

Improving health care access and equity for children
and youth with special health care needs

Alliance Summit 2022

Christy Blakely
Megan Bowser
Kiera Zink



OUR MISSION:

Making COLORADO a better place
for children with special health
care needs

OUR WORK:

**provides public
awareness of
challenges and
barriers**

**helps families navigate
healthcare systems and
understand their rights
and resources**

**works to improve
health equity,
access and quality
of care**



INTERVENER PILOT PROGRAM

There is a new program for children experiencing deafblindness!

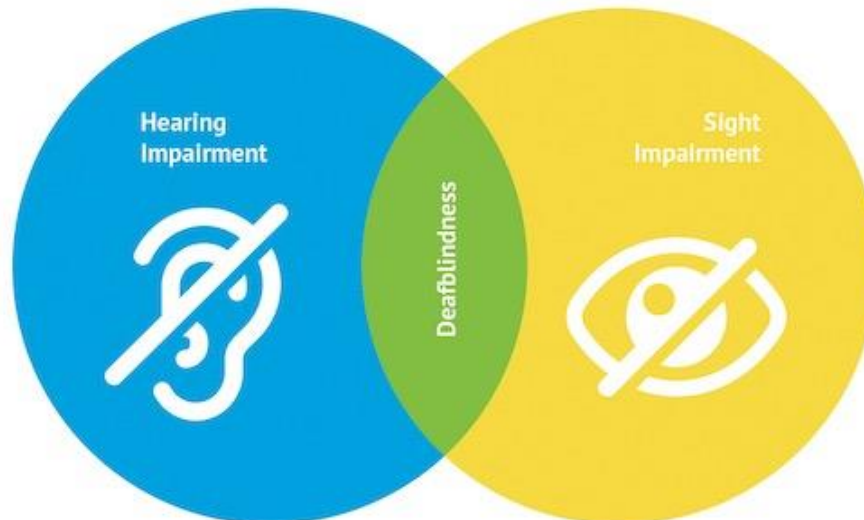
The Intervener Community Pilot Program, hosted by Family Voices CO, will provide intervener services for 10 hours a month, improving Colorado children with deafblindness' access to their environments and ability to communicate within their homes and communities.

Children you work with may be eligible for this year-long pilot!

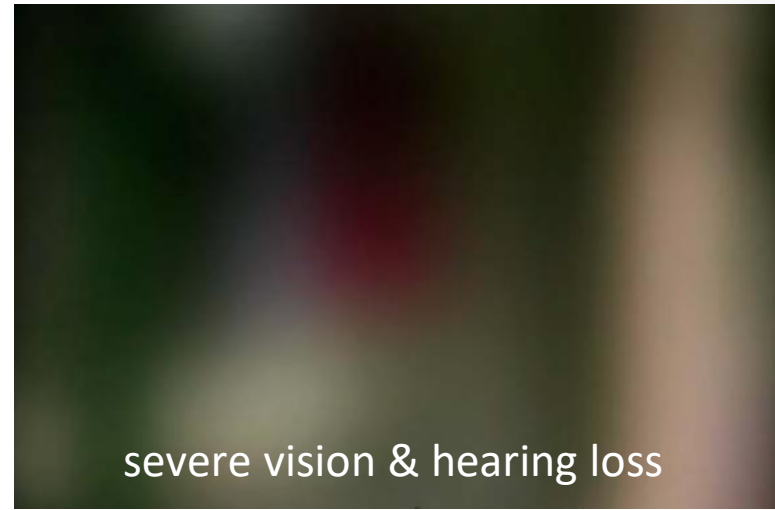
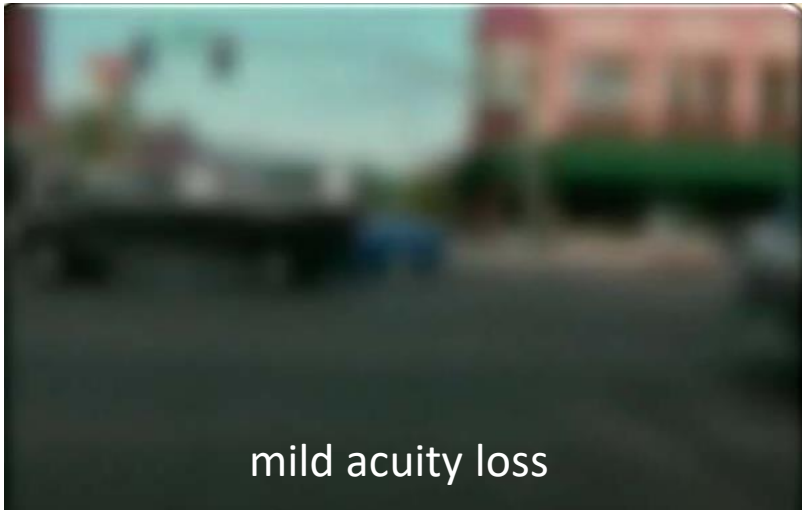
Impact of Deafblindness on Development

