

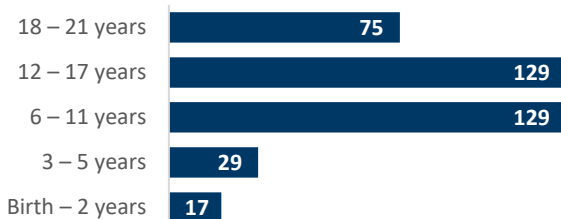
SUPPORTING DEAFBLIND CHILDREN AND YOUTH IN MINNESOTA

OVERVIEW OF THE DATA-INFORMED STRATEGIC PLAN

In 2021, the Minnesota Commission of the Deaf, DeafBlind & Hard of Hearing (MNCDHH) partnered with Wilder Research to create a data-informed strategic plan, with the goal of better supporting DeafBlind children and youth in Minnesota.

There are between 360-379 DeafBlind children and youth in Minnesota. ^{1,2}

Number of children and youth in Minnesota who are DeafBlind



Note: This chart is based on the National Center for Deaf-Blindness' 2019 National Deaf-Blind Child Count.

To create the data-informed strategic plan, we conducted 45 in-depth interviews with DeafBlind young adults, parents of DeafBlind children and youth, and professionals who serve DeafBlind children and youth. We then asked the project's advisory group about how to better support DeafBlind children and youth in Minnesota based on the interview findings.

KEY FINDING: Minnesota lacks a cohesive system for supporting DeafBlind children and youth.

Parents feel over-extended, want more support, and often coordinate their child's services among multiple service providers.

"It's never ending. You are constantly advocating. There's nothing that we do that's by accident. Everything is planned, everything is purposeful. It's just plain exhausting and there's only so many hours in a day." – *Parent*

Professionals recommend a number of system improvements:

1. Improved coordination and communication among service providers
2. More and better training for professionals who serve DeafBlind children and youth
3. More professional support and guidance for loved ones of DeafBlind children and youth

"From a systems standpoint, it's such a struggle." – *Medical professional*

"I feel like that would make a huge difference—a case manager to help families navigate and be with them for the long run, somebody that families could establish a trusting relationship with; somebody who could recognize where the parents are, in terms of what they are ready for, what their needs are, and how to address things." – *School-based professional*

¹ National Center on Deaf-Blindness. 2019. *2019 National Deaf-Blind Child Count*. National Center on Deaf-Blindness.

² Minnesota Department of Health Early Hearing Detection and Intervention program. 2021. *Deafblindness risk among children reported to the Minnesota Department of Health (MDH) Early Hearing Detection and Intervention program as deaf or hard of hearing*. Minnesota Department of Health.

QUESTION: How can DeafBlind children and youth in Minnesota be better supported?

ANSWER: Convene, organize, and expand the existing network of DeafBlind service providers—throughout schools, nonprofits, medical centers, and government programs.

Goals for supporting DeafBlind children and youth in Minnesota	Possible options for the network of DeafBlind service providers to pursue these goals
Promote coordinated services and the sharing of information among service providers	<ul style="list-style-type: none"> • Convene, organize, and expand the network of DeafBlind service providers who work in schools, nonprofits, medical centers, and government programs • Create a statewide early vision detection and intervention program • Streamline processes for sharing critical data and information about DeafBlind children and youth among providers (e.g., address barriers related to HIPAA)
Help DeafBlind children and their families coordinate their services	<ul style="list-style-type: none"> • Catalogue, maintain, and share an up-to-date list of available services and how to access them, so that all DeafBlind service providers can provide useful, timely information about requested services • Establish key relationships in various fields and sectors (e.g., education, government, medical) so that any provider can give a direct referral to DeafBlind individuals to receive applicable services and information
Provide education about deafblindness to parents and providers	<ul style="list-style-type: none"> • Continue bringing parents together to learn about deafblindness and available resources, as well as to share stories and connect with each other • Offer education certificates or credentials to providers who serve DeafBlind children and youth who complete deafblindness education programs or courses
Offer social connection and emotional support to DeafBlind children and youth and their families	<ul style="list-style-type: none"> • Create a DeafBlind mentor program for DeafBlind children and youth • Create a DeafBlind family mentor program for the loved ones of DeafBlind individuals • Continue providing opportunities for DeafBlind individuals and their loved ones to connect and socialize, with an emphasis on children and youth
Prepare DeafBlind youth for the transition to community-based services at age 21	<ul style="list-style-type: none"> • Start planning with DeafBlind youth prior to grade 9 for the transition from school-based services to community-based services • Create a transition mentor program for DeafBlind young adults • Increase the age limit for receiving school-based services (e.g., from age 21 to 25) • Grow the intervener profession so that there are more community interveners available to assist with this transition
Contribute to legislative and policy-focused activities that could improve the lives of DeafBlind children	<ul style="list-style-type: none"> • Create a DeafBlind waiver program • Create and professionalize a Teachers of the DeafBlind Teaching specialization • Add intervener language to the Minnesota Rule for the DeafBlind

For more information

This summary presents highlights of the report *Supporting DeafBlind Children and Youth in Minnesota: A Strategic Plan to Move Forward*

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