



W

INSTITUTE ON HUMAN
DEVELOPMENT & DISABILITY

UNIVERSITY *of* WASHINGTON



All people should have the right to:

Feel safe, valued, & included

Have access to education, medical care, transportation, housing, & good nutrition

Maximize strengths, minimize weaknesses to grow into their best selves



Pre-pregnancy



Pregnancy



Baby



Toddler



Elderly



Adult

Life Cycle



Young adult

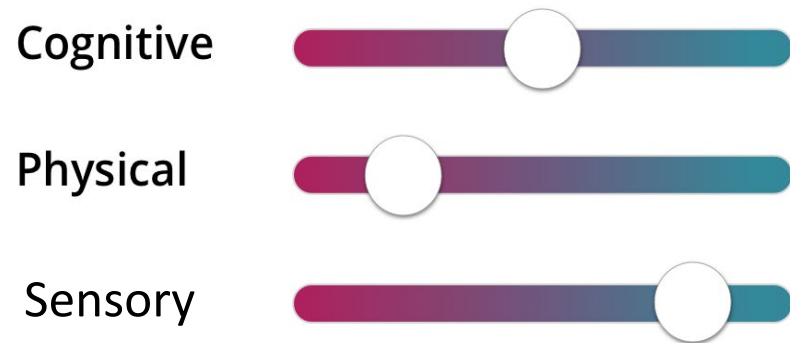


School Age

Disabilities can be...

- Visible/Invisible
- Stable/Progressive
- Genetic-syndromic/Acquired
- Cognitive, Physical or Sensory

Disabilities can coexist



Barriers include...

- Attitude
- Communication
- Physical
- Policy
- Social
- Transportation

Public Law 88-164: Initial federal legislation establishing university-based entities AND RCW 28.77.439 (now B.20.410) establishes WA State Commitment

Center on Human Development and Disability (CHDD)

1967

2023

1963

Child Development and Mental Retardation Center (CDMRC)

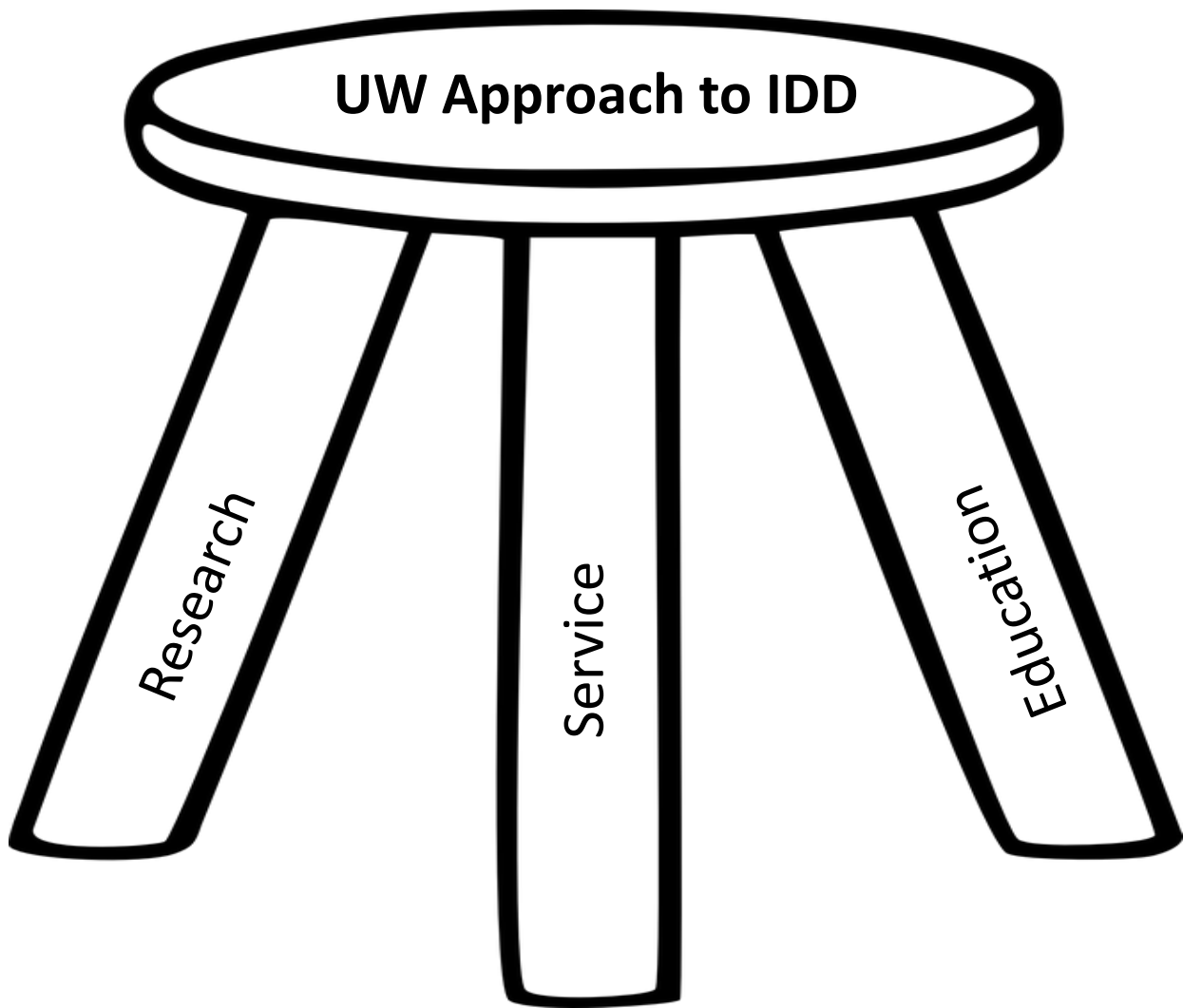
1995

Institute on Human Development and Disability (IHDD)

