



**National Center
on Deafblindness**

The Deafblind Child Count: Identification Takes a Village

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Purpose

- Increase knowledge of National Deafblind Child Count
- Highlight common etiologies & causes of deafblindness & share associated resources
- Highlights of child count data birth - 3 and their implications for your work
- Potential next steps to improve identification of deafblind infants and toddlers

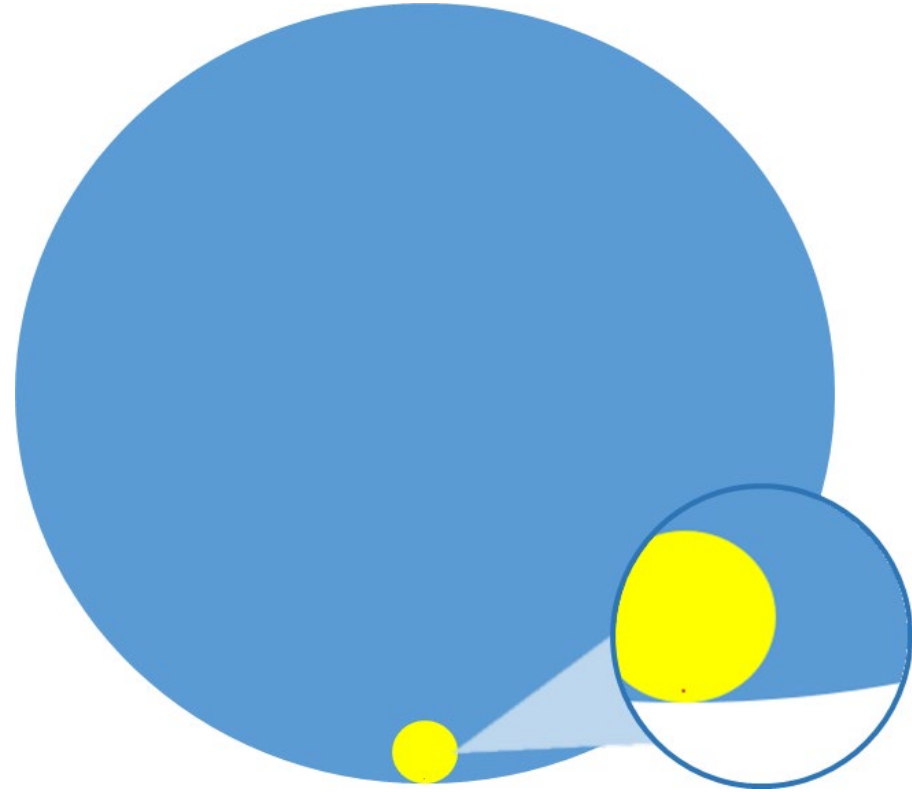
What is the Child Count?

- Began in 1986: [2022 National Child Count of Children and Youth who are Deafblind](#)
- Provides extensive information on the population of children identified as deafblind in the U.S., ages birth through 21
- Data includes state and national information on:
 - Population demographics (age, race/ethnicity/gender), type and severity of vision and hearing loss, causes of deafblindness, presence of additional disabilities, educational setting, living setting

