

Supporting DeafBlind Children and Youth in Minnesota: A Strategic Plan to Move Forward

Prepared for the Minnesota Commission of the Deaf, DeafBlind & Hard of Hearing (MNCDHH)

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Executive summary

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 children and youth with combined hearing and vision loss in Minnesota.

Throughout this report, individuals with combined hearing and vision loss are referred to as DeafBlind. The term “DeafBlind” is often misunderstood as referring to individuals who are completely deaf and blind. However, only a small proportion of DeafBlind individuals are completely deaf and blind; many have partial hearing or vision.

Throughout the project, we worked with an advisory group of 22 DeafBlind adults, parents of DeafBlind children and youth, and professionals who serve DeafBlind children and youth and their families. Please see the Appendix for our advisory group members.

We conducted 45 in-depth interviews with DeafBlind young adults, parents of DeafBlind children and youth, and professionals who serve DeafBlind children and youth. The findings from these interviews cannot be generalized in a statistical sense to the total population of DeafBlind children and youth in Minnesota. Rather, these interviews should be viewed as a starting point for understanding the nuances of what’s working well and what needs to be improved regarding how to best support children and youth with combined hearing and vision loss.

We learned through our interviews that Minnesota lacks a cohesive system for supporting children and youth with combined hearing and vision loss. DeafBlind youth and their families often coordinate their own services between numerous service providers, including medical, education, government, and nonprofit providers. In interviews, parents said that they feel over-extended and expressed a desire for more support in navigating these disparate service systems.

“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

What are your biggest hopes and dreams for yourself?

“It’s pretty basic—to be happy.”
—DeafBlind young adult

“I am hoping to live a productive life. Regardless of the adversity I live through, I want to live independently. I consider myself no different than other people in society.”
—DeafBlind young adult

“Use all the skill sets I have to break down barriers and exceed expectations people have of me, and to give back to other DeafBlind individuals and the community. Participating in this study is one of the things that I can do to give back to the DeafBlind community.”
—DeafBlind young adult

Professionals likewise noted systemic challenges for DeafBlind children and youth and their families. They recommended a number of system improvements based on these challenges, such as better communication and coordination between service providers, more and better training for professionals who serve DeafBlind children and youth, and more professional support for parents and young people as they navigate service systems. As one medical professional said, “From a systems standpoint, it’s such a struggle.”

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

Answer: Convene, organize, and expand the existing network of DeafBlind service providers—throughout schools, nonprofits, medical centers, and government programs—so that any of these entry points can serve as a “one-stop shop” of DeafBlind services, resources, support, and information.

Upon seeing the interview findings, one advisory group member commented, “This mimics everything I experienced as a young person growing up DeafBlind.” We asked the advisory group one overall question: Based on the interview findings, how can DeafBlind children and youth be better supported in Minnesota?

There was one overwhelming suggestion from advisory group members and interviewees—create a “one-stop shop” that centralizes DeafBlind services, resources, support, and information. That being said, our advisory group advised against creating a new system or approach, saying that this would only makes things more complicated for DeafBlind individuals. Instead, advisory group members suggested convening, organizing, and expanding the existing network of DeafBlind service providers—throughout schools, nonprofits, medical centers, and government programs—so that any of these entry points serves as a one-stop shop of DeafBlind services, resources, support, and information.¹

“There is a gap in terms of having some sort of centralized number or website or go-to place. There is no go-to starting point for families specifically for deafblindness.”
—Medical professional

¹ Deafblindness is defined under the Individuals with Disabilities Education Act (IDEA) as “concomitant (simultaneous) hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.”

Suggestions for better supporting DeafBlind children and youth in Minnesota

The overwhelming suggestion from advisory group members and interviewees was to create a one-stop shop that centralizes DeafBlind services, resources, support, and information. Advisory group members offered this recommendation after reviewing the key findings from the interviews, which are presented later in this report. Similarly, many interviewees suggested creating a one-stop shop during interviews.

While the idea of a “one-stop shop” was poignant for many interviewees and advisory group members, after further conversation, our advisory group advised against building an entirely new approach or otherwise adding anything more to the system of DeafBlind services. As one advisory group member said, “We need to simplify, not make things more complex for families.” Ultimately, our advisory group suggested leveraging the already-existing network of DeafBlind service providers—throughout schools, nonprofits, medical centers, and government programs—to help coordinate and streamline the largely disconnected systems of providers that serve children and youth with combined hearing and vision loss.

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Many advisory group members suggested designating the Minnesota DeafBlind Project as the lead organizer and convener of this network of DeafBlind service providers. With the Minnesota DeafBlind Project as the hub, this network could branch into the various areas that serve DeafBlind children and youth and their families—schools, nonprofits, medical centers, and government programs—so that a provider working in any of these areas could serve as an entry point for DeafBlind children and youth to get the support that they want.

A few advisory group members suggested starting with a smaller pilot of networked DeafBlind service providers, perhaps just the providers who work with students of a particular school district. As envisioned by our advisory group, this network could extend beyond just school-based providers in the chosen school district, including service providers based in nonprofits, medical centers, and government programs who serve DeafBlind students in the district. Advisory group members expect that useful insights could come from

a pilot approach like this, which could then guide the “scaling up” of a statewide network of DeafBlind service providers.

Advisory group members and interviewees offered some specific functions that this network of DeafBlind service providers might fulfill. These functions include:

- Promote coordinated services and the sharing of information among service providers
- Help children who have combined hearing and vision loss and their families coordinate services
- Provide education about deafblindness to parents and providers
- Offer social connection and emotional support to DeafBlind children and youth and their families
- Prepare DeafBlind youth for the transition to community-based services at age 21

In addition, some advisory group members and interviewees suggested some legislative and policy-focused activities to which MNCDHH or this network of DeafBlind service providers might contribute. These include: 1) establishing a DeafBlind waiver program similar to [Texas’s waiver program](#); 2) creating and professionalizing a new teaching specialization in Minnesota—Teachers of the DeafBlind, similar to [Texas’s DeafBlind teaching specialization](#); 3) adding intervener language to Minnesota state law as part of [the Minnesota Rule of the DeafBlind](#); and 4) preparing to make policy and practice changes in accordance with [the Cogswell-Macy Act](#), assuming it is adopted as federal law.

Promote coordinated services and the sharing of information among service providers

Many parents and professionals talked about the lack of coordination among providers who serve children and youth with combined hearing and vision loss. As a result, parents feel over-extended (because they have to act as their child’s service coordinator) and they want more support navigating disparate service systems to meet their child’s needs. Likewise, the most common recommendation from interviews with professionals was better communication and coordination among service providers. See pages 15-19 and 26-27 for more information about this finding from the interviews.

“We need full circle communication so I won’t have to spend two, three, four, five hours on the phone repeating myself to people. I won’t have to say, ‘Well, I talked to Suzie and she told John who then told Bill’—and then have none of those people actually know what’s going on.”
—Parent

Many parents and professionals talked about difficulties with identifying deafblindness, with some professionals attributing these difficulties to the lack of coordination among service providers. Early identification and intervention is critical to ensure that DeafBlind

children have the best possible quality of life (Purvis et al., 2014). In our interviews, professionals mentioned the state’s Early Hearing Detection and Intervention (EHDI) program as a positive aspect of the current system. EHDI identifies hearing loss among newborns and infants, which can lead to the identification of children who are also at risk of vision loss and thus deafblindness. However, they also noted that there is no parallel system for the early identification of vision loss, nor is there a process to systematically refer, test, and identify children who may have or be at risk for vision loss based on genetic conditions that may be identified when the child’s hearing difference is first diagnosed.

There is reason to believe that infants and toddlers who have combined hearing and vision loss are severely undercounted in the U.S.; for example, there are twice as many children age 3-6 who are identified as being DeafBlind as there are in the 0-2 age range (Purvis et al., 2014; Wiley et al., 2016). While it’s possible for deafblindness to develop after the infant and toddler years, it commonly develops because of hereditary syndromes and disorders or from complications of prematurity, all of which can be identified very early in life (National Center on Deaf-Blindness, n.d.). Increased coordination among service providers—and specifically an early vision loss identification program that works in coordination with EHDI—could drastically improve the lives of DeafBlind children and youth in Minnesota by identifying deafblindness as early as possible.

Professionals and parents also talked about the challenge of sharing information among service providers. In particular, medical professionals noted that, while necessary, the Health Insurance Portability and Accountability Act (HIPAA) poses cumbersome barriers to sharing information with non-medical providers. In response to this challenge, this network of DeafBlind service providers could help guide professionals through the process of getting data sharing agreements in place or otherwise helping to streamline this process for children and youth with combined hearing and vision loss. Additionally, education professionals noted that they sometimes don’t get the information they need from medical professionals. This DeafBlind provider network could also build the capacity of professionals in this regard, such as educating all service providers about the information needed to best serve DeafBlind children and youth.

“From a HIPAA standpoint, being able to communicate with non-medical providers and getting forms signed is hard. For example, it’s hard to get information to an educational audiologist. There are just lots of hoops to jump through.”

—Medical professional

“Medical professionals are not familiar with the data that we need. I have gone as far as reaching out to an audiologist—obviously having a release of information in place—before a test was conducted. I would say, ‘I know you don’t typically test kids this way, but I need a particular type of test on record at school so that we can refer to it throughout the student’s educational experience. This is how the state criteria is asking us to gather information.’”

