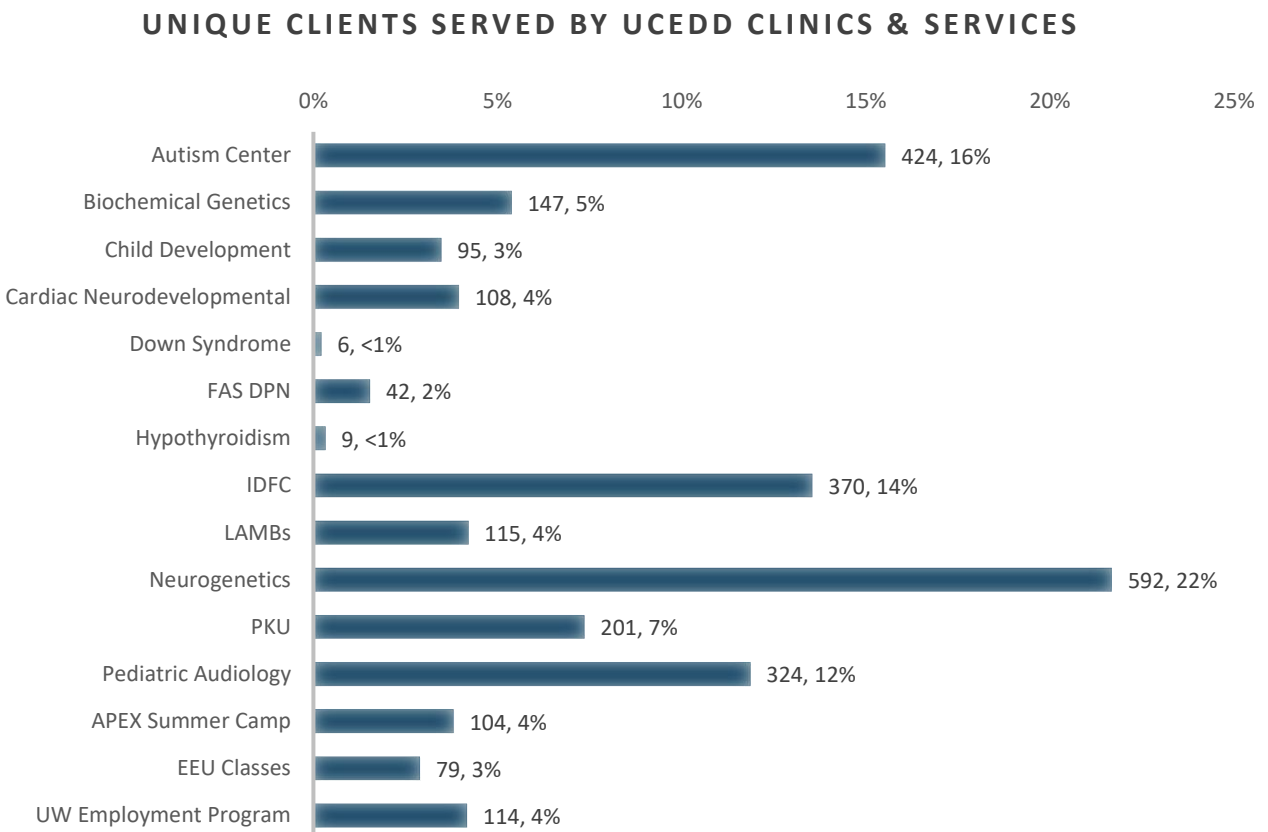


Quantity of Services Provided

Between January 1 and December 31, 2020, the UCEDD clinics and services served an estimated 2,730 unique clients, a 4% decrease from that of 2019. This change was expected as the pandemic has disrupted operations. In addition, 2020 also marked the closure of the Hypothyroidism Clinic after 40 years in service since the 1980s. This reflects the effort of clinics and services outreached to clients especially during the pandemic, including the implementation of telehealth services.



The UCEDD currently has fifteen (15) affiliated subspecialty clinics and programs. Among the clinical programs, Neurogenetics (22%), Autism Center (16%), and Infant Development Follow-up Clinic (14%) had the most number of unique clients served.

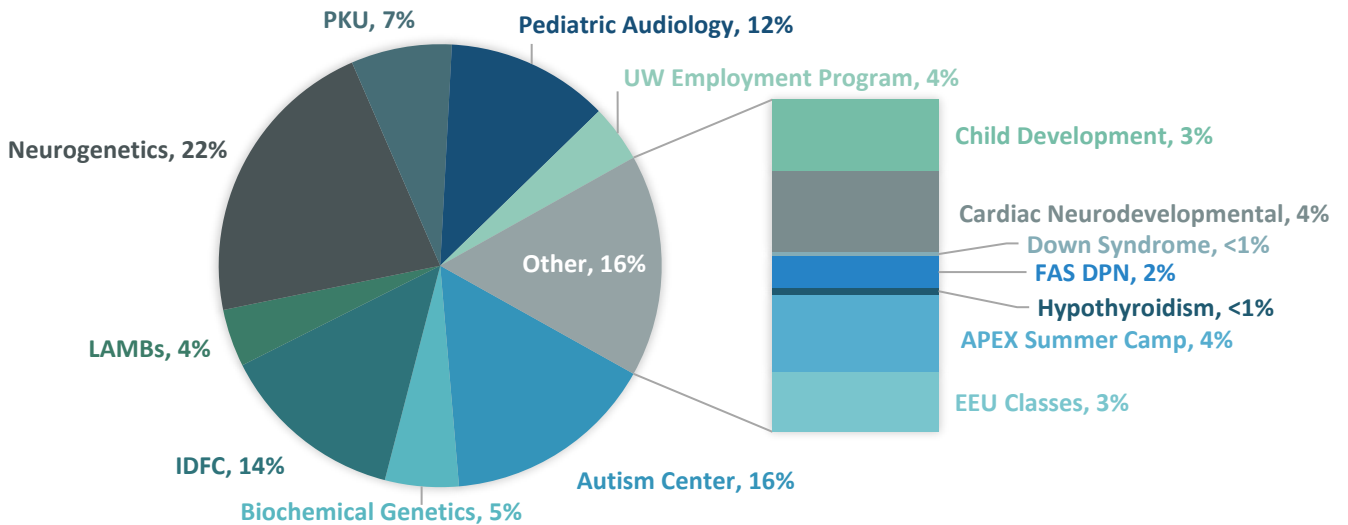


Client Visits by Clinical Service Programs

A visit is counted every time a client comes to a clinic to receive services. On average, each client had more than one visit to the UCEDD clinics and services. Due to the intensive ABA/BEC treatment offered at the Autism Center and the APEX program, client may have multiple visits for their individualized therapy plans. These two program had the highest average visit per client ratios. This reflect the intervention-oriented clinical activities at the Autism Center and the APEX program. While APEX has both clinical and educational components, the EEU classes and UW Employment Program provide ongoing interaction; thus, visit numbers are not appropriate for these two services.

UCEDD Clinics & Services	Unique Clients	Client Visits	Average Visits per Client
Subspecialty Clinics			
Autism Center	424	9,354	22
Biochemical Genetics	147	261	2
CDC	95	325	3
CNC	108	128	1
Down Syndrome	6	9	2
FAS DPN	42	42	1
Hypothyroidism	9	13	1
IDFC	370	474	1
LAMBs	115	130	1
Neurogenetics	592	1,595	3
PKU	201	1,254	6
Pediatric Audiology	324	459	1
Special Programs			
APEX Summer Camp	104	3,380	33
EEU Classes	79	-	-
Employment Training			
UW Employment Program	114	-	-
Total	2,730	17,424	6

UNIQUE CLIENTS SERVED BY UCEDD CLINICS & SERVICES

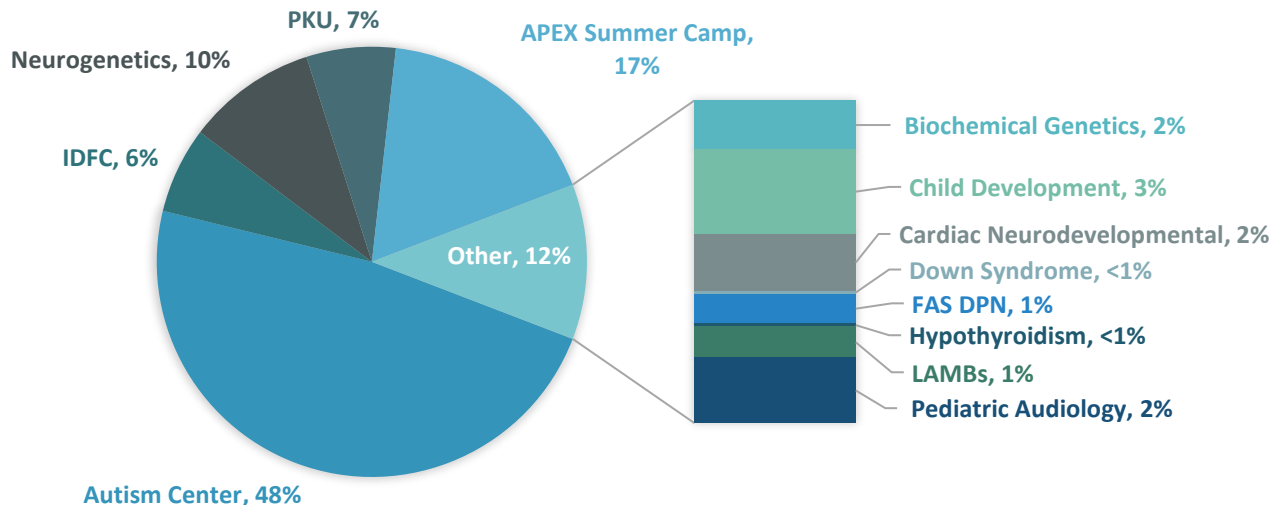


Clinician-Client Interactions by Clinical Service Program

Most CHDD subspecialty clinics at the UCEDD are interdisciplinary, particularly diagnostic and follow-up oriented clinics. A client may have a care team of clinicians from a wide range of disciplines. A clinician-client interaction is defined as every time a client is served by a clinician. During a visit, a client may have more than one interaction or encounter with clinicians across different disciplines. Thus, 17,424, visits produced 19,472 clinician-client encounters. The table below shows individual clinic clinician-client interaction per client ratio. This ratio represents how many times a clinicians would see a client at a particular subspecialty clinic.