The IHDD addresses a broad spectrum of problems relevant to individuals with developmental disabilities.

- 600 faculty and staff
- 125 faculty members
- 26 academic departments





IDDRCs – Intellectual and Developmental Disabilities Research Center. Research to understand normal and atypical brain development, the biologic basis of autism, brain malformation disorders, brain injury and repair, epilepsy, and hearing disorders and treatments. (funding thru NICHD)

UCEDD - University Center for Excellence in Developmental Disabilities. Funding thru Administration on Intellectual and Developmental Disabilities (AIDD)

LEND - Leadership Education in Neurodevelopmental and Related Disabilities
Funding through the federal Health Resources and Services Administration (HRSA) and Maternal and Child Health Bureau (MCHB)



AUCD

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

Research, Education, Service

The IHDD Federal and State Ecosystem

Intellectual and Developmental
Disability Research Center (IDDRC)

UW Institute on
Human Development
and Disability (IHDD)

University Center for Excellence in
Developmental Disabilities (UCEDD)

DD Network Partners

Protection and Advocacy System (DRW)

Developmental Disabilities Council (DDC)

Allies in Advocacy

Center for Technology & Disability

Genetics Program

Autism Center

Adults and Elders

Community Disability Policy Initiative

Haring Center for Inclusive Education

Clinical Training Unit

Leadership Education in
Neurodevelopmental &
Related Disabilities (LEND)

The UW IHDD is one of only 9 organizations in the U.S. that receive funding from all three programs.

IHDD Vision



Inclusive communities where people with intellectual and developmental disabilities can live, learn, work, and thrive.

