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A Tribal Based Developmental Program with Community Collaboration

Lummi Nation Health Center

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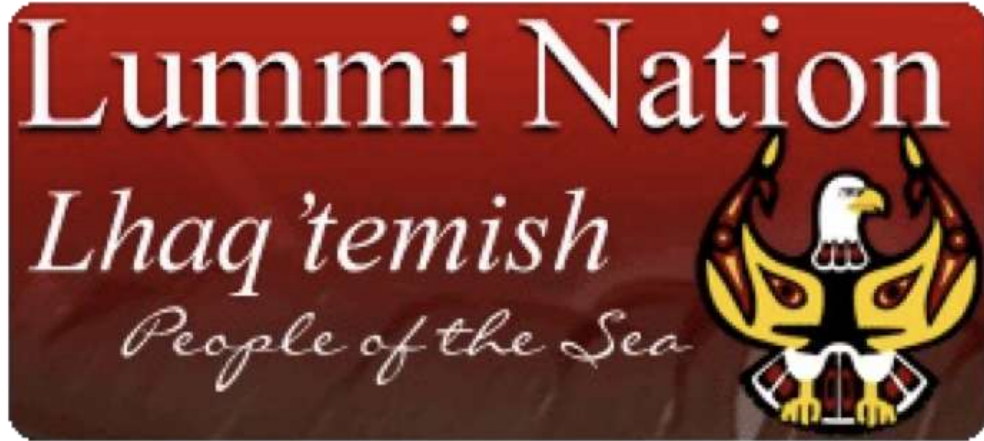
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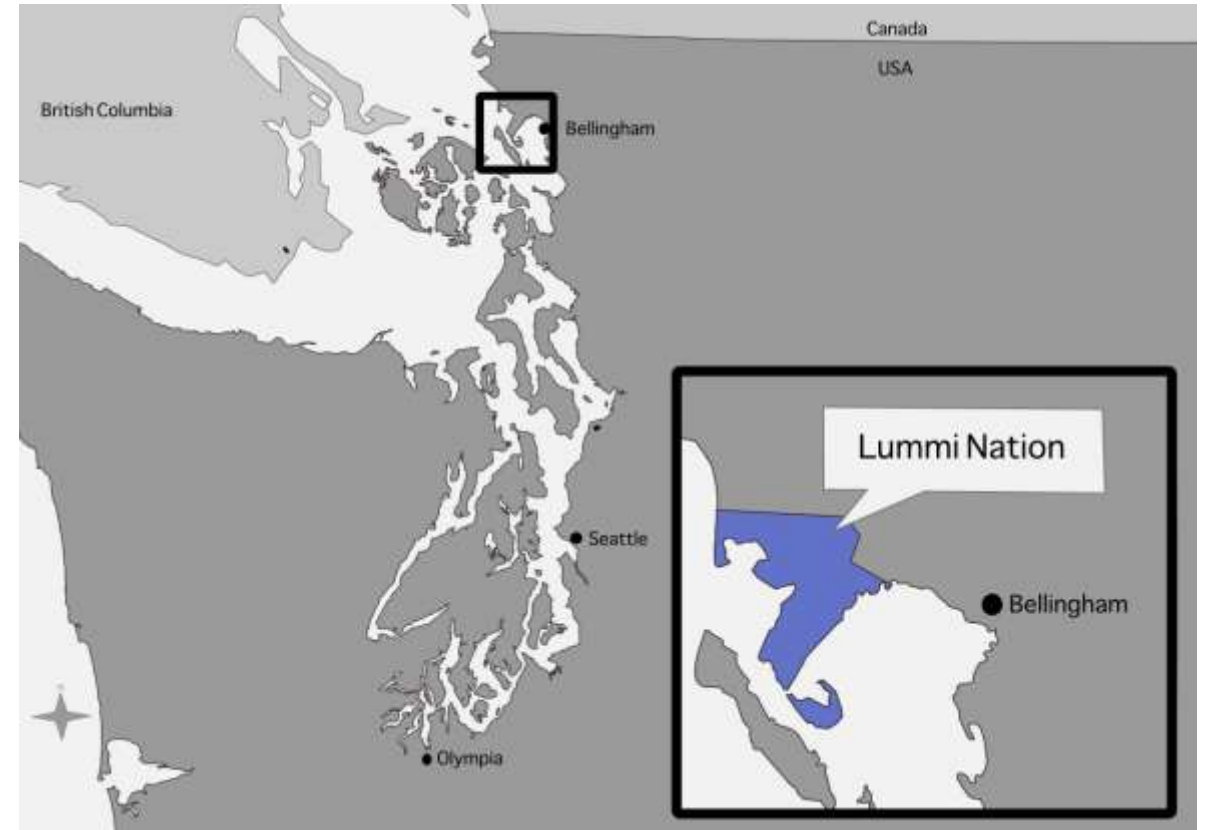
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Learning Objectives

