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Describing Disability Among Children Served by the Portland Area IHS

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About Molly

- Member of the Confederated Tribes of Warm Springs
- Goal of being a physician since the age of 4
- April 27, 1996
  - Sister with C1 spinal cord injury
  - Inpatient rehabilitation for 2 months
  - Family had to move from Warm Springs
  - Exposure to many fields of medicine

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About me

- With IHS since 1998
- Inspired to a career in medicine by my parents
- August 16, 1958
  - Mother diagnosed with polio at age 21
  - Hospitalized for 9 months
  - Used crutches/wheelchair
  - Later in life developed post-polio syndrome

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Describing Disability Among Children Served by PAIHS

Molly Fuentes, MD, MS and Capt. Thomas Weiser, MD, MPH

- This study aims to describe among children served by the Portland Area Indian Health Service (PAIHS):
  - Prevalence of children with disabling diagnoses
  - Most common disabling diagnoses
  - Proportion of visits associated with disabling diagnoses.
  - Types of health care services used by children with disabling diagnoses

Defining Disability

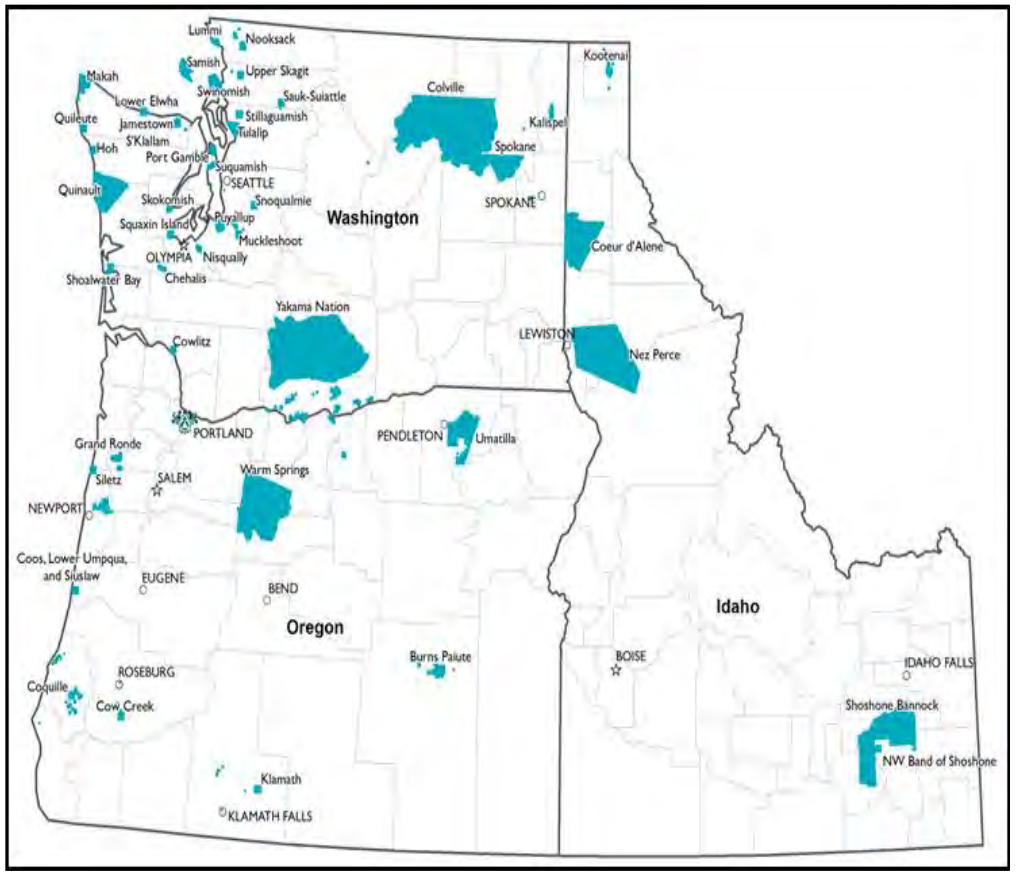
- 2006 UN Convention on the Rights of Persons with Disabilities
  - “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

Defining Disability

- Children With Disabilities Algorithm (CWDA, Chien et al)
  - Developed by multidisciplinary team (including parents) to identify children with disabilities from administrative or clinical databases
  - Tool to evaluate quality of care for children with disabilities
  - 669 ICD-9 diagnostic codes likely to indicate a child with disability
  - We grouped these diagnostic codes into broader diagnostic categories, etiologic categories and impairment categories

Describing Disability Among Children Served by PAIHS

- Portland Area Indian Health Service records, 2006-2014
  - Epi Data Mart
  - All encounter records for children age 0 to17-years-old and identified as AI/AN



Patient Visit, IHS/Tribal/Urban Site

Electronic reporting systems

Clinic/ Area Server

IHS Server

.ftp

Area Tribal Epidemiology Centers

Epi Data Mart

General Data Mart

Data Quality Mart

Data Integrity Mart

Userpop Mart

Export Tracking Mart

National Data Warehouse

Identifying individuals with CWDA

- Numerator:
  - For each year, we identified case-patients as any American Indian/Alaska Native, 17 or younger at the time of their visit who was seen at least once in that calendar year with a CWDA diagnosis
- Denominator
  - Patients who were AI/AN, 17 or younger with at least 1 visit in the past 3 years

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- Identified CWDA diagnoses coded in the first 11 ICD-9 fields
- Each encounter could have multiple diagnoses
  - e.g. Cerebral palsy, hemiplegia, acute upper respiratory infection, and vitamin D deficiency
- Encounters were classified by impairment group and etiology.

