

Working Together for People with Developmental Disabilities

The UW Institute on Human Development and Disability (IHDD) and the UW University Center for Excellence in Developmental Disabilities (UCEDD)

Mark Harniss, PhD

Interim Director, IHDD, and Director, UCEDD



What we will talk about today



Part 1

Who we are



Part 2

What we do



Part 3

Our priorities



Part 4

**How we work
with the
Council**

Part 1 of 4

Who we are



Part 1: Who we are

A large center at the University of Washington that brings experts from many fields together to focus on issues that matter to people with developmental disabilities.



Our vision and mission

Our vision

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



Live



Learn



Work



Thrive

Our mission

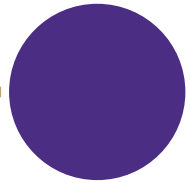
We help people with developmental disabilities be included, independent, and healthy.

We do this through research, education, and service.

Our history: more than 55 years

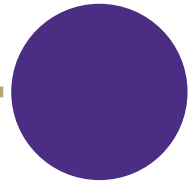


1960



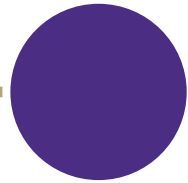
Washington State leaders ask for a center for children with disabilities

1963



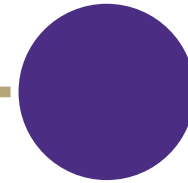
President Kennedy signs a law to build disability centers at universities

1969



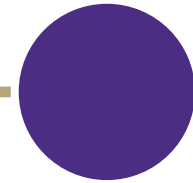
Our center opens at UW in 4 new buildings

1995



We become the Center on Human Development and Disability

2023



We become the Institute on Human Development and Disability (IHDD)

Three centers, three jobs



Research

Learns new things
about the brain, health,
and development

Intellectual and Developmental
Disabilities Research Center
(IDDRC)

1 of 15 in the U.S.



Education

Trains future leaders,
including self-
advocates and family
members

Leadership Education in
Neurodevelopmental and
Related Disabilities (LEND)

1 of 62 in the U.S.



Service

Works with
communities, shares
information, and
supports good policy

University Center for Excellence
in Developmental Disabilities
(UCEDD)

1 of 68 in the U.S.

Who leads our work



Mark Harniss

**Interim Director, IHDD;
Director, UCEDD**

Community, training, and
information



Kathleen Lehman

Director, LEND
Training future leaders



Sunny Juul

Director, IDDRC
Research

We are part of the UW School of Medicine, Department of Pediatrics.

The IHDD today

610+

people work through the
IHDD

127

UW faculty members

32

UW academic
departments

12

specialty clinics

4,857

patients seen in our
clinics in 2024

1 of 9

universities in the U.S.
with all 3 of our federal
centers

Part 2 of 4

What we do

With a focus on the UCEDD and LEND



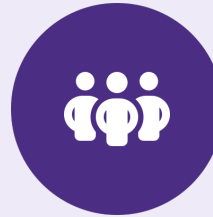
The UCEDD: a "knowledge engine"

The UCEDD turns knowledge into action so people with developmental disabilities can be included in all parts of community life.



Training

We teach new leaders and workers



Community service

We give training, technical help, and develop model programs



Research

We study what works, including policies



Sharing information

We get useful information to the people who need it

Our 7 UCEDD programs



Adults and Elders

Health, quality of life, and transitions as adults age



UW Autism Center

Services, training, and research about autism



Center for Technology and Disability

Technology that helps people with disabilities do more



Clinical Training Unit

Clinics and training for the care of children and adolescents. Home of the LEND.



Community Disability Policy Initiative

Working to change systems and policy



Genetics Program

Care and counseling for genetic conditions



Haring Center for Inclusive Education

Inclusive early learning for all children

Part 3 of 4

Our priorities



Our 5 priorities

1



**People with
IDD and
families guide
our work**

2



**Health and
well-being at
every age**

3



**Training
future leaders**

4



**Inclusion in
school, work,
and
community**

5



**Better
policies and
systems**

How we are working on our priorities (1 of 2)



1. People with IDD and families guide our work

- Most members of our UCEDD advisory council are people with IDD and family members
- We rewrote the council's rules in plain language and are changing its name to the Community Voices Council.
- Community members help to develop and review the UCEDD 5-year plan



2. Health and well-being at every age

- 12 specialty clinics for children and adults
- LEND prepares trainees in 16 disciplines to be future leaders and advocates for the IDD community
- ECHO programs help doctors, providers, and families in rural and remote areas
- Lots of other health-focused programs (medical homes, nutrition, genetics, etc.)

