WA INCLUDE

EDUCATE. PROMOTE. EMPOWER.

Addressing Inequitable Behavioral Health Outcomes in Intellectual and Developmental Disabilities Across the Lifespan:

The impact of intersectionality, systems of care, and community-based approaches

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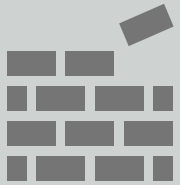
OBJECTIVES

Review inequitable outcomes for individuals living at the intersection of Intellectual/Developmental Disabilities (I/DD) and Mental Health



Understand systemic barriers impacting individuals with I/DD and mental health needs, as well as the providers that support them

Introduce three community-based initiatives designed to address inequitable outcomes for marginalized I/DD populations

UNDERSTANDING THE OVERLAP BETWEEN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (I/DD) AND MENTAL HEALTH

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (I/DD)

Brain-based differences with complex etiologies

Affect overlapping areas of development (e.g., physical, adaptive, cognitive, social, emotional, occupational)

Often diagnosed with more than one

DIAGNOSTIC OVERSHADOWING

"Describes the tendency of the clinicians to overlook symptoms of mental health problems in this client group and attribute them to being part of 'having an intellectual disability'."

Dell'Armo, K. & Tassé, M. J. (2024). Diagnostic Overshadowing of Psychological Disorders in People With Intellectual Disability: A Systematic Review. American Journal on Intellectual and Developmental Disabilities, 129(2), 116-134. https://doi.org/10.1352/1944-7558-129.2.116

Reiss S. & Syzszko J. (1983) Diagnostic overshadowing and professional experience with mentally retarded persons. American Journal of Mental Deficiency 87, 396–402. https://pubmed.ncbi.nlm.nih.gov/6829617/

I/DD AND MENTAL HEALTH COMORBIDITY RATES

Anxiety (~7%)

- ADHD: ~30-40%
- ASD: ~20-50%
- ID: ~3-20%

OCD (~1%)

- ADHD: ~8%
- ASD: ~5%
- ID: ~1%

Depression (~7%)

- ADHD: ~30-50%
- ASD: ~20-70%
- ID: ~1-5%

Suicidality (SI: 10-25%; SB: 4-8%)

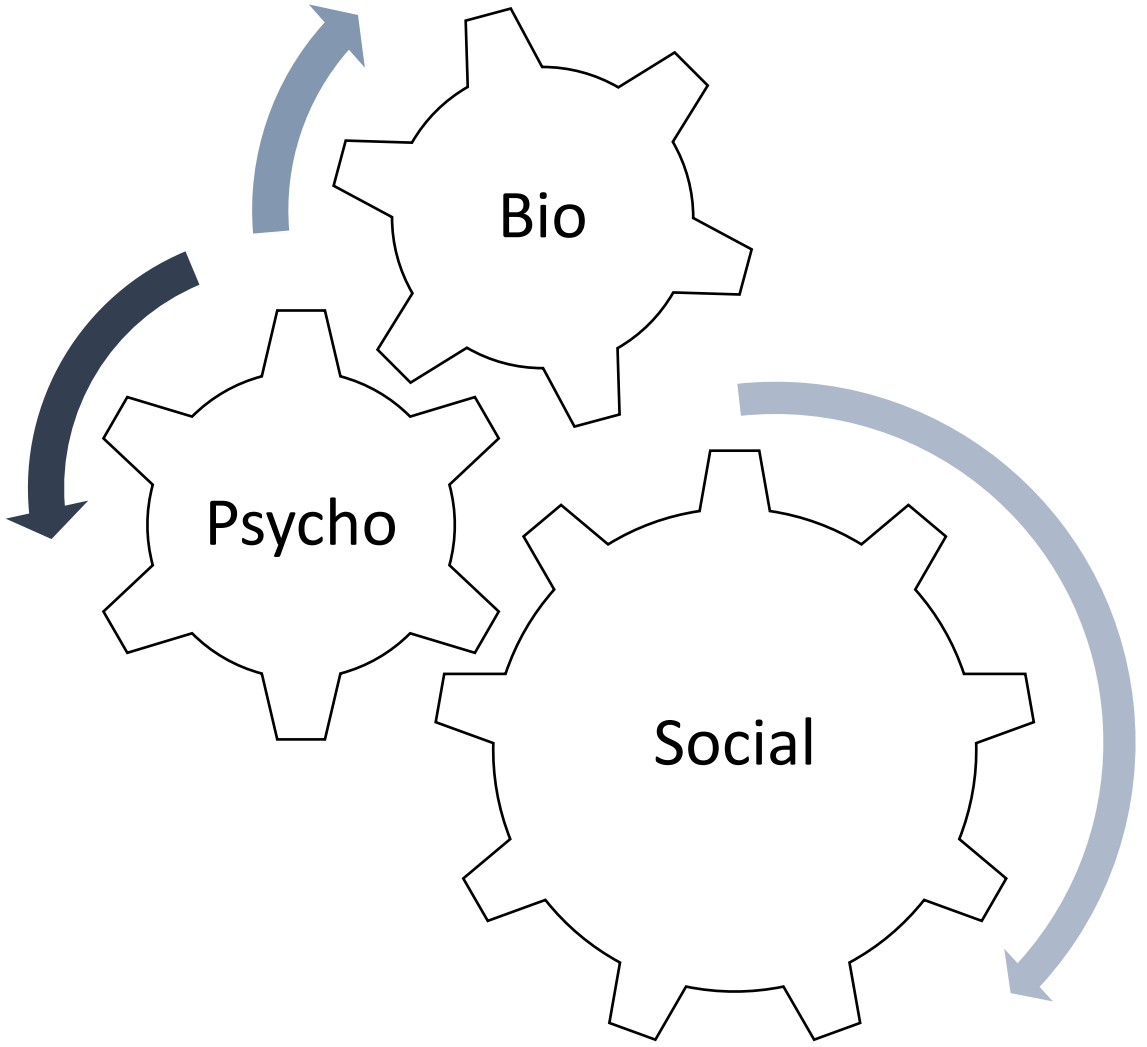
- ADHD: SI 68%; SB18%
- ASD: SI 60-70%; SB 7-47%
- IDD: SI 20-60%; SB 17-48%

**Reference list at the end*

CONTRIBUTING FACTORS

*START: The Biopsychosocial Approach MHDD Case Conceptualization for Clients with IDD: The utility of the BPS Model