UCEDD Clinics & Services	Unique Clients	Clinician Client Interaction	Average Clinician Client Interaction per Client
Subspecialty Clinics			
Autism Center	424	9,354	22
Biochemical Genetics	147	345	2
CDC	95	594	6
CNC	108	405	4
Down Syndrome	6	17	3
FAS DPN	42	210	5
Hypothyroidism	9	22	2
IDFC	370	1,258	3
LAMBs	115	219	2
Neurogenetics	592	1,904	3
PKU	201	1,305	6
Pediatric Audiology	324	459	1
Special Programs			
APEX Summer Camp	104	3,380	33
EEU Classes	79	-	-
Employment Training			
UW Employment Program	114	-	-
Total	2,730	19,472	7

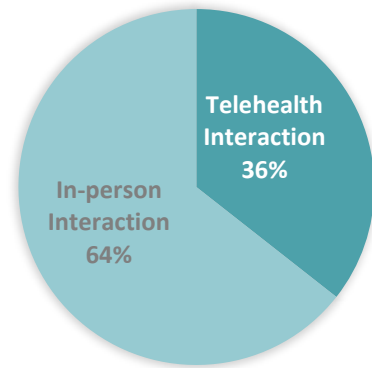
CLINICIAN CLIENT INTERACTION BY UCEDD CLINICS & SERVICES



Telehealth Services

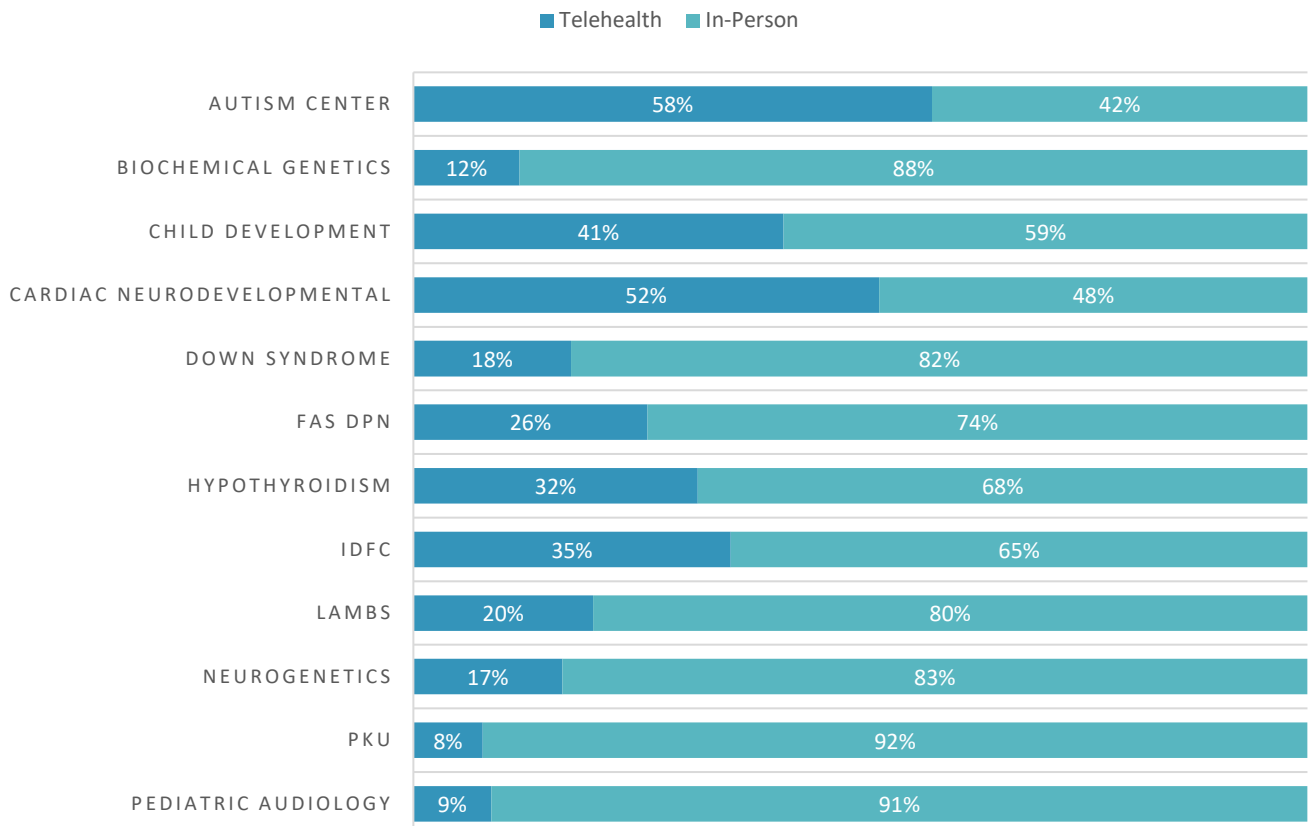
The COVID-19 pandemic has accelerated adoption of virtual telehealth instead of traditional in-person visits due to social restrictions. After an initial three week closure of the clinics, the UCEDD clinics had a transition to provide some telehealth service to our clients. Overall, about 36% of the total clinician client interactions in 2020 were telehealth interaction. For the purpose of telehealth, we only included those clinical services here. EEU Classes and UWEP virtual services were not counted in this analysis.

CLINICIAN CLIENT INTERACTION VIA TELEHEALTH VS IN-PERSON



During 2020, all UCEDD clinics offered telehealth services, Autism Center and Cardiac Neuro developmental clinics had the highest percentage of telehealth interactions, at 58% and 52% respectively.