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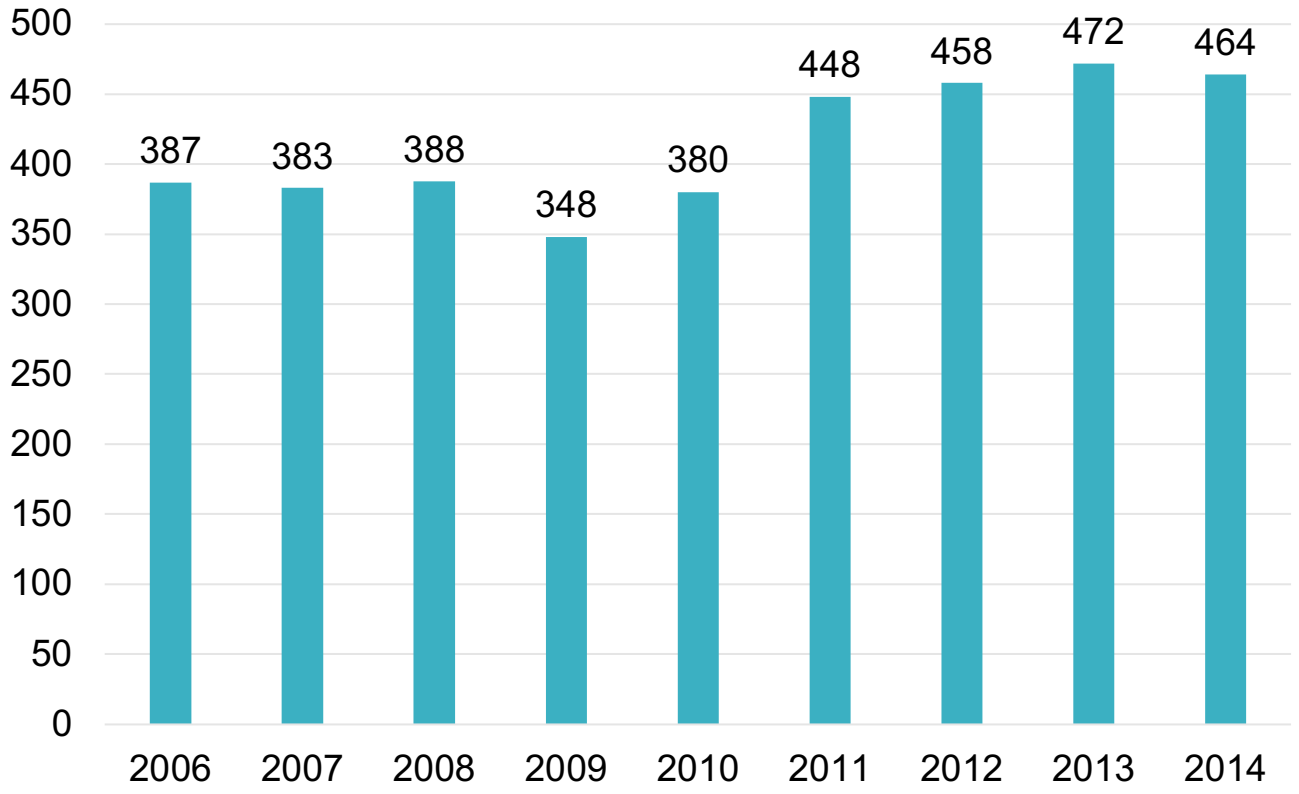
- To determine impairment categories, five pediatric rehabilitation professionals assigned functional impairment categories to each diagnostic code
  - Physical, cognitive, communication, sensory, or emotional impairments
- Differences in these assignments were resolved by consensus among the five raters