- Biological
  - Varied medical, genetic, and physical differences and vulnerabilities
  - Increased health issues
- Psychological
  - Cognitive and emotional differences
  - Skills, strengths, and interests
  - Trauma, abuse, and stress
- Social
  - Stigma, isolation, and rejection
  - Systems of support (or lack thereof)
  - Identity empowerment/affirming care



ACCESS ISSUES AT THE INTERSECTION OF I/DD AND MENTAL HEALTH

BARRIERS TO APPROPRIATE CARE

High rates of co-occurring mental health challenges

Siloed service and state support systems

Long waitlists for preventative and routine care

Shortage of providers trained in mental health AND development

High costs for families and low reimbursement for providers

May not have a natural support system or people to advocate

Barriers exacerbated by COVID-19 pandemic, policy changes, and patient identity

MISDIAGNOSIS AND MISSED DIAGNOSES

BIPOC
(Black, Indigenous, and People of Color)

- More likely to be misdiagnosed with a disruptive behavior disorder (e.g., oppositional defiant disorder/conduct disorder) or adjustment disorder
- Cultural stigma and linguistic barriers can affect information shared to aid in appropriate diagnosis

AFAB
(Assigned Female at Birth)

- More likely to be misdiagnosed with internalizing disorders (e.g., anxiety, bipolar) or personality disorders (e.g., borderline)
- I/DD diagnostic criteria developed primarily around AMAB symptom presentations

Both groups often **diagnosed later** than their peers, and inappropriate and/or delayed diagnosis leads to inappropriate treatment

COMMUNITY BEHAVIORAL HEALTH

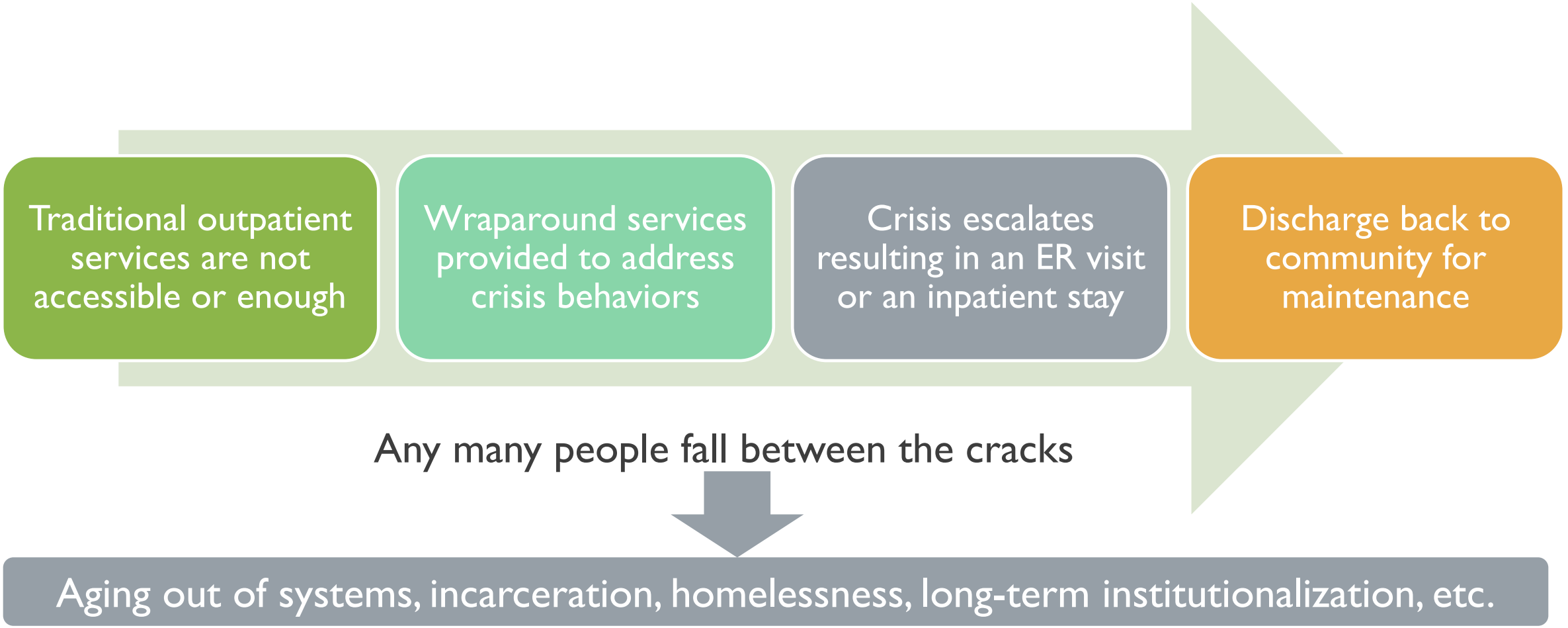
Issues with workforce recruitment and retention in behavioral health across the state of Washington

Limited teams and funds for crisis or intensive support services, such as through WISe (Wraparound with Intensive Services) and DDA

Limited access to training, support, and supervision for providers working with I/DD populations in community settings

Washington State Behavioral Health Workforce Assessment (https://familymedicine.uw.edu/chws/studies/wabh/)

MOVEMENT ACROSS SYSTEMS



VOICES OF LIVED EXPERIENCE

- AuDHD (Autistic/ADHD) human
- Advocate with WA INCLUDE
- Parent of and sibling to other neurodivergent and twice exceptional (2e) humans
- Currently a Developmental Disabilities/ Mental Health Program Consultant for the DCYF
- Past experience in direct care roles, care coordination, and case management

Supporting primary care and behavioral health providers using Project ECHO

Extensions for Community Healthcare Outcomes

Project ECHO® is a lifelong learning and guided practice model that revolutionizes medical education and exponentially increases workforce capacity to provide best practice specialty care and reduce health disparities through its hub-and-spoke knowledge sharing networks

People need access to specialty care for complex conditions

Not enough specialists to treat everyone, especially in rural areas

ECHO® trains primary care clinicians to provide specialty care services

Patients get the right care, in the right place, at the right time.