—School-based professional

Help children with combined hearing and vision loss and their families coordinate services

Many parents and professionals shared that parents often act as their child’s services coordinator—largely because service providers rarely coordinate with each other and because there is no organization or existing system that helps coordinate DeafBlind services. A coordinated network of DeafBlind service providers could help support parents in this respect—especially if they had up-to-date information about all available services, how to access them, and a direct connection to the professionals who provide them. This could be a first step for this network to undertake—compiling and cataloguing this information and then maintaining it over time so that any provider could make a direct connection to a provider when needed or requested. See pages 15-17 for more information about this finding from the interviews.

“There isn’t good coordination. The things that need to happen do happen, but it falls back on the support person—their parent, for instance—to make sure that it happens.”
—Parent

While many parents talked about a lack of communication and coordination among providers, our interviews provided a few positive examples of providers coordinating with each other. Some parents had to outright demand coordination from their providers; in other cases, parents described it as a “new approach” from a particular hospital or medical center. Parents also mentioned that various nonprofits helped them access different services. This network of DeafBlind service providers could document and catalogue these new or promising practices for coordinating services among providers, and then explore ways of introducing or implementing similar practices among the variety of providers that serve children and youth with combined hearing and vision loss.

“I finally just kind of blew up and started yelling at everybody since there were so many people I had to talk to—and they said, ‘Well, would you like a care conference?’ We had probably 11 different specialties coming in To get them all in a room to talk about her case and her care and make a plan going forward was life changing.”
—Parent

Provide education about deafblindness to parents and providers

A recurring observation from DeafBlind youth, parents, and professionals was the lack of knowledge among service providers about the impact of deafblindness. Interviewees shared many negative experiences wherein a teacher or doctor, for instance, knew very little about deafblindness and, as a result, worked inappropriately with them or gave them unhelpful guidance or advice. Other times, parents themselves didn’t recognize signals of hearing or vision loss, or just didn’t have the necessary information to communicate effectively with providers about their child’s needs. Parents often contrasted these negative

experiences with when a provider knew a lot about deafblindness. In these experiences, parents and young adults talked about feeling reassured as well as receiving helpful advice. See pages 19-20 and 29-30 for more information about this finding from the interviews.

“I’ve heard from different families that perhaps the speech and language pathologist in the school is not trained to work with somebody who’s DeafBlind. They are using a device that they were schooled on—that they know—and this is what they were taught to use with all children, but it’s not as appropriate for a DeafBlind child.”

–Nonprofit professional

“We immediately did our own online research and found two organizations that really helped us—they know a lot more about Usher [Syndrome]. We saw them and they gave us a totally different outlook. Their advice was to not bring [our daughter] to see ‘normal’ hearing and vision loss providers. She has to see super specialists.”

–Parent

To help improve the experiences of DeafBlind children and their families as they work with providers, a coordinated network of DeafBlind service providers could oversee the design and/or delivery of education programs about deafblindness to providers and parents. In particular, this network of DeafBlind providers could create and oversee DeafBlind-specific certificates or credentials for providers that serve children and youth with combined hearing and vision loss.

For example, the National Center on Deaf-Blindness maintains a library of courses about deafblindness, how to work with individuals with combined hearing and vision loss, and other topics related to hearing and vision loss. In addition, some advisory group members noted that the Minnesota DeafBlind Project and some school districts have designed and delivered various educational offerings about deafblindness. These are a few existing resources that this network could leverage to help educate the parents and providers of DeafBlind children and youth.

In addition to providing or coordinating education about deafblindness generally, it is important for parents and providers to learn about common co-occurring conditions as well, such as Usher or CHARGE syndrome. Information about other kinds of disabilities and mental health issues that may accompany deafblindness is also needed. Many parents noted the lack of knowledge about co-occurring conditions as a challenge when getting their child the services or attention they needed. That being said, there are numerous complexities involved in identifying co-occurring disabilities or conditions along with deafblindness. For example, DeafBlind children and youth have been observed to exhibit “autistic-like behaviors,” but these behaviors may stem from the lack of visual or auditory stimuli rather than neurodevelopmental difference (Belote & Maier, 2014).

“They were trying with organizational skills for him because of his ADHD. He was really resistant to that because it took extra time. ... The teachers would send me pictures of his messy locker and his messy desk. ... It seemed to be just a really terrible source of contention between him and his teachers.”

–Parent

“A lot of people we saw would say, ‘He’s not autistic, just blind.’ We had to really fight that battle for a long time. ... Eventually he was tested for it—and yeah, he’s got them both. A lot of people did not know how to work with him. If they specialized in autism, they just dealt with the autism. They did not deal with an autistic child that was blind and Deaf.”
—Parent

Offer social connection and emotional support for DeafBlind children and youth and their families

Many DeafBlind young adults, parents, and professionals talked about the lack of social connection and emotional support. Because most of the world communicates differently than DeafBlind children and youth, and because deafblindness significantly constricts the child’s ability to access language and environmental information, they may face a variety of mental health challenges including depression, anxiety, and withdrawal (Bodsworth et al., 2011; Gosney et al., 2009). What’s more, many individuals with combined hearing and vision loss experience social isolation, which is a risk factor for mental health problems (McDonnall, 2009; Mind, 2004). See pages 29-30 and 32-33 for more information about this finding from the interviews.

“I haven’t felt like there’s a DeafBlind community because there’s the sighted community, there’s the unaided community, there’s the speaking community. There’s so many variants of this that it’s hard to find where you fit.”
—Parent

Parents and young adults reported feeling less isolated when they interacted with people with shared experiences. In particular, advisory group members and interviewees noted the significance of both peer relationships and mentorships for DeafBlind individuals and their families. This DeafBlind provider network could consider how to help DeafBlind youth and their families connect with other DeafBlind individuals, as well as how to support them emotionally and psychologically. This may include cataloguing and promoting already-existing opportunities for social connection and emotional support, as well as ensuring that there are opportunities for social connection and emotional support for DeafBlind individuals of all ages, languages, geographies, cultural groups, and communication preferences throughout the state.

“At the Academy [referring to the Minnesota Academy for the Blind and Minnesota Academy for the Deaf], my son doesn’t feel like he’s the only one with a problem. He can see that other children have similar challenges—maybe not the same diagnosis necessarily—but he doesn’t feel as singled out, like, ‘Why is this happening to me and nobody else?’ Nobody else in our close circle has something like it, so it helps him to not feel alone.”
—Parent

“One of the most helpful things for me was when the Minnesota DeafBlind Project did a mom’s retreat. ... Those types of retreats are really helpful. It was nice to have a break because it’s a pretty intense thing—to raise a kiddo that’s DeafBlind.”
—Parent

Lastly, our interviewees noted the importance of having emotional support at critical moments in the lives of DeafBlind children and youth and their families, such as when children are identified as having combined hearing and vision loss. In addition to the responsibilities of caring for a child with a disability, parents and other caregivers might face uncertainties about their child’s health, education, future, and financial situation (Barnett et al., 2003). Other critical moments might include starting school, adolescence, and finishing K-12 education and transitioning to community-based services.

“I would like parents to be connected with adults who are Deaf or DeafBlind first and then they can meet other professionals. They need to meet all of those kinds of professional people—who are important for sure—but based on my experience, [when their child is identified] many parents are just in shock and they don’t know what their child’s life will look like. They wonder if their child can drive or go to prom.”
—Medical professional

Prepare DeafBlind youth for the transition to community-based services at age 21

Overall, parents and young adults expressed negative experiences with transition planning and accessing community-based services after their Individualized Education Program (IEP) and access to services through the K-12 public school system ends at age 21. They also mentioned negative experiences with transition-related services, such as working with a transition specialist to find a job or coordinating with the numerous people and organizations involved in their transition plan. See pages 31-32 for more information about this finding from the interviews.

“There ends up being a cliff once you leave special education at 21 years old. For instance, no one coordinates transportation. They train you on how to get an Uber, but what if you can’t afford that? Or what if you can’t walk to the bus because it’s a bad vision day?”
—Parent

“I was basically job searching myself. [My transition specialist] had low expectations for me and did not try to address the barriers that were preventing me from getting the job. It was just hard to work with them.”
—Young adult

During grade 9, Individualized Education Program (IEP) teams in Minnesota are required to address DeafBlind students’ needs in regards to transitioning from secondary education to post-secondary education and community living. This age is in line with recommendations to help ensure positive outcomes for young adults with combined hearing and vision loss (The Ohio Center for Deafblind Education, 2017). DeafBlind students are increasingly graduating high school and earning a diploma, with 53% of students with combined hearing and vision loss in the United States graduating in 2014 (Zatta & McGinnity, 2016). Based on our interviews, after high school, DeafBlind young adults experience challenges finding gainful employment and making meaningful connections in their communities.

Our advisory group suggested that transition planning—and the skill-building that goes along with it—should begin prior to grade 9 so that DeafBlind young adults are well-equipped to create the life they want, and to obtain the needed resources and accommodations they need, after leaving high school. In particular, a few advisory group members noted that there are significant differences between accessing and using community-based services as compared to school-based services (particularly in regards to leveraging various funding sources to access different services). This network of DeafBlind service providers might consider creating or coordinating a DeafBlind transition mentor program so that DeafBlind young adults and their families can learn about transitioning from someone who has done it before.

Relatedly, some advisory group members noted that the Minnesota DeafBlind Association has strong connections to older DeafBlind adults in Minnesota, but that there is a gap in regards to an organization or program specifically for DeafBlind young adults (roughly age 21-26 or 27). Even though the Minnesota DeafBlind Association does not have age-based eligibility criteria (one of our advisory group members joined when they were a teenager), multiple advisory group members shared the perception that they serve primarily older adults with combined hearing and vision loss. Further, one advisory group member commented that joining the Minnesota DeafBlind Association is not feasible or realistic for many DeafBlind individuals, due to their emergent communication skills.