Number of Children with CWDA Diagnoses, by Year



2,507 unique children with CWDA diagnoses

Period Prevalence of CWDA=1.5%

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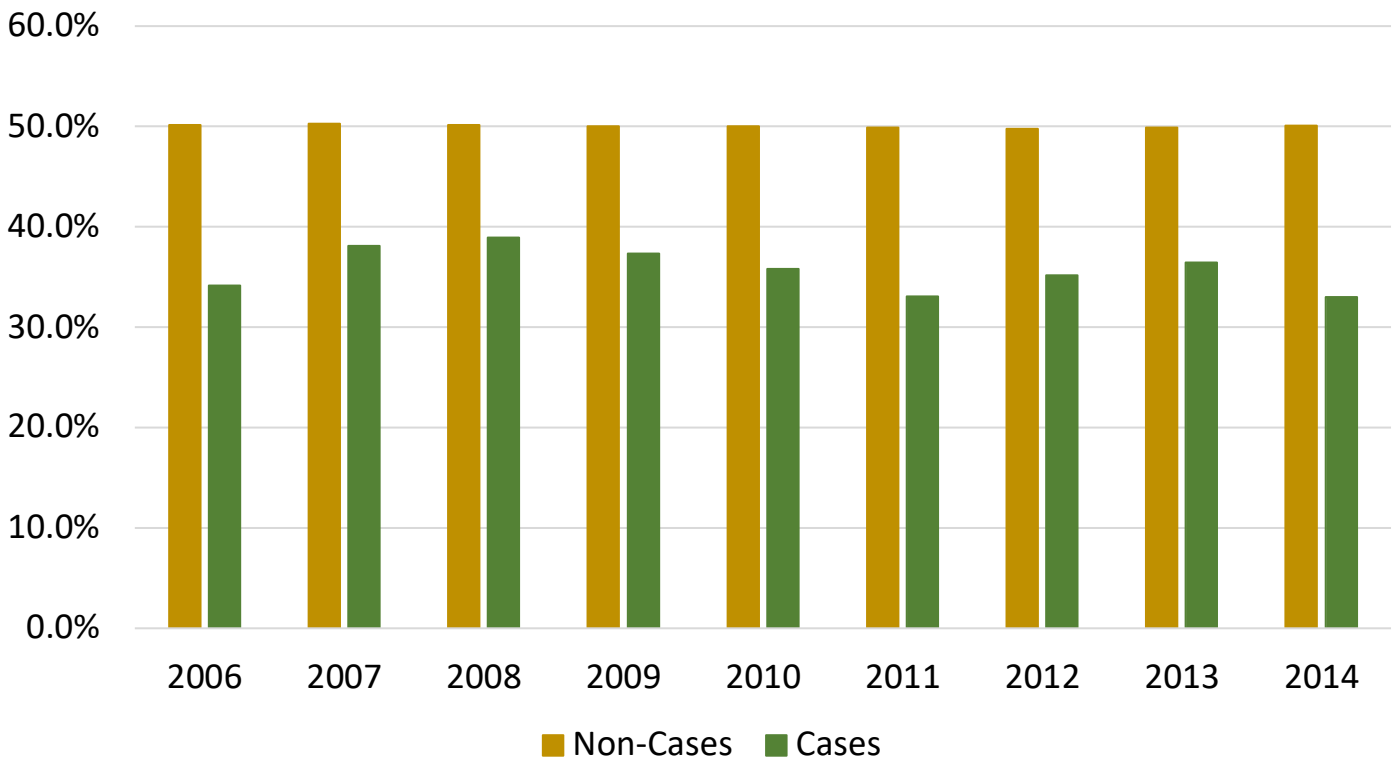
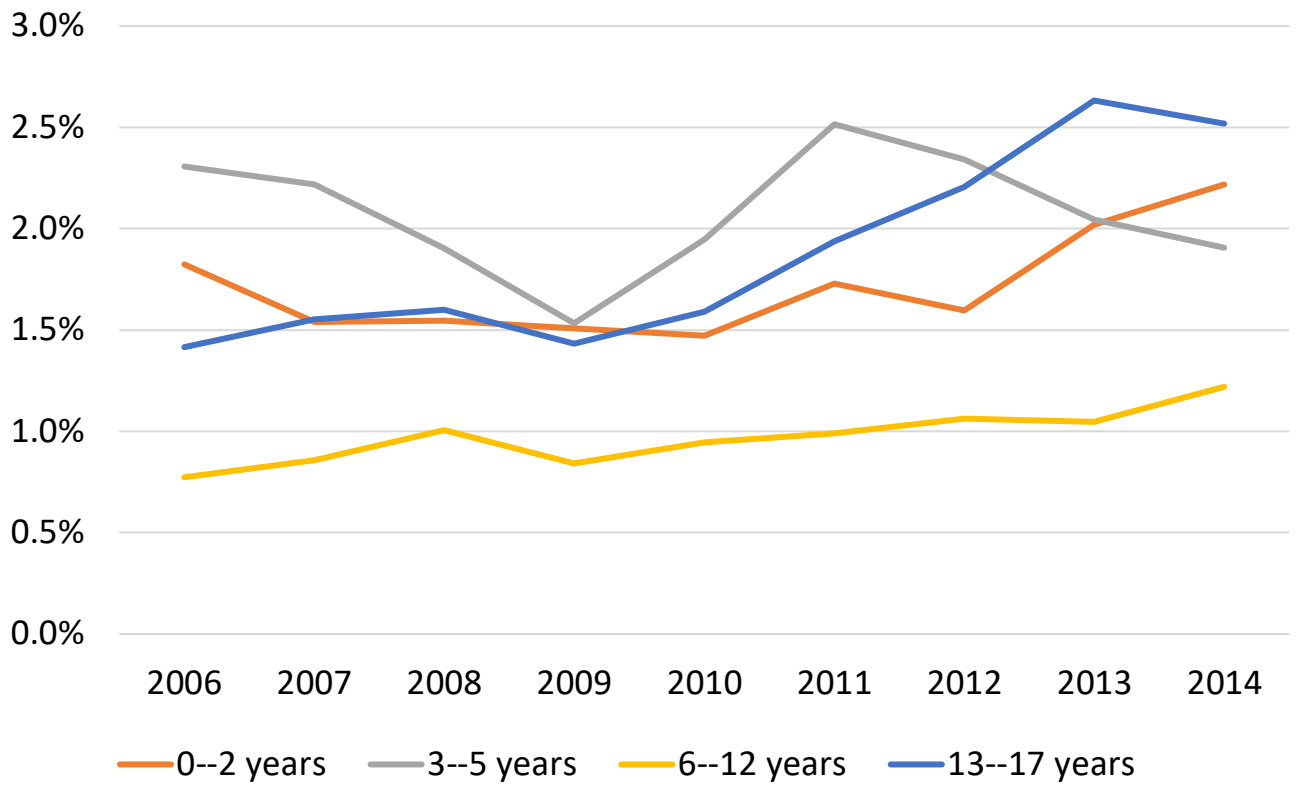
Percent Female for CWDA Cases and Non-Cases