https://hsc.unm.edu/echo/

https://projectechoannualreport.unm.edu/

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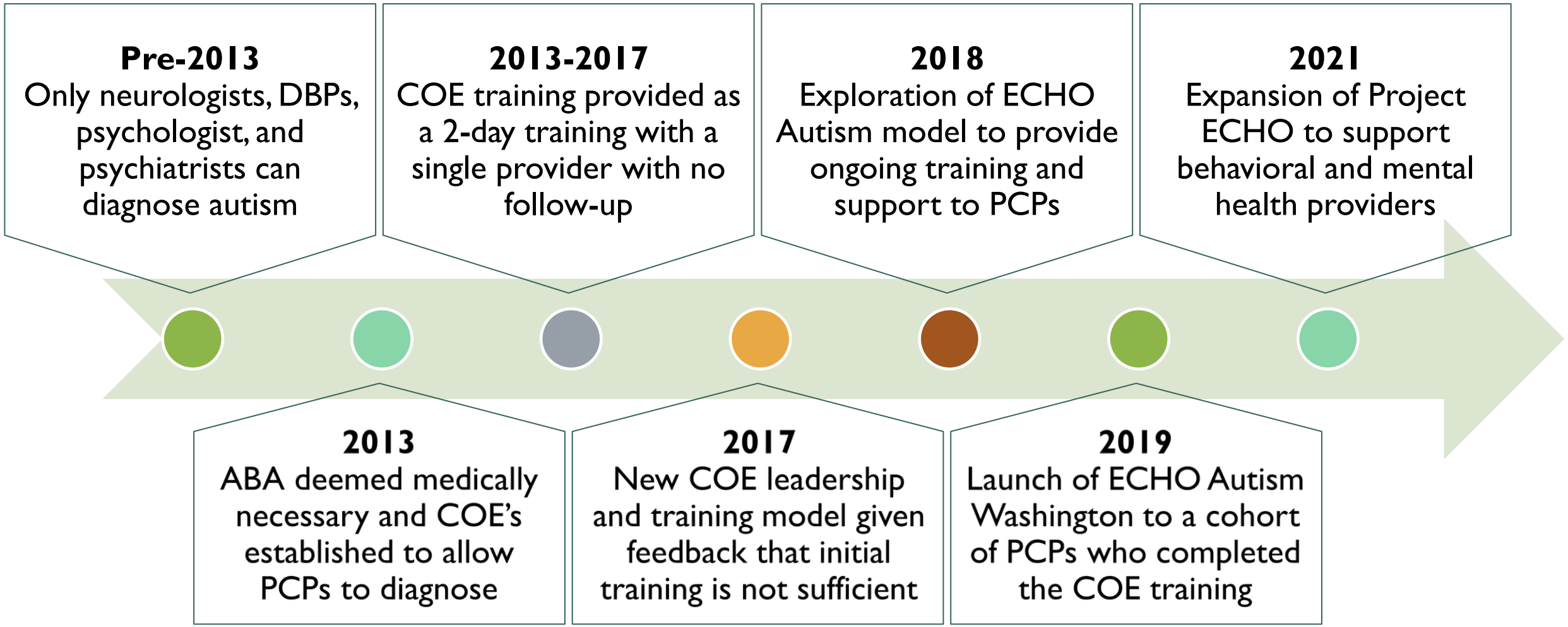
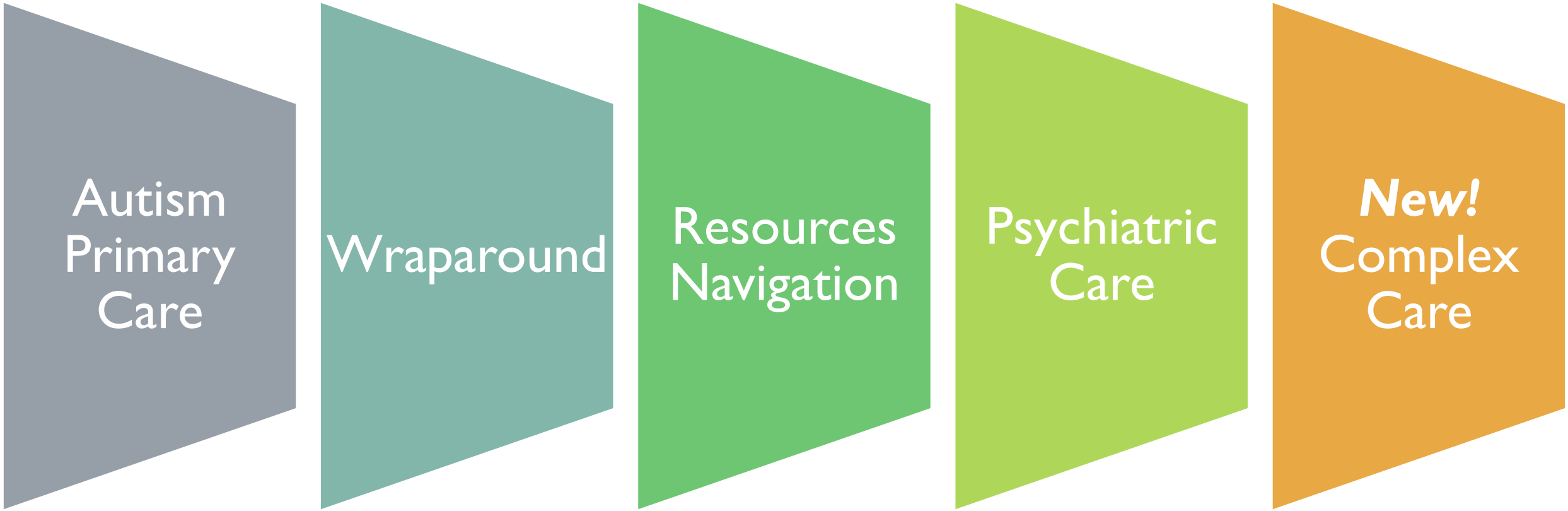
THE HISTORY OF ECHO IN WASHINGTON STATE