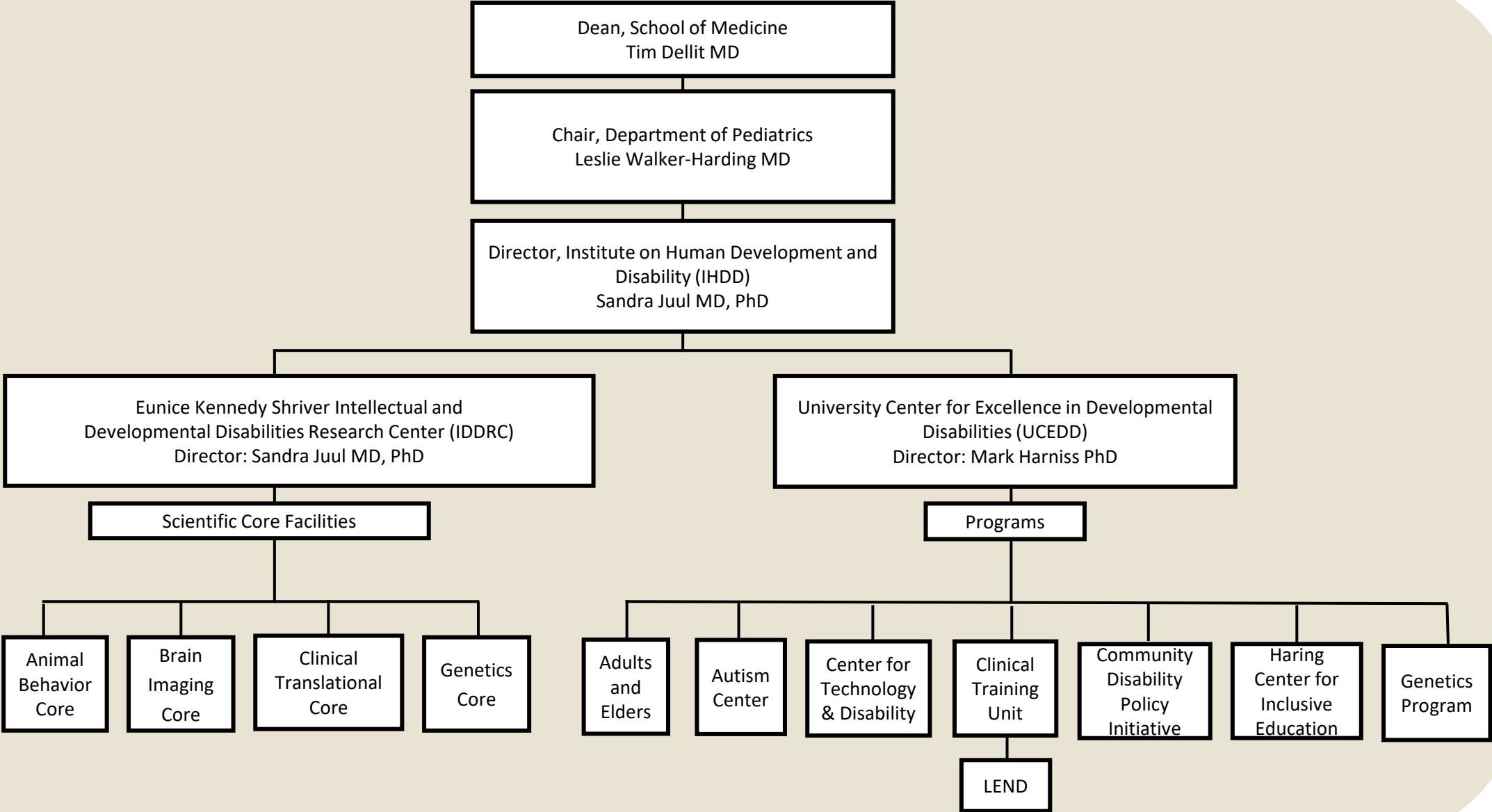


IHDD Mission

To support our vision through:

- Scientific Discovery (IDDRC)
- Education and Training (UCEDD, LEND)
- Leadership Development (LEND)
- Clinical Services (12 Clinics)
- Direct Services (Assistive technology, UW Employment)
- Community Engagement (UCEDD)
- Policy Change (UCEDD)
- Advocacy Activities (UCEDD)

IHDD Organizational Chart



Intellectual and Developmental Disability Research Center (IDDRC)