Children with deafblindness have incomplete, distorted, or unreliable access to visual and/or auditory information.

Clear and consistent flow of visual and auditory information is necessary for learning, interaction, and overall development



Impact of Deaf/Blindness on Development



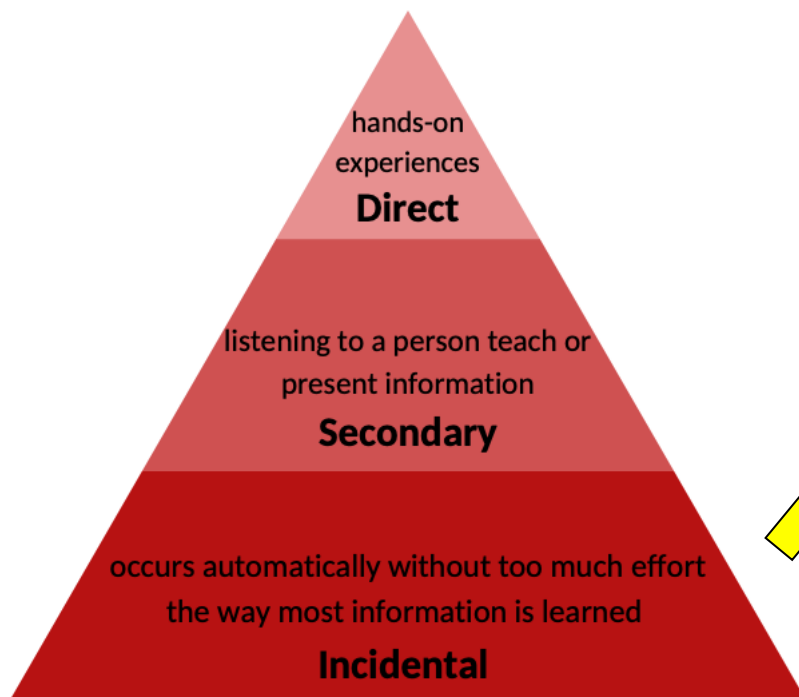
The term DeafBlind does not necessarily refer to total deafness and total blindness. Indeed, degrees of vision and hearing loss vary greatly. In addition, many children who are DeafBlind have other disabling conditions such as physical disabilities, health problems, and cognitive challenges.

Overall, as a group, children who are DeafBlind are diverse, and each child has unique needs. Yet, they all share similar **learning, communication, and social and emotional** challenges.