ECHO PROGRAMS WITH WASHINGTON INCLUDE



https://wainclude.org/echo-programs/

WHO WE ARE AND WHO WE SUPPORT

HUB

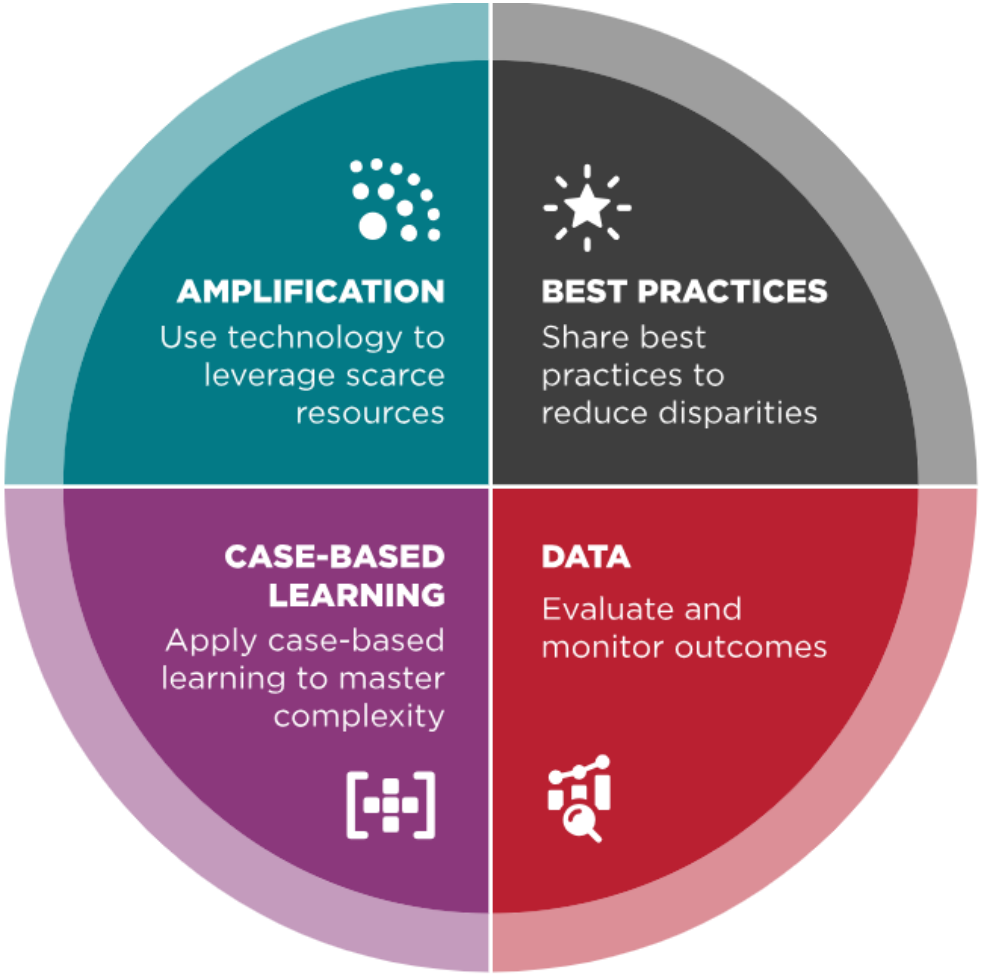
- Self and Family advocates
- Neurology
- Developmental Medicine
- Clinical Psychology
- Behavior Analysis
- Speech-language
- Occupational Therapy
- Nutrition
- Resource navigation

SPOKES

- Primary Care
- Psychology
- Psychiatry
- Behavioral Health
- Care Coordination
- Family and Peer Partners
- Education
- Resource navigation
- Administration

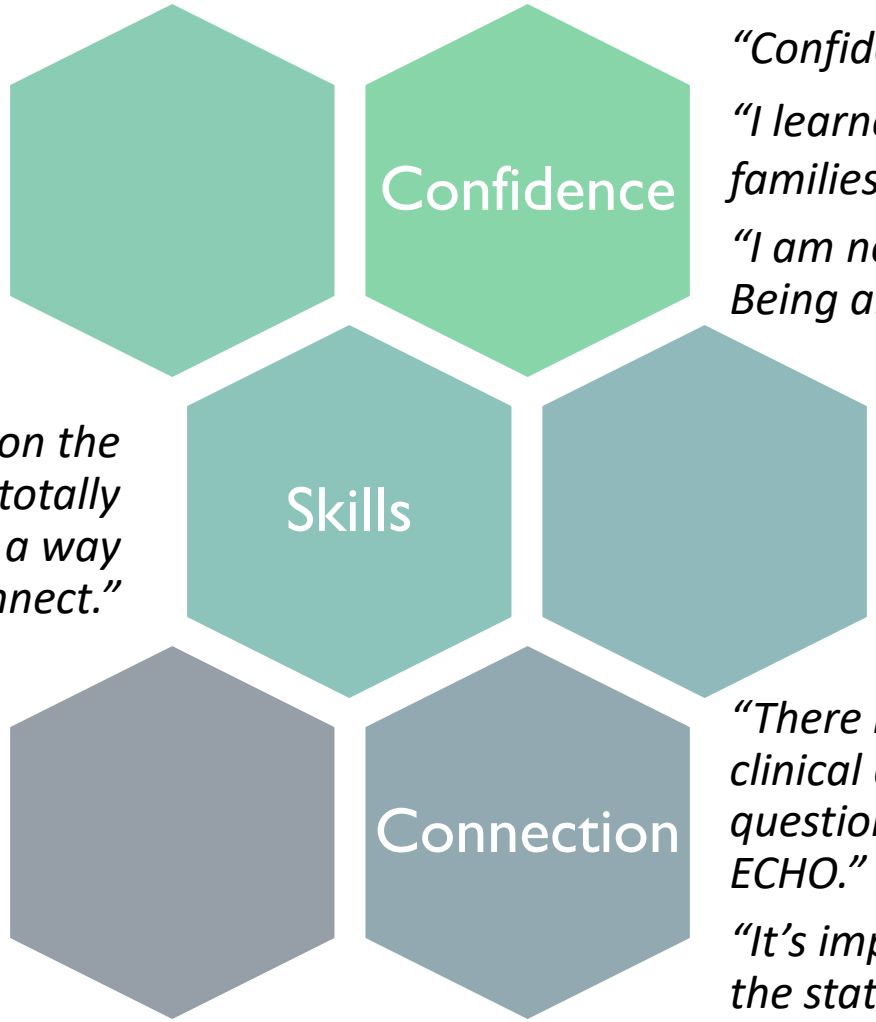
More about self-advocate involvement in ECHO:
https://ihdd.org/2024/08/24/new-publication-nothing-about-us-without-us-meets-the-all-teach-all-learn-model/

WHAT ECHO SESSIONS INVOLVE



- Introductions & Announcements
- Case Presentation
- Clarifying Questions & Case Discussion
- Case Recommendations
- Didactic

STRENGTHS



"Confidence, empowerment to say 'I can do this'"

"I learned the art of partnership and readiness with families."

