

# Training Tomorrow's Leaders for Successful Transition – How LEND and DBP Networks are Shaping the Future of Health Care Transition

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25th Annual Chronic Illness and Disability  
Conference: Transition from Pediatric to  
Adult-Based Care, Houston, TX





Association of University Centers On Disabilities

- **Introduction**
- **What is AUCD, LEND, & DBP?**
- **Texas LEND & DBP Program Highlights**
  - **Focus on Adolescents, Youth, and Adults with Special Health Care Needs (AYASHCN)**
- **AUCD Programs and Initiatives Related to Health Care Transition (HCT)**

# Kate Thompson, LMSW, CAS

## Senior Program Manager, MCH Engagement, AUCD

### ITAC – Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities

- Provides technical assistance to interdisciplinary training programs, primarily LEND and DBP Programs
- A MCHB funded project at AUCD that supports Autism CARES programs

### Funded by Division of Maternal and Child Health Workforce Development

- Maternal and Child Health Bureau (MCHB)
  - Health Resources and Services Administration (HRSA)
    - U.S. Health and Human Services





Association of University Centers On Disabilities



# Definitions

- **AUCD:** Association of University Centers on Disabilities
- **UCEDD:** University Centers of Excellence in Developmental Disabilities
- **LEND:** Leadership Education in Neurodevelopmental and Other Related Disabilities
- **DBP:** Developmental-Behavioral Pediatrics
- **Self-Advocate:** A person with an apparent or non-apparent disability, who identifies as a disabled person or as a person with a disability
- **Person-First vs. Identity-First Language:** Ex: “Person with autism” vs. “autistic person.” Identity-first language is frequently preferred by some disabled communities, such as Autistic or Deaf individuals.
- **When in doubt: ASK!**



**AUCD Network**



Association of University Centers On Disabilities

- National non-profit since 1971
- Supports members in their research, training, education, & service
- Promotes the quality of life, health, and well-being of people with disabilities
- Based in Silver Spring, MD – Washington D.C. metro





# Our Mission

“To advance policies and practices that improve the health, education, social, and economic well-being of all people with developmental and other disabilities, their families, and their communities by supporting our members in research, education, health, and service activities that achieve our vision.”



# Our Impact

By the numbers . . .



The AUCD Network provided technical assistance to nearly **2 million people** and organizations. More than **750,000 received continuing education** and **155,000 families received clinical services** such as an assessment or therapy.



The AUCD Network produced more than **12,700 expert products** including newsletters, books and book chapters, conference presentations, academic and online courses, fact sheets, and press communications.