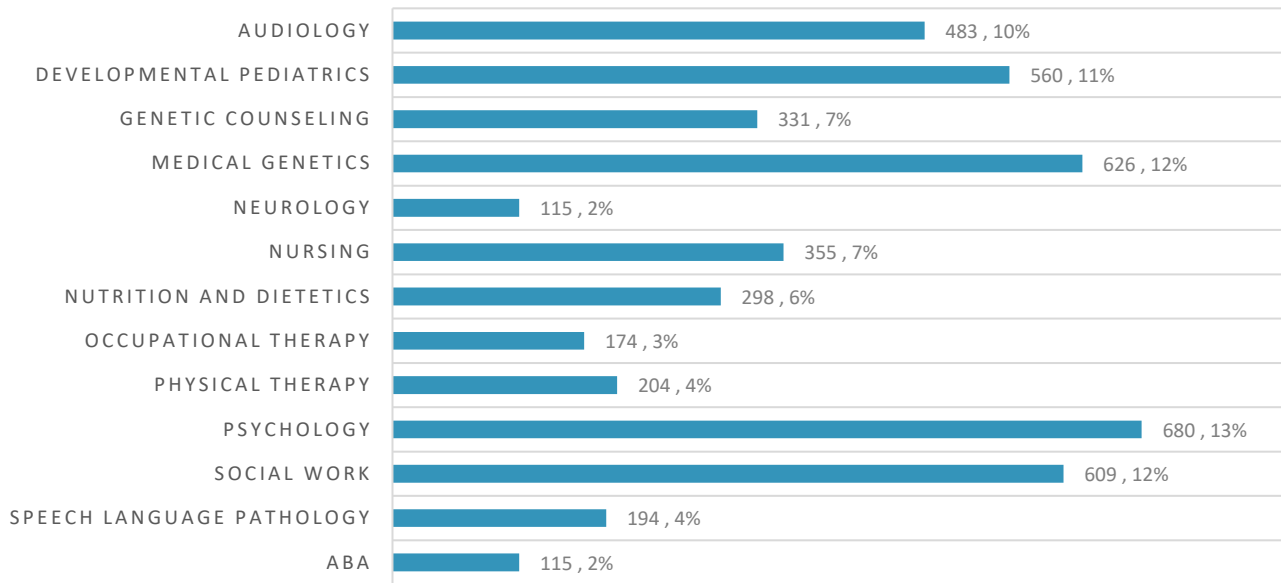
TELEHEALTH AND IN-PERSON INTERACTIONS BY UCEDD CLINICS



Interdisciplinary Involvement

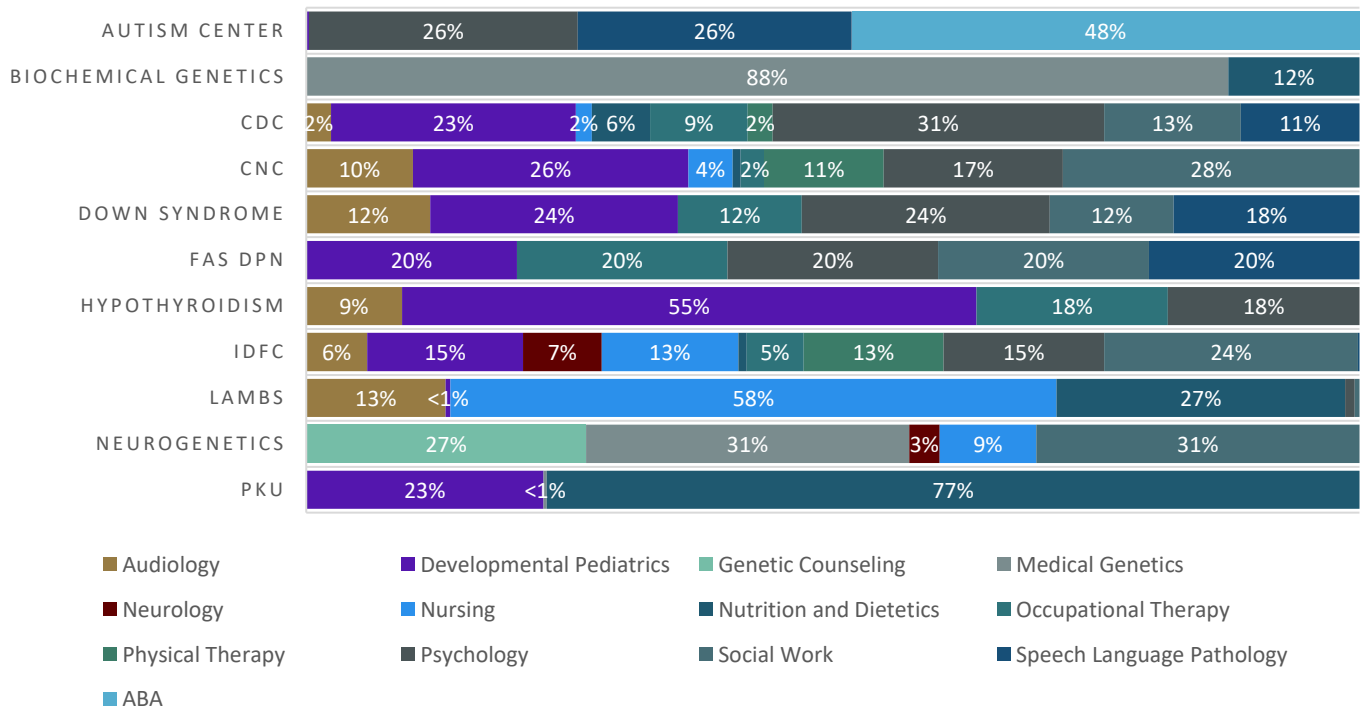
Most clinical service programs at the UCEDD are interdisciplinary; as many as nine unique disciplines may provide services within one clinical service program.

UNIQUE CLIENTS BY UCEDD CLINICS & SERVICES



Except Pediatric Audiology clinic, all other UCEDD clinics have at least 3 disciplines involved in their care team. Child Development clinic has the most number of disciplines involved, up to 9 disciplines, including Audiology, Developmental Pediatrics, Nursing, Nutrition and Dietetics, Occupational Therapy, Physical Therapy, Psychology, Social Work, and Speech Language Pathology.

INTERDISCIPLINARY APPROACH



Client Diagnosis

Understanding Diagnosis Data

Clinical services at the CHDD are provided through subspecialty clinics that are based on referrals from primary care, health care providers, or self-referrals. For this reason, we assume that all of our clients come to CHDD are at risk for a particular disorder or have a diagnosed disorder such that they require a more in-depth evaluation to design treatment more effectively.

The basis of diagnosis data used in this report is the International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM) given to a client during a visit at the CHDD clinics and service programs. The ICD-10 version used for this report was the 2020 version obtained from the Centers for Medicare and Medicaid Services (CMS) website [cms.gov](https://www.cms.gov). One or more ICD-10 codes may be used based on the decisions of an interdisciplinary team of clinicians. These ICD-10 codes may be diagnostic codes or billing codes for an evaluation; thus, it is important to stress that these codes do not always represent a confirmed diagnosis, but rather a client came for an evaluation of a disorder or a condition. Using the ICD-10 code data for this reporting year, we group clients by broader categories to illustrate the diversity of individuals served within the CHDD while maintaining a consistent reference with ICD-10. Two categories are used for this purpose: Risk Factors and Categorical Diagnosis.

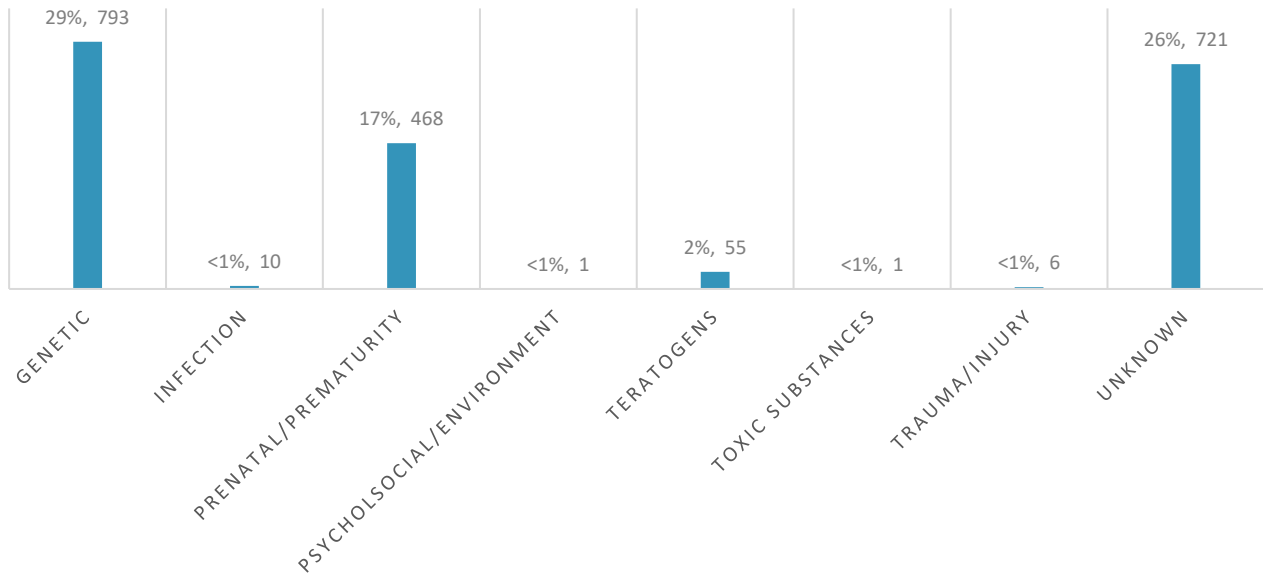
Risk Factors

To the extent possible, we identify ICD-10 codes that are indicative of the associated risks or potential causes of disorders of individuals served at the CHDD. However, in case of known causes for a certain disorders, we may use the term etiology (e.g., Down syndrome). A client may have one or multiple risk factors. The risk factors are defined as followed:

1. Genetic (relevant G, Q00-Q99 codes): Due to variants in genes or chromosomes which may or may not be inherited.
2. Infections (P35-P39, A, B codes): Bacterial or viral infections such as Guillian-Barre syndrome, cytomegalovirus, etc., occurring in intrauterine or postnatal environments.
3. Prenatal/Prematurity (P05-P08, P19-P29, P50-P96 codes): Premature birth or injury at birth or around this period including trauma, asphyxia, hemorrhage, etc.
4. Psychosocial/Environment (Z55, Z65 codes): Psychological or social factors (e.g., abuse, neglect) which have a bearing on a person's health and/or development (especially cognitive or social).
5. Teratogens (P04, O35, O99.330): Maternal exposure to drugs, chemicals, or other agents that result in damage to the unborn child either intrauterine or during lactation.
6. Toxic Substances (T36-T65): Exposure to drugs, chemicals, or other agents in the environment.
7. Trauma/Injury (P10-P15, S, T14 codes): Other adverse injuries to the child postnatally such as head injury.

During 2020, of the identified risk factors, the top three were Genetic (n=793), Unknown (n=721), and Prenatal/ Prematurity (n=468).

CLIENTS BY RISK FACTORS



Categorical Diagnoses

Following identified relevant ICD-10 diagnosis codes reported, we grouped specific codes into broader Categorical Diagnoses in the table below. Diagnoses that were not associated with a visit during the reporting were not included in this analysis. In addition, a client could have more than one diagnosis. Terminology has been altered to be more consistent with other commonly used systems, for example, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).