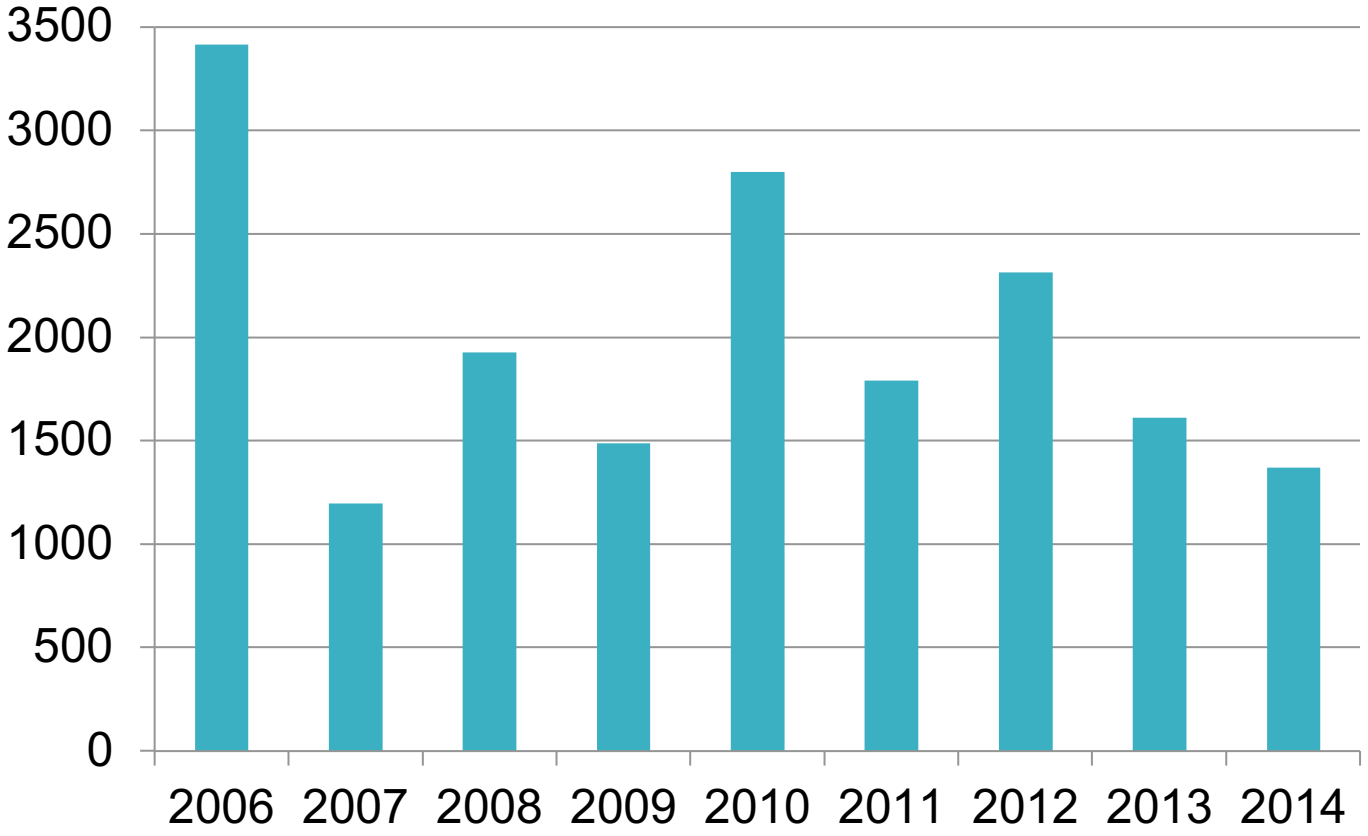


Fewer CWDA cases are female compared to Non-cases

Annual Prevalence of CWDA by Age Group



Frequency of CWDA Encounters, by Year (2006—2014)