1. Participants will be able to evaluate the need for pediatric developmental and autism services in their indigenous care settings.
2. Participants will have a replicable model of care for creating a pediatric developmental clinic or program.
3. Participants will have increased access to autism resources that are tailored to Indigenous families.



- Federally recognized tribe, sovereign nation
- Population ~6500 (~2000 children ages 0-21)
- Tribal government
 - Health and Human Services--> Health Center
 - Education (K-12, Early Learning, ESIT)



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Lummi Nation Health Center

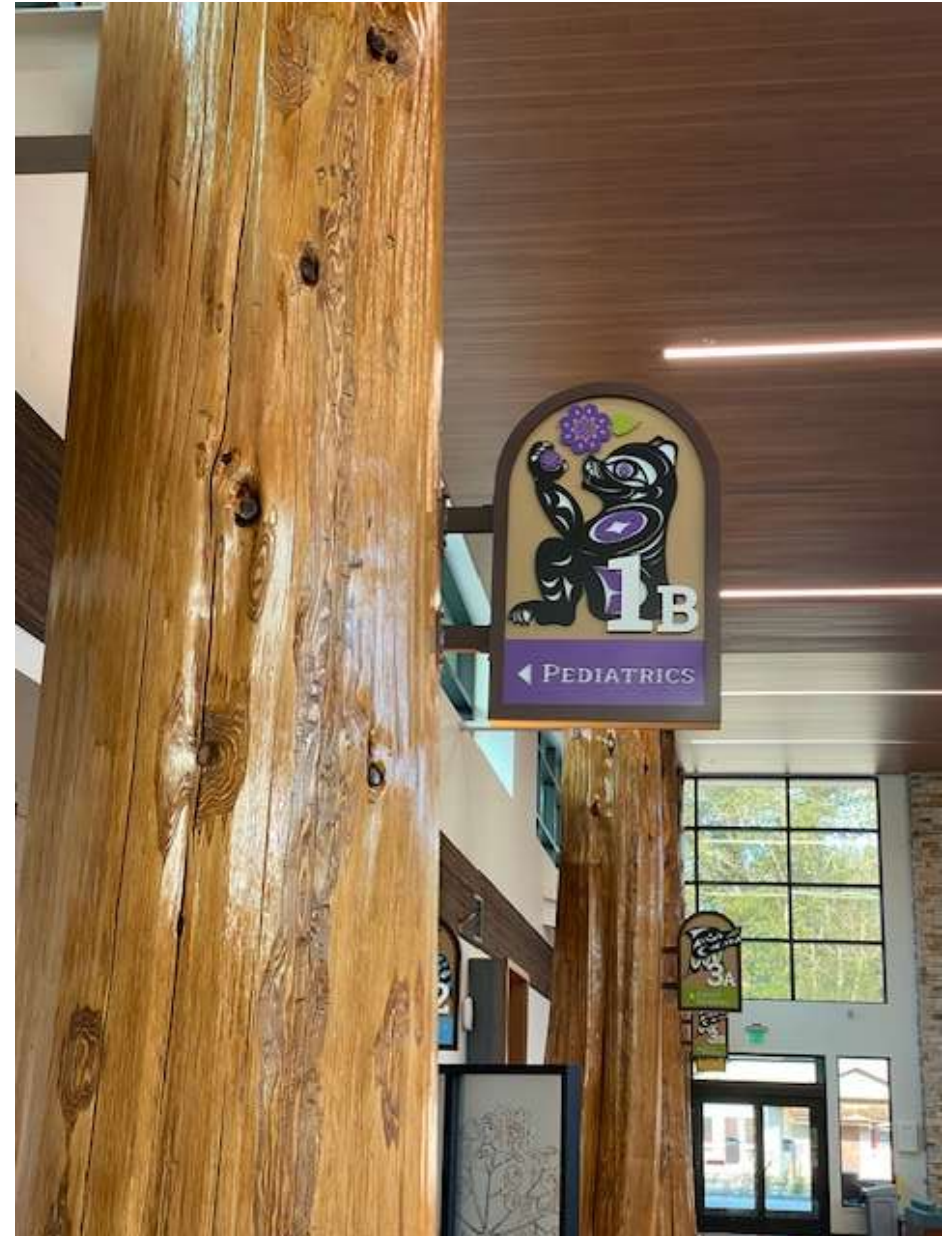
- Managed by Lummi Nation, funding from IHS
- Under health division of tribal government
 - Challenge: Programming may require consultation outside direct healthcare (health commission and tribal council)
 - Benefit: community voice
- Multidisciplinary medical home
- Small community, direct access to partners
- Opportunities for innovation