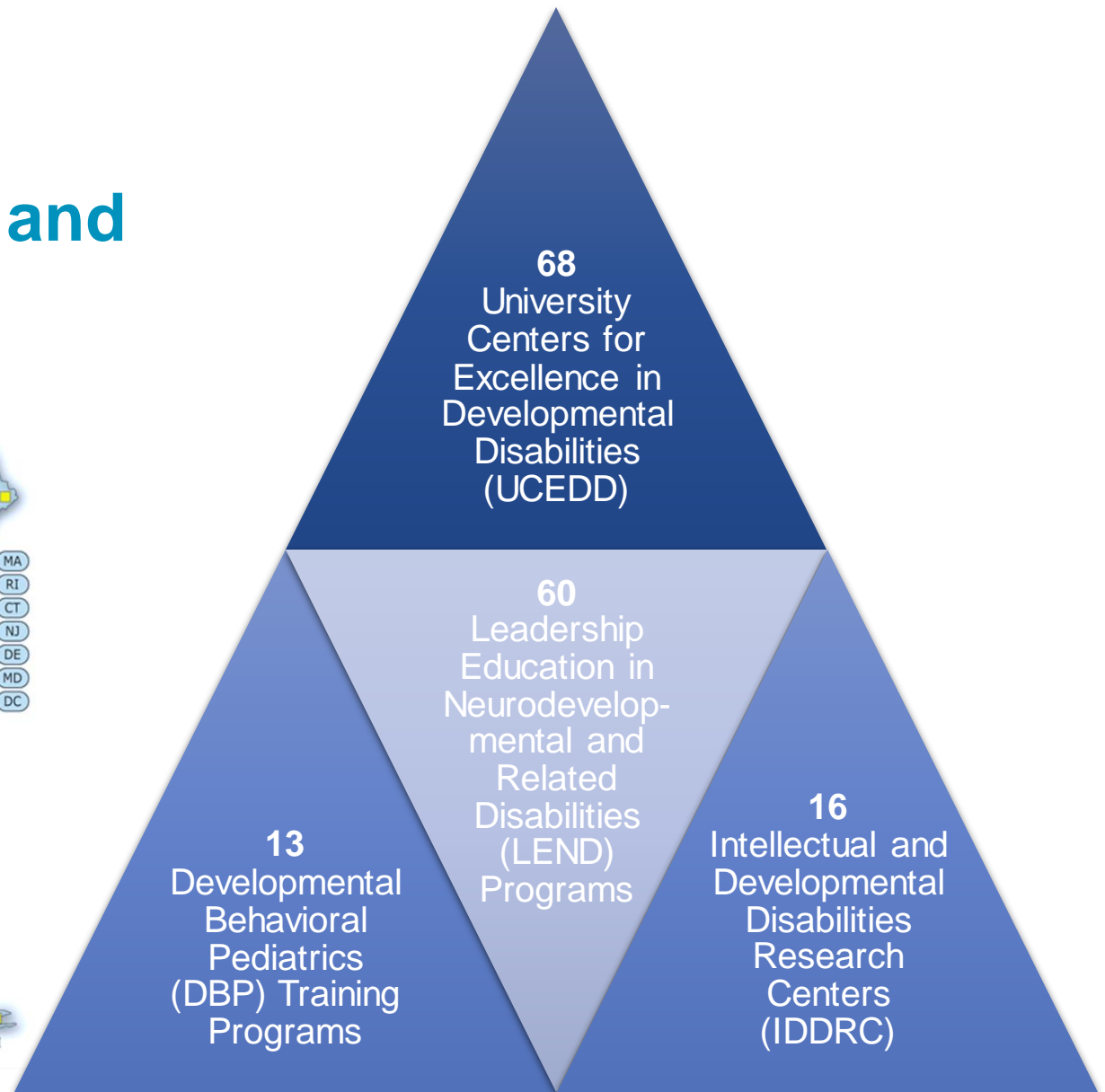
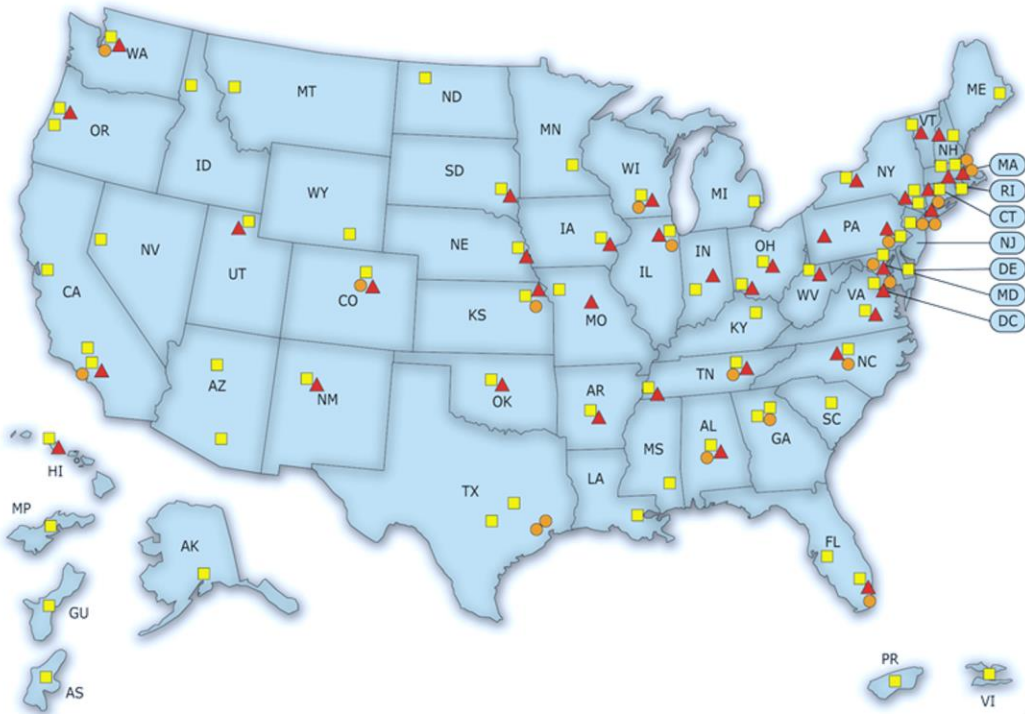
The AUCD Network trained **5,046 trainees in more than 48 disciplines** such as audiology, physical therapy, social work, dentistry, child development, early intervention, amongst others.