17,915 unique encounters with CWDA diagnoses

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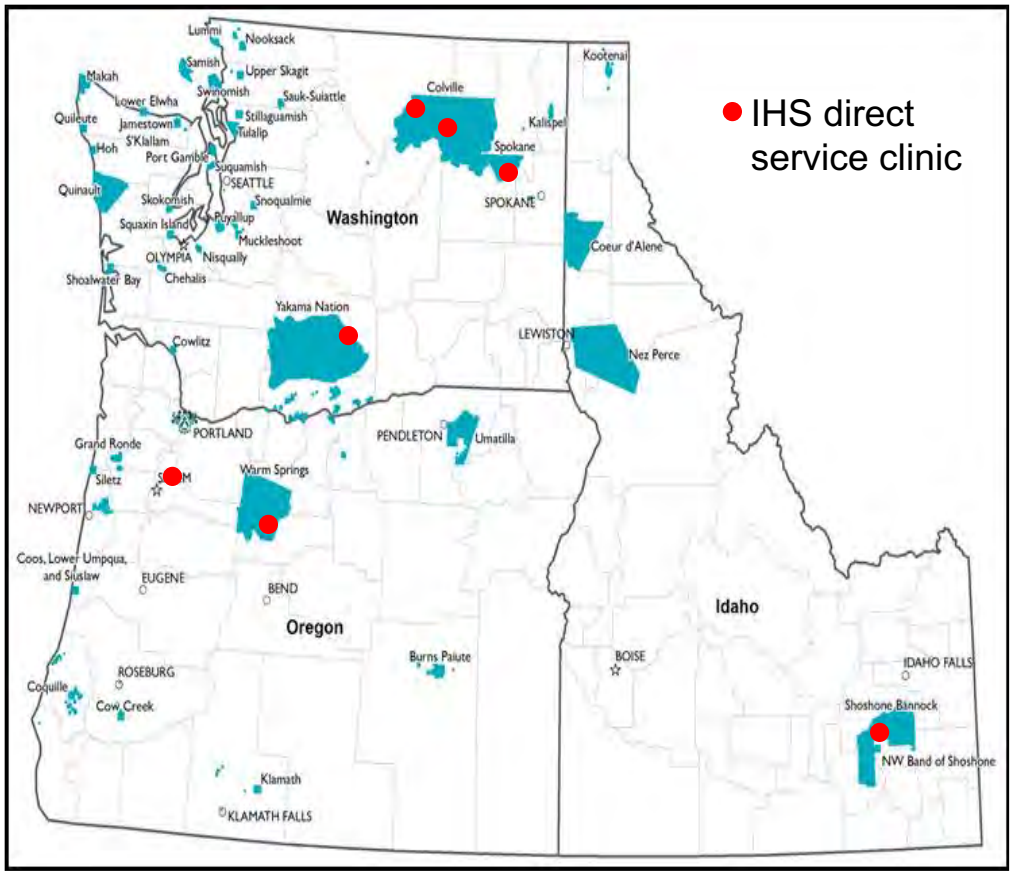
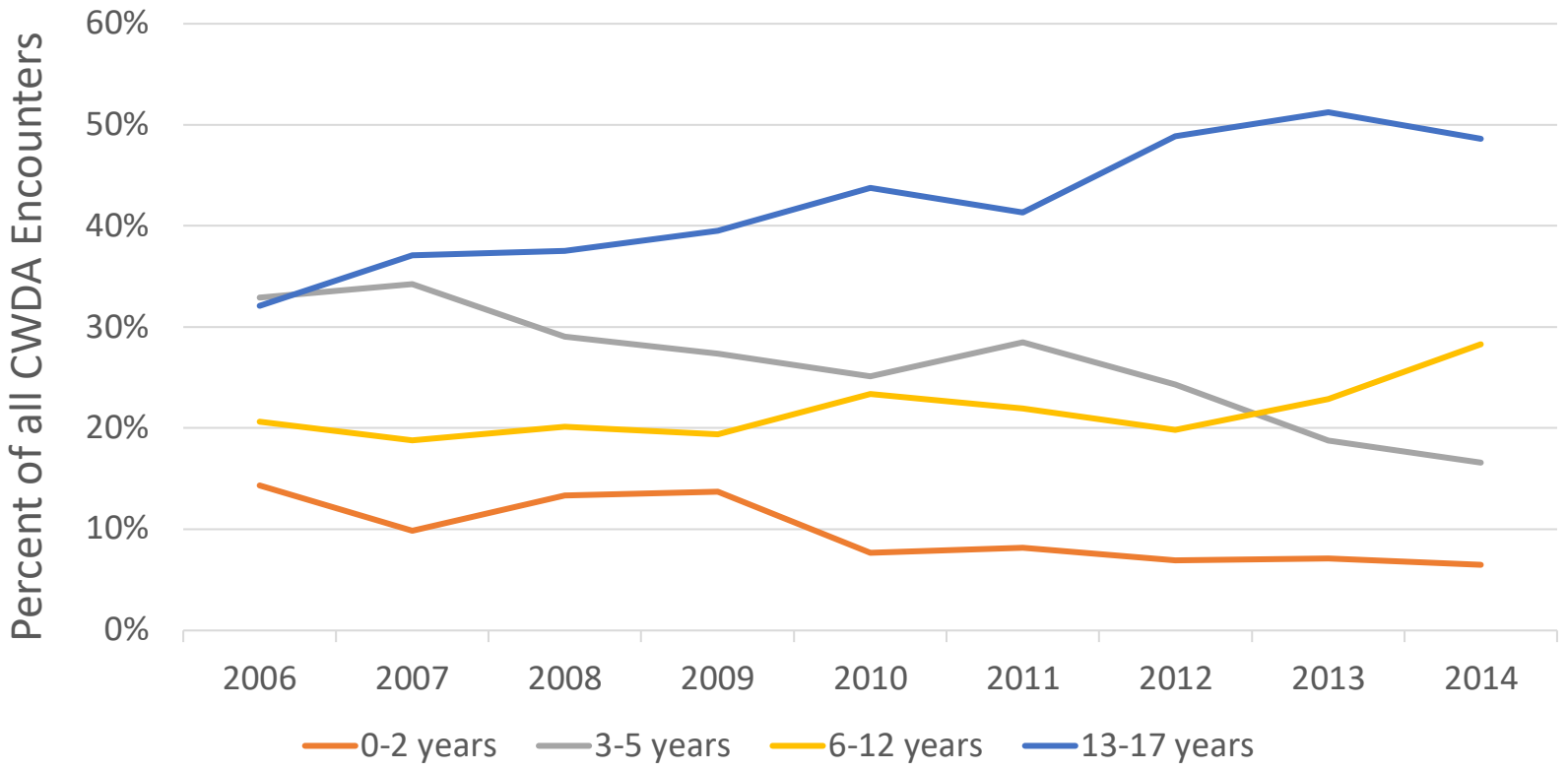
17,915 encounters with CWDA diagnosis