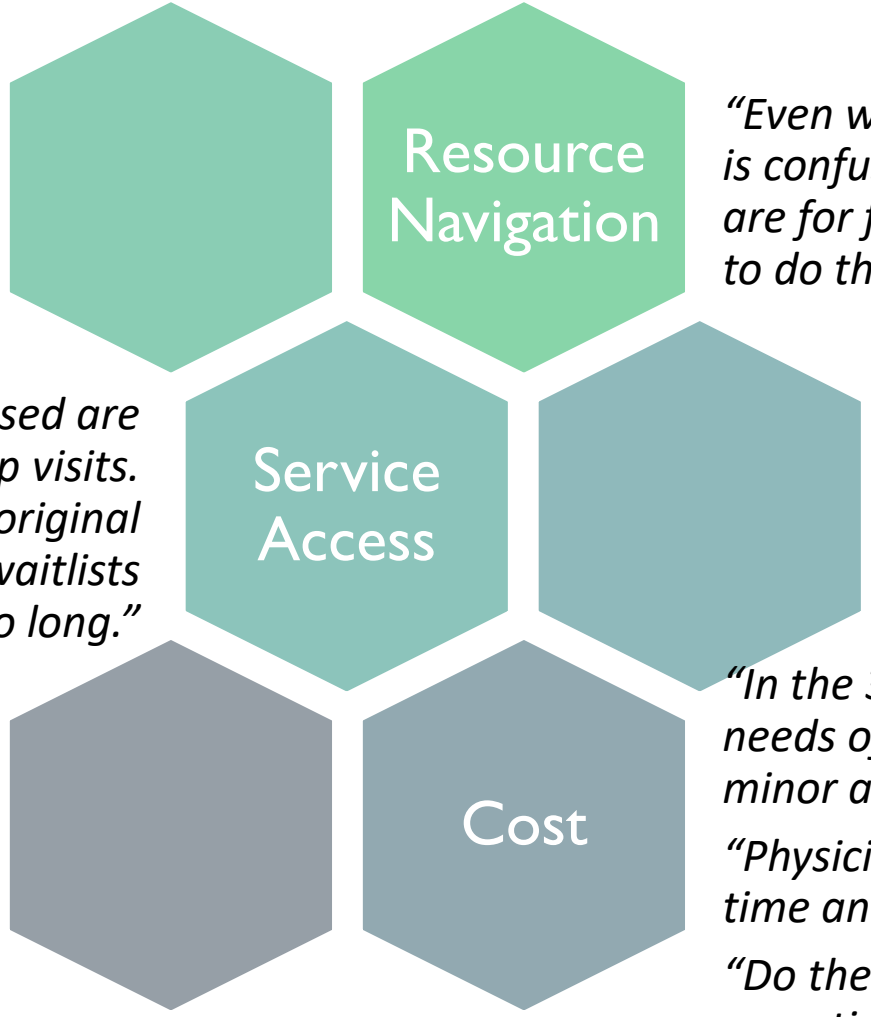
"I am not afraid to do it, not second guessing myself. Being able to trust my self in doing this work."

"I attended the COE training based on the need in my community. I left it feeling totally underprepared. I sought out ECHO as a way to build the skills and connect."

"There is no one in my professional friend group or clinical circle doing this work. When I have specific questions about how to get something done, I have ECHO."

"It's impressive to me, the number of people across the state who are so committed to this work."

ONGOING CHALLENGES



"Even when I'm referring patients to all these services it is confusing for parents to understand what the steps are for following up with the referrals. Right now I try to do that for my patients. But it is hard. It takes time."

"Now families I have diagnosed are coming back for their follow-up visits. And I don't know what to do. My original referrals didn't go anywhere. And waitlists for services are so long."

"In the 30 minutes I spend carefully addressing the needs of one autistic patient, I could easily have 4 minor acute visits and generate 3-4x the revenue"

"Physicians are currently becoming a COE on their 'own time and own dime.'"

"Do the E&M codes pay adequately for my time and expertise? The answer is definitely no."

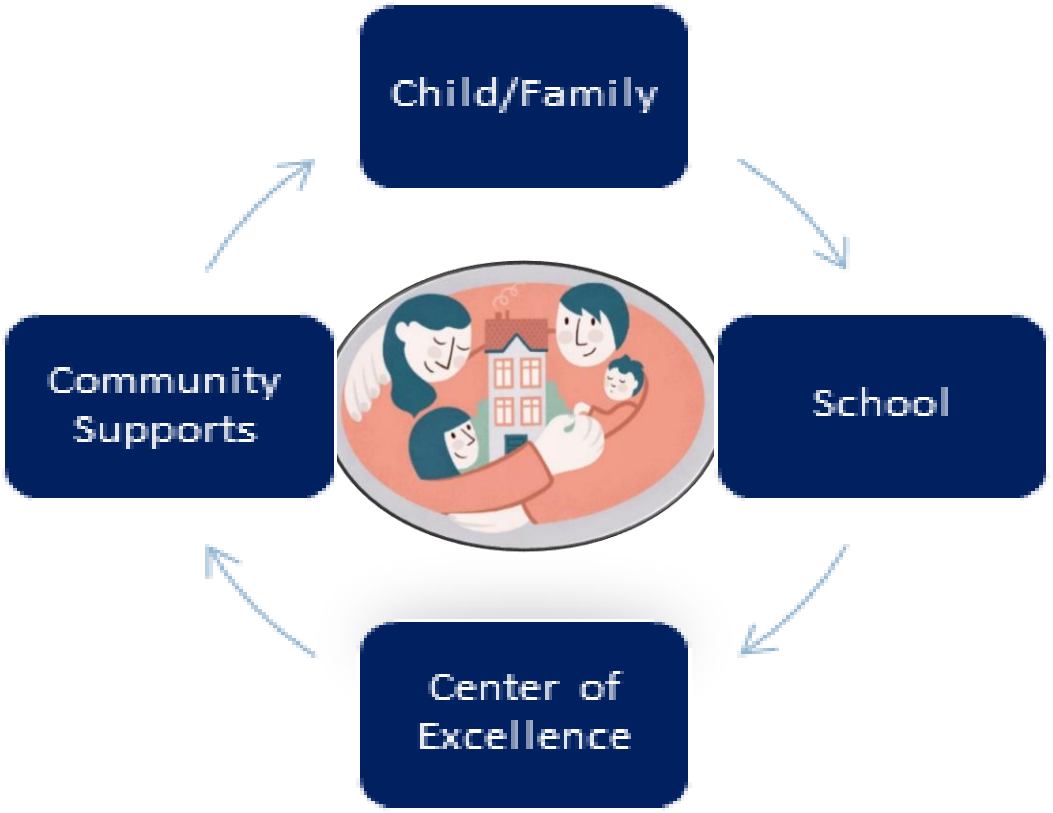
An Alternative Pathway to Equitable and Accessible Autism Evaluation for Underserved Youth

Felice Orlich, PhD; Founder & Co-director
Thanh Nguyen, PhD; Co-director

CASCADES MISSION

Collaborative school-clinic model of care:

- Training to fidelity
- Consultation support
- Partnership in assessing for autism in youth
- Connecting families to community resources



PROCESS

School team trained in autism assessments by clinical team.