In addition, Michigan’s education system allows some students to continue receiving services via their Individualized Education Program (IEP) through age 25, depending on the individual students’ needs, preferences, and circumstances. Passing similar legislation in Minnesota could help address the “gap” between education-based services and community-based services, which was noted as a persistent need by interviewees.

Lastly, many interviewees and advisory group members noted that community interveners are of immense help to children and youth with combined hearing and vision loss. This DeafBlind provider network could also consider how to grow the intervener profession in Minnesota as a strategy for improving the transition to community-based services. As a note, in 2019, [a definition for “family and community intervener” was added to Minnesota state law](#), thereby providing some legal standing for community intervener services for DeafBlind children and youth.

“The community intervener is really a cool thing—it’s made her world substantially larger. For example, we’ll go to the park and she has siblings and stuff, but they’re all ‘normal,’ and so [my daughter] is kind of left out because she sees but not as well as her siblings and she can’t hear—so there’s naturally some barriers. The community intervener really helps a lot in crossing that boundary.”
—Parent

Contribute to legislative and policy-focused activities that could improve the lives of DeafBlind children

Some advisory group members and interviewees mentioned a number of legislative and policy-focused activities that could benefit the lives of children and youth with combined hearing and vision loss. These included creating a DeafBlind waiver program (similar to Texas’s DeafBlind waiver program), creating and professionalizing a Teachers of the DeafBlind teaching specialization (similar to Texas’s DeafBlind teaching specialization), and adding intervener language to the Minnesota Rule for the DeafBlind.

- **Create a DeafBlind waiver program.** This recommendation stems from respondents’ experiences of enrolling in one waiver program and then realizing later on that it was not the best fit for them or their child. In addition, such a program could spur increased knowledge about deafblindness among service providers as well as ease the burden of services coordination for DeafBlind children and youth and their families—because the program could serve as a catalogue of waived services specifically for DeafBlind children and youth and their families. Lastly, eligibility for existing waiver programs is largely determined by medical needs—rather than communication and access needs--which represent some of the major unmet needs among DeafBlind children and youth in school and community settings. It should be noted that Minnesota has the Deaf-Blind Consumer-Directed Services (DBCDS) grant program, but that many DeafBlind children and youth utilize waiver programs because of complex medical or behavioral needs that are outside the scope of DBCDS.
- **Create and professionalize a Teachers of the DeafBlind teaching specialization.** This recommendation stems from the prominent finding that many teachers and school-based professionals do not have specific training in working with students who have combined hearing and vision loss, including those with multiple disabilities. There are efforts by the Minnesota DeafBlind Project and various school districts to provide ongoing technical assistance to support professional development for teachers and school-based professionals in this respect. A Teachers of the DeafBlind teaching specialization could build on these ongoing efforts, but its feasibility would need to be carefully assessed.

“The problem is that our public school staff aren’t trained to care for kids with hearing issues and vision issues.”
—Parent

- **Add intervener language to [the Minnesota Rule for the DeafBlind](#).** This recommendation stems from the findings that 1) there is a shortage of school-based interveners in Minnesota and 2) parents experienced challenges with helping school-based professionals to understand the critical role that interveners play in their child’s education. Adding intervener language to the Minnesota Department of Education’s Rule of the DeafBlind could provide legal support for ensuring that DeafBlind students have access to an intervener in school settings, and that intervener services are represented in students’ Individualized Education Programs (IEP).

“The level of education and expertise that an intervener has is impressive. They came right in with the skills so that my kid didn’t have to wait for me to learn how to do that. They gave an immediate access to education and information for my child.”
–Parent

“The role of the intervener is foreign to most schools. I have found it hard to make that communication breakthrough regarding how vitally important that person is to my son’s day.”
–Parent

Lastly, a number of interviewees and advisory group members mentioned [the Cogswell Macy Act](#) as a potential opportunity for MNCDHH and the network of DeafBlind service providers to better support DeafBlind children and youth. If passed, the Cogswell-Macy Act “would strengthen the Individuals with Disabilities Education Act (IDEA) and improve [education] results for children and youth with deafblindness” (Cogswell-Macy Act, n.d.). In particular, this legislation could help ensure that students with combined hearing and vision loss can access school interveners and other school-based professionals with the appropriate knowledge and skills to effectively work with them.

About the interviews

We conducted 45 in-depth interviews with DeafBlind young adults, parents of DeafBlind children and youth, and professionals who serve DeafBlind children and youth. Of these, 23 interviews were with parents of DeafBlind children and youth (age birth-30), 5 with DeafBlind young adults (age 16-30), and 17 with professionals who serve DeafBlind children and youth. Each interview was 45-75 minutes in duration, totaling roughly 45 hours of interviews. We coordinated with MNCDHH to ensure that requested accommodations were available for each of these interviews. The advisory group helped to finalize the interview questions, identify and recruit interviewees, make meaning of the resulting data, and produce a strategic plan for how to better meet the needs of children and youth with combined hearing and vision loss in Minnesota.

Based on a census conducted by the National Center on Deaf-Blindness, there were 379 children and youth with combined hearing and vision loss residing in Minnesota in 2019. Our 28 interviews with young adults and parents represent nearly 10% of this total 2019 population (three parents spoke on behalf of two DeafBlind children, meaning that through the interviews we received information about the experiences of 31 DeafBlind children and young adults).

The findings from these interviews cannot be generalized in a statistical sense to the total population of DeafBlind children and youth in Minnesota. Rather, these interviews should be viewed as a starting point for understanding the nuances of what's working well and what needs to be improved regarding how to best support children and youth with combined hearing and vision loss. The key findings from these interviews were vetted by our advisory group and their feedback indicated the findings are a good reflection of the biggest needs and gaps in support for DeafBlind children and youth and their families. As one advisory group member commented upon reviewing the findings, "This mimics everything I experienced as a young person growing up DeafBlind."

Additionally, we would like to note that we interviewed fewer DeafBlind young adults and parents of DeafBlind children and youth than we initially planned. We heard from young adults and parents that they were particularly busy and stressed during 2020 and into 2021, primarily due to COVID-19, and that making time for a 45-minute interview was difficult. It is also important to note that the DeafBlind young adults that we interviewed are likely not representative of all DeafBlind children or young adults due to differences in communication skills that allowed our interviewees to complete an interpreted interview with us. Lastly, we would like to note that we only interviewed one respondent whose family speaks a language other than English at home (Spanish). As such, the findings presented here may not adequately represent the needs of DeafBlind children and youth whose families speak a language other than English at home.

In interviews with young adults and parents, we asked about their experiences with a wide variety of services and supports. Please see the Appendix for our interview questions. Parents spoke of their own experiences and on behalf of their children with combined hearing and vision loss; young adults spoke of their own experiences. Each parent and young adult received a \$30 gift card to Target or Amazon as a thank you for participating in an interview. Figure 1 depicts the ages of the child or young adult at the time of the interview.

1. Age of DeafBlind child or young adult at time of interview

Age	Age at time of interview ^a (N=28)
At birth	--
0-4 years old	5
5-12 years old	8
13-18 years old	11
19-21 years old	4
22 years old or older	3

Note. The total number of children or young adults is 31 because three parents spoke on behalf of two DeafBlind children.

^a These figures refer to the age of the young adult or parent's child at the time of the interview.

In interviews with professionals, we asked about their professional role, how they coordinate with other professionals, any gaps they see in the services and supports available to DeafBlind children and youth, and any difficulties in how these services and supports are accessed by DeafBlind children and youth and their families. Professionals who we interviewed did not receive a gift card for their participation. Figure 2 depicts the number of professionals we interviewed in three fields: the education field (8 professionals), the medical field (5 professionals), and the nonprofit field (4 professionals).

2. Field in which professionals worked

Field	Number of respondents (N=17)
Education	8
Medical	5
Nonprofit	4

Key finding: Minnesota lacks a cohesive system for supporting DeafBlind children and youth

A note about this report: We wrote the report so that each section builds on the previous sections. As a result, the findings and recommendations from the previous sections appear again in subsequent sections of this report, but with more details and context than in the previous sections.

Overall, young adults and parents often noted that they do not know about all of the services and supports that are available to them. When they do know about a service or support they want, it is often tiring and time-consuming to navigate Minnesota’s various service systems to access it. Interviewees highlighted many specific barriers to knowing about and getting the services they want or need. We address these barriers in detail later in this report. Some commonly mentioned barriers include:

- A lack of centralized and coordinated “sharing of information” about what services and supports are available
- A lack of communication and coordination among service providers, such as between medical professionals and school-based professionals
- A lack of guidance or support as young adults and parents navigate disparate service systems to meet their needs

When considered together, barriers such as these can be succinctly summarized as a lack of a cohesive system for meeting the needs of DeafBlind children and youth.

“Communicate what is available. I still don’t know what’s available these days.”
—Young adult

“We need full circle communication so I won’t have to spend two, three, four, five hours on the phone repeating myself to people. I won’t have to say, ‘Well, I talked to Suzie and she told John who then told Bill’—and then have none of those people actually know what’s going on. John didn’t talk to Bill, Bill didn’t talk to Suzie, and nobody documented anything—and if they did, John can’t look at Suzie’s notes and Bill can’t look at John’s notes, so nobody knows anything. Then it’s a month later before you get the answer that you need.”
—Parent

Professionals who serve DeafBlind children and youth and their families corroborated these insights from young adults and parents. For instance, professionals called for better communication and coordination among service providers, more and better training for professionals who serve children and youth with combined hearing and vision loss, and more professional support for parents and young people as they navigate service systems.