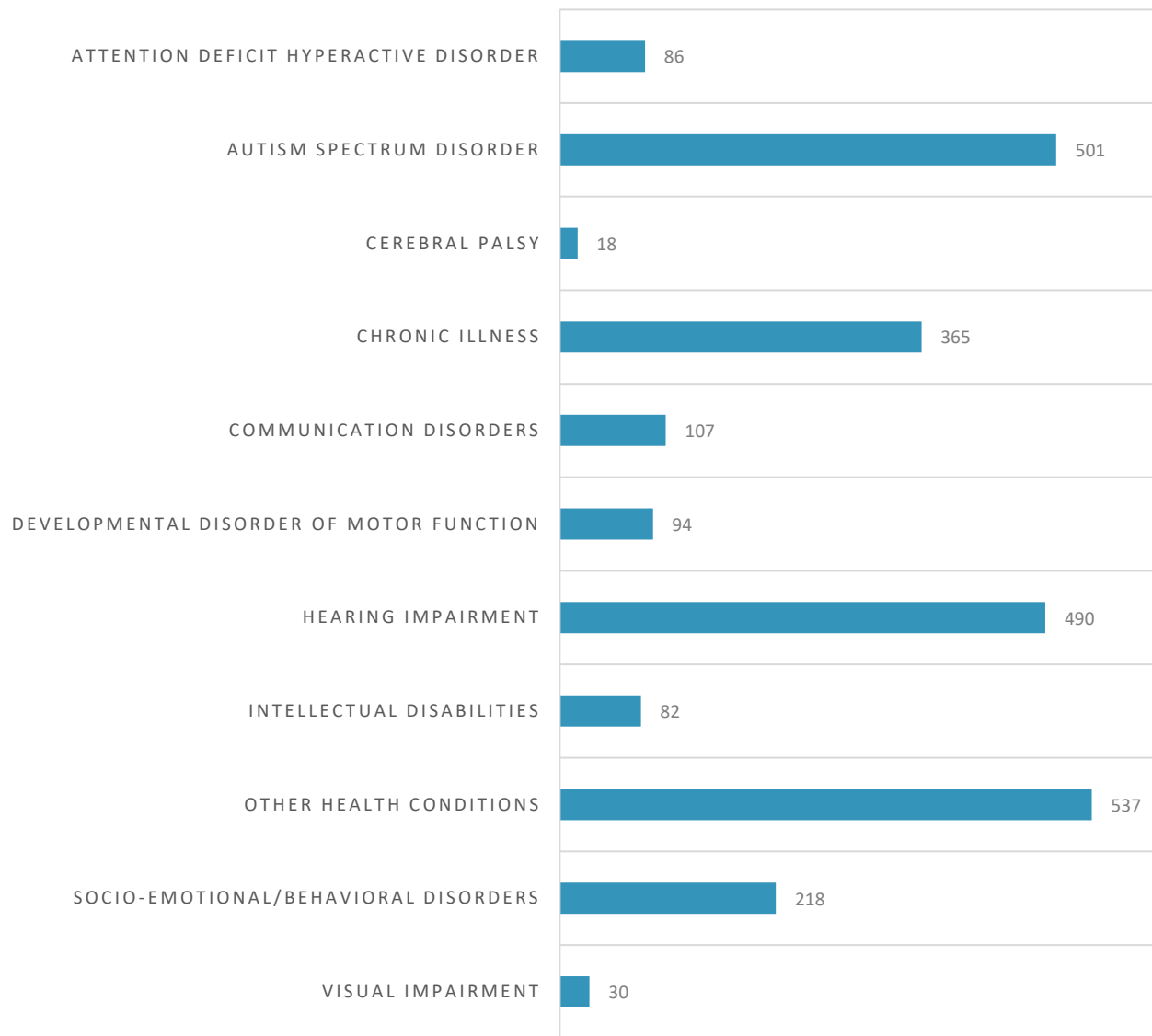
Categorical Diagnosis (ICD Codes)	ICD-10 Codes
Attention Deficit Hyperactive Disorder (ADHD)	F90
Autism Spectrum Disorder (ASD)	F84
Cerebral Palsy	G80-G83
Chronic Illness	G and I codes (exclude G80-G83)
Communication Disorders	F80
Developmental Disorder of Motor Function	F82
Hearing Impairment	H60-H95
Intellectual Disabilities	F70-F79, Q90
Other Health Conditions	E00-E89, Q00-Q99 (exclude Q90)
Socio-Emotional/Behavioral Disorders	F01-F99 (exclude F80-82, F84, F90)
Specific Learning Disorders	F81
Visual Impairment	H00-H59

Chronic Illness and Other Health Conditions cover broad range of diagnoses. Chronic Illness category includes conditions such as Huntington’s disease, hereditary ataxia, or Parkinson’s diseases. Other Health Conditions cover category of endocrine, nutritional, and metabolic diseases and congenital malformations and chromosomal abnormalities. Some specific conditions in Other Health Conditions include Fabry (-Anderson) disease, Congenital hypothyroidism, Classical Phenylketonuria, or Congenital malformation of heart. These specific conditions are noted as applicable in each individual clinic profile.

During this reporting year, 74% of our clients (n=2,032) were identified with at least one of the Categorical Diagnoses. Of those with at least one Categorical Diagnosis, 179 had two Categorical Diagnoses, and 119 had three or more Categorical Diagnoses.

Other Health Conditions (537), ASD (501), and Hearing Impairment (490), were the top reported Categorical Diagnoses during 2020.

CLIENTS BY CATEGORICAL DIAGNOSES



Subspecialty Clinics

Autism Center

The UW Autism Center's Clinical Services provide state-of-the-art, comprehensive, coordinated services to families and individuals at risk or with autism spectrum disorder (ASD) from birth through early adulthood. Services are provided at both the UW Seattle and UW Tacoma campuses. Some of the clinical services offered at the UWAC include Diagnostic Evaluation, Medical Consultation, Speech Assessment and Treatment, Applied Behavior Analysis Interventions, and Psychological Therapy.

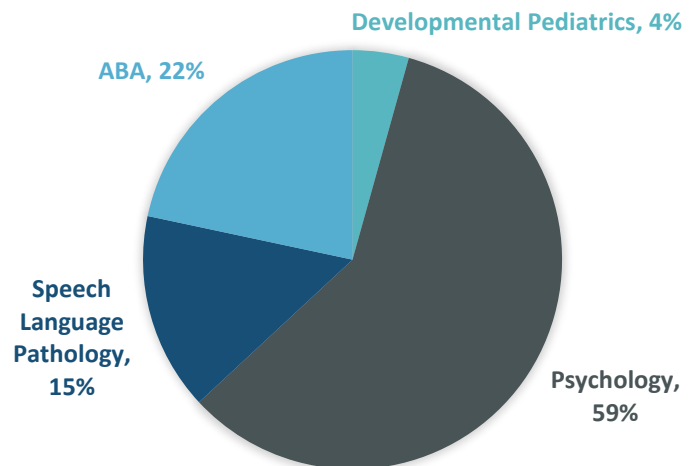
Autism Clinic	2020
Number of Unique Clients	424
Number of Visits	9,331
Visit per Client Ratio	22

Of the 424 clients that came to the Autism center in 2020, 86% of the clients were younger than 19 years. Compared to other CHDD clinics and services, the Autism clinic had the highest visit per client ratio in 2020, as a major focus of the clinic was intervention.

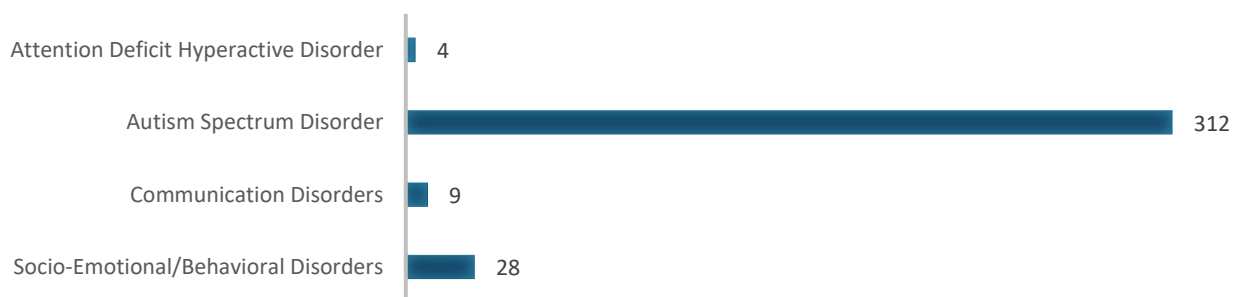
By number of unique clients, the Psychology discipline served the most clients during 2020, 59% (312 clients). Due to the intensity and the length of time for ABA therapy, a client had multiple visits per week over a one to two-year period. As a result, ABA (115 clients) made up 48% (4,511) of all clinician client interactions.

The majority of clients had a categorical diagnosis of ASD (312 clients). The next most common categorical diagnosis was Social Emotional / Behavioral Disorders (28 clients).

AUTISM CENTER CLIENTS BY DISCIPLINES



AUTISM CENTER CLIENTS BY CATEGORICAL DIAGNOSES



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 particular disorders and guidance on family planning.

Biochemical Genetics Clinic	2020
Number of Unique Clients	147
Number of Visits	261
Visit per Client Ratio	2
Number of Clinician-Client Interactions	345
Clinician-Client Interaction per Client Ratio	2

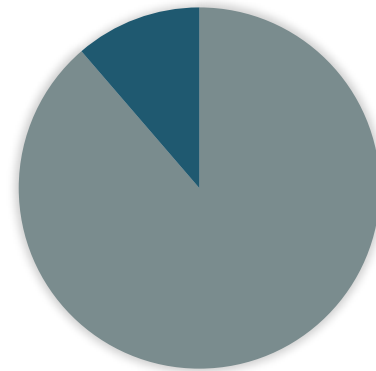
Biochemical Genetic clients tend to be in older age group, with 58% (n=85) clients older than 30 years old. About 21% (n=32) of Biochemical Genetics clients were in the 0-19 age group, which is much less compared the CHDD client population.

During 2020, a Biochemical Genetics client typically had two visits per client with a Medical Genetics physician and a Nutritionist. Medical Genetics is the most commonly participated discipline serving 89% of clients coming to the clinic.

The most common Categorical Diagnoses at Biochemical Genetics Clinic were the Other Health Conditions (n=102) with most common ICD-10 codes for Fabry (-Anderson) disease, Medium Chain Acyl CoA Dehydrogenase Deficiency, and Gaucher disease. Most clients (n=105) had a Genetic Categorical Risk Factor based on the ICD-10 diagnosis code.

BIOCHEMICAL GENETICS CLIENTS BY DISCIPLINES

Nutrition and Dietetics, 11%



Medical Genetics, 89%

BIOCHEMICAL GENETICS CLIENTS BY CATEGORICAL DIAGNOSES



Cardiac Neurodevelopmental Clinic

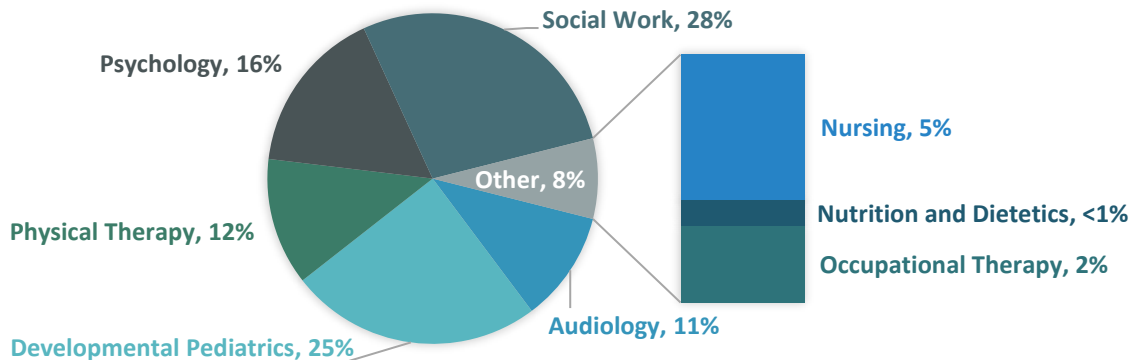
Children who are born with complex congenital heart disease (CHD) are at risk for problems with growth and development. The Cardiac Neurodevelopmental Clinic (CNC) evaluates and treats infants and children with complex congenital heart defects who had heart surgery before their first birthday. The clinic 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 August 2015, 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.