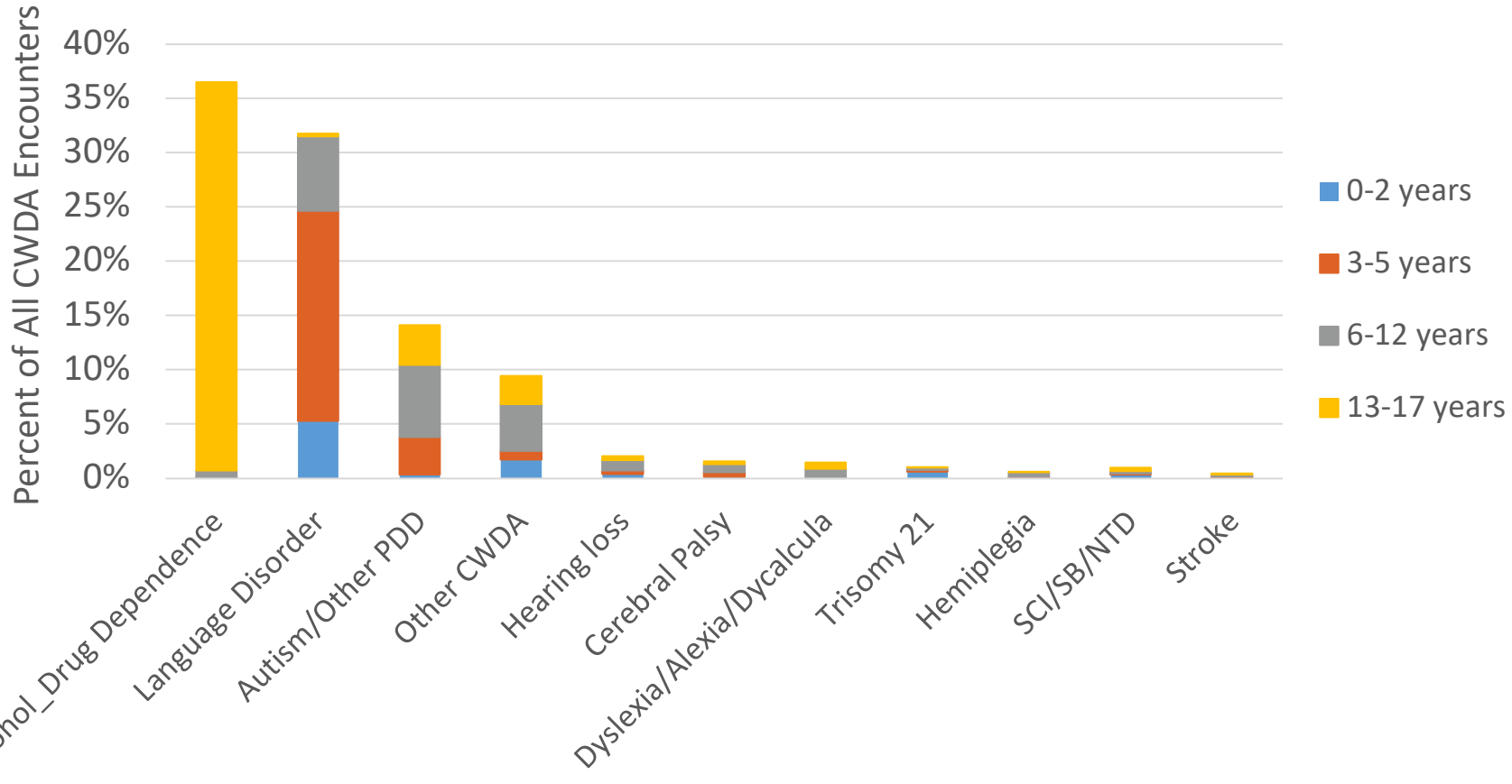
- Location
  - 72% at Tribal/638
  - 11% at IHS/direct service
  - 8% Contract health
  - 8% Missing