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Eunice Kennedy Shriver Intellectual and
Developmental Disabilities Research Center

One of 15
federally
funded IDDRCs

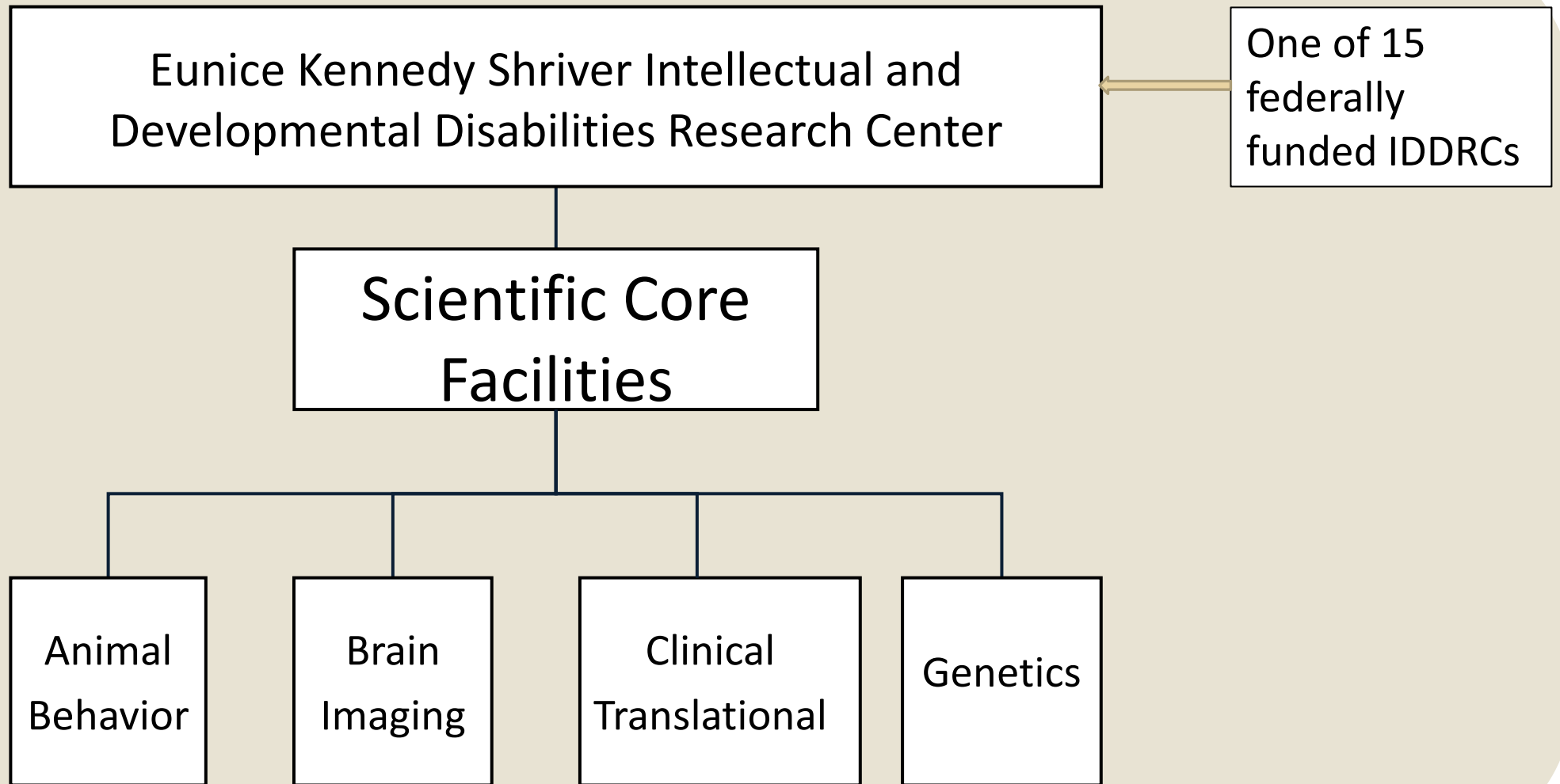
Scientific Core
Facilities

Animal
Behavior

Brain
Imaging

Clinical
Translational

Genetics





Animal Behavior Core

The Animal Behavior Core provides multi-pronged services for Research Affiliates using preclinical animal models of developmental disorders.