Cardiac Neurodevelopmental Clinic	2020
Number of Unique Clients	108
Number of Visits	128
Visit per Client Ratio	1
Number of Clinician-Client Interactions	405
Clinician-Client Interaction per Client Ratio	4

Cardiac Neurodevelopmental Clinic primarily serves a younger client population from 0 to 5; 90% of CNC clients were younger than three years of age. On average in 2020, a client had one visit, during which could have as many as 4 different disciplines involved in the care

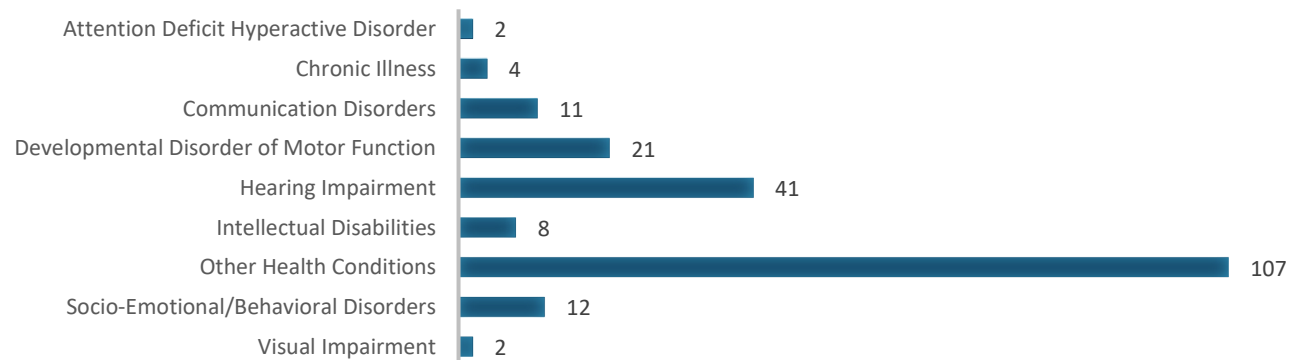
team. In 2020, the most commonly participating disciplines at CNC were Social Work (28%), Developmental Pediatrics (25%), Psychology (16%), Physical Therapy (12%), and Audiology (11%).

CARDIAC NEURODEVELOPMENTAL CLIENTS BY DISCIPLINES



In 2020, most commonly associated Categorical Diagnoses for CNC clients was Other Health Conditions (n=107) with the most common ICD-10 code for Congenital Malformation of Heart. Top two associated Categorical Risk Factors were Genetics (n=107) and Prenatal / Prematurity (n=10).

CARDIAC NEURODEVELOPMENTAL CLIENTS BY CATEGORICAL DIAGNOSES

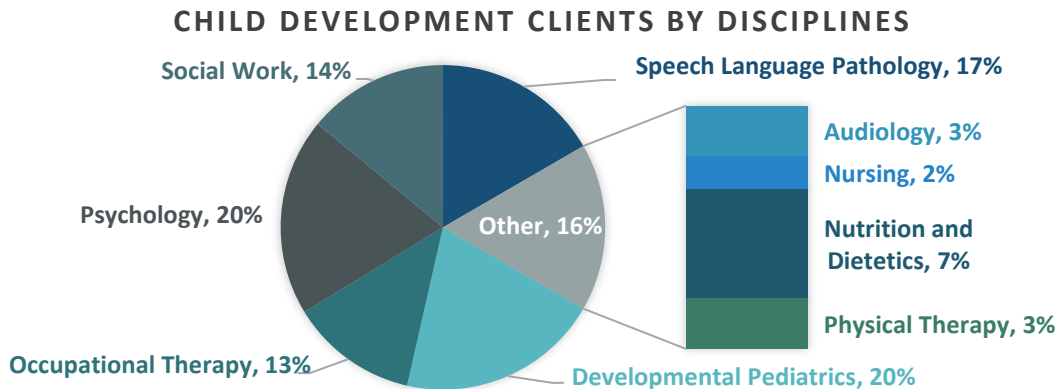


Child Development Clinic

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 from 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 CHDD for interdisciplinary clinical training under the auspices of the Leadership Education in Neurodevelopmental Disabilities training grant awarded by the Maternal and Child Health Bureau.

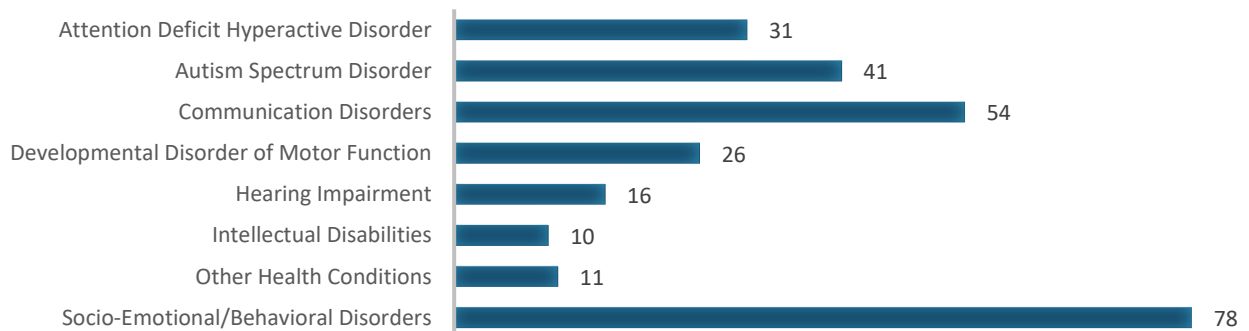
Child Development Clinic	2020
Number of Unique Clients	95
Number of Visits	325
Visit per Client Ratio	3
Number of Clinician-Client Interactions	594
Clinician-Client Interaction per Client Ratio	6

During 2020, most CDC clients (n=94) were under the age of 19. A CDC client typically had 3 visits at which could have as many as 6 different disciplines involved in the care team. Top commonly participating disciplines were Psychology (20%), Developmental Pediatrics (20%), and Speech Language Pathology (17%), Social Work (14%), and Occupational Therapy (13%).



As CDC evaluates a wide range of clients with neurodevelopmental disabilities and clients typically had multiple concerns represented in the Categorical Diagnoses. Top Categorical Diagnoses at CDC are Socio-Emotional / Behavioral Disorders (n=78), Communication Disorders (n=54), and ASD (n=41). Most common associated risk factors among CDC clients were Unknown (n=127), Genetics (n=17), Prenatal / Prematurity (n=7), and Teratogens (n=7).

CHILD DEVELOPMENT CLIENTS BY CATEGORICAL DIAGNOSES



Hypothyroidism Follow-Up Clinic

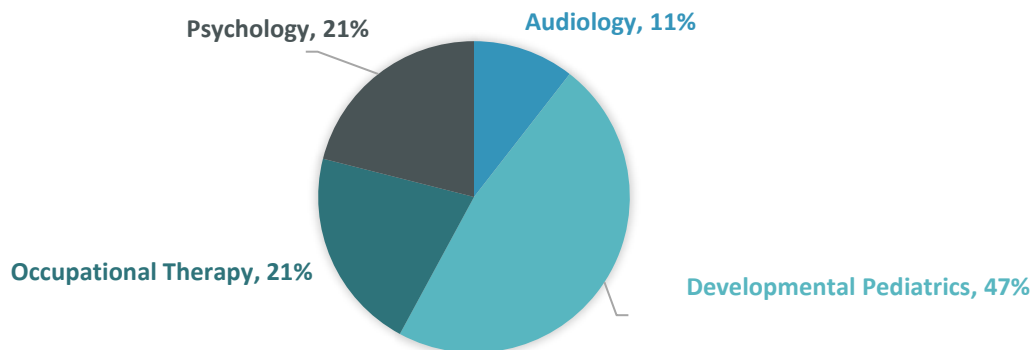
The Hypothyroidism Follow-Up Clinic provides developmental follow-up for children who have been identified through the Washington State Newborn Screening Program and diagnosed with congenital hypothyroidism. Children seen in the clinic receive periodic developmental assessments to evaluate developmental progress and the need for intervention services. Congenital hypothyroidism is a condition of thyroid hormone deficiency present at birth. Approximately one in 4,000 newborn infants has a severe deficiency of thyroid function, while even more have mild or partial degrees of thyroid dysfunction. If untreated for several months after birth, severe congenital hypothyroidism can lead to growth failure and permanent intellectual disability. Treatment consists of a daily dose of thyroid hormone by mouth. Because the treatment is simple, effective, and inexpensive, newborn screening is used to detect and treat congenital hypothyroidism in the first weeks of life.

The Hypothyroidism Follow-up Clinic opened in 1980. Infants are seen by a developmental pediatrician and a pediatric occupational therapist shortly after their diagnosis at 6-12 months and by developmental pediatrician and psychologist at their follow-up visits at ages three, five, and 12 years. After 40 years serving community, the Hypothyroidism clinic was closed at the end of June 2020. This report is also the last report for the clinic.

Hypothyroidism Follow-up Clinic	2020
Number of Unique Clients	9
Number of Visits	13
Visit per Client Ratio	1
Number of Clinician-Client Interactions	22
Clinician-Client Interaction per Client Ratio	2

During 2020, all Hypothyroidism clinic clients were younger than the age of 9. Most clients typically had one visit to the clinic. At each visit, as many as four disciplines can involve in the care team. Most commonly participating disciplines were Developmental Pediatrics (40%), Psychology (25%), and Audiology (25%).