“I’m not even sure there is a system. We have the Minnesota DeafBlind Project; I’ve relied on them.”
—School-based professional

“Sometimes parents feel more comfortable with the medical community, and, therefore, if the doctor says it, that’s what’s true. Sometimes the parents are more comfortable in working with the education side of the child’s program, so then they need some support in navigating the medical side of it. You just wonder if there could be someone in between to help families navigate everything—someone who is familiar with the fact that parents are in different places with their needs.”
—School-based professional

Parents are over-extended, want more support, and often coordinate their child’s services with multiple service providers

Due to the lack of a cohesive system for supporting children and youth with combined hearing and vision loss in Minnesota, parents often find themselves acting as their child’s service coordinator. For example, they bring medical records to each of their specialist appointments, they coordinate and share information between their child’s school and medical providers, and they work with government-based agencies and service providers to get direct financial assistance or otherwise access needed services.

“It’s overwhelming to stay on top of everything in terms of the appointments and coordinating all of that. This person wants to see him working on this thing and this other person wants to see him working on this other thing. It’s a lot of time and it’s a lot of coordinating and it’s a lot of effort.”
—Parent

“There isn’t good coordination. The things that need to happen do happen, but it falls back on the support person—their parent, for instance—to make sure that it happens. If that support person isn’t doing it, services fails and then the DeafBlind individual suffers for it. I use visually formatted information as much as possible that captures what my child needs—I give that to multiple providers. That doesn’t bring people together, but it at least shares information readily. That is not fair—no other parents have to coordinate things like this.”
—Parent

Parents do these service coordination tasks in addition to typical parenting responsibilities, like promoting their child’s emotional and physical development, staying abreast of their child’s schoolwork and extracurricular activities, and meeting their child’s daily needs by providing food, shelter, safety, love, and attention. As a result, parents feel over-extended and want more support and guidance as they navigate disparate service systems to meet the needs of their children.

“When the therapists aren’t there, they give us stuff to continue working on. When the teachers aren’t there, they give us stuff to continue working on. You’re trying to stay on top of that, and all the while just wanting to love on him and have fun with him.”
—Parent

“The list never ends—let’s put it that way. One of the areas that I think is trying is there’s no respite ever. It’s really hard to find staff and it’s not like I can just drop her off at gymnastics and say, ‘See you in two hours.’ That just never happens. That’s kinda the harder part—finding support for the parents and caregivers, finding time to have a break.”
—Parent

Professionals identified a number of system and practice issues, with the most prominent being a lack of communication and coordination among professionals who serve DeafBlind children and youth

The professionals we interviewed identified a number of system and practice issues in regards to supporting children and youth with combined hearing and vision loss. These issues include: a lack of communication and coordination among service providers, a lack of DeafBlind-specific knowledge and skills among professionals who serve DeafBlind children and youth, and a lack of professional support and guidance for families and loved ones of DeafBlind children and youth as they access needed services. We address each of these system and practice improvements in detail in this section of the report.

In addition, the professionals we interviewed talked about the need to increase access to services for children and youth of all ages, for children and youth who do not identify with dominant Minnesotan culture (that is, White and English-speaking), and for children and youth who live in greater Minnesota. In regards to age-specific gaps in services, most of the professionals mentioned a gap in services for older youth or for youth who are transitioning out of school settings. However, some professionals also mentioned a gap for younger DeafBlind children, such as a lack of pediatric specialists or a gap in available services for elementary-age children. Regarding children and youth who are not White or whose families do not speak English at home, professionals mentioned that it is often more difficult for these children and youth and their parents to access needed services due to language barriers and differences in cultural perspectives on disability and communication. Lastly, professionals mentioned that it is difficult for children and youth to receive needed services if they live outside of the Twin Cities metro area or not in or near Faribault (where the State Academies for the Deaf and the Blind are located).

“When kids start to reach adolescence, parents are not sure how to address some of that adolescent behavior in girls and boys. It not only is a brand new concept for parents for whom their oldest child is moving into adolescence, but this is the oldest child and he has significant needs.”
—School-based professional

“I know students who are DeafBlind and also speak a language other than English as their primary language. For those students, I think it’s really hard because you have the additional barrier of language and additional cultural perspectives—maybe parents’ perspective of disability and expectations of what a student can do. Sometimes the student is comfortable with English, but the parents aren’t. Then you need two layers of interpretation—ASL and a language interpreter for the parents. In those situations I would say services are really hard to access.”
—Nonprofit professional

“If they live in a big school district and get the low vision educators and the deaf educators mobilized quickly then they’re good. If a child is born in Fergus Falls or Cloquet, it’s going to take a long time. If your child is born in or near Faribault and can access the Academies for the Deaf and the Blind there, then it can happen pretty quickly, too.”
—Medical professional

A lack of communication and coordination among service providers

Many professionals talked about the need for better communication and coordination among service providers. One aspect of this finding is the need for better communication and coordination *within* service fields, such as a medical provider talking with another medical provider (e.g., a family practice doctor sharing information with an Ears, Nose, and Throat (ENT) specialist). Another aspect of this finding is better communication and coordination *between* service fields, such as a medical provider talking with a school-based provider (e.g., a family practice doctor sharing information with a special education professional).

“I think it’s the same with any child who sees multiple specialists—it can be difficult to track medical records and there is a lack of communication between providers. There’s all these different medical records. While communication between systems is getting better, it’s still a challenge. You rely on families to tell you about other visits.”
—Medical professional

Many professionals mentioned the same nonprofit and government organizations numerous times—for example, Minnesota DeafBlind Project, PACER, Lifetrack Resources, Minnesota Hands & Voices, DeafBlind Services of Minnesota, State Services for the Blind, and Help Me Grow.² Many professionals also mentioned that these organizations coordinate to some extent with each other and with other medical and education professionals, but that parents carry much of the coordination work themselves. As a potential solution, a number of professionals suggested creating a streamlined coordination approach that supports identification and referral services, professional support to parents (including connecting parents to other parents), and service coordination for families with DeafBlind children and youth. A few professionals mentioned creating a starting-at-birth vision loss identification system that parallels Minnesota’s Early Hearing Detection and Intervention (EHDI) program, for instance.

“We have newborn hearing screening but not newborn vision screening of any sort. We have this 1-3-6 infrastructure for identifying hearing loss. By one month, every newborn has their hearing screened. By three months, every baby should have their hearing re-screened if they don’t pass in both ears. Then at six months, every baby identified with hearing loss should be seen by a pediatric audiologist. That system isn’t perfect, but there is an infrastructure there. There is nothing like that for vision loss.”
—Medical professional

² As of July 2021, Lifetrack Resources merged with Lutheran Social Service of Minnesota, and operates under the latter’s name. This report reflects the organizational status of Lifetrack Resources as of June 2021—that is, an independent nonprofit organization. For those interested in learning more about Lifetrack Resources and the services and supports it offers, contact Lutheran Social Service of Minnesota.

A lack of DeafBlind-specific knowledge and skills among professionals who serve DeafBlind children and youth

Many professionals talked about the need for more and better training for professionals who serve DeafBlind children and youth, even if this is not their specialty. Referring to school-based professionals, respondents mentioned that many mainstream teachers and school staff do not know how to effectively work with children and youth with combined hearing and vision loss. A few professionals also mentioned that even school-based specialists—such as special education teachers or speech and language pathologists—don’t know how to effectively work with DeafBlind students. For instance, they may be well versed in working with some specialized tools or even working with deaf or hard of hearing students or blind students, but often these tools or pedagogies are not effective for teaching students with combined hearing and vision loss.

“There are no trained teachers who specialize specifically in teaching DeafBlind children. You’ll have a teacher who is trained in Deafness and they push their students to learn from other senses like their vision. Or you have a teacher who’s trained in blindness and they really work with their kids on using what hearing they have. In Minnesota, we now have teachers for the deaf and teachers for the blind. You sometimes put them together, but it’s not the best unless you have two people who have a lot of training together and who work together a lot. I would say that’s the biggest challenge—people who are not trained to work with our kids.”

—Nonprofit professional

Referring to medical professionals, professionals noted that many doctors—especially primary care or family practice doctors—do not know enough about hearing and vision loss to adequately guide parents in caring for their children with combined hearing and vision loss. Similarly, professionals mentioned that some medical professionals are not aware of how to partner effectively with the school-based professionals who work with their patients. For instance, one professional mentioned a lack of awareness of the policies that dictate the information that school-based professionals need to effectively teach and advocate on behalf of their DeafBlind students.

“I would say that the key challenge among medical professionals is a misunderstanding that both hearing and vision loss can be progressive. For the child, they might be too little to say that they can’t see that or it’s blurry. Also, many primary care providers and family medicine folks will see that a child passes the newborn hearing screen and assume that that means that their hearing is just fine. In fact, there are many types of early childhood hearing loss that progress in the first several months of life. It’s not malpractice, it’s complacency about the hearing screen. Then there is the misunderstanding that a very young baby cannot be evaluated for hearing and vision loss. They’ll say ‘Oh we need to wait until the baby is two years old or until the baby can talk,’ which isn’t true.”

—Medical professional

“Medical professionals are not familiar with the data that we need. ... I’ve heard the Teacher for the Blind and Visually Impaired reference medical records she too has gotten, saying, ‘This test wasn’t done how we needed it to meet our criteria.’”

—School-based professional

A lack of professional support and guidance for families and loved ones of DeafBlind children and youth

Many professionals spoke of the need for more support and guidance for families and loved ones of DeafBlind children and youth. Professionals mentioned the need for support and guidance generally, such as parents getting emotional support from other parents, as well as in regards to accessing services, such as families and loved ones getting help as they navigate service systems on behalf of their child or loved one.