Collaborative assessment integrated into students' IEP

Collaborative team feedback with the family and student

Diagnostic determination, recommendations, and referrals completed

"CASCADE"-ING GROWTH

2018
First school district collaboration

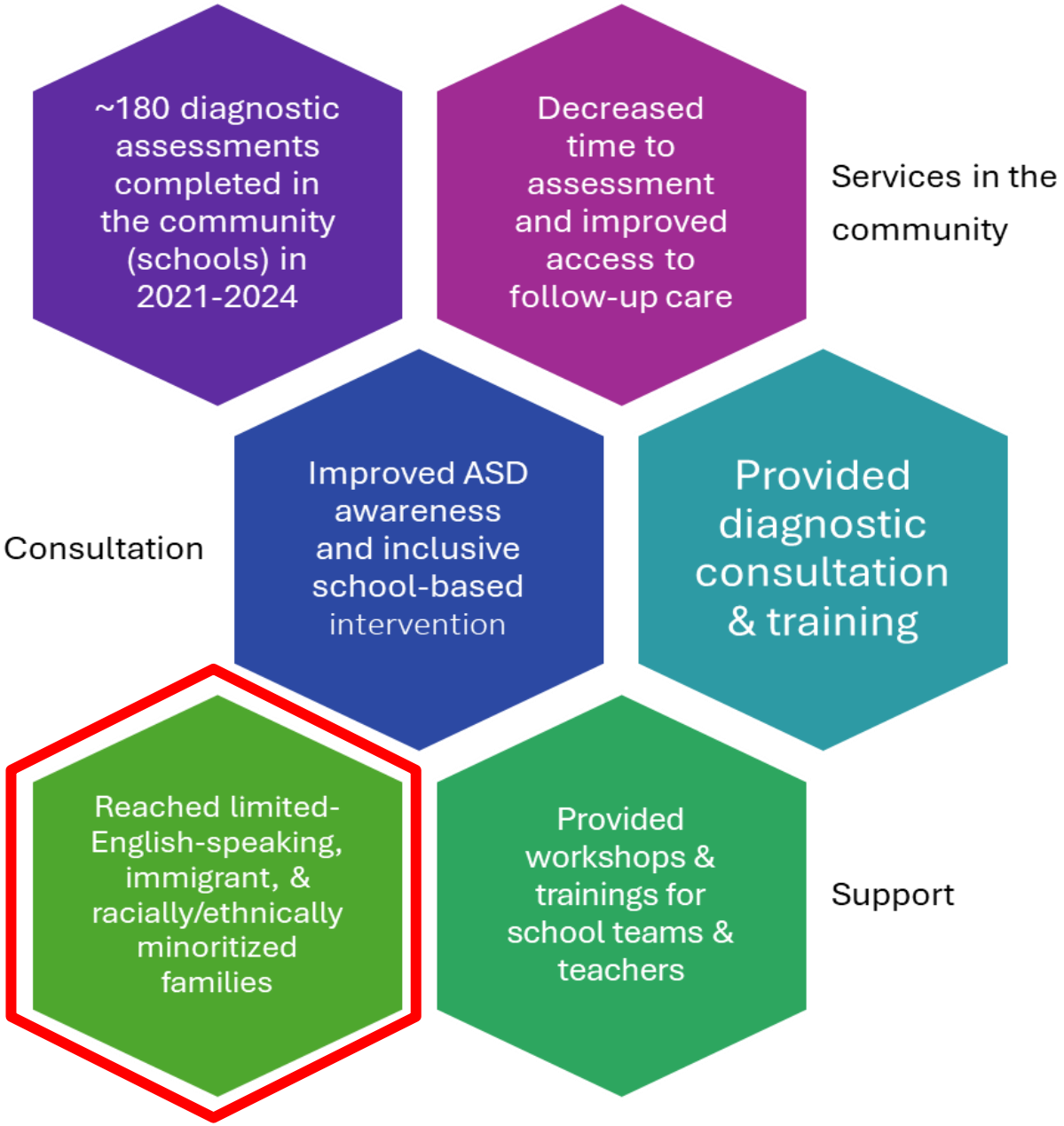
2019 to 2021
Trained seven providers to fidelity in "gold standard" autism diagnostic evaluation

2022
Added three school districts and trained eleven providers

2023
Thirteen more providers trained to fidelity

2024 to now
Five total districts with over 35 providers trained to fidelity

CASCADES IMPACT AND OUTCOMES



Examples of families we've reached & served:

- Black/Afro-Latin family; Spanish speaking; Single parent
- Medicaid
- Male child; age 6yo
- Parent’s concerns:
  - “not talking"
  - "only repeats and sing songs”
  - "easily angry"
  - “doesn’t play with his older brother”
  - “can’t take him to see a doctor because he’s too scared to go in the hospital or clinic”

Examples of families we've reached & served:

- Asian immigrant family; Multi-lingual household; Parents speak limited English
- Medicaid
- Female child; age 7yo
- Parents’ concerns:
  - “too stubborn”
  - “difficult to teach academic skills”
  - “not talking much”
- School team's concerns:
  - Parents' "resistance" to an autism evaluation

Examples of families we've reached & served:

- Non-Hispanic White family; Single parent; Living in a shelter
- Medicaid
- Siblings; ages 5yo & 7yo; history of neglect
- Parent’s concerns:
  - “does their own thing”
  - “difficult to communicate with them”
  - “very picky with food”
  - Living situation

CASCADES BENEFITS AND CHALLENGES

Benefits

- Equity focused
- Improved access
- Lower impact to families (travel time, coordination related issues, etc.)
- Obtain comprehensive data via evidence-based tools
- School staff retention and development
- Standardizes educational determination process