HYPOTHYROIDISM FOLLOW UP CLIENTS BY DISCIPLINES



During 2020, all clients had Other Health Conditions categorical diagnosis, with the most common ICD-10 code for Congenital Hypothyroidism without Goiter. In addition, 22% (n=2) had Hearing Impairment. All clients had Genetic risk factor.

HYPOTHYROIDISM FOLLOW-UP CLIENTS BY CATEGORICAL DIAGNOSES



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.

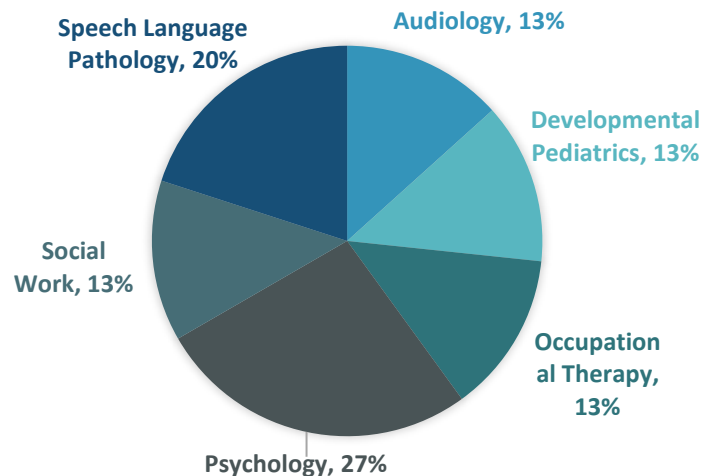
Down Syndrome Specialty Clinic	2020
Number of Unique Clients	6
Number of Visits	9
Visit per Client Ratio	2
Number of Clinician-Client Interactions	17
Clinician-Client Interaction per Client Ratio	3

On average, a client had one to two visits to the Down Syndrome Clinic. At each visit, a client had four to five clinician-client interactions depending on the complexity of the situation.

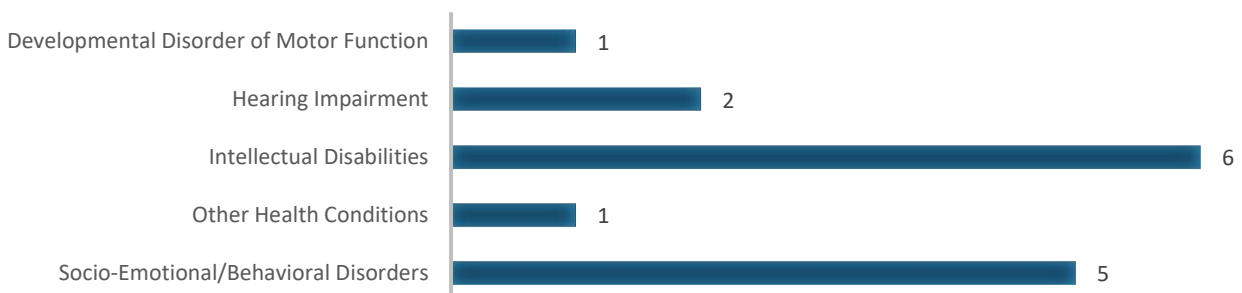
Most commonly participating disciplines were Psychology (27%), Speech Pathology Language (20%) Developmental Pediatrics (13%), Social Work (13%), and Audiology (13%).

The most common associated disorders were Intellectual Disabilities (n=6) and Socio-Emotional / Behavioral Disorders (n=5). Down Syndrome Specialty clinic clients had multiple disorders including Developmental Disorder of Motor Function (n=1), Hearing Impairment (n=2), and Other Health Conditions (n=1). All clients had Genetic risk factor.

DOWN SYNDROME CLIENTS BY DISCIPLINES



DOWN SYNDROME CLIENTS BY CATEGORICAL DIAGNOSES



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 CHDD. The core clinic at the CHDD 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.

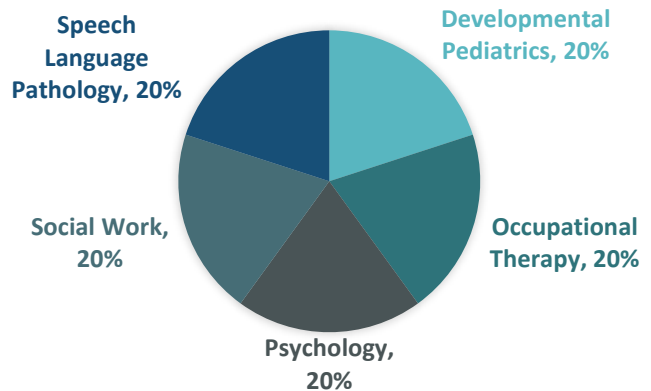
Each clinic in the network uses the same interdisciplinary approach and systematic diagnostic method, the 4-Digit Diagnostic Code and FAS facial recognition software developed by FAS DPN faculty. The FAS DPN has diagnosed over 3000 patients to date. The FAS DPN has expanded both nationally and internationally through the training of interdisciplinary teams. CHDD faculty members have trained over 210 interdisciplinary teams worldwide.

FAS DPN Clinic	2020
Number of Unique Clients	42
Number of Visits	42
Visit per Client Ratio	1.00
Number of Clinician-Client Interactions	210
Clinician-Client Interaction per Client Ratio	5.00

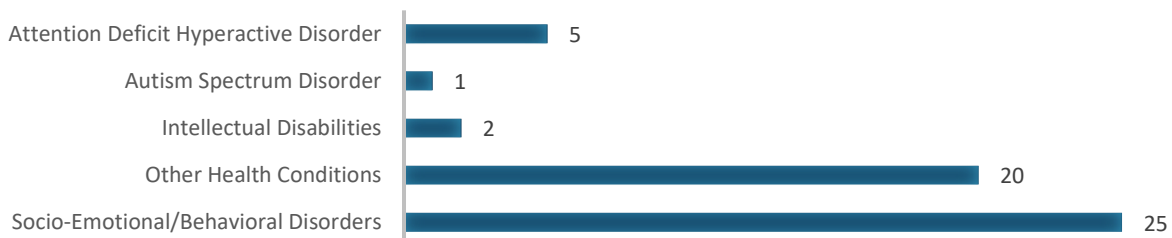
On average, a client had one visit to the FAS clinic. At each visit, a client often saw a team of interdisciplinary clinicians including a developmental pediatrician, a speech language pathologist, a social worker, a psychologist, and/or an occupational therapist.

In 2020, top Categorical Diagnoses were Socio-Emotional/ Behavior Disorders (n=25), Other Health Conditions (n=20), and ADHD/ADD (n=5). Of all FAS clients during 2020, the most common categorical Risk Factors were Genetic (n=20) and Teratogens (n=18).

FAS DPN CLIENTS BY DISCIPLINES



FAS DPN CLIENTS BY CATEGORICAL DIAGNOSES

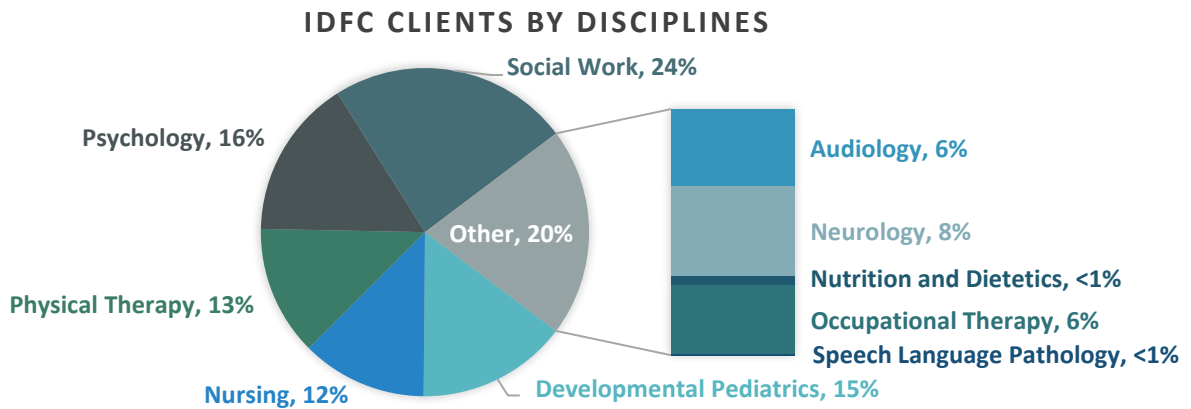


Infant Development Follow-Up Clinic

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 CHDD by the University of Washington Medical Center. The clinic also conducts long-term follow-up clinical research concerning neonatal outcomes, complications, and treatment.

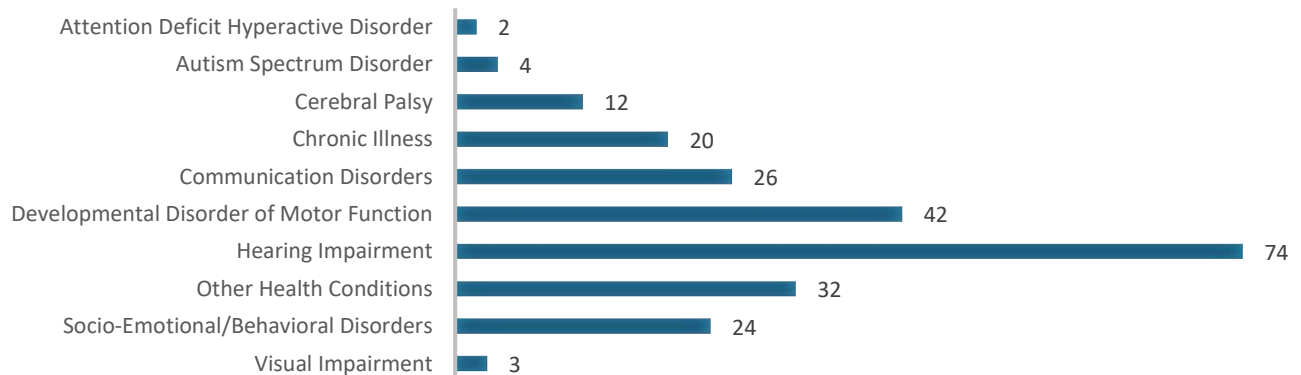
Infant Development Follow-Up Clinic	2020
Number of Unique Clients	370
Number of Visits	474
Visit per Client Ratio	1
Number of Clinician-Client Interactions	1,258
Clinician-Client Interaction per Client Ratio	3

In 2020, all IDFC clients were under the age of 6 years, of which, 92% were in the 0-3 age group. A client usually had one to two visits to the IDFC clinic. At each visit, a client had a care team that was comprised of three to four clinical disciplines. The top three participating disciplines were Social Work (24%), Psychology (16%), Developmental Pediatrics (15%), and Nursing (12%).