CWDA Encounters by Age Group, 2006-2014



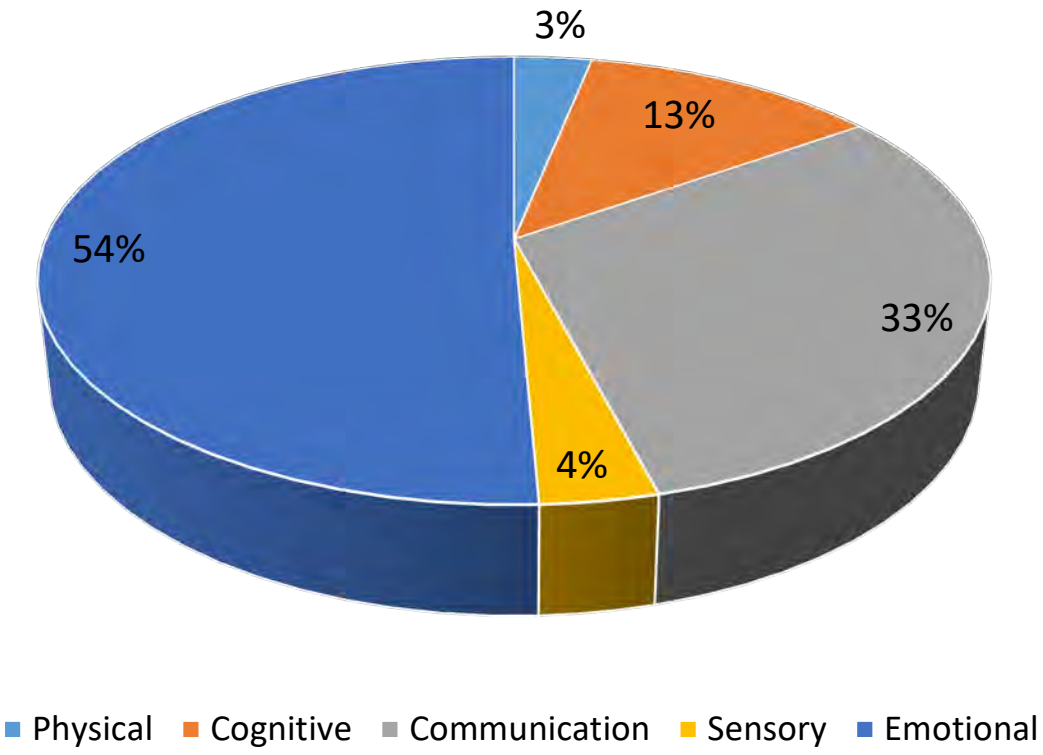
Age Distribution of Disabling Diagnoses for Encounters



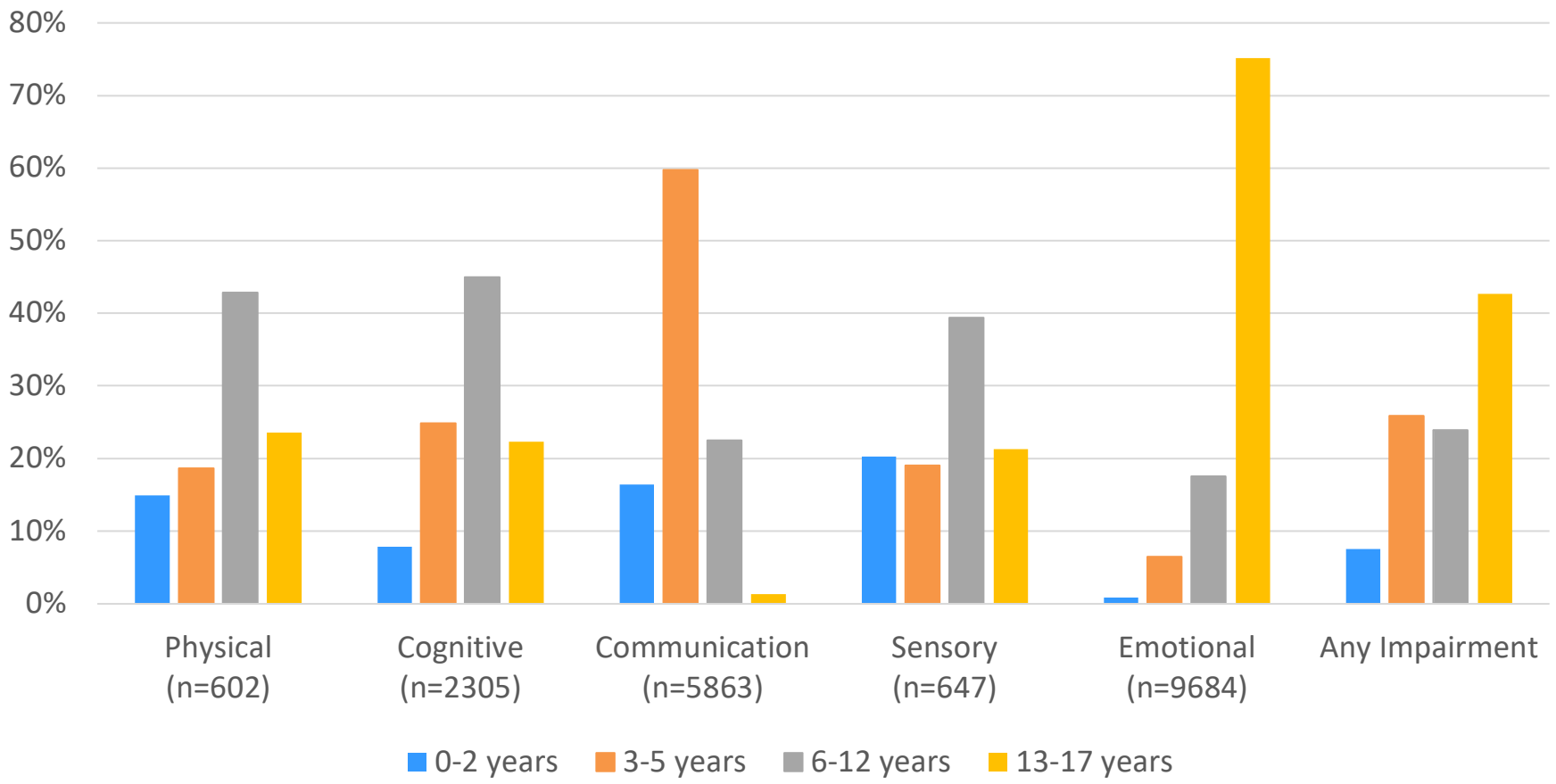
Describing Disability Among Children Served by PAIHS