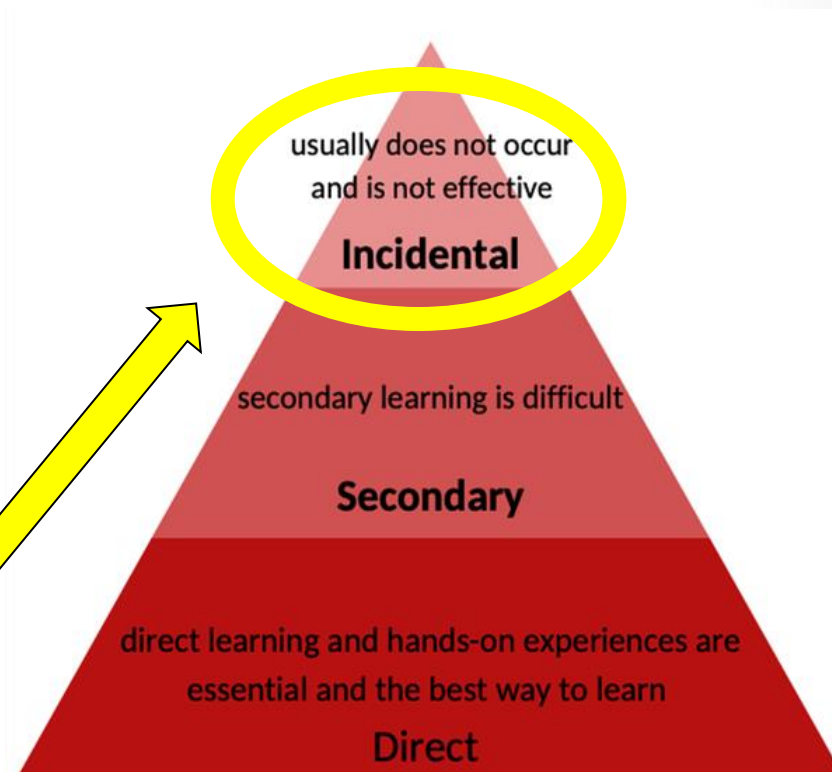


LEARNING

TYPICAL



DEAFBLIND



COMMUNICATION

Children who are DeafBlind miss opportunities to **observe** the communication of others and **participate** in communication themselves



SOCIAL & EMOTIONAL DEVELOPMENT



- Emotional bonding and trusting relationships may be difficult
- Self-identity and self-determination are difficult to achieve
- Educational environments may not be emotionally manageable

Interveners can help children who are DeafBlind overcome these challenges by providing access to clear and consistent **visual and auditory information**, support for the development and use of receptive and expressive **communication**, and support for **social and emotional well-being**.

WHAT IS AN INTERVENER?

- Works consistently one-to-one with an individual who is deafblind
- Has training and specialized skills in deafblindness



WHAT IS AN INTERVENER?



- Works closely with all team members (i.e. OT, PT, TB/VI, TD/HH, O&M, SLP etc.) to implement the child's goals on a day to day basis
- Facilitates the student's connection to others by creating a safe and supportive environment that encourages successful communication and interaction

ROLE OF AN INTERVENER

- Facilitate **access to the environmental information** that is usually gained through vision and hearing, but which is unavailable or incomplete to the child who is DeafBlind.
- Facilitate the **development and/or use of receptive and expressive communication** skills.
- Develop and maintain a trusting, interactive relationship that can promote **social and emotional well-being** for the child who is deafblind.

PROCESS OF INTERVENTION

In each of these areas, access to information, communication, and social and emotional well-being, the intervener facilitates the process of intervention in all educational programming, including academic work, self-care routines, specialized therapies, and social activities.



PROCESS OF INTERVENTION

Interveners are trained to promote independence for the child who is DeafBlind rather than dependence.

Interveners are not a barrier between the child and the world, but a bridge to the world – a vital link to people and things in the environment.

Learn more at intervener.org



<https://www.youtube.com/watch?v=Tm4DfGS5bew>

Filling A Gap

1. Parent Advocacy
2. Identified a Gap
3. Committed to filling the gap
4. Interviewed Minnesota
5. Collaborated within the state
6. Found Funding
7. Lots and lots of paperwork
8. Started providing services
9. Year 2!



Two Committees

1. Oversight and Planning Committee-
 2. Education & Recruitment Committee-
- *Each committee met monthly



Challenges

1. Creating the many documents for both families and interveners
2. The time to onboard for both families and Interveners took much longer than expected
3. Families wanted most of the hours in summer for camps, rather than through the year
4. Creating awareness of this newer role in CO & Attracting new Interveners to train

GOAL

1. Place this program in the State of Colorado following legislation to fund this needed program
2. Provide children with deafblindness access to their community, as we do children with physical or developmental disabilities
3. Provide a Navigator specifically for this population

We NEED Interveners!

Help us Identify people who may wish to become Interveners.



1. Paraprofessionals
2. Behavioral Technicians
3. Respite workers
4. Interpreters
5. SSPs
6. Other caring adults!

We NEED Children!

Help us Identify children who may benefit from this program.

- Birth-age 21
- Combined Vision and Hearing loss that impacts their ability to access their environment



Success Stories



Success Stories





QUESTIONS?

Contact Information

Family Voices CO

Megan@familyvoicesco.org

Elli@familyvoicesco.org



THANK YOU FOR YOUR TIME!

www.familyvoicesco.org