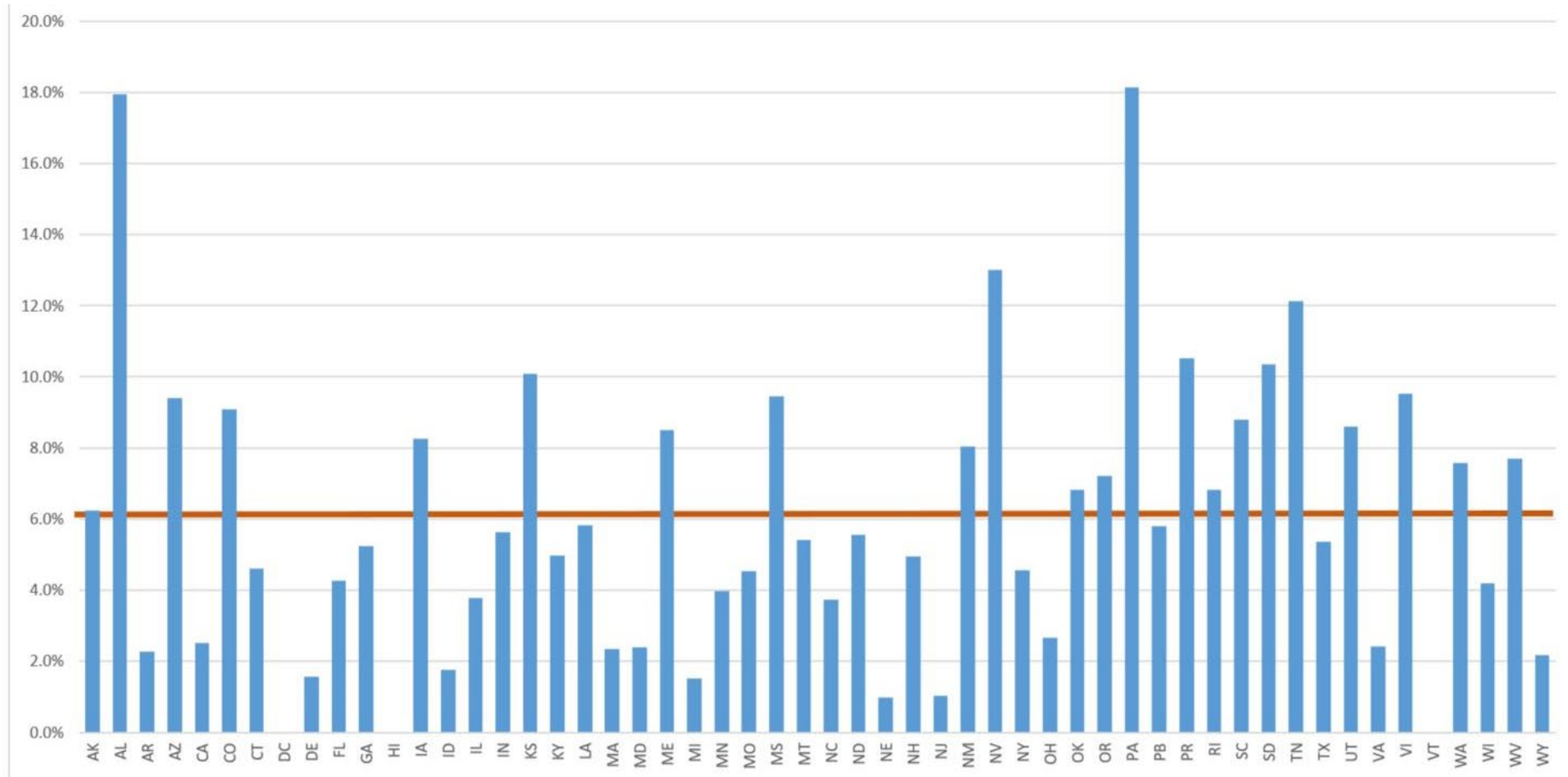
Low Incidence Population

Children Birth - 21

- Blue circle: All children in the U.S. (~90 mil*)
- Yellow circle: Children in special education (~7.3 million**) 8% of U.S.
- Red circle: Children with deaf-blindness (10,585^)
.14% of special education