[More about the Animal Behavior Core](#)



Brain Imaging Core

The overall goal of the Brain Imaging Core is to support affiliates and train junior investigators to perform scientifically sound research by providing...

[More about the Brain Imaging Core](#)



Clinical Translational Core

The Clinical Translational Core functions as a service to IDDRC scientists to organize, integrate, and promote the use of translational research resources.

[More about the Clinical Translational Core](#)



Genetics Core

The Genetics Core is designed to integrate cutting-edge genomic technologies into the research programs of investigators to enhance the understanding of IDD..

[More about the Genetics Core](#)

IDDRC Core Services

IDDRC supports:

UW faculty engaged in funded research of relevance to intellectual and developmental disabilities. The project must be extramurally funded, peer reviewed, and require core support.

CORE FUNCTIONS

Research

Education

Knowledge dissemination

CORE SERVICES

Consultation on experiment design

Consultation on grant development

Equipment access

Training of staff

Biostatistical/bioinformatics support

Coordinate with other UW resources

Intellectual and Developmental Disability Research Center (IDDRC)

Areas of research focus at the UW IDDRC:

- 1) Biologic Basis of Developmental Disorders
- 2) Acquired Brain Injury and Repair
- 3) Developmental Toxicology
- 4) Epilepsy
- 5) Disorders of Hearing and Vision
- 6) Autism: Genetics, biomarkers & therapeutics
- 7) Development and Evaluation of Therapeutic Interventions

Prematurity and Perinatal Asphyxia

1 in 10 babies are born preterm, 1 in 500 suffer from lack of oxygen during birth

Clinical Significance: ~50% of survivors develop developmental impairments

Basic research: What are the mechanisms of brain injury?

- Basic research: What treatments might help?
- Basic research: Development of appropriate animal models
- Basic research: Development of high throughput screening

Basic research: Do treatments work in animal models?

Clinical trials: testing the treatments in babies

Dissemination and Implementation: Get the word out!

Outcome: Work in progress!

Intellectual and Developmental Disability Research Center (IDDRC)

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Fetal Alcohol Spectrum Disorder

Clinical Recognition: Distinct facial and behavioral characteristics identified

Basic research: Is it really alcohol? Animal models and more clinical research

Advocacy: Actionable data to bring to advocacy at the state level, nationally and internationally.

Results: Screening programs, clinical treatment programs, public education

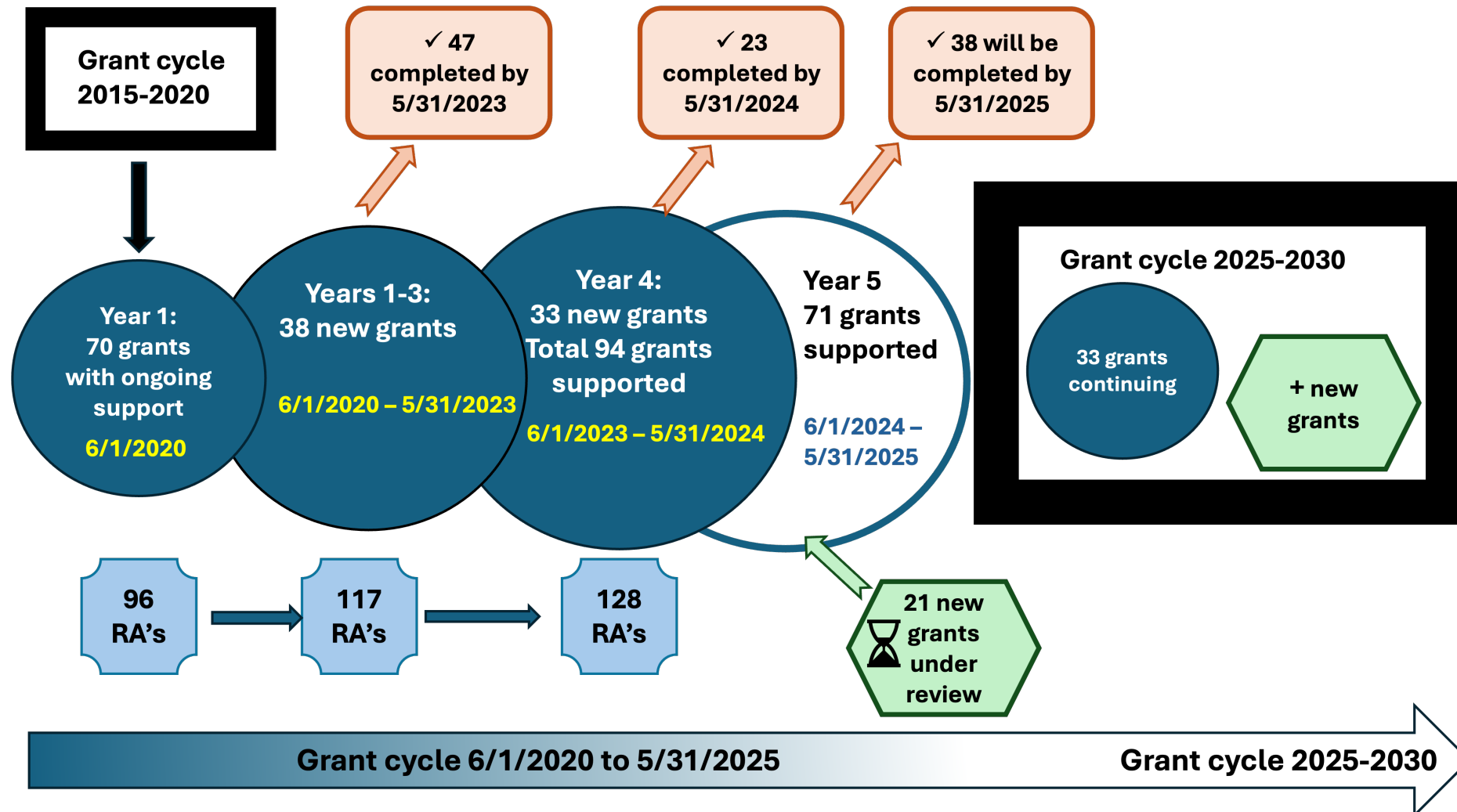
Outcome: Significant decrease in fetal exposure to alcohol and a corresponding decrease in children with FASD