CASCADES BENEFITS AND CHALLENGES

Challenges

- Training time and added demands for school providers
- Current administrative cost to school districts for training
- Family support for accessing community services post diagnostics
- Long wait times for community services

ADULT NEURODEVELOPMENTAL WELLNESS PROGRAM (ANeW)

Restoring Trueblood Class Members with IDD to their communities of choice (SB5440)

TRUEBLOOD, COMPETENCY SERVICES, AND IDD

Individuals have a constitutional right to understand and participate in their defense

- 7,543 people were referred for competency evaluation in Washington State between March 2024 and March 2025
- I/DD is under identified in this population, but identified individuals make up about between 5-10% of Trueblood class members

ANeW PROJECT TIMELINE

2015

Trueblood Lawsuit

DSHS violates the constitutional rights of individuals waiting for competency evaluations

2018

Settlement Agreement

State and prosecution agree to invest in diversion, competency services, and community based supports

2023

SSB 5440 Passes

WA State Legislature recognizes the unmet needs of Trueblood class members with IDD, TBI, and Dementia

2024

ANeW Launched

Interdisciplinary research and pilot program with the goal of reintegrating IDD class members into their communities

2026

Report to Legislature

20 pilot program participants; report on outcomes, retrospective review, and provide recommendations

SSB5440 PROVISO

Retrospective Review:

- shall report on the background of current and former Trueblood class members with IDD. DSHS shall share data as needed to assist in report development. **Report due November 30th 2026.**

Prospective Pilot Program:

- tasked with the implementation of a pilot project to provide short-term stabilization and transition support for individuals found non-competent and non-restorable to competency due to an IDD who are or have been Trueblood class members.

The Sequential Intercept Model (SIM) | SAMHSA

IDD IN THE TRUEBLOOD CLASS

More likely to carry multiple mental health and developmental diagnoses

Low educational attainment, significant high school drop out proportion

Population lacks long term services and supports

High rates of housing instability

IDD class members are racially diverse and primarily male

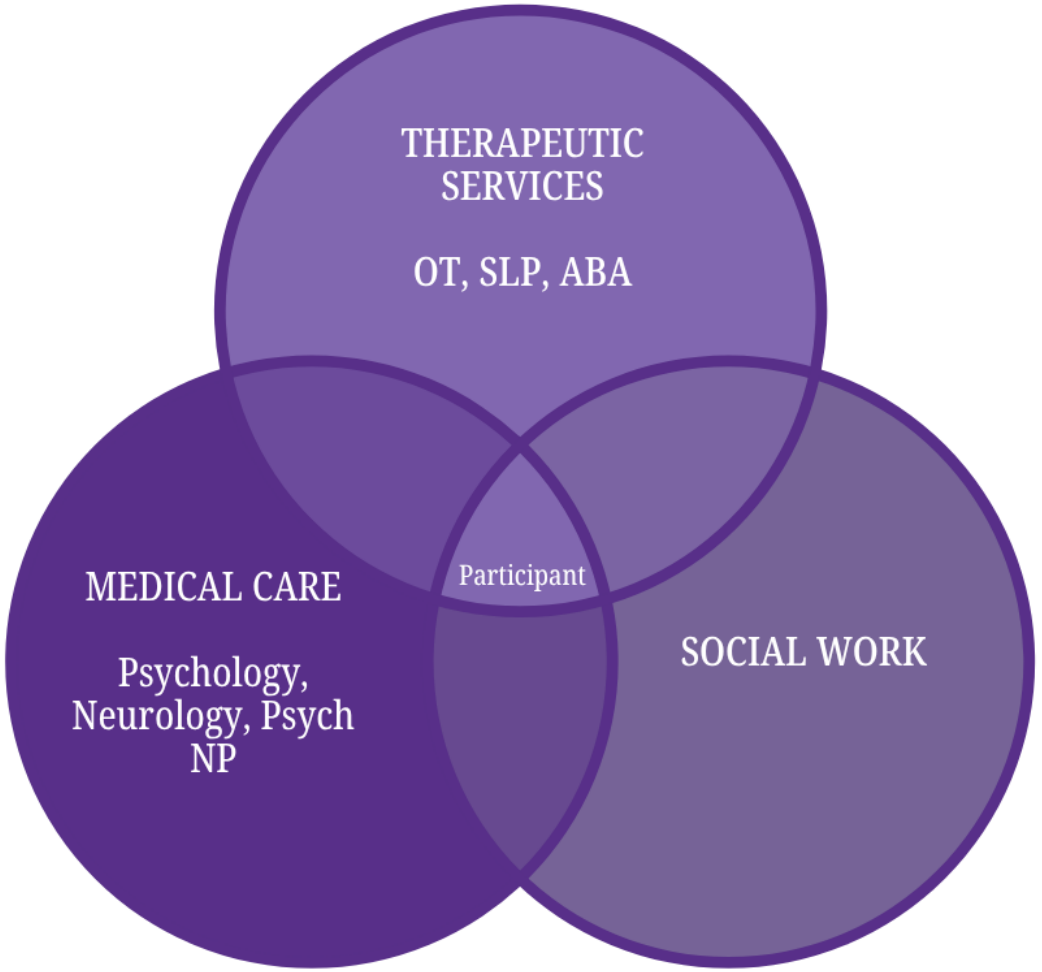
ANeW PROGRAM SUMMARY

Goal: *Provide temporary, transitional wraparound services to support participants with safe and successful community re-integration*

Who	• Trueblood class member adults with IDD who were deemed non-restorable and non-competent after arrest
What	• Interdisciplinary clinical team providing transitional wraparound support services
When	• Approximately 6 months duration of active treatment*
Where	• Wherever the participant is currently located (community, institution, group housing, etc.)
Why	• Outlined in amendment to WA SB5440 and based on the result of Trueblood et al. v. Washington State DSHS, 2015

ANEW PILOT PROGRAM AND RETROSPECTIVE REVIEW

- Describe population demographics and background
- Identify facilitators and barriers to community reintegration
- Identify and analyze protective and risk factors for the IDD Trueblood population
- Provide interdisciplinary services to 20 individuals by 2026 to support participants in safe and successful community re-integration



ANEW PILOT FEEDBACK

Summary of ANeW Parent Feedback

- With the UW team the client's rights were able to stay on the table and concerns were able to be worked on, when before they had been ignored

Organizational Administrator working with ANeW Clients

- "I have found ANeW to be a really positive resource, I have learned from working with them and appreciate all of the great insight they brought to our team. It was refreshing and positively challenged how we thought about things."