Of the 370 clients who visited IDFC in 2020, the most common were Hearing Impairment (n=74), Developmental Disorder of Motor Function (n=42), Communication Disorders (n=26), and Socio-Emotional/ Behavioral Disorders (n=24). The most common Categorical Risk Factor found in IDFC clients were Prenatal/ Prematurity (n=334).

IDFC CLIENTS BY CATEGORICAL DIAGNOSES



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

The Late and Moderate Preterm Babies (LAMBs) Follow-up Clinic at the CHDD 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.

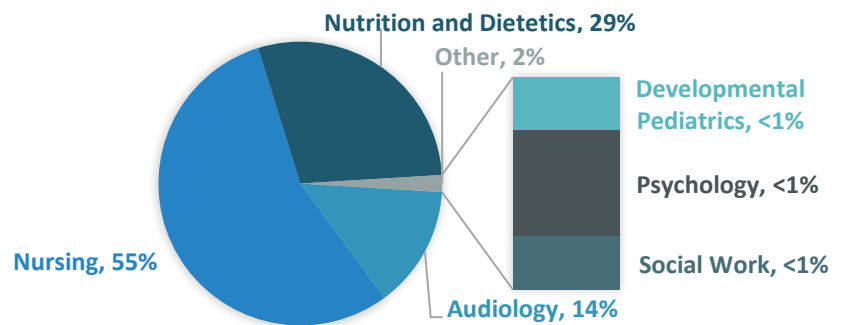
LAMBs clinic patients typically see a developmental pediatric nurse practitioner. The child also sees a pediatric registered dietician or pediatric audiologist depending on the child's age. Pediatric physical therapists, pediatric occupational therapists, developmental pediatricians, social workers, and psychologists are also available for on-site consultations.

LAMBs Follow-up Clinic	2020
Number of Unique Clients	115
Number of Visits	130
Visit per Client Ratio	1
Number of Clinician-Client Interactions	219
Clinician-Client Interaction per Client Ratio	2

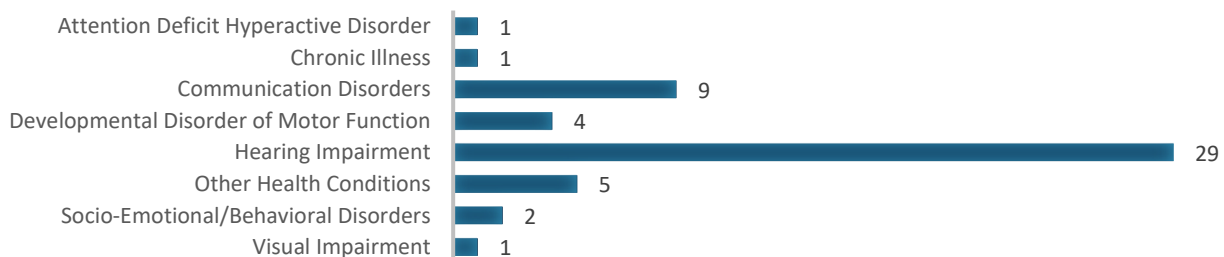
In 2020, LAMBs served 115 unique clients, all of whom were in the age group of 0-3 years. A client typically had one to two visits to the LAMBs clinic and saw two clinical disciplines at each visit. Nursing (50%) and Nutrition (35%) were the two disciplines that accounted for most clinician-client interactions.

The top Categorical Diagnoses were Hearing Impairment (n=29), Communication Disorders (n=10), and Developmental Disorders of Motor Function (n=7). All LAMBs clients had a Prenatal/Prematurity Categorical Risk Factor (n=114).

LAMBS CLIENTS BY DISCIPLINES



LAMBS CLIENTS BY CATEGORICAL DIAGNOSES



Neurogenetics Clinic

The UCEDD's 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.

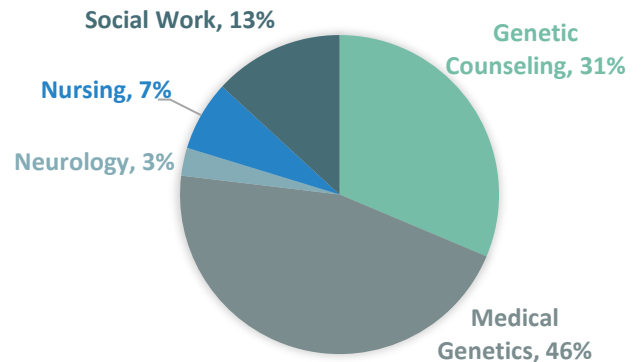
Neurogenetics Clinic	2020
Number of Unique Clients	592
Number of Visits	1,595
Visit per Client Ratio	3
Number of Clinician-Client Interactions	1,904
Clinician-Client Interaction per Client Ratio	3

Most clients (98%) who came to Neurogenetics Clinic were older than 19 years. A client typically had two to three visits to the clinic. At each visit, clients often saw two to three unique clinical disciplines in their care team.

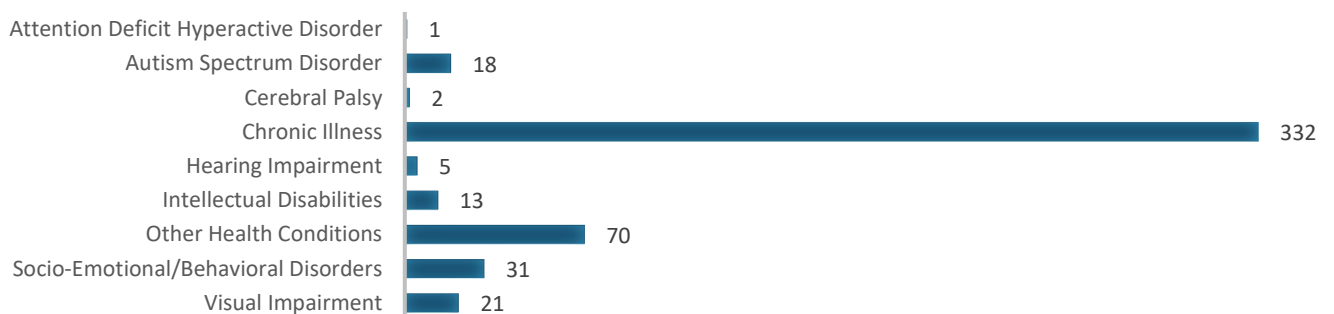
The two most commonly participating disciplines in 2020 were Medical Genetics (46%, 575) and Genetic Counseling (31%), and Social Work (13%).

The most common Categorical Diagnoses was Chronic Illness (n=332) with most common ICD-10 for Huntington's disease. The next top common Categorical Diagnoses included Other Health Conditions (n=70) and Socio-Emotional/Behavioral Disorders (n=31). The most common Categorical Risk Factor was Genetic (n=368).

NEUROGENETICS CLIENTS BY DISCIPLINES



NEUROGENETICS CLIENTS BY CATEGORICAL DIAGNOSES



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 CHDD 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.

Pediatric Audiology Clinic	2020
Number of Unique Clients	324
Number of Visits	459
Visit per Client Ratio	1

The Pediatric Audiology Clinic served over 300 clients in 2020 at CHDD. Two third of the clinic clients were under the age of 3. Different from most UCEDD clinics, pediatric audiology is not interdisciplinary; however, pediatric audiologists also see clients in other clinics in an interdisciplinary setting.

In 2020, clients typically had one to two visits to the clinic. The Visit per Client ratio is the same as Clinician-Client Interaction per Client ratio because clients only see one discipline (audiology) at the time of visit. Of 290 clients, 322 (89%) had a Categorical Diagnosis of Hearing Impairment. The majority of clients had Unknown Risk Factors.

PEDIATRIC AUDIOLOGY CLIENTS BY CATEGORICAL DIAGNOSES



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.

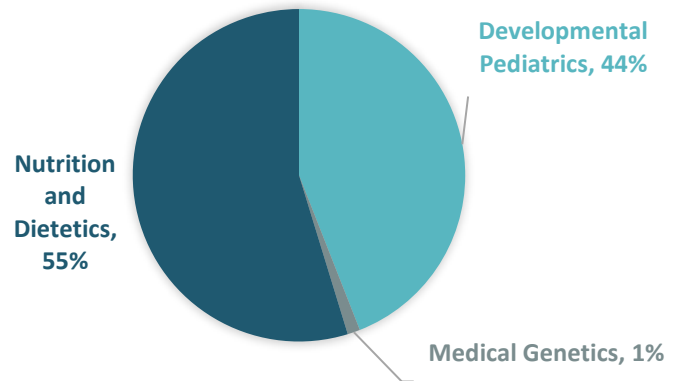
The PKU Clinic is comprised of a team of trained health care professionals that represent multiple disciplines. Long-term interdisciplinary planning and follow-up services are provided.

Phenylketonuria (PKU) Clinic	2020
Number of Unique Clients	201
Number of Visits	1,254
Visit per Client Ratio	6
Number of Clinician-Client Interactions	1,305
Clinician-Client Interaction per Client Ratio	6

During 2020, the PKU clinic served 201 unique clients, 55% of whom were under age of 19. Most clients typically had 6 visits to the PKU clinic. At each visit, a client may have one to two clinicians from two different disciplines.