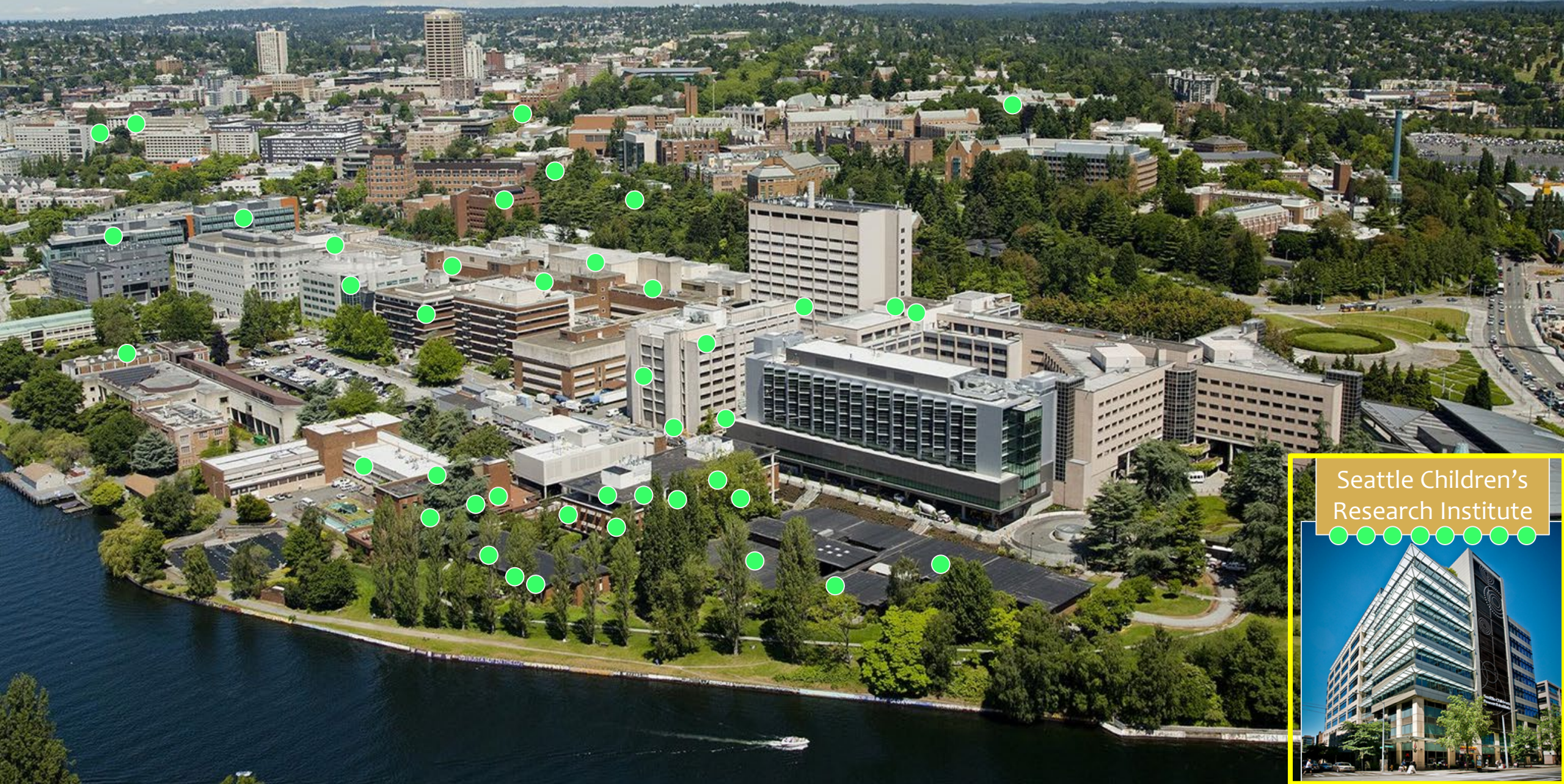
Examples of Other Ongoing Work

- Ø Identifying early biomarkers to diagnose autism (ASD)
- Ø Identifying genetic causes for autism and other developmental disabilities (DD)
- Ø Developing training models for best practices for children with ASD and other IDD.
- Ø IHDD, driven by discoveries by our research scientists work to enhance the quality of the lives of individuals with intellectual and developmental disabilities.

Grants and Research Affiliates supported during the current grant cycle



IDDRC Network: Research Affiliate Labs Receiving Core Support



Seattle Children's
Research Institute



University Center for Excellence in Developmental Disability (UCEDD)



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Purpose of UCEDDs

UCEDDs are the 'knowledge engine' of the DD Network. They generate knowledge to promote inclusion and independence for people with intellectual and developmental disabilities.

UCEDDs are lifespan programs with programs that function from pre-birth to seniors.

UCEDDs are community-engaged programs operating to connect universities to the communities they serve.



Core Functions of the UCEDD

Interdisciplinary training

For new
leaders, direct
service, clinical,
or other
personnel.

Community service

Including
training,
technical
assistance,
model and
demonstration
services

Research

Including basic,
applied,
evaluation, and
analysis of
public policy

Information dissemination

Related to the
activities
undertaken to
improve service
systems for
individuals with
IDD

UCEDD Programs

The UCEDD has 7 programs.

Adults and Elders

Autism Center

Center for
Technology and
Disability

Clinical Training
Unit

Genetics Program

Haring Center in
Inclusive Education

Community
Disability Policy
Initiative



Adults and Elders

To promote the health and overall quality of life of adults with developmental disabilities

- Adult Autism Clinic
- ECHO (Extension for Community Healthcare Outcomes) training
- ANeW (Adult Neurodevelopmental Wellness) project



Director: Gary Stobbe



Autism Center

Clinical services for individuals with or at risk for autism
from birth through early adulthood

Preservice and professional training

Research

Community Engagement

Director: Annette Estes

3,600

Client Visits

1,391

Diagnostic Evaluations

8,247

Intervention Sessions



Center for Technology and Disability

- Assistive Technology & Independent Living
 - Washington Assistive Technology Act Program (WATAP)
 - iCanConnect (National Deaf-Blind Equipment Distribution Program)
 - Independent Living Services for the Blind (ILOB)
 - UW Employment Program
- Knowledge Translation
 - ADA Knowledge Translation Center

Director: Mark Harniss



Clinical Training Unit (CTU)

Interdisciplinary training

Clinical services in the assessment and treatment of children with or at risk for developmental disabilities

Research

Director: Kathleen Lehman

IHDD Clinics

Autism

- Adult Autism Clinic
- UW Autism Center

Genetics

- Biochemical Genetics Clinic
- Genetic Medicine Clinic
- Neurogenetics Clinic
- Phenylketonuria (PKU) Clinic

Child Development

- Cardiac Neurodevelopmental Clinic
- Child Development Clinic
- Down Syndrome Clinic
- Fetal Alcohol Clinic
- Infant Follow-Up Clinic
- Preterm Babies Clinic



Exist to meet the UCEDD's goals of community services and interdisciplinary training

Funding from UWMC, Seattle Children's, WA Dept. of Health, and endowments

Administration and billing based on funding sources



Leadership Education in Neurodevelopmental and related Disabilities

Interdisciplinary training program in intellectual and developmental disabilities