Services

- Primary Care: Family Medicine (7) and Pediatrics (2)
- Developmental and Behavioral Pediatrics (1)
- Perinatal RN
- WIC
- Social Work, Care Navigators/Community Health Workers
- Adult Psychiatry(1)
- Child and Adolescent Psychiatry (1)
- School-Based Health Center
- Public Health
- Harm Reduction
- Community Health/Home Visiting nurses
- Dental and Orthodontics
- Physical Therapy
- Behavioral Health
- Pharmacy
- Lab and Imaging

Pediatric Developmental Clinic



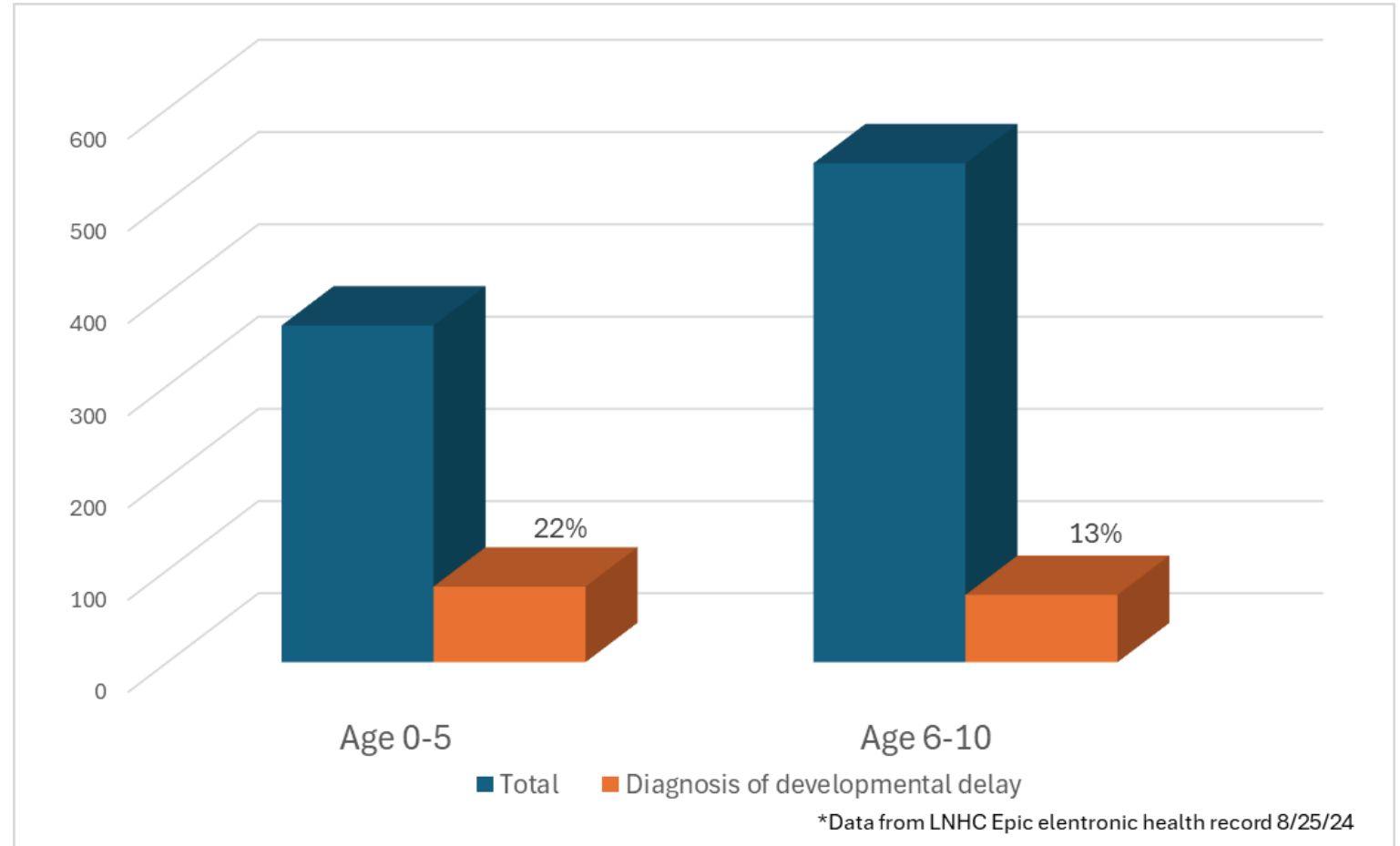
Background

Lummi Nation Health Center leadership and Tribal Council saw an unmet need for timely and culturally appropriate access to pediatric developmental and behavioral services

About 30% of children served by the Lummi Nation School qualify for special education. Only 14 children ages birth-21 years had an autism diagnosis in 2022. If 1 in 36 children are expected to have ASD, that would correlate to a pediatric population of 504. LNHC has 1800-2000 active patients, suggesting underdiagnosis.

Nationally, AI/AN children are the least likely racial/ethnic group to receive an autism diagnosis, but are the mostly likely group to be in special education. This represents a health disparity in diagnosis and management of early onset developmental disorders.

Developmental Delay and Differences at LNHC



Barriers to Access

- 1-5 year wait for autism or neurodevelopmental evaluation
- 90-mile distance to autism/neurodevelopmental provider
- No integration of care and resource support between distant providers and LNHC
- Local ABA providers with up to 1 year waiting list
- Medicaid not always accepted or capped
- Caregiver time and transportation often limited
- Historic racism limits trust
- "Disorder/disability" language can be stigmatizing
- Cultural understanding often limited in external providers

LNHC Developmental Clinic

Launched in October 2023. Integrated with pediatrics department.

Open to ages birth-21 years. Available 2 days per week.