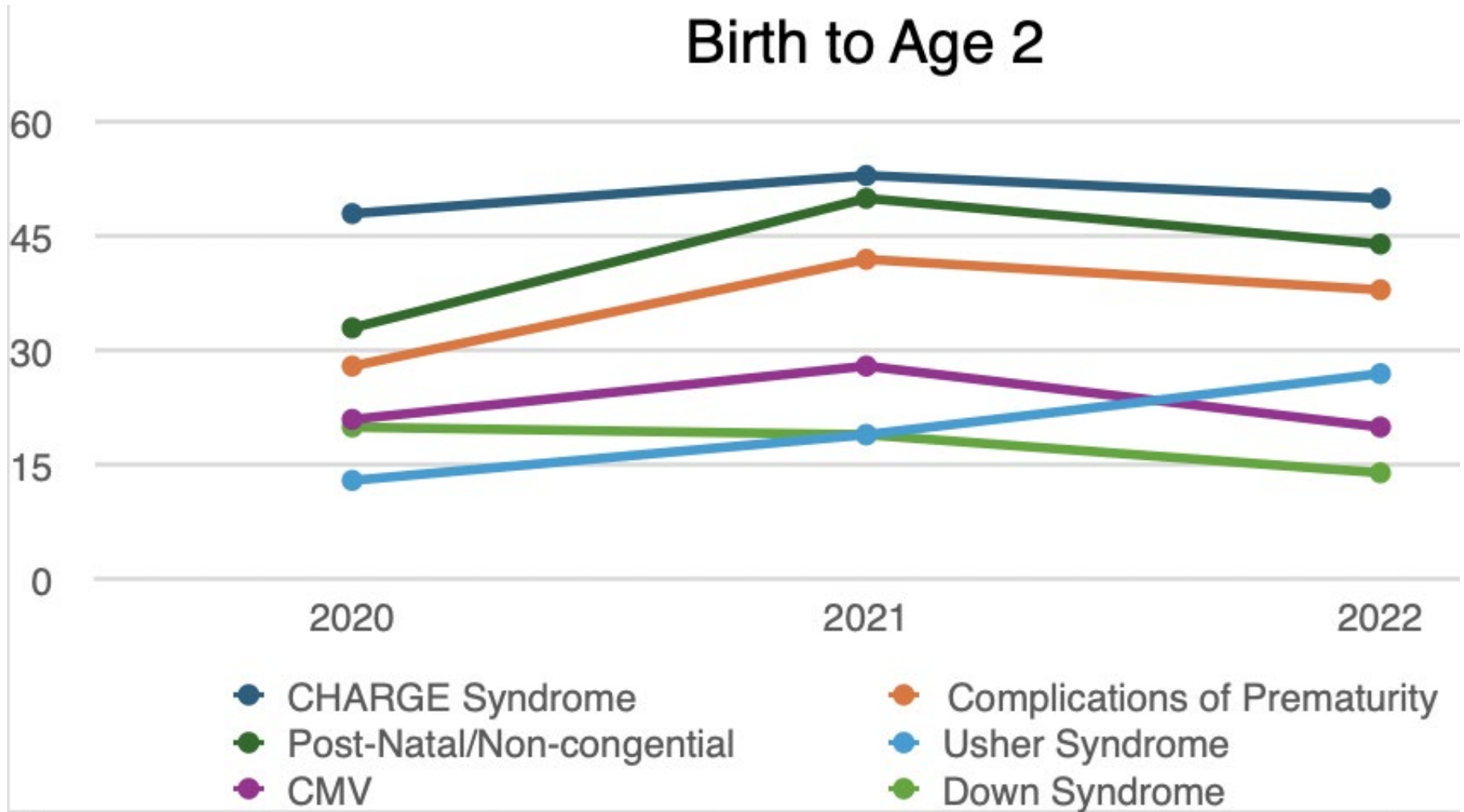


National DB Count: Percent Birth to 2

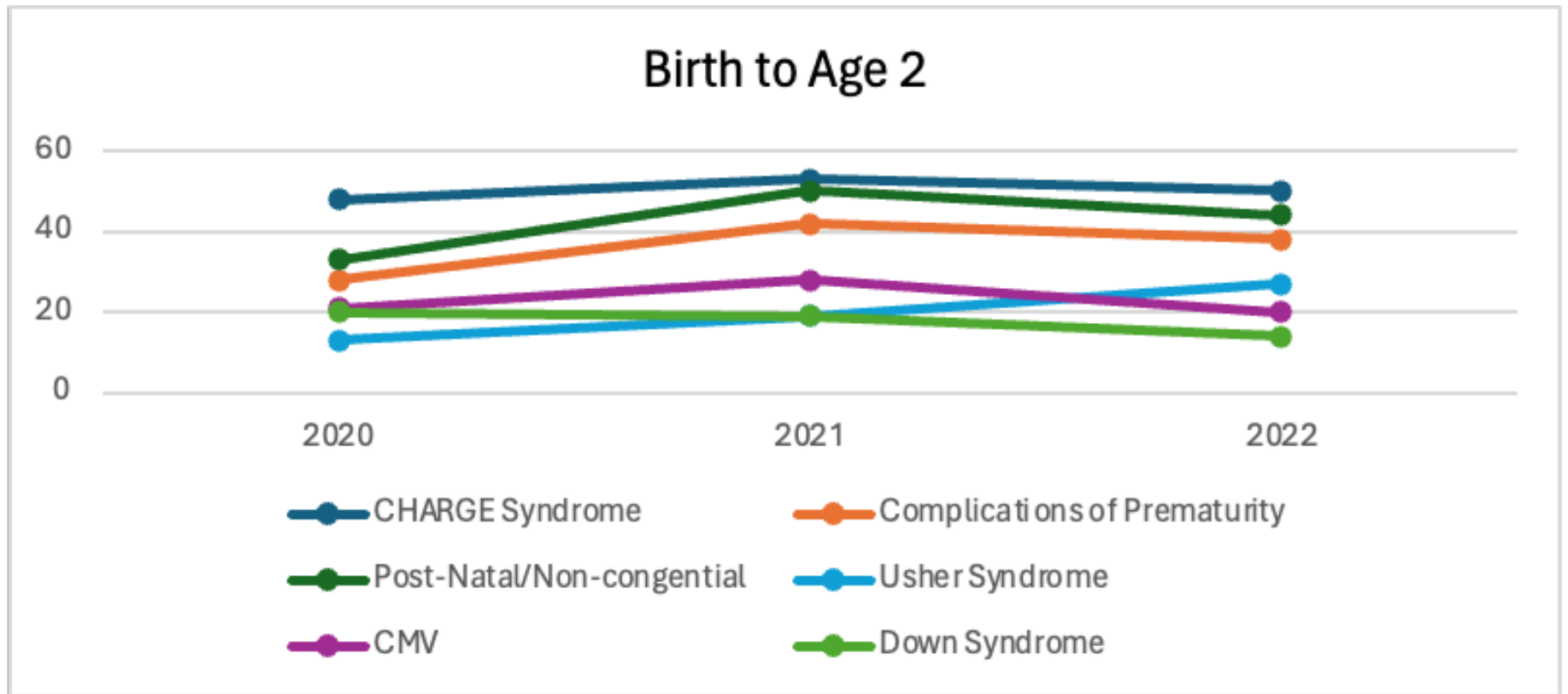


State	Birth to Age 2 percentages per state
California	3.4%
Pennsylvania	14.4%
Tennessee	18.0%
Vermont	2.8%

Top Etiologies & Causes: Birth - 2



Early Identification Trends (1 of 2)



Early Identification Trends (2 of 2)

	2020	2021	2022
CHARGE syndrome	48	53	50
Complications of Prematurity	28	42	38
Post-Natal or Non-Congenital	33	50	44
Usher syndrome	13	19	27
CMV	21	28	20
Down syndrome	20	19	14

Potential Issues Around Identification

- Misunderstanding around the term “deafblind”
 - Identification of vision loss, Deaf/hard of hearing
 - Identification of child as deafblind
- Delays between diagnosis, referral, and services
- Assumptions on family readiness
- The pandemic- numbers are beginning to finally stabilize

It Takes a Village!

- Partnering is critical because of limited time and funding
- We share these families so knowledge around suspected combined vision and hearing loss is critical for identification and referral
- Early ID leads to better services and supports for families
- We're better together!

Helpful Next Steps

- Check out your state's data from the [National Deafblind Child Count](#)
- Make connections with your [state deafblind project](#)
- Check out the following NCHAM trainings:
 - [Webinar](#)
 - [Coffee Chat: Data](#)
 - [Coffee Chat: Minnesota](#)
- Reach out to share feedback about additional resources, training and supports that might be helpful to you efricke@helenkeller.org



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