Enroll an annual cohort of ~35 trainees

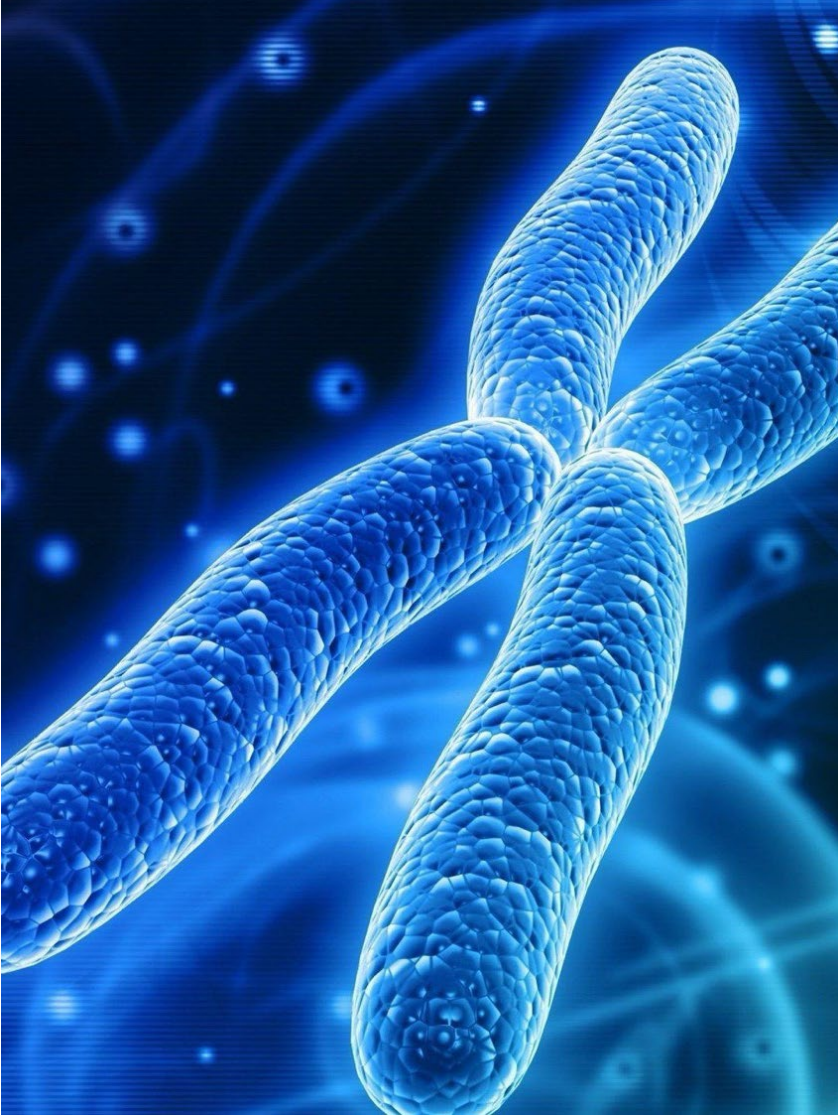
Graduate students, post-graduate fellows, mid-career community-based health professionals, families and self-advocates

Longstanding (50+ years!) funding through Maternal and Child Health Bureau Workforce Development Grant

12+ disciplines represented annually

Director: Kathleen Lehman

Training Director: Susan Wendel



Genetics Program

The Genetics Program comprises clinics that serve individuals at risk for or with a genetic disorder or disability

It also is home to the University of Washington Genetic Counseling Graduate Program (GCGP) that trains future genetic counselors

Fuki Hisama



Genetic Counseling Graduate Program

Master of Science degree from the Division of Medical Genetics in the Department of Medicine

Rotations through in-house clinics, including Fetal Alcohol Syndrome, Biochemical Genetics, PKU, and Down Syndrome, to gain hands-on experience

Capstone projects with the opportunity to collaborate with the LEND program

Haring Center for Inclusive Education



The Haring Center

- Champions inclusive education practices so every child can reach their full potential,
- Provides early childhood education to over 200 children from birth through kindergarten, with and without disabilities,
- Conducts leading-edge research to advance inclusive learning, with over \$11.5 million in active grants and contracts
- Provides a training site for students from multiple academic departments,
- Works with school districts across the state to help build the capacity for inclusive schools.

Director: Kathleen Artman Meeker



Community Disability Policy Initiative

Community engagement

Policy research

DD Network collaboration

Interim Director: Mark Harniss

Washington State Collaboration

DD Network: Statewide Planning and Advocacy

Disability Rights Washington

- *Protection and advocacy*
- *Legal rights*

Developmental Disabilities Council Collaborations

Make public policy recommendations to the Governor and state policy makers on issues of importance to individuals with intellectual and developmental disabilities (IDD) and their families



UCEDD

Self-Advocates

- *Identify existing resources that support the development of the self-advocacy movement*
- *Educate the wider community on the self-advocacy movement*

UCEDD Consumer Advisory Council (CAC)

- *CAC is composed of self-advocates, family members of children and adults with intellectual/developmental disabilities, and directors from the UCEDD, Disability Rights Washington, and the Washington State Developmental Disabilities Council*

Cross-Program Initiatives: IHDD ECHOs

Medical

- Autism Washington—2 cohorts
- IDD Wraparound
- Psychiatric Care
- Resource Navigation

Education

- ECHO in Special Education: Teachers, Educators, & Related Service Staff
- ECHO in Special Education: Parents, Caregivers, & Families
- ECHO Early Autism: Collaboration
- ECHO Early Autism: Navigation
- ECHO Early Autism: Parents



Washington INCLUDE Collaborative

JIM MANCINI, MS CCC-SLP

DIRECTOR

UNIVERSITY OF WASHINGTON

WA INCLUDE Collaborative

Interdisciplinary Network of Community Leaders with focus on the Underserved and Disability Education