*All figures based on 2023 data.*





**AUCD Network is a strong presence in every U.S. state and territory.**



Training tomorrow's leaders for successful transition –  
How LEND and DBP networks are shaping the future of HCT

# Intellectual and Developmental Disabilities and HCT

- 750,000 youth transition into adulthood each year<sup>1</sup>
- **1 in 6 have a developmental disability<sup>2</sup>** (n = ~125,000)
- **1 in 36 are diagnosed with autism spectrum<sup>3</sup>** (n = ~21,000).
- Lack of a formal transition plan = delayed care, poor health outcomes, especially among those with chronic health conditions<sup>5,6,7</sup>
- **Only about 1 in 6 teenagers** (age 12-17) with a mental, behavioral, or developmental disability received recommended transition planning for moving from pediatric to adult health care
  - **Only about 1 in 10 of younger teens** (12-14) got recommended transition planning<sup>8</sup>

# Barriers to Care for Individuals with Autism and IDD



## Lack of trained providers

Treatment must be tailored to unique needs of individual



## Rigid approaches to care

Unwillingness to change from status quo  
Communication differences  
Unique pharmacological needs



## System-level barriers

Long wait lists  
Complex onboarding requirements  
Feeling rushed through treatment<sup>9</sup>



# **LENDs and DBPs**

# About LENDs (60 Programs)

## Objectives:

Advance the knowledge and skills of all child health professionals to improve health care delivery systems for children with developmental disabilities.

Provide high-quality interdisciplinary education that emphasizes the integration of services from state and local agencies and organizations, private providers, and communities.

Provide health professionals with skills that foster community-based partnerships.

Promote innovative practices to enhance cultural competency, family-centered care, and interdisciplinary partnerships

## LENDs Vary By:

Geographical area/population served

Where it sits:

- School of Social Work, Education, etc.
- Medical Center vs University Center
- Connected to a UCEDD

Disciplines

Partnerships

Operations (Virtual, Hybrid, In-Person)

Unique focus

Length of program (typically 1 year, sometimes up to 2)



## Core Disciplines

- Pediatrics
- Nursing
- Special Education
- Social Work
- Audiology
- Pediatric Dentistry
- Nutrition
- Psychology
- Speech & Language
- Health Administration
- Occupational Therapy
- Physical Therapy
- Family and PWD
- Genetics

## LEND Activities

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Interdisciplinary academic, clinical, leadership and community training

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Cultural and linguistic competence using family-centered approaches

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Continuing education to practicing professionals

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Collaboration with State Title V agencies

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Long-Term, Medium-Term, and Short-Term Traineeships



# Traineeships Include...

Classroom  
coursework

Individual  
Leadership  
Training Plan

Mentoring

Research

Clinical Skill  
Building

Community  
Outreach

Continuing  
Education /  
Technical  
Assistance

Advocacy /  
Policy  
Education

# Developmental-Behavioral Pediatrics Programs (DBP)

- 13 funded programs
- The purpose of DBP training programs is to expand the Developmental-Behavioral Pediatrics workforce
- By expanding the DBP workforce, children with a wide range of developmental and behavioral concerns will have increased access to evaluation and services that address medical and psychosocial aspects of development





**AUCD in Texas**

# AUCD Network in Texas

## Austin

 The University of Texas at Austin  
Texas Center for Disability Studies  
Steve Hicks School of Social Work



Autism Consortium of  
Texas (ACT) LEND

## College Station



Center on Disability and  
Development (UCEDD)

## Houston

 UTHealth  
Houston



LoneStar LEND  
Leadership Education in Autism and  
Neurodevelopmental Disabilities

 Baylor  
College of  
Medicine

- DBP Fellowship
- IDDRC at BCM



# ACT LEND – The University of Texas at Austin



## Program Information

- Sandy Magaña, PhD, MSW – Program Director of ACT LEND, Executive Director of TCDS
- Based at the Texas Center for Disability Studies (UCEDD) at UT Austin, housed in Steve Hicks School of Social Work
- Started in 2021, now in 4<sup>th</sup> cohort of program
- Includes graduate students from UT-Austin, Baylor University (Waco), and Texas State University (San Marcos); family members, and self-advocates