“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

In addition to support related to accessing services, numerous professionals noted that some providers do not assist families aside from giving them a name and phone number of who to call next. Other professionals mentioned that sometimes providers ignore the observations of parents regarding their child’s vision or hearing loss, or that parents miss important signals themselves because they do not know what to look for. In instances like these, a support worker—or simply another parent who has gone through this before—could play a significant role in helping to meet the needs of DeafBlind children and youth.

“We have a good healthcare system and I think geneticists do a good job, but sometimes all parents get is a name of what the syndrome is—no help beyond that. Most medical experts will give the name and send parents on their way without any suggestions of what resources are available to them.”
—Nonprofit professional

“Sometimes parents will say that their child isn’t visual tracking—those kinds of things. Developmental observations from parents like this, I’m sad to say, will often be discounted. The parents themselves won’t pick up on it or they will be brought to a primary care person and then the primary care person doesn’t know what to do or discounts it by referring to the [successful] screening.”
—Medical professional

Lastly, some professionals talked about the need for DeafBlind children and youth and their families to have emotional support and mentorship, potentially through a meaningful relationship with another parent or with an adult who is DeafBlind. A few professionals suggested creating a mentorship program, beginning at identification, between parents and an adult with combined hearing and vision loss. A few professionals referred to the Deaf Family Mentor program through Lifetrack Resources as a model for a DeafBlind-specific program.

“Some parents want all of the information and crave it, while other parents are not ready for that. I find that when Minnesota Hands & Voices reaches out to parents who have children who were just newly identified, I’d guess that 90% of those families are not ready to talk. They’re like, ‘I just found out. I don’t want to talk to somebody I don’t know. I’m not sure what you can do for me.’ Nothing against Minnesota Hands & Voices, they’re a great resource, but I don’t think that’s where the parents’ attention is at that particular moment.”

–School-based professional

“I would like parents to be connected with adults who are Deaf or DeafBlind first and then they can meet other professionals. They need to meet all of those kind of professional people—who are important for sure—but, based on my experience, many parents are just in shock and they don’t know what their child’s life will look like. They wonder if their child can drive or go to prom. That’s how the Deaf Family Mentor program at Lifetrack really helps. Can they have a job, get married? What does it mean for family relationships? The professionals tend to keep the focus on procedural things—first meet with the audiologist, then go from there. They don’t address the life skills, the human part. No one is told that their child will grow up to be successful—those fears need to be addressed up front.”

–Medical professional

There is a piecemeal “system” for serving DeafBlind children and their families that is comprised of slightly coordinated institutions, organizations, and people

While Minnesota lacks a cohesive system for meeting the needs of DeafBlind children and youth, we do have a piecemeal “system” comprised of slightly coordinated institutions, organizations, and people. These institutions, organizations, and people include:

- Schools and school-based professionals (e.g., the State Academies, Metro Deaf School, Teachers of the Blind and Visually Impaired, Teachers of the Deaf and Hard of Hearing)
- Hospitals, clinics, and medical professionals (e.g., university hospitals, audiologists, ENT specialists)
- Government-based service providers and the numerous services accessed through our waiver system and other public funding avenues (e.g., State Services for the Blind, Deaf and Hard of Hearing Services Division, county social workers)
- Nonprofits that provide guidance and connect parents and families together (e.g., Minnesota DeafBlind Project, Lifetrack Resources, PACER, DeafBlind Services of Minnesota)
- Interveners and other one-to-one direct service professionals (e.g., personal care assistants, homecare nurses)
- Community- and transition-oriented services and professionals (e.g., services and professionals that seek to increase independence and participation in community life)

- Parents of DeafBlind children and youth and our DeafBlind children and youth themselves—as well as their networks of support and connection

While largely critical of this piecemeal DeafBlind services system, interviewees also highlighted positive experiences they’ve had with these different institutions, organizations, and the people within them. The rest of this report provides an overall assessment of each system component listed above (e.g., “Overall, there were mixed experiences with schools and school-based professionals”), as well as highlights positive and negative aspects of the system component in question. Figure 3 provides an overview of the seven system components that we address.

3. Number of young adults and parents who had ever interacted with various system components and their overall experiences with them (N=28)

System component	Number of respondents	Number of mentions ^a	Mostly positive, negative, or mixed experiences ^b
Schools and school-based professionals	28	272	Mixed
Medical care and medical professionals	28	136	Mixed
Government agencies, programs, and professionals	26	85	Mixed
Nonprofits and nonprofit professionals	23	126	Positive
Interveners and other one-to-one direct service professionals	20	94	Mixed
Community- and transition-oriented services and professionals	20	61	Negative
Parents, friends, and networks	17	54	Positive

^a A “mention” refers to whenever a respondent talked about a system component. We include both the number of respondents who talked about a system component and the number of times a system component was mentioned as two measures of thematic saliency.

^b “Positive” refers to when the percentage of positive mentions is at least double the percentage of negative mentions. “Mixed” refers to when neither the percentage of positive mentions nor negative mentions is at least double the other. “Negative” refers to when the percentage of negative mentions is at least double the percentage of positive mentions.

Schools and school-based professionals (mixed experiences)

Young adults and parents talked about positive as well as negative education experiences. When talking about positive education experiences, they mentioned experiences with programs specifically for children with hearing or vision loss as well as blended programs where a specific teacher or support worker is with their child in a mainstream setting. In particular, parents appreciated that teachers and staff in programs like these welcomed the opportunity to work with their child, that they have deep experience with DeafBlind children, and that, generally speaking, they remain in their child's life for multiple years (as opposed to only being with their child for one year, which is typical in many mainstream education settings).

"It was 6-9 months [at age 13] after his diagnosis that we put him in a center-based program. I saw an immediate connection with that place, whereas at his public school they just threw up their hands. When the Deaf and Hard of Hearing Teacher came, she couldn't wait to work with him. Everyone else has always been hesitant."
—Parent

"Prior to COVID, the Early Childhood Special Education (ECSE) kids would be immersed with the general education preschoolers—they'd have their special education teacher plus the preschool teacher—and then the therapist would hop in and out, or they'd take the kids out of the room for a little bit for whatever reason, for their therapy session or this and that."
—Parent

"There was just a lot of issues in mainstream education. But down at the Academies, they have a running start because they obviously understand blindness better, they understand Deafness better, and they understand deafblindness better. The fact that her team doesn't change is great. Imagine every fall bringing a whole new team on board—new teacher, new Teacher for the Deaf and Hard of Hearing, new Teacher for the Blind and Visually Impaired, a new intervener. That was never consistent in mainstream education, and so every year that just got to be exhausting."
—Parent

Parents often elevated specialized teachers and staff as playing a positive role in their child's education, such as Teachers for the Deaf and Hard of Hearing, Teachers for the Blind and Visually Impaired, special education teachers, Individualized Education Program (IEP) case managers, and accessibility staff at the post-secondary level. In many cases, parents contrasted the skills and knowledge of these teachers and staff—and the impact they made in their child's life—with the lack of appropriate skills and knowledge among mainstream teachers and staff.

"Our Teacher for the Deaf and Hard of Hearing will be forever part of our family for the rest of our lives. She just will. She was the biggest advocate and the biggest source of information for us."
—Parent

"If he were to stay in public school, yes they would have to provide his accommodations, but they would not have the knowledge to do it well. The teachers at the Academy, they actually had the knowledge. They were trained to teach braille. They were trained to help kids with visual impairments learn in a different fashion."
—Parent

“The Deaf and Hard of Hearing Teacher noticed that he was saying ‘What?’ a lot when she was walking behind him. That’s different than his normal, so they had the audiologist come down, because she was there that day and did a test on his hearing aids. They called and said, ‘We just wanted to let you know.’ That communication is nice.”
–Parent

“They made sure that he met with the people that were on his floor. They include him in different activities—the things that are happening on campus, he knows about and he can easily join. If I need anything, all I have to do is call this gal who works with him and she takes care of it. It’s just instantly, ‘Yep, we got it, don’t worry about it, we’ll take care of him.’ He had a surgery a couple of months ago, a minor surgery, but he wanted to stay in his room by himself. As a mom, I felt uneasy about that. I called and they made sure that someone went in and checked on him two or three times over the course of that next two days. They’re very accommodating and help him with whatever he needs.”
–Parent

Young adults and parents also talked about negative education experiences. In particular, parents commonly talked about how staff at public or mainstream schools did not have the knowledge or skills to support their child. Many parents also talked about experiencing pushback from school staff when requesting an intervener or other important services for their child, and that the school’s approach to distance learning during COVID-19 was not appropriate for their child.

“I’m not trying to throw anyone under the bus, but starting in middle school, her teacher was woefully underprepared. They didn’t even read the Individualized Education Program (IEP). I wouldn’t say the school system was horrible—it was just a bad teacher. I’ve had to micromanage that a bit.”
–Parent

“The school should be more accepting of help from outside interveners and should get more training for school staff on hearing and vision loss. I know the school only has so much money and so much professional development time for teachers, but if you know you have a kid coming up through Early Childhood Special Education (ECSE) or that has an Individualized Education Program (IEP), they should work to develop those skills before they are in their class.”
–Parent

“COVID has been a huge barrier. We got nothing from the school for special education distance learning. There was nothing for hearing- or vision-impaired kids. They sent packets home that had fonts that were too small for my son to see. He needs one-color, no-words packets with big pictures. This past year with COVID, education has been a no-go.”
–Parent

“My child sees to some degree. They wanted to send a Chromebook to us for distance learning, but Chromebooks are not appropriate for him. It took me two months to get an iPad, which is more accessible for him. But when they did send the iPad, the apps weren’t appropriate. He is profoundly blind. They had books for him to read loaded onto the iPad, but he couldn’t see them—so that didn’t work.”
–Parent

Some parents mentioned that part of why their child had negative experiences in school was that the teachers and staff did not recognize the intersection of their child’s multiple needs—such as hearing loss and vision loss, or deafblindness and autism, or any number of co-occurring conditions that may accompany combined hearing and vision loss. That being said, there are numerous complexities involved in identifying co-occurring disabilities or conditions along with deafblindness. For example, other researchers have found that DeafBlind children and youth have been observed to exhibit “autistic-like behaviors,” but these behaviors may stem from the lack of visual or auditory stimuli rather than neurodevelopmental difference. Additionally, a few parents noted that while some states have Teachers for the DeafBlind, Minnesota does not. Further, one young adult mentioned not feeling like they “fit” at schools that specialize in deaf teaching or in blind teaching because they have combined hearing and vision loss.