Education and
training

Building
networks

Community
outreach

Advocacy and
policy change

<https://wainclude.org/>





Overview of INCLUDE Initiatives

Community Building, Outreach, Training, and Research

Autism COE Certification

SMART

ECHO Programming

Trainings

ECHO Autism Washington

ECHO IDD Wraparound

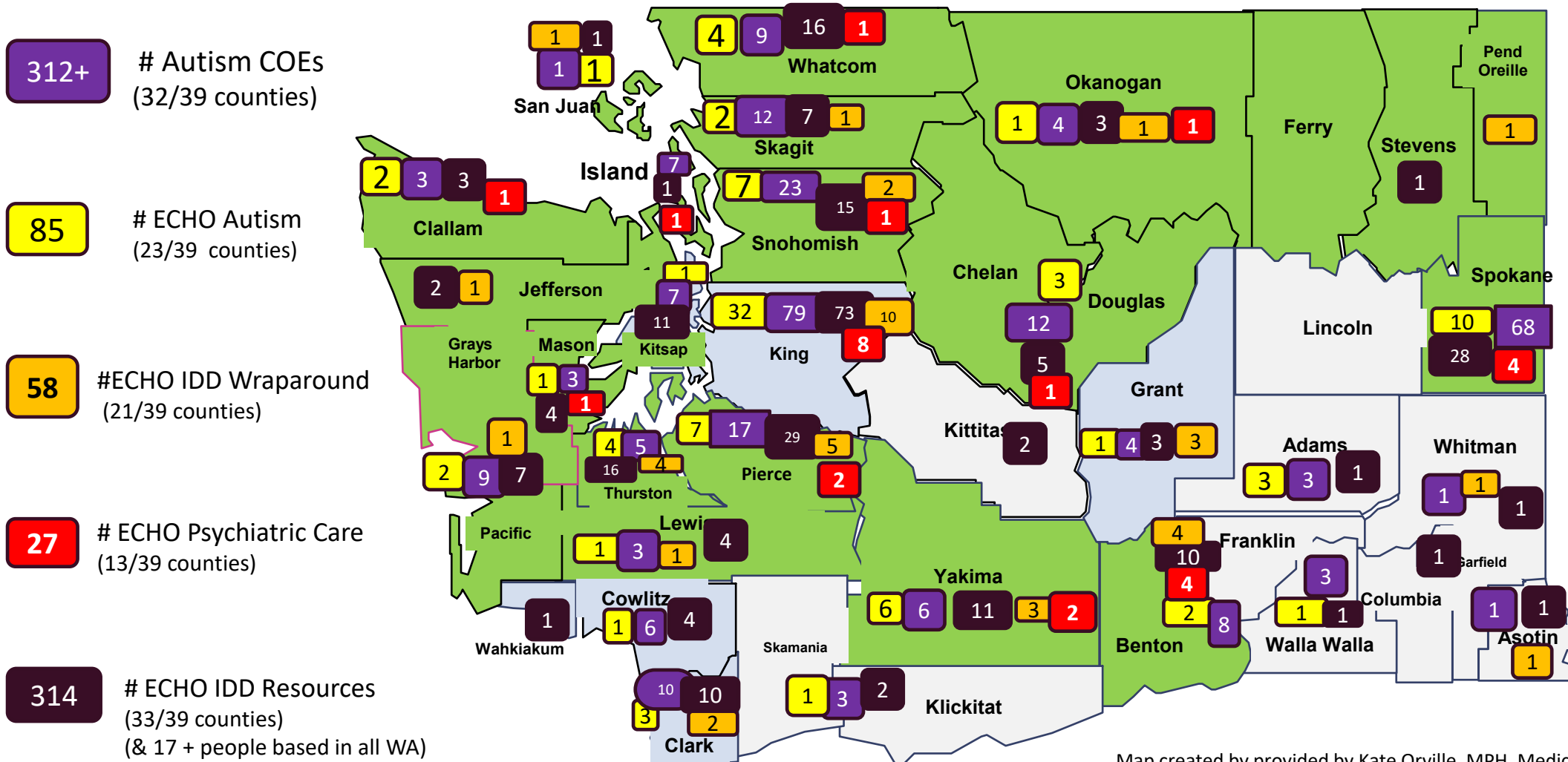
Community

ECHO Psychiatric Care

ECHO Resources Navigation

YOU!

INCLUDE Serves WA State



School and Medical Autism Review Teams (SMART)

- Established or developing SMART Team/Network
- Interest in SMART

Note: Grays Harbor/Pacific, Chelan/ Douglas, Benton/Franklin, Skamania/Klickitat and Garfield/Asotin are paired with each other



WA INCLUDE – Next Steps

Launch updated website to provide support and connection

Expand collaborations across systems to connect with school systems

- CASCADES

Expand ECHO IDD program with a focus on complex care for those with ID/D and mental health and stuck in crisis

Develop a training for care coordinators for complex cases

Explore utilization of community health workers

Build community, relationships and trust in underserved communities

- Specific training/support for indigenous communities

Contact us:

Jim Mancini: jmancini@uw.edu

Website and to register: <https://wainclude.org/>

Help us spread the word to your communities!

Thank you!

Challenges & Opportunities

Challenges

- Significant reductions in federal healthcare funding (Medicaid)
- Significant reductions in federal research funding (e.g., NIH, NSF)
- Proposed elimination of long-standing federal agencies and programs (e.g., ACL, UCEDDs)
- Diverting responsibility from the federal government to the state government (block grants)

Opportunities

- High demand for services
- Potential for greater collaboration within and across organizations (e.g., UW Medicine and Seattle Children's)
- Strong DD Network with new leadership
- Strong advocacy network (e.g., Arc, Allies, SAIL, People's First, etc.)
-

Contact Us

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