The most commonly participating discipline in 2020 was Nutrition and Dietetics (55%) Developmental Pediatrics (44%). Other disciplines included Medical Genetics (1%). All PKU clients had a Categorical Diagnosis of Other Health Conditions (n=144), all of which were ICD-10 code for Classical phenylketonuria. A small number of clients had additional Categorical Diagnoses including Communication, Disorders, Intellectual Disabilities, and Socio-Emotional/Behavioral Disorders. In addition, all PKU clients also had Genetic risk factor.

PKU CLIENTS BY DISCIPLINES



PKU CLIENTS BY CATEGORICAL DIAGNOSES



Special Programs:

APEX Summer Camp

The Apex Summer Camp program at the UW Autism Center provides advanced peer experiences for children with autism spectrum disorder, ADHD, and related disorders. This summer day camp program is designed to build social and behavioral skills, positive relationships, and self-esteem in structured recreational and learning activities.

Naturalistic environments offer the best opportunities for learning and generalizing meaningful skills. Children participate in typical camp activities including sports, games, and arts and crafts. New skills are introduced through direct teaching, explicit rehearsal including modeling and role-playing, with practice and reinforcement throughout the day across activities. Each day focuses on a specific skill such as turn taking or eye contact, with broad emphasis on key themes such as communication, participation, and cooperation. Targets of treatment include improvements in the quality of peer interactions, increases in self-efficacy and confidence, and enhanced self-regulation of emotions and behavior.

The program includes the implementation of a reward system in which children earn points for appropriate behavior, such as helping peers, staying on task, following rules, and appropriate social interaction (e.g., maintaining personal space, initiating social approaches, appropriate questions). Point accumulation entitles children to rewards on a daily and weekly basis. Behaviors are tracked throughout the day, with each hour divided into four intervals. Data tracking proceeds continuously, with individual progress monitoring occurring on a daily and weekly basis. Daily report cards are sent home to parents to provide feedback to the child and parent regarding daily and weekly performance. Expert clinical supervision occurs weekly, with individualized intervention programs implemented and modified accordingly.

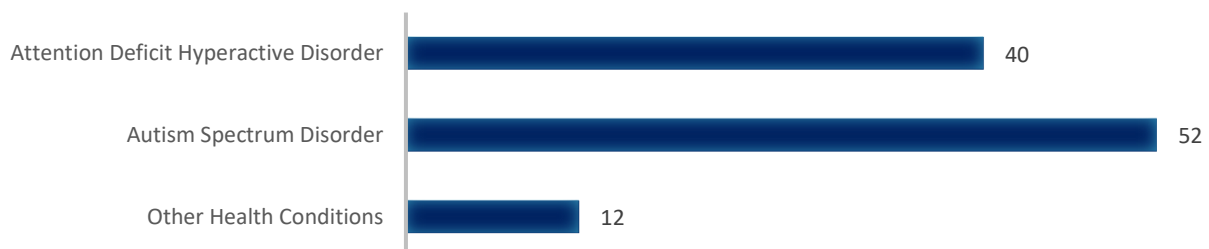
Children aged 6-12 with ASD, ADHD, as well as siblings and peers, participate. The 5-week program runs Monday through Friday 9:00 am to 3:00 pm offering 150 hours of treatment; roughly the equivalent of two years of clinic or school-based social skills training. Leading experts are engaged to provide clinical training, supervision, support, and consultation.

Apex treatment hours provided

Total clients	104 campers
Average number of treatment hours per camper	150 hours
Total hours of treatment APEX provided	15,600 hours

During this reporting year, the APEX program provided services to 104 campers, of whom 81% identified as male and 19% as female. In 2020, APEX provided about 15,600 hours of treatment during 3,380 client visits. The top two Categorical Diagnoses reported were ASD (n=52) and ADHD (n=40).

APEX CLIENTS BY CATEGORICAL DIAGNOSES



Experimental Education Unit Classes

The EEU serves as a training and research model site for inclusive education, and provides professional development for the Seattle Public School staff in evidence-based practices for meeting the needs of children with disabilities in inclusive settings. The EEU provides inclusive interdisciplinary education classes and services to children ranging from birth to 7 years of age. EEU classes include:

Infant/Toddler program (ITP) includes Infant Playgroup and Toddler Playgroup programs. The Infant Playgroup offers a playgroup for newborn children to 12 months who have developmental delays.

Preschool includes three programs: part day classroom, Seattle Preschool Program (SPP, full day), and Project Developmentally Appropriate Treatment for Autism (DATA). Project DATA is a project implemented in 2006 for preschool students on the autism spectrum to receive services integrating the best, most current educational practices from the fields of early childhood special education and applied behavior analysis in addition to their regular classes. Project DATA is the model for which SPS designed its extended day special education program. Of 79 students, 26% (n=21) participated in Project DATA during this school year.

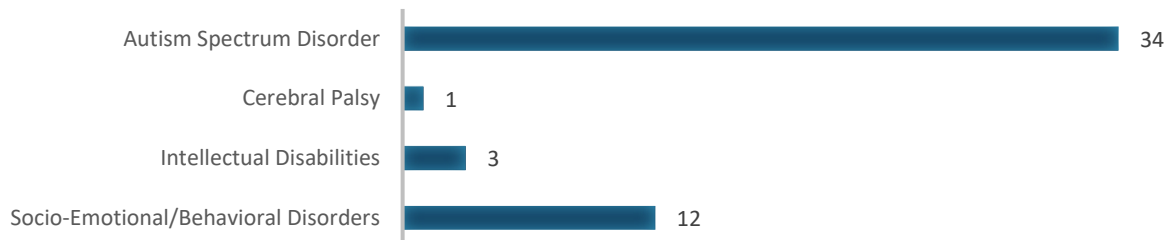
Kindergarten: the kindergarten teams meet the needs of all students by following and adapting the district’s general education curriculum, and providing instruction in both large and small group settings. These decisions are made on a child-by-child basis and change based on learning outcome and needs throughout the school year.

During 2020-2021 school year, the EEU classes were closed during the first two months and the reopened in early November, 2020 with remote learning for ITP students. For older students in preschool and kindergarten, the EEU offered a hybrid model of in-person and remote learning, about two days in-person and two days remote learning. Of the total student in special education, 62% were identified as male, 38% female. The top Categorical Diagnosis was ASD (n=34).

Experimental Education Classes	<i>Total Clients</i>	<i>Avg. Days per Client</i>	<i>Total Days</i>	<i>Avg. Hrs per Day</i>	<i>Total Hours</i>
Infant-Toddler (birth-3 yrs) ¹	21	40	840	2.0	1,680
Preschool (3-5 yrs) SPP Full Day ^{2,3}	18	80	1,440	6.5	9,360
Preschool (3-5 yrs) ^{2,3}	24	80	1,920	2.7	5,184
Kindergarten (5 yrs) ²	16	80	1,280	6.5	8,320
Total	79	70	5,480	4.4	25,544

¹ Remote learning only; ² Hybrid learning model; ³ Include Project DATA hours

EEU CLIENTS BY REPORTED CATEGORICAL DIAGNOSES



Employment Training

UW Employment Program

The UW Employment Program (UWEP) works to create and support mutually beneficial relationships between people with disabilities and the businesses that hire them. In order to accomplish this mission, UWEP staff address three major goals: 1) to develop and implement new or expanded programs relating to employment of persons with disabilities; 2) to provide outreach and marketing of all program services to the community; and 3) to provide direct services to clients with a wide range of disabilities.

UWEP staff members serve and advocate for adolescents and adults with developmental disabilities and other types of physical and cognitive disabilities such as acquired brain injury. They also provide direct services to clients and work to ensure successful and equitable employment through working with employers, parents, agencies, and other support personnel. Direct services include job development, job placement, job training, and continued employment support.

During 2020, the UWEP served 114 clients and 6 clients exited the program during the year. The average age of clients was 34 years (the youngest was 17 and the oldest 72). Prior to the pandemic, estimated 68% (n=77) UWEP clients were employed; however, the employment rate decreased to about 52% (n=60) after the pandemic struck.

Employment Services

Total Clients	114
Average Hours of Employment Services Provided per Client	37.19 hrs
Total Sum of Employment Services	4,090 hrs

On average, a UWEP client worked 16 hours per week during 2020. Considering wages and benefits, all clients employed in 2020 earned at or over the minimum wage of \$13.51/hour. Of the 77 employed clients during the year, 85% (n=66) clients reported at least one employer-provided benefit including vacation (n=26), health care (n=16), sick leave (66), and/or retirement (n=15).

Among the UWEP clients, the most common disabilities reported were Intellectual Disabilities (n=39), Autism Spectrum Disorder (n=37), and Other Health Conditions (n=34)

UWEP CLIENTS BY REPORTED CATEGORICAL DIAGNOSES



Contact Information

- [Biochemical Genetics Clinic](#) 206-598-1800
- [Cardiac Neurodevelopmental Clinic](#) 206-598-3327
- [Child Development Clinic](#) 206-598-9346
- [Congenital Hypothyroidism Follow-Up Clinic](#) 206-598-1800
- [Down Syndrome Specialty Clinic](#) 206-598-3327
- [EEU Classes at the Haring Center](#) 206-543-4011
- [FAS Diagnostic and Prevention Network Clinic](#) 206-598-7666
- [Genetic Medicine Clinic](#) 206-598-4030
- [Infant Development Follow-up Clinic](#) 206-598-9348
- [Neurogenetics Clinic](#) 206-598-4030
- [Pediatric Audiology Clinic](#) 206-598-9347
- [PKU \(Phenylketonuria\) Clinic](#) 206-598-1800
- [Autism Center Clinical Services](#) 206-221-6806
- [UW Employment Program](#) 206-543-6387

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