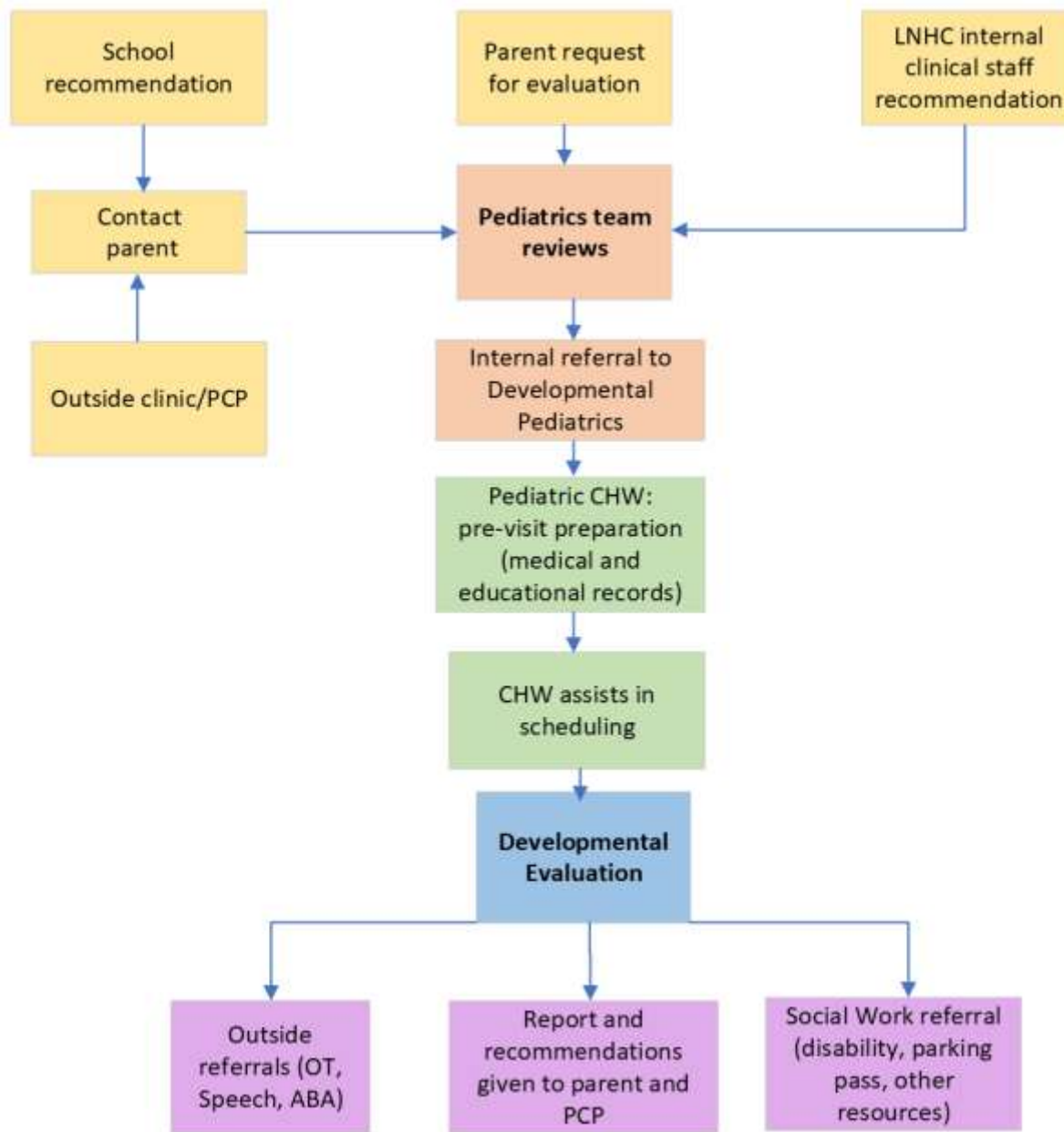
Priority given to Lummi tribal members but also accepting referrals from other tribes. Nooksack, Tulalip and Swinomish Tribes coordinate referrals with LNHC. PCP may be at any health facility.

Developmental team includes Dr. McLaurin; Katie Goger, MSW; Joanna Lane, Tribal Community Health Worker; and coordination with pediatric and psychiatry providers.

Beginning to collaborate with LNHC Behavioral Health. A well-outfitted play and observation room is used for evaluations.