How we are working on our priorities (2 of 2)



3. Training future leaders

- LEND trains over 30 leaders each year
- Trainees include self-advocates and family members
- Trainees learn from many fields together



4. Inclusion in school, work, and community

- Haring Center: children with and without disabilities learn together
- UW Employment Program
- Technology that supports independence



5. Better policies and systems

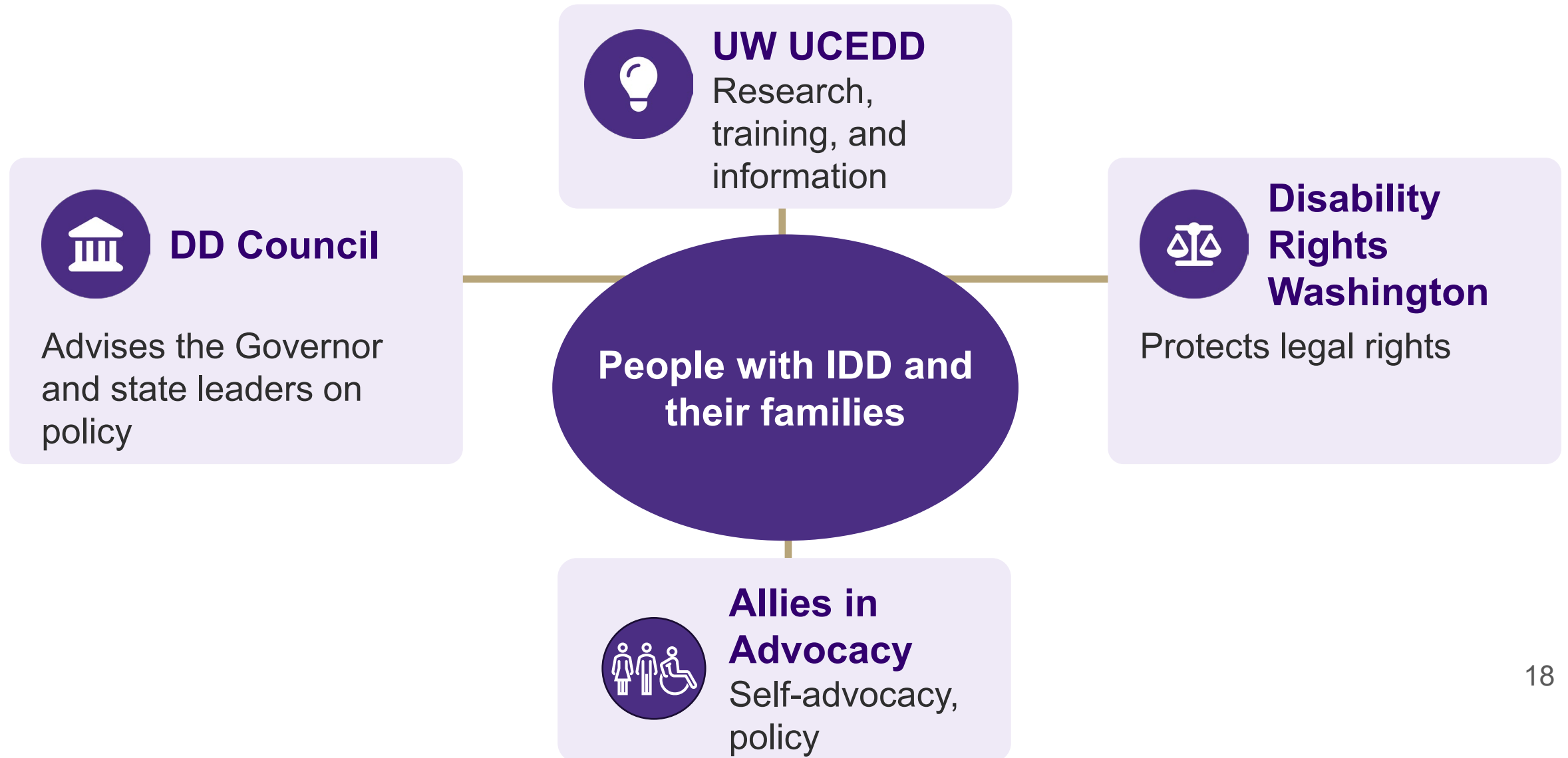
- Community Disability Policy Initiative
- Sharing research with leaders who make policy
- Partnering with self-advocacy groups

Part 4 of 4

How we work with the Council



Washington's DD Network: four partners



How our work connects with the Council



A seat at each other's table

A Council representative is a member of our UCEDD advisory council and vice versa.



Shared goals

Our work helps the Council reach goals in its state plan.



Knowledge for policy

We share research and data to support the Council's policy work.



Working side by side

We work on events, training, and projects with DD Network partners.

Questions?

Thank you!

Mark Harniss

Email: mharniss@uw.edu

Website: ihdd.org