## Healthcare Transition Research

- Sandra Vanegas, PhD – *ACT LEND Clinical Training Director.*
  - **EMPOWER Study** (<https://sites.utexas.edu/empowerstudy/>)
  - NIDILRR-funded study to examine HCT readiness in youth with IDD from underrepresented backgrounds and their caregivers. Will identify key areas for the future development of support programs to increase access to healthcare transition services
- Catherine Harwood, MSSW – *ACT LEND Trainee 2022-2023, PhD Student at UT-Steve Hicks School of Social Work, Self-Advocate.*
  - **“The Provision of Optimal Medical Care for Adults with Chronic Health Conditions Originating in Childhood.”**
  - [caharwood@utexas.edu](mailto:caharwood@utexas.edu)



# LoneStar LEND – UT Health Houston



## Program Information

- Pauline A. Filipek, MD – Director
- Housed in Department of Pediatrics, McGovern Medical School
- In collaboration with University of Houston, Texas Woman's University, University of Houston – Clear Lake, Baylor University, and Baylor College of Medicine and Texas Children's Hospital
- Trainees include medical residents and fellows, professionals, graduate students, family members, and self-advocates

## Healthcare Transition Learning

- Long-Term Trainees required each year to attend the *Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care*
- Focus on underrepresented and underserved children with AS/DD across Texas
- Houston-area Practitioners: get connected! Invite LoneStar LEND Trainees to observe in your clinics for more experience in transitional medicine!





# Developmental Behavioral Pediatrics Fellowship

## Program Information

- Holly K. Harris, MD – Fellowship Program Director  
Jordan Kemere, MD – Co-Project Director
- The Meyer Center for Developmental Pediatrics at Baylor College of Medicine and Texas Children's Hospital
- Three-year fellowship includes formal didactic instruction as well as clinical experiences in a range of factors that contribute to behavioral concerns related to IDD and other disabilities
- One-year clinical fellowship for providers interested in caring for adults with IDD, funded through HRSA Grant

## Healthcare Transition Projects

- “Primary Care for Youth and Adults with IDD” – ECHO program includes CEs, in second year
- Webinars for families to help navigate high school and early adulthood years, available on TCH website
- Spring 2023 Senior Fellows pursued a quality improvement project to improve the transition process for individuals in the Fragile X Syndrome Clinic at TCH
- Dr. Ellen Fremion – Transition clinic at TCH focusing on spina bifida



# **Brief Introduction to UCEDDs and IDDRCs**

# What is a UCEDD?

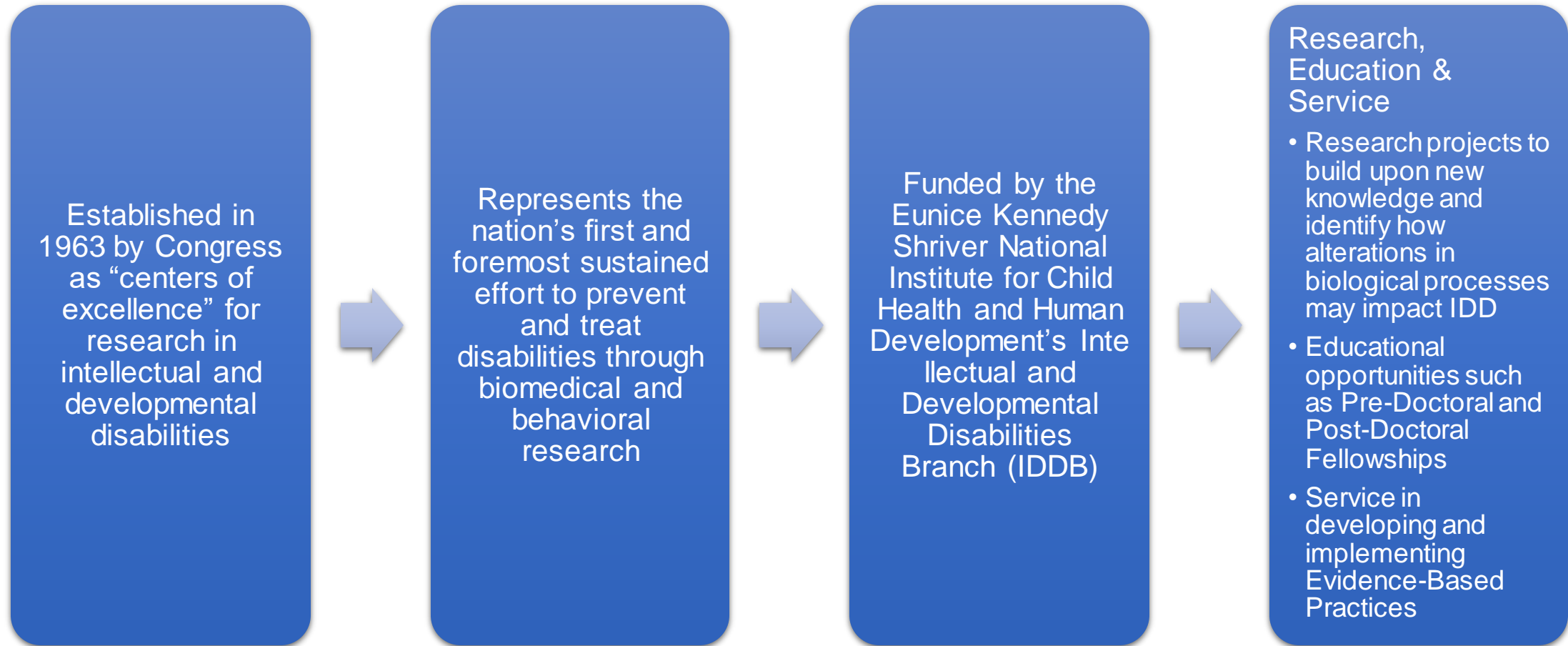
In 1963, President John F. Kennedy signed an Act into law, which established 19 university-based centers focused on intellectual disability research.