“There are some deaf schools here like the Minnesota Academy for the Deaf. There is also the Academy for the Blind, but that school is not very friendly for the DeafBlind either. There was not really anywhere for me to go that I felt like I fit [as a DeafBlind student]. It was either the deaf school or the blind school.”

—Young adult

“The Council on Exceptional Children (CEC) standards calls for my daughter to have a Teacher of the Deafblind, but there are none here. Minnesota needs to come up to date with the CEC standards that call for Teachers of the DeafBlind.”

—Parent

“They were trying with organizational skills for him because of his ADHD. He was really resistant to that because it took extra time. He’s just a really, really messy person. The teachers would send me pictures of his messy locker and his messy desk, and it’s like, ‘Well, I don’t know what I’m supposed to do.’ I could talk to him about that, but I’m not going to go to school and organize it for him because he’ll just unorganize it again. It seemed to be just a really terrible source of contention between him and his teachers.”

—Parent

“A lot of people we saw would say, ‘He’s not autistic, just blind.’ We had to really fight that battle for a long time. In fact, up until he was like 14 or 15 years old, they kept saying that what’s going on with him has nothing to do with autism. A blind child doesn’t go up and down the stairs 400 times, or doesn’t open and shut the door 400 times. That’s not part of a blindness. That is part of autism. Eventually he was tested for it—and yeah, he’s got them both. A lot of people did not know how to work with him. If they specialized in autism, they just dealt with the autism. They did not deal with an autistic child that was blind and Deaf.”

—Parent

Medical care and medical professionals (mixed experiences)

Young adults and parents talked about positive as well as negative medical experiences. When talking about positive medical experiences, they mainly mentioned appreciating a provider’s knowledge about or familiarity with deafblindness, or simply that a provider knew enough about deafblindness to connect them to another provider that specializes in hearing or vision loss. In particular, young adults and parents greatly appreciated providers who connected them directly to other medical professionals or took initiative themselves

to work directly with other providers (so that the task of coordinating that care did not fall solely on the young adult or parent).

“We went to the University of Minnesota Lions Children’s Hearing and Ear, Nose, and Throat Clinic—the audiologist there was just amazing. She works with children that have no language and did all these tests for hours and hours, and did that on a daily basis. She was aware of Usher syndrome and what the next steps should be when that diagnosis is positive. I think she was even the one who mentioned Northern Voices School to me. Northern Voices changed our lives.”

–Parent

“When we were at the University of Minnesota and they were figuring out that there was a retinitis pigmentosa problem, they coordinated with us like a one-stop shop to get the genetic testing involved right away so that we didn’t have to go to a hundred different appointments, which was nice. I think that approach was really new.”

–Parent

“I finally just kind of blew up and started yelling at everybody since there were so many people I had to talk to—and they said, ‘Well, would you like a care conference?’ We had probably 11 different specialties coming in to poke at her and look at her and assess her. We had her hearing and vision looked at. We had the physical development people, we had genetics, we had surgery. We had just everybody. Everybody was there. To get them all in a room to talk about her case and her care and make a plan going forward was life changing.”

–Parent

Young adults and parents also talked about negative medical experiences. They often mentioned that providers lacked DeafBlind-specific knowledge or training, and so the medical care and advice they received wasn’t appropriate or helpful. Other times, parents noted that they knew who to go to for specialized medical care, but they weren’t able to get an appointment because the provider was too busy. In addition, young adults and parents mentioned that there was a lack of coordination and communication among medical professionals, resulting in them needing to coordinate between medical providers themselves.

“I would stress the importance of understanding the difference between an optometrist and a pediatric ophthalmologist. We were told many times that there was fluid in his ears, and the optometrist had a very good reputation. Our son worked so hard for 13 years to learn reading and sight words; we could have supported him so much better. The local eye doctor is not the same as a pediatric ophthalmologist.”

–Parent

“Nobody knew enough about Usher. I know there’s a guy at the University of Iowa who is an Usher syndrome specialist, but you can’t get an appointment with him because he’s the main specialist in the country.”

–Parent

“I’ve learned to be persistent with people in the medical field and make sure that they are communicating—my experience as a nurse helps with that. There are doctors who think they know better than me, so it isn’t always smooth. I make sure to bring all of the documentation from other appointments with me so I can help as much as I can.”

–Parent

“We didn’t know she had Usher syndrome until she was 15. We went through the whole hearing loss piece, navigating that with the school district mostly. Then it was a whole new thing when she was 15 with the vision stuff. When she was diagnosed, it was hard because the medical providers weren’t very good. We went to the University of Minnesota because we knew they had someone who knew a lot about retinitis pigmentosa. That person just told us that she would go blind soon. That was a really bad way to tell us. We immediately did our own online research and found two organizations that really helped us—they know a lot more about Usher. We saw them and they gave us a totally different outlook. Their advice was to not bring her to see ‘normal’ hearing and vision loss providers. She has to see super specialists.”
—Parent

In addition, parents talked about not receiving much guidance or support from medical professionals during the identification process or after hearing or vision loss has been identified. This finding from the interviews with parents aligns with a similar insight from professionals—that parents need more guidance in supporting their children. In particular, parents expressed wanting guidance around the real-life implications of their child’s hearing and vision loss.

“After they did the check on his eyes, the doctor came in and said, ‘Well, your son has Norrie disease. He’ll be blind the rest of his life. Have a nice day,’ and he left. He just left us in the room. That was literally the last time we heard from them.”
—Parent

“My sons were young adults when their vision got bad; they were 20. I had questions like, ‘Should they still be driving? How do I know if they should still be driving?’ Questions like that—and we had zero resources. I still have those questions! I asked the doctor, and the doctor was like, ‘Well, I don’t know.’ It’s like, ‘What do you mean you don’t know? You’re a retina specialist! Would you want to be on the same road as those kids or not?’”
—Parent

Government agencies, programs, and professionals (mixed experiences)

Young adults and parents talked about positive as well as negative experiences with government agencies, programs, and professionals. When talking about positive experiences, they mentioned that direct financial assistance is helpful, that they appreciated the existing coordination between medical providers and government agencies or programs, and that they enjoyed working with certain government workers, such as those at State Services for the Blind or at Help Me Grow.

“It is helpful getting services through county agencies. We have a waiver for [our child]. It’s wonderful—it pays for things insurance won’t pay for.”
—Parent

“I am thankful that her medical provider talked behind the scenes with someone at the Department of Human Services. Someone called me and it ended up being her case manager for birth to three—they said, ‘Hey would you like services?’ Then she told me about the birth to three program. I said, ‘Is it free?’ She said, ‘Yep.’ I said, ‘Okay, I’ll take you.’ Help Me Grow I think is what it’s called.”
—Parent

“When she was born, I had to give up my job to stay home and take care of her. When she was 7 or 8 years old, our budget quadrupled because we got on the waiver she’s now on, which allowed us then to pay parent funds and other staff funds, and it allowed her to have access to all these different alternative therapies—art, camps, massage. It also pays for her nursing staff, which is crucial for me being able to work again and for her to have some support people that are able to manage all of her complexities. It’s made a huge difference at keeping her at home and keeping her healthy.”
—Parent

“He wants to become a famous musician and he’s told that to his State Services for the Blind worker. The State Services for the Blind, they try to take every aspiration seriously, even though we’re like, ‘Yeah, that’s never going to work.’ But the State Services for the Blind guy was like, ‘Okay, what steps could we take for that to become a reality for you?’ I think [our son] is coming to the realization that he won’t become a famous musician, and so he’s opening his mind up a little more to what could he do instead. He’s thought about being a 911 dispatcher, a suicide hotline guy—different things like that.”
—Parent

Young adults and parents also mentioned negative experiences with government agencies, programs, and professionals. Mostly, they talked about limitations to the assistance they received (such as not getting enough help or guidance), not being able to get in touch with a program or a professional at all, or getting a lot of information but no guidance on how to put it to use.

“When I was doing my job search, State Services for the Blind did not really help. I was basically job searching myself. They had low expectations for me and did not try to address the barriers that were preventing me from getting the job. It was just hard to work with them.”
—Young adult

“I’m having a hard time really deeply connecting with State Services for the Blind. I keep touching base and then losing touch. I have to chase them down.”
—Parent

“We were thoroughly overwhelmed having a newborn with this life-long diagnosis, and we just had all of this information coming at us. I have the big binder here, actually—Children and Youth with Special Health Needs. There was a lot of stuff in there—resources and this and that. I didn’t feel like I had time to look through it and digest all the stuff. I couldn’t sit and go to all these other websites and do all this other research.”
—Parent

Nonprofits and nonprofit professionals (mostly positive experiences)

For the most part, young adults and parents talked about positive experiences with nonprofits and nonprofit professionals. In particular, parents mentioned that they appreciated learning more about deafblindness through these nonprofits as well as having one-on-one support from staff who know a lot about deafblindness and have connections to the variety of services available to DeafBlind children and youth. For example, one parent commented, “We’ve learned so much through the Minnesota DeafBlind Project.”