Process

- Referral by PCP, Behavioral Health, or Lummi Nation School
- Community health worker provides pre-visit support (ROIs for prior medical and educational records, appointment reminders, transportation assistance)
- Parent questionnaire, IEP, school records, medical and birth records reviewed before visit if possible
- Initial two-hour appointment. 1-hour follow ups.
- Evaluation in large BH room with adjunct use of diagnostic tools
- Referrals to ABA, speech, occupational therapy, genetics, psychiatry as needed
- After visit referral to MSW and CHW (understanding diagnosis, resources, care navigation)



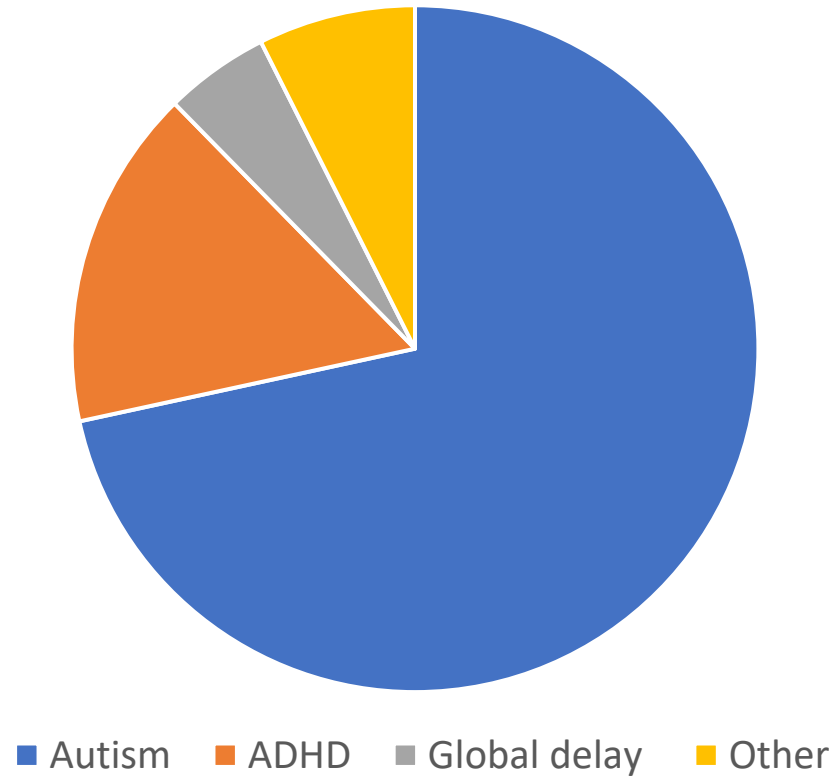
Progress
while
keeping
cultural roots



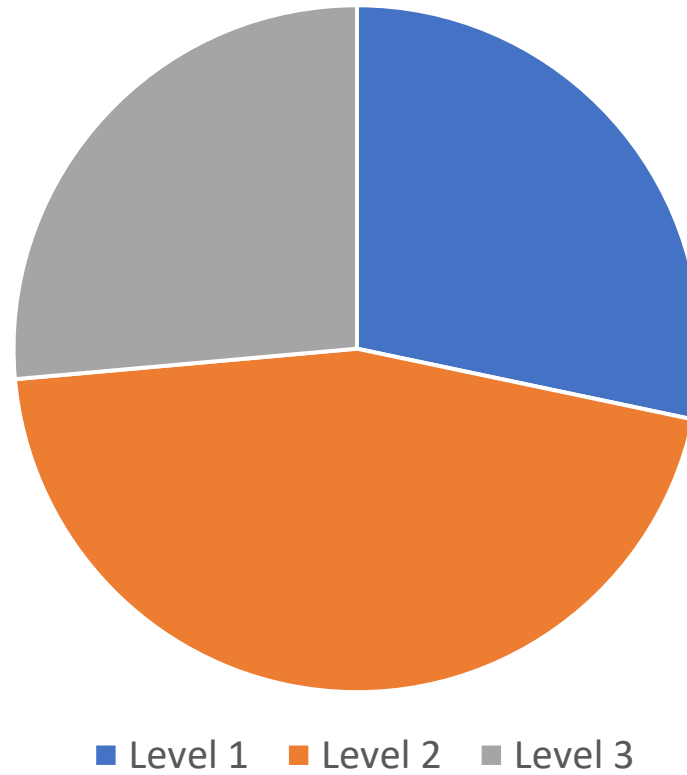
Year 1 overview

- 83 individual children seen, ages 2-20
- 60 with autism spectrum disorder (4 with prior diagnosis; 56 new diagnosis)
 - 19 diagnosed under age 5
 - 24 diagnosed age 5-10
 - 17 diagnosed age 11-20
 - *Average age at diagnosis 5.33 years
- 36 boys, 24 girls