- Over time, changes and improvement led to the current Developmental Disabilities Assistance and Bill of Rights Act (DD Act).
- The DD Act ensures that individuals with IDD and their families participate and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity and integration and inclusion in all parts of the community life.
- The DD Act authorizes the UCEDDs as part of the Developmental Disabilities Network in each state.

## University Centers for Excellence in Developmental Disabilities (UCEDD) Network

- Aims to positively affect the lives of all people with disabilities by building and strengthening systems that support full community participation.
- They work toward a vision of self-determination, independence, productivity, and community inclusion for people with disabilities throughout the lifespan.

# Intellectual and Developmental Disabilities Research Centers (IDDRCs)





# **Additional AUCD Transition- Related Projects**

# Healthcare Transition 4All Initiative National Learning Group

## 2018 – 2019

AUCD's Public Health Team facilitated exploratory conversations on this topic in various venues including:

- Convenings and Conferences (June 2018 LEND Directors meeting, 2018 AUCD Conference in DC)
- AUCD Network member organization special interest groups (SIG) and work groups, e.g. AUCD Health and Disability SIG, and the LEND Family Discipline Network (LFDN)

## 2019 – 2020

### Learning Group Focus – The “How”

- How you implement and use transition resources
- How you involve families and people with disabilities
- How we can do this together as a Network

### Three Focus Areas:

- Training
- Community Outreach/Education
- Policy/Systems Change

### Group Goal:

- Use as space for sharing lessons learned and apply to individual work

### Group Future Goal:

- Collective action as the AUCD Network





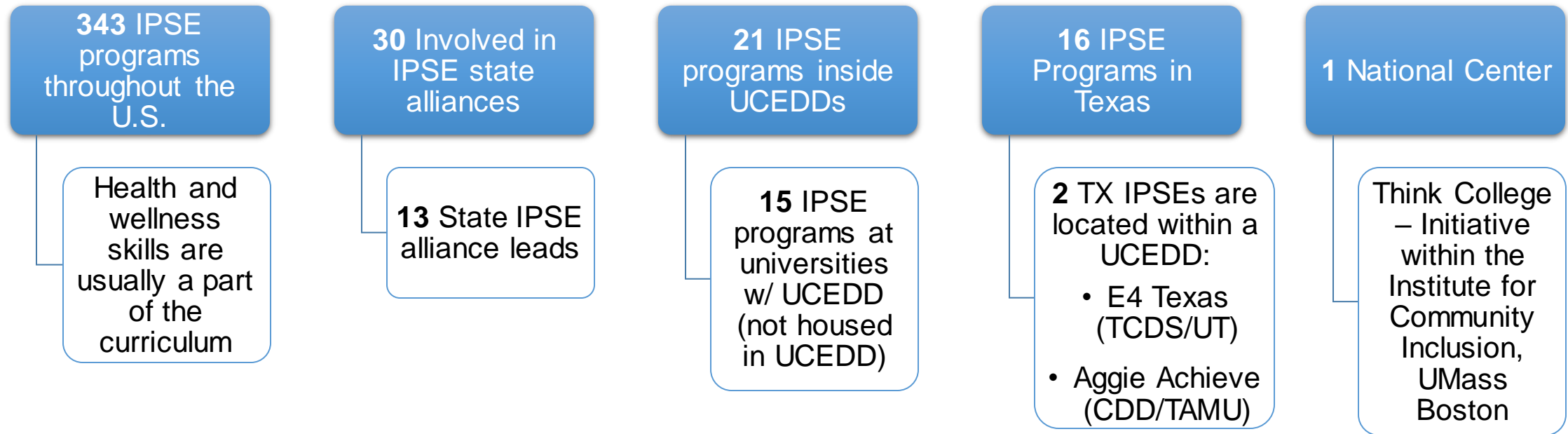
# PacWest ITAC Learning Modules: Cultural Crossroads in Disabilities (2022)