PRELIMINARY RETROSPECTIVE FINDINGS

Housing

High Rates of Instability

Limited effective supports lead to recidivism and increase length of stay

Community

Low Education Low Employment

Opportunities for community involvement are limited, significant social isolation

Medical

Complex and Co-Occurring

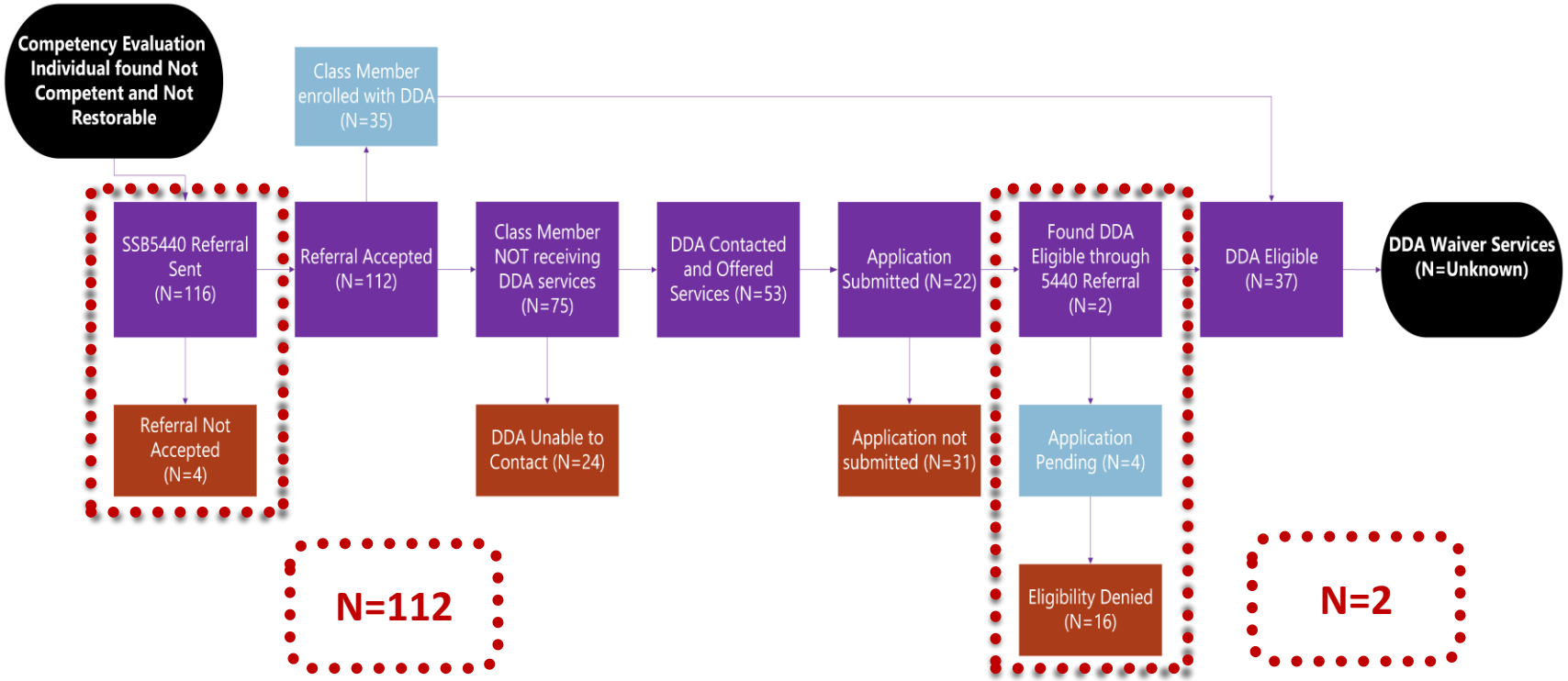
High rates of substance use disorder, mental illness, and inpatient hospitalization

Support

Limited and Variable

Limited family supports, guardianship can be a barrier or facilitator to discharge

DDA PATHWAY TO SERVICE



- ¾ of individuals referred do not have disability services, yet only 2 individuals were found eligible over the course of 8 months

OVERALL

Services and Support

Appropriate services are essential and historically inaccessible or unavailable

Insufficient Data

Disability is poorly captured in our systems

Breaking the Cycle

Diversion and prevention requires sustained investment

Interdisciplinary Approach

Medical, social, community support working in conjunction

QUESTIONS

- Karís Casagrande, PhD
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Learn more and register for WA INCLUDE at https://wainclude.org/

RESOURCES FOR FURTHER LEARNING (WEBINARS/PRESENTATIONS/WEBSITES)

Understanding and assessing I/DD and Mental Health

- NADD training on Emerging Best Practices for People with an Intellectual Developmental Disability Co-Occurring: https://www.nasmhpd.org/content/presentation/ta-coalition-webinar-emerging-best-practices-people-intellectualdevelopmental (slides, transcript, and recording)
- NADD Comprehensive Assessment practices: https://easacommunity.org/PDF/IDD_Handouts/IDD-2_Comprehensive-Assessment-Practices.pdf (slides only)
- Mental Health Diagnosis in IDD: Bio-psycho-social Approach: https://www.aucd.org/template/event.cfm?event_id=7992&id=740&parent=740 (recording and slides)
- MHDD Training Modules (https://www.mhddcenter.org/learn-now/)
- MHDD training on Case Conceptualization for Clients with IDD: The utility of the BPS Model: https://youtu.be/4IpLSc69Oqs?si=i_IGG121cDhNjUnn (slides and materials at https://bit.ly/ud_therapy)
- START Orientation Series: The Biopsychosocial Approach: https://www.youtube.com/watch?v=jW8mkmY5Ex4 (Video and transcript)

Adaptations to treatment for neurodivergent youth

- Adapting Cognitive Behavioral Therapy for People with Intellectual / Developmental Differences: https://complexmhidd-nc.org/physical-behavioral-healthcare/ebp-idd/cbt-adaptations-idd
- Modular Evidence-based practices for Youth with Autism spectrum disorder (MEYA): meya.ucla.edu/public
- The Neurodivergent Friendly DBT Workbook: https://www.livedexperienceeducator.com/store/p/neurodivergent-friendly-workbook-of-dbt-skills
- Effective A.C.T. for Autism: https://www.amazon.com/Effective-ACT-Autism-Easy-Read/dp/B0C9S54RQN

RESOURCE FOR FURTHER LEARNING (BOOKS)

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