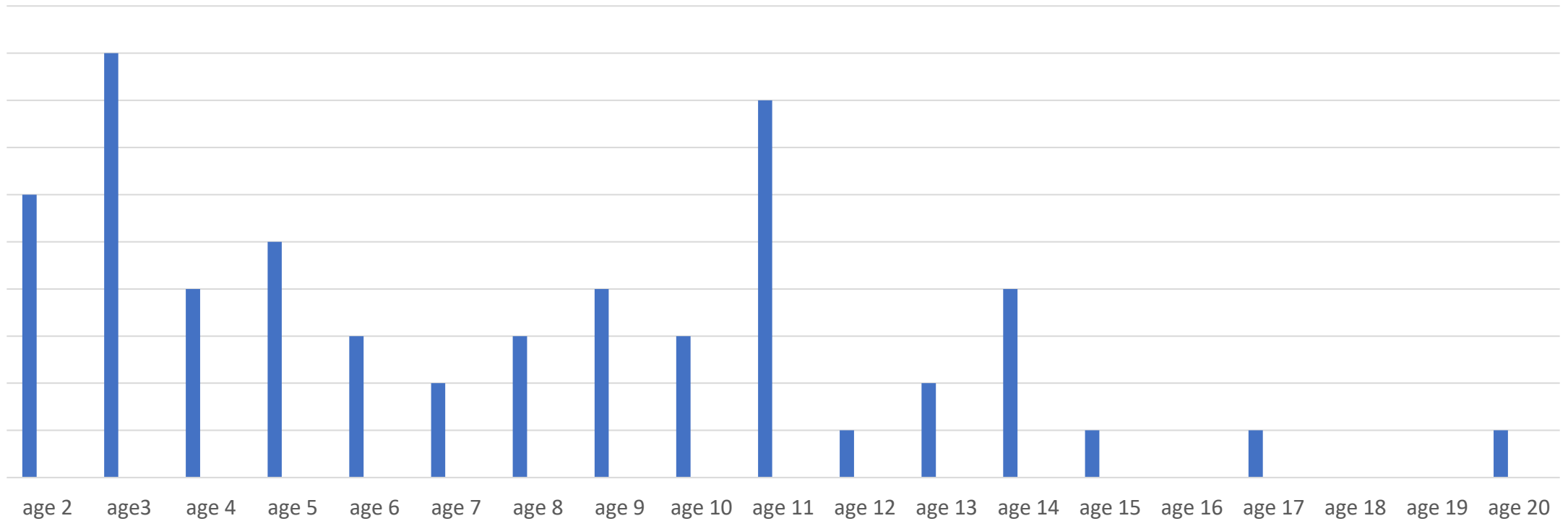
Primary Diagnosis



Autism by Severity



Age at diagnosis (AAP standard before age 4)



Autism Comorbidities

- Speech disorders and delays
- Oppositional behavior, disruptive mood dysregulation disorder
- Anxiety
- ADHD
- Restrictive feeding disorder*
- Sleep disorder
- Toileting/GI conditions*
- Genetic syndromes suspected
- Selective mutism
- Intellectual delay
- Fetal Alcohol Syndrome
- In-utero exposure to substances
- Primary enuresis