## Module 8: Adolescent-to-Adult Transition for youth with Intellectual and Developmental Disabilities (I/DD)

- Created by PacWest LEND Regional Consortium
- Series of 9 modules as a resource for LENDs and other Programs across the network
- Addresses a range of topics relate to AS/IDD, focused on cultural disparities in intervention
- May be accessed on ITAC website at <https://www.aucd.org/itac/resource-detail?id=193>



# UCEDD Support of Inclusive Postsecondary Programs (IPSE) for Students with IDD



# AUCD Support of IPSE (not including any funding)

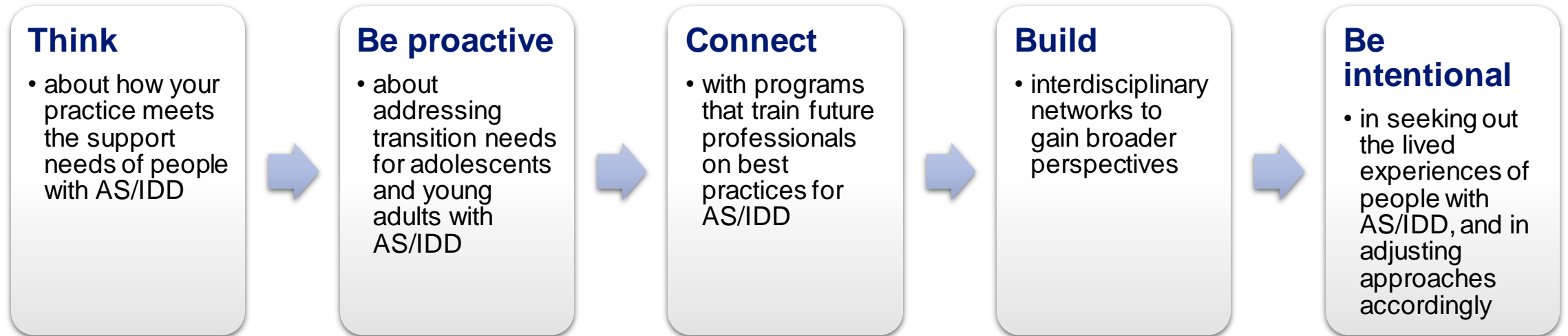
## LEND Support

- Internships
- Projects – research, survey, studies
- Mentors
- IPSE in the curriculum
- Self-advocate pathway for trainees, faculty and speakers
- Teaching – LEND trainees to IPSE students; IPSE students to LEND trainees

## UCEDD Support

- Evaluation and research
- Web site sponsorship
- Gathering/sponsoring coalitions
- Sharing contacts
- State and Regional Alliance support and leadership... and of course...
- Hosting IPSE program!

# Next Steps





Association of University Centers On Disabilities

## Special Thanks to:

**ACT LEND:** Dr. Sandy Magaña, Dr. Sandra Vanegas, and Kate Harwood  
<https://disabilitystudies.utexas.edu/act-lend>

**LoneStar LEND:** Dr. Pauline Filipek  
<https://med.uth.edu/pediatrics/neurology/pediatric-neurology-fellowship-programs/lonestar-lend-fellowship/>

**Baylor DBP Fellowship:** Dr. Holly Harris, Dr. Jordan Kemere, and Dr. Ellen Fremion  
<https://www.bcm.edu/departments/pediatrics/divisions-and-centers/developmental-pediatrics/education/developmental-behavioral-pediatrics>

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AUCD Information: <http://www.aucd.org> (throughout)

# Thank You!