“Our family didn’t know a ton of ASL, but I took classes from Lifetrack and through St. Paul College. Through those classes and through conversations with our Deaf mentor at Lifetrack, I learned how to be around a Deaf person and how to be considerate of their needs. Our mentor introduced me to different events and to d/Deaf culture, which is really important. We are raising our son and getting him to be part of a culture and community that we weren’t part of. You are really counting on these people—the Deaf mentors—to include him in their culture. They are really helpful.”
—Parent

“I’m more of a verbal person. Getting a lot of brochures does not compute in my mind. Having those individuals at Minnesota Hands & Voices to be able to talk through stuff was very important. It’s the one with the person that helps you with your journey, they come out to your home. It was stressful having a newborn, but it was really nice to just have somebody to encourage you and say everything is going to be okay. I was thankful that Minnesota has those resources.”
—Parent

Parents also talked about the significance of meeting other parents and families of DeafBlind children and youth through their connections with nonprofits. In particular, they mentioned get-togethers and retreats hosted by the Minnesota DeafBlind Project as well as getting to know parents and families through classes and groups, such as those hosted by Minnesota Hands & Voices.

“The Minnesota DeafBlind Project has things that meet more than just the immediate needs, like a family picnic once a year—we would go to that [before COVID]. That was fun and nice. They would also take moms [with children with combined hearing and vision loss] and put on a retreat for them. All the moms would meet up at a hotel and just be moms with each other who all have this shared experience of having a special needs kid. That was pretty cool.”
—Parent

The audiologist at Children’s provided me information to Minnesota Hands & Voices. I started taking classes there and started to feel connected with other families with kids with the same situation. I took classes in both English and Spanish at first and currently I’m just involved with the Spanish classes. It’s been great for us. I have met so many great parents and feel included and we share information about so many things to help our children. We support each other in Spanish—different tips and ways of dealing with our kids. We get to listen to guest speakers who bring us so much wonderful resources to get connected with.”
—Parent

Very few respondents talked about negative experiences with nonprofits and nonprofit professionals. For example, one parent mentioned the lack of coordination between nonprofit and medical professionals and another noted that some nonprofits (that do not specialize in deafblindness) do not know how to work well with children and youth with combined hearing and vision loss.

Interveners and other one-to-one direct service professionals (mixed experiences)

Young adults and parents shared positive as well as negative experiences with interveners and other one-to-one direct service professionals. When talking about positive experiences, young adults and parents talked about how significant and effective interveners are at helping DeafBlind children and youth interact with their larger community. As one parent put it, speaking of their daughter’s intervener services, “It’s made her world substantially larger.”

“Interveners are really good because they are so hands-on. They work at home, out in the community, at school—in a variety of settings. They really know their way around working with kids who have vision and hearing loss, and work with them to explore and learn about their environment. I wish I would have known sooner about interveners.”
—Parent

“Interveners here in Minnesota have a nine-month course that explains deafblindness to them and explains different ways of communicating, different ways of interacting with kids who are DeafBlind. If they go through that course, they understand how to modify things, how to change things, how to make things better without us as parents having to constantly explain to them, ‘Well, you shouldn’t be doing that with her. She can’t see those letters or that word; it’s all mushed together, she needs it spaced out or she needs a spotlight on it.’”
—Parent

Young adults and parents also talked about negative experiences with interveners and other one-to-one direct service professionals. The majority of these experiences stemmed from systemic issues that present barriers to accessing interveners, such as high levels of turnover in the intervener profession, the process by which interveners are assigned to DeafBlind individuals, and the lack of access to interveners in greater Minnesota. Due to these issues, some parents noted that it has been hard to find an intervener that works well with their child and that sometimes their assigned intervener has still been in training (so they don’t have all of the appropriate or necessary skills yet).

“There is a lot of turnover [with interveners]—who is assigned to your child—which isn’t helpful for forming that trusting relationship. It’s been very inconsistent who will be working with him.”
—Parent

“We’ve had a series of community interveners, unfortunately. But her school intervener has been with her since the second grade. Because we live in such a rural area—we live about 30 miles from the nearest grocery store—you really can’t find trained interveners. We have no Deaf community around us or anyone else who’s blind.”
—Parent

“I had a hard time finding a good intervener for my daughter. I had to do some legwork, which is the same thing I have to do for personal care services, so it doesn’t break me up. But if I wasn’t somebody who naturally builds networks, I could see me quitting on the interveners because I don’t even know who’s running that program right now.”
—Parent

“Our daughter’s first intervener—now her community intervener—was actually her school intervener to start. That’s how we learned that, if your school intervener turns into your community intervener, they won’t let them be both. That was super frustrating to me because I’m like, ‘Our daughter really trusts this person,’ but for some reason her trusting that person was bad or undesirable.”
—Parent

Community- and transition-oriented services and professionals (mostly negative experiences)

Only a few young adults and parents talked about positive experiences with community- and transition-oriented services and professionals—services and professionals that seek to increase independence and participation in community life. The few interviewees who did mention positive experiences with these kinds of services or professionals typically mentioned a community intervener working with their child or their child attending camps or programs specifically designed for young people with disabilities.

“On weekends, her intervener was bringing her to church, pre-COVID. She seemed to be enjoying that. There is a youth group at the church that she was participating in—the church is primarily Deaf. They welcome anyone but they have organized themselves to be focused on the Deaf community, so she has some connections to people in the Deaf community there.”
—Parent

“The newest one she’s doing is called 21 Roots Farm. It’s not DeafBlind specific, but is for all disabilities. She gets to be outside and we get to interact with the animals. We get to learn about plants. They have different themes for each week, and she gets to interact with other people with disabilities.”
—Parent

Young adults and parents mostly mentioned negative experiences when talking about community- and transition-oriented services and professionals. In particular, they mentioned a decrease in services or supports once a DeafBlind individual is no longer eligible for an Individualized Education Program (IEP) at 21 years old. For example, young adults and parents noted that it’s difficult to find a job, sometimes because employers are not comfortable hiring a DeafBlind employee. Some parents also expressed concern or fear about their child’s life in the next 10-30 years, noting that they will not be able to provide the same level of care, attention, and coordination to their child as they age and get older.

“He’s got the whole summer where now he’s trying to find a job, and it’s nearly impossible. Once people find out that he’s blind and deaf, they’re like, ‘We don’t want you.’”
—Parent

“My wife and I are in our 50s and our daughter is not quite 20. I want her to be independent—as independent as she can be—but I’m also pretty concerned because she’s always going to be vulnerable to a degree. I’m too old to really be able to do a lot for her, but she’s right there in the prime of her life, living her best life. Absolutely I want all that for her, but I don’t know how to protect her from predatory people.”
—Parent

Parents, friends, and networks (mostly positive experiences)

Young adults and parents talked about appreciating their DeafBlind friends as well as other parents of children with combined hearing and vision loss. In particular, they appreciated meeting other DeafBlind people or meeting parents of DeafBlind children because it allows them to share resources as well as simply connect with someone with a relatively rare shared experience.

“One of the most helpful things for me was when the Minnesota DeafBlind Project did a mom’s retreat. They had speakers and gave us information. We also had time to connect with each other, hear each other’s stories, and share what resources might be out there that maybe we didn’t see or know about yet. Those types of retreats are really helpful. It was nice to have a break because it’s a pretty intense thing—to raise a kiddo that’s DeafBlind.”
—Parent

“I was lucky enough to find a Facebook group. There’s just like 30 parents on it maybe, and they’re from all over the world because the syndrome is so rare. My usual approach when I have questions is, ‘Well, I can ask the Facebook group because they’re the ones that would have the most up-to-date knowledge.’”
—Parent

“It was my friend and neighbor who has a son with CHARGE syndrome—she saw how my son embraced ASL and she suggested that he might have hearing and vision loss. She gave me the pediatric ophthalmologist’s name and number, and that’s where we found it was profound loss in his left eye and moderate in his right—and that led to identifying the failed optic nerve. That opened up the world of services that could support him, but not until he was 13 years old—well into his school career. I don’t know what his life would have looked like if it had not been for my friend, she’s the one who really got the ball rolling.”
—Parent

The only negative that young adults and parents mentioned regarding friends, parents, and networks is that they had a difficult time meeting and connecting with other people who have experience with deafblindness. Many young adults and parents expressed wanting to be more connected to DeafBlind individuals as well as loved ones of DeafBlind individuals so that they might feel a sense of connection and belonging.

“I haven’t felt like there’s a DeafBlind community because there’s the sighted community, there’s the unaided community, there’s the speaking community. There’s so many variants of this that it’s hard to find where you fit. My child is aided and if she doesn’t have her hearing aids in and her glasses on, she can’t see or hear so her communication is completely screwed. But that’s not necessarily the case for someone else because they might know sign language, so finding your place is really messy.”
—Parent

Appendix

A. Advisory group members

Name	Experience
Allison Aubrecht	Education
Ann Mayes	Education, Nonprofit
Carrie Zeman	Parent
Christian Wernau	Education
Darcia Dierking	Medical, Government
Darlene Zangara	Government
Deanne Curran	Parent, Nonprofit
Elizabeth Laffen	Education, Nonprofit
Jamie Taylor	Lived Experience, Government
Jessica Eggert	Lived Experience, Government
John Filek	Nonprofit
Kim Johnson	Nonprofit
Morgan Nodsle	Education
Nanette McDevitt	Medical, Nonprofit
Nicole Eck	Education
Robin Coninx	Parent, Nonprofit
Ryan Odland	Lived Experience, Nonprofit
Sally Prouty	Parent, Nonprofit
Sara Kreiling	Government
Shannon Zywiec	Education
Wendy DeVore	Nonprofit
Wendy Harris	Education

B. Literature review

Wilder reviewed the following articles and publications as part of this project. We cite only some of them throughout the body of this report, but each contributed to the project in various ways—such as by informing the study design or interview question development, or during analysis and helping to make meaning of primary data and resulting themes and findings.