Other Diagnoses in children without ASD

Genetic syndromes

Fetal Alcohol Syndrome

Neurodivergence

Global developmental delay

Attention Deficit Hyperactivity Disorder

Sensory processing disorder or sensory sensitivities,
behavioral issues

Supportive Care Arranged by Social Work

- Disability parking pass for safety (elopement concerns)
- Applications for DDA and SSI
- Applied Behavioral Analysis application
- Feeding therapy referrals for restrictive eating
- Occupational and speech therapy referrals
- Hearing screen or audiology referral
- Communication with schools, IEP attendance
- Application for developmental preschool
- Recommendations for sensory tools and accommodations (weighted vest, mouthing toys, augmentative communication devices, safety kit, etc.)
- Lock boxes or bags for medications to decrease ingestions



Current and Planned Collaborations

Developing tribe-based ABA services and other autism supports

- Supporting Behavioral Health plan for ABA
- Goal for tribal members to become certified ABA technicians
- Locate services at tribal school, clinic, or patient home per family preference
- Partner with others cohesive messaging

Parent and community program development

- Parent and staff training at Early Learning Program and K-12 school
- Staff coaching from Seattle Boyer Children's Clinic Parent Support lead
- Parent group development

Collaborations, cont'd

- Child and Adolescent Psychiatry: dedicated faculty member to see patients 2 days/week via telemedicine with periodic in-person care
- STAT training for pediatric providers
- LNHC staff training on sensory friendly health center visits
- Dimmer lights in BH and medical exam rooms installed
- Outreach at school and community events
- County grant for clinic-based promotion of kindergarten readiness

Outcomes in First Year

Before 1/1/2023

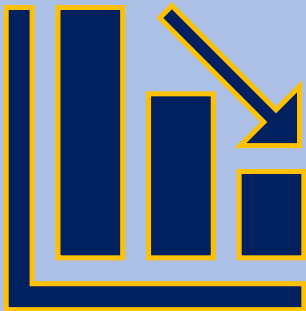
- 14 children diagnosed with autism spectrum disorder
- 73 children with any kind of developmental delay noted
- Most ASD diagnosed elsewhere, a few through child psychiatry

October 2023-September 2024

- 55 new diagnoses autism (corresponds to pediatric population of 2000)
- 82 children seen in developmental clinic, many with multiple visits
- Waiting time less than 4 weeks
- Missed appointments rare

Trends in First Year

Decreasing severity,
younger age at diagnosis,
and gender parity with
program growth!



	6 months of program operation	12 months of program operation
Average age at diagnosis	6.6 years	5.3 years
Level 3 severity	Over 50%	26%
Gender	16 M : 2 F	35 M : 24 F

Ongoing Needs and Challenges

- Understanding the intersection between intrauterine substance exposure, adverse childhood experiences, child development, and autism
- Fostering family and community awareness of critical early developmental years, resources to help catch delays early
- Time between referral for services/therapies and receipt of such
- School resources and training for children with developmental disorders or sensory needs

Anticipating Future Needs

How will (future) adults with severe autism navigate the world?

- Tribal operated group home?
- Tribal operated skill development and work opportunities?
- Access to technology that assists daily living?
- Managing safety considering law enforcement reactions or community misunderstanding
- Training on avoidance of manipulation around illicit substances, sex, gambling, other financial situations and scams

Hopes for Growth

- Developmental Preschool
- Lummi based speech, occupational therapy, and ABA for ages 1-18
- Parent Support Groups
- General training on autism and neurodiversity for community, including dental, behavioral, medical, legal, educational



Resources: Simple Starts

Common Screening Tools:

- MCHAT-R (Modified Checklist for Autism in Toddlers): Ages 16-30 months
- STAT (Screening Tool for Autism): takes 20 minutes. Ages 24-36 months
- SCQ (Social Communication Questionnaire): older children and adolescents

Evaluation/Observation Tools:

- CARS2 (Childhood Autism Rating Scale)
- ADOS-2 (Autism Diagnostic Observation Schedule)

WA COE Quick Start Guide: <https://medicalhome.org/COEquickstart.pdf>

Disability Parking Pass: Prescribe for safety concerns and anxiety in public places

Disability services and supplemental income (DDA and SSI)

You can prescribe ABA therapy if diagnosis already made

Share and post about neurodivergence and autism so families get good early information

Design sensory friendly visits

Contact Us!

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