Overall	2006	2007	2008	2009	2010	2011	2012	2013	2014
Speech/ Language	Speech/ Language	Speech/ Language	Speech/ Language	Speech/ Language	Speech/ Language	Speech/ Language	Speech/ Language	Speech/ Language	Speech/ Language
Mental Health	Mental Health	Mental Health	Mental Health	Mental Health	Mental Health	Mental Health	Mental Health	Mental Health	Mental Health
Soc/Behav	Soc/Behav	Soc/Behav	Soc/Behav	Soc/Behav	Soc/Behav	Soc/Behav	Soc/Behav	Soc/Behav	Soc/Behav
Hearing	Hearing	Hearing	Hearing	Hearing	Hearing	Hearing	Hearing	Hearing	Hearing
Non-traumatic brain	CP	Genetic Disorder	CP	Non-traumatic brain	Genetic Disorder	Stroke	Genetic Disorder	Genetic Disorder	Learning Disorder
Learning Disorder	Genetic Disorder	CP	Genetic Disorder	Stroke	Non-traumatic brain	CP	CP	CP	CP
CNS anomaly	Learning Disorder	Visual	CNS anomaly	Congenital MSK	Other Med Complex	CNS anomaly	CNS anomaly	Learning Disorder	Genetic Disorder
Stroke	Non-traumatic brain	CNS anomaly	Non-traumatic brain	CNS anomaly	Stroke	Genetic Disorder	Learning Disorder	Visual	Dev Delay
Genetic Disorder	Plegia/ Paresis	Learning Disorder	Learning Disorder	CP	CNS anomaly	Learning Disorder	Other Med Complex	Plegia/ Paresis	CNS anomaly
Cerebral Palsy	CNS anomaly	Non-traumatic brain	Plegia/ Paresis	Genetic Disorder	CP	Non-traumatic brain	Stroke	Non-traumatic brain	Non-traumatic brain

Types of impairments for CWDA Encounters



Age Distribution of Impairments for CWDA Encounters



Clinic Type and Primary Provider Type for CWDA Encounters

Clinic Type	n	% of encounters
Mental Health	9412	52.5
Primary Care	3491	19.5
Rehab Services	527	2.9
Pharmacy	297	1.7
Diagnostics	218	1.2
Home Care	160	0.9
ER/Urgent Care	86	0.5
Other	332	1.9
Missing	3019	16.9%

Primary Provider Type	n	% of encounters
Counselor	7235	40.4
Rehab Therapist	3032	16.9
Physician/ARNP/PA	2235	12.5
Nurse/CNA/MA	1725	9.6
Pharmacist	353	2.0
Diagnostic specialist	173	2.0
Other	1603	8.9
Missing	1506	8.7

n=17,915 Encounters

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Discussion

Why is the prevalence of children with CWDA diagnostic codes in the PAIHS encounter records so low??

Possible reasons

- Different methods of identifying disability
  - Self-report versus provider-identified
- Native children with disabilities in the PNW may receive primary care outside of the IHS/Tribal health system
  - Is care culturally appropriate?

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Discussion

- Speech Language disorders were the second most prevalent type of potentially disabling diagnosis
  - 32% of children with CWDA diagnoses
    - But only 17% of encounters were with a Speech Language Pathologist
  - Are diagnoses reflective of true language or communication impairment?
    - Not much literature about linguistic development in Native children

Describing Disability Among Children Served by PAIHS

Discussion

- Very few children with traumatic injuries, <20 children with TBI or spinal cord injury
  - Based on AI/AN injury literature, we expected more traumatic diagnoses

Limitations of Study

- Diagnoses included (or excluded) from CWDA
  - Included drug-related ICD codes, but not alcohol
  - FASD not included
  - Depression?
  - Arthritis and other rheumatologic disorders
- Dental visits were not recorded reliably in the data-base
- Limited geographic are (PNW)
- Does not include information for Native children who receive care outside of IHS and tribal health systems

Conclusions

- This is the first study to describe American Indian/Alaska Native children with disabilities:
  - Using IHS administrative data
  - Using the CWDA algorithm
- The prevalence of disabilities identified (1.5%) was much lower than has ben described using census data (~8%)
- The 3 most common diagnosis categories accounted for >80% of patients:
  - 37% Substance use disorders
  - 32% Speech/Language disorders
  - 14% Autism/Persistent Developmental Delays

Next steps - Understanding the Experience and Priorities of AI/AN Children with Disabilities and Their Families

- In-depth interviews
  - AI/AN youth (age 7-24) with disabilities/functional differences
  - Parents/caregivers of AI/AN children/youth (6 months to 17-years-old) with functional differences
- Questions to elicit experience of health, activity, participation, health/rehabilitation service utilization, intersection with culture
- Identify priorities of consumers/communities in order to develop culturally-relevant interventions

Further down the road – Other stakeholder input

Elicit opinion of stakeholders other than individual/family

- Tribal leaders (tribal government/council, community program directors, elders)
- Adults with childhood/adolescent onset disabilities
- PCPs and Rehab professionals

Stakeholder engaged intervention development and testing

Crossing fingers that grants get funded!

Thank you!

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