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C. Interview questions

Youth interview questions

1. What are your biggest hopes and dreams for yourself?
2. Do you have any hobbies? How do you like to spend your free time?
3. Right now, which of these resources have you used or which activities do you participate in?
 - Medical professionals or resources, such as audiologists, ophthalmologists, pediatricians, or others
 - School-based professionals or resources, such as special education professionals, physical therapists, occupational therapists, speech therapists, school specialists, or others, including whether you had an Individualized Education Program (IEP) and/or participated in Early Childhood Special Education (ECSE)
 - Mental health professionals or resources
 - Social workers (public or private)
 - Interpreters or other assistive technologies for communication
 - Interveners or other independent living services
 - Services or resources through non-profits, such as the Minnesota DeafBlind Project
 - Government-based services or resources, such as getting services through county agencies or State Services for the Blind
 - Services and supports for youth/young people who are transitioning to adulthood
 - Employment training, vocational rehabilitation, or paid work services
 - Extra-curricular activities or clubs through school
 - Extra-curricular activities or camps that are not through school, such as Special Olympics, Best Buddies, Blind and Socially Savvy, Camp Inspiration, Courage North Camp, or other activities or groups through church or other organizations
 - Social media groups, like Facebook groups
 - Do you use other services or participate in other activities not listed already? If so, please specify: _____
4. Which of these services has been the most helpful or beneficial to you? Why?
5. Which has been the least helpful or beneficial to you? Why?

6. Are you able to get all the help you want or need to reach your goals and be as independent as possible?
 - If no, what kind of help do you still need? What have been the biggest challenges to getting these services?
 - Is there anything in your life that you would like help or assistance with, such as a problem you need to solve or a goal you want help to achieve?
7. Next, I'd like you to tell me about your experience with the schools you went to.
 - Do you still go to school? If so, where are you attending school? If you are done with school, where did you go?
 - What were some good experiences you had with the schools you went to?
 - What was not so good or could have been improved?
 - What services and supports did you receive as part of your experience in school that was the most helpful? The least helpful? (PROBE: School staff, interveners/ interpreters, tutors, student clubs or groups, etc.)
 - How can schools be improved for students who have a combined hearing and vision loss?
 - Were there any additional supports you felt you needed in school that you did not get (if any)? If so, what were they?
8. Now we'll talk more about your transition out of school.
 - Do you have a coordinated plan and/or transition plan? Can you tell me about how these plans were created? Did you help create the plan or just create it yourself, or did someone create it for you?
 - During your transition out of school, what services and supports did you get to help make your life easier?
 - Do you think these plans are in line with your goals? (PROBE: like getting a job, more schooling, etc.)
 - What services and supports do you need or want but do not have? What has stopped you from getting these?
9. What is the best way to reach out to you and your family with new information about services or programs that might be able to help you? How should professionals communicate with young adults who have a combined hearing and vision loss in order to get them the services they need?
10. From your experience, what, if anything, might cause a young adult to discontinue, give up, or stop seeking certain services for themselves?

11. What, if anything, do you think is the most important improvement that could be made to the service system for young adults who have a combined hearing and vision loss, in order to best meet their needs?

Parent interview questions

1. When your child was first identified to have a combined hearing and vision loss, what are the key resources, connections, or information your family needed right away?
 - How were you given information or connected with resources?
 - What challenges or barriers did you have to getting connected?
 - Who was it that first suggested you see if your child may be deaf, blind, or have combined vision and hearing loss?
 - How did you make the decision to look into one or both of these conditions?
2. Throughout your child's life, which of these resources have you connected with or used to help your child? I'm going to read from a list, and please answer "yes" or "no" if your family has used these resources for your child(ren) who have a combined hearing and vision loss.
 - Medical professionals or resources, such as audiologists, ophthalmologists, pediatricians, or others
 - School-based professionals or resources, such as special education professionals, physical therapists, occupational therapists, speech therapists, school specialists, or others, including whether you had an Individualized Education Program (IEP) and/or participated in Early Childhood Special Education (ECSE)
 - Mental health professionals or resources
 - Social workers (public or private)
 - Interpreters or other assistive technologies for communication
 - Interveners or other independent living services
 - Services or resources through non-profits, such as the Minnesota DeafBlind Project
 - Government-based services or resources, such as getting services through county agencies or State Services for the Blind
 - Services and resources that support parents with DeafBlind children
 - Services and supports for youth/young people who are transitioning to adulthood
 - Employment training, vocational rehabilitation, or paid work services
 - Extra-curricular activities or clubs through school

- Extra-curricular activities or camps that are not through school, such as Special Olympics, Best Buddies, Blind and Socially Savvy, Camp Inspiration, Courage North Camp, or other activities or groups through church or other organizations
 - Social media groups, like Facebook groups
 - Do you use other services or participate in other activities not listed already? If so, please specify: _____
3. Which of these services or resources has been most helpful to you or your child? Why?
 4. Which of these services has been least helpful to you or your child? Why?
 5. Are you able to access all of the services you, your family, or your child wants or needs?
 - If no, what services does your child still need that they are not currently getting? What have been the biggest challenges to getting these services?
 - Is there anything in particular in your child's life that you would like help or assistance with, such as a problem you want help with solving or a goal of theirs that you want to help them achieve?
 6. In your experience, to what extent do your child's service providers coordinate with each other, if at all? Were you satisfied with the level of communication and coordination between these services?
 - What could these organizations have done to better coordinate their services?
 - What is the best way to reach out to your family with new information? How should professionals communicate with families in order to get them the services they need without overwhelming families?
 7. For parents with school aged children (or children who have been through the K-12 education system)
 - Where does/did your child attend school?
 - At what age did your child begin receiving services from the school or school district? Did your child receive Early Childhood Special Education (ECSE)?
 - Have the services and supports your child has received in the K-12 education system been helpful? Why or why not?
 - What services and supports were the most helpful for your child? The least helpful?
 - In what ways could these educational services and supports be improved?
 - What are some ways that the school and interveners could work with parents?

- In your experience, to what extent have the school services your child is receiving connected with non-school related services (if at all)? What could be improved in connecting services for your child?
 - What are additional supports you felt you needed from the K-12 school system that you did not get (if any)?
8. (For parents with older children/youth) Now we'll talk more about your child's transition out of school.
- Do you have a coordinated plan and/or transition plan? Can you tell me about how these plans were created? To what degree has your child been involved in creating this transition plan?
 - During your child's transition out of school, what services and supports did you get to help make the transition easier?
 - Do you think these plans are in line with your child's goals? (PROBE: like getting a job, more schooling, etc.)
 - What services and supports do you need or want but do not have? What has stopped you from getting these?
9. From your experience, what might cause a family to discontinue, give up, or stop seeking certain services for their child who has a combined hearing and vision loss? Why?
10. What, if anything, do you think is the most important improvement that could be made to the service system for families of children who have a combined hearing and vision loss, in order to best meet their needs?

Professionals interview questions

1. To start, can you tell me about your role and how you work with children or young adults who have combined hearing and vision loss?
 - How do families typically get connected with you?
 - Do you collaborate with other providers working with families of DeafBlind children? (Who, how?)
2. When a child is identified with combined vision and hearing loss, or with a syndrome that tends to lead to combined vision and hearing loss, what would you say are the key resources a family needs right away?
 - When you are working with a child, what would trigger you to refer them to other resources or supports? When do you think it is best for a child to be referred to you?
 - What would you say is "the standard approach" for connecting families to resources? What challenges or barriers have you noticed?

3. To your knowledge, what are the key challenges associated with identifying combined hearing and vision loss?
4. Do you feel there are unmet needs in the existing system? What are they? Why do you think that gap exists?
 - What can systems or service providers do to address these unmet needs?
5. How easy or difficult do you think it is for a family to access the services and supports they need for their child who is DeafBlind? Why do you say that?
 - Are there certain services or supports that are particularly easy to access? Particularly difficult to access? Why do you say that?
6. (For medical professionals only) Thinking about the medical needs of children and young adults who are have a combined hearing and vision loss, what medical supports and services do they need as they age? Are there points in a person's life where you notice a lack of support or increased difficulty in accessing these services or supports?
 - What types of medical supports and services do they need at this point? Who or what is best positioned to provide that support?
 - How are families or medical professionals involved in planning for transitions like these? Are there connections or collaborations that are needed but don't currently exist?
7. (For all other professionals) Thinking about the needs of children and young adults who are DeafBlind, are there points in that person's life where you notice a lack of support?
 - What types of support would be helpful at these points? Who or what is best positioned to provide that support?
 - How are families or professionals involved in planning for transitions like these? Are there connections or collaborations that are needed but don't currently exist?
8. What one systems change would make the greatest positive impact in the lives of children who are DeafBlind and their families?
 - Are you aware of any promising practices that are working well in other parts of the state/country?
 - Are there any programs or policies that work well in other states we should be aware of?
9. Is there anything else we should know or didn't ask about that is important to understanding the needs of children who are DeafBlind and their families?

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