Strengths, Weaknesses, Opportunities, and Threats Analysis

Minnesota's service system for children age birth to 21 who are deaf, deafblind, and hard of hearing and their families

The following analysis synthesizes results from two sources: 49 interviews with parents and professionals and notes from facilitated discussions with three Collaborative workgroups (birth to age 5, school-age groups, and transition age). Wilder Research conducted the interviews and led the facilitated discussions. This summary of responses and themes is intended to inform the priorities in the 5-Year Collaborative Plan.

Strengths

Multiple themes emerged from discussions about strengths in Minnesota's service system, including **early** *intervention*, successful *collaboration* across systems, and robust *resources* supporting families. These are things that have gone well in the past and that we want to maintain and build on as we determine strategic priorities for this 5-Year Collaborative Plan.

I think the newborn screening is what they're doing well, better early identification, early services. Families are getting services younger than they used to. As a result, I think the children have more language if they're identified early.

-Professional

The Deaf Mentor program is great. So is Minnesota Hands and Voices. I couldn't imagine doing it without them.

-Parent

Disabilities in general are becoming more accepted. We're learning that it's okay. Bullying is more identified as an issue. A lot of those things are going in a really good direction.

-Parent

- The Early Hearing Detection and Intervention system is doing a good job of identifying hearing loss among newborn babies quickly and referring families for audiology and support services.
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 - Clear and strong guidance from the Joint Committee on Infant Hearing.
- State agencies generally work well together to coordinate services and resources. Minnesota is one of only six states that has coordinated services from birth through age 21.
 - Data sharing supports this coordination (Early Childhood Longitudinal Data System and Statewide Longitudinal Educational Data System; Memorandum of Understanding among Minnesota Departments of Education, Health, and Employment and Economic Development).
 - Good professional development opportunities (regional low incidence communities of practice, University of Minnesota and MNCDHH teacher resources).
 - Collaborative's work, facilitated by MNCDHH.

- Early intervention services (Part C) are beneficial for families and provide crucial early language/communication education for families and infants/toddlers.
 - Family-focused, families are in charge.
 - The "binder" has useful information (but perhaps parents aren't always able to understand how it all connects or what to prioritize based on the binder).
 - Some early intervention materials now available in languages other than English.
- We do a good job of collecting data and assessing students academically.
- Social service programs and state resources do a great job in supporting families.
 - Deaf Mentors and DHH Role Models; MNHV and Parent Guides; Help Me Grow; PACER.
 - Minnesota Department of Human Services Consumer Support Grant, which offers greater freedom
 of choice for consumers using home care services.
 - DeafBlind Project Minnesota is very innovative ("best in country"); we have a grant and a DeafBlind intervener.
 - IEP Guide and online resources to help families navigate the IEP process.
 - VECTOR program to help kids prepare for transition and build soft skills for employment; transition guide and online resources for families; summer transition program.
 - PSEO grant (from pepNET \rightarrow National Deaf Center) to help students access postsecondary options.
- Minnesota State Academy for the Deaf and the Metro Deaf School.
- Access to hearing aids has improved in recent years.
 - Hearing aid loan program through University of Minnesota Lions.
 - Mandate for insurance coverage of hearing aids for children up to age 18.
- As a society, we are becoming more inclusive and accepting of disability and differences.

Opportunities

A range of opportunities were identified through the interviews with parents and professionals and the three workgroup sessions, including **new and different models of care** from different fields that can be applied to deaf, deafblind, and hard of hearing services and systems, as well as **specific programs and services that could be expanded**. These opportunities were identified by key stakeholders as things that positively affect the system and the system's ability to meet the needs of children and youth who are deaf, deafblind, and hard of hearing and their families.

Parents need to be given all of the options. I get frustrated when they only get one option, and they should be given all.

-Parent and professional

We have no control over YouTube to make captions better. More teachers are using this, but captions are not sufficient. Some schools have had to send home letters apologizing for the words that have been shown. Technology is not sufficient. But teachers don't have time to watch a whole video beforehand. So we need to make that more accessible for everybody.

-Parent

Type and degree of hearing loss and age makes a difference. The milder the hearing loss the less support there is – students are overlooked and identified later. They think if it's mild to moderate hearing loss it's a mild impact, and that's not true. The later identification – the harder. If a child is identified right away they have a greater advantage.

-Professional

Just people understanding that kids can have hearing loss too, and that doesn't mean that they can't talk. Because it's a low incidence disability, creating awareness for the general public would be great.

-Parent

- Improve education to ensure that families understand that they don't have to choose just one option and stick with it forever; they can try various communication modes and technologies to find the best fit.
- Learn more about how trauma-informed care models can ensure better identification and services.
- Lead K show how MN aligns with this model or consider if MN should participate.
- Expand the Deaf Mentor program.
 - Continue using/strengthen use of the Visual Communication and Sign Language Checklist (standardized assessment tool) to assess the child's progress learning ASL.
 - Need mentors for youth who have cochlear implants and communicate orally; DHH adults who are accepting of children who use these technologies, and more young adult mentors who have experiences more similar to DHH youth today.
- Identify ways to incorporate emerging technologies throughout services and supports.
 - Earlier identification of hearing loss.
 - Assistive hearing technology, personal communication technology.
 - Expand captioning services; remote captioning.
 - Distance technology/distance learning, "flip classroom."
- Expand DHH teacher mentoring.
- Add/expand ASL in schools; add ASL as a world language option for all students.
- Build/strengthen relationships with Indian Reservations.
- Learn from and collaborate with other states.
- The Workforce Innovation and Opportunity Act (WIOA) of 2014 requires states to coordinate workforce development programs to help people get the training, support, and education they need to be successful in the workforce, including pre-employment transition services for youth with disabilities.
- As it continues to be interpreted and implemented, Minnesota's Olmstead Plan (named for a 1999 Supreme Court decision regarding the Americans with Disabilities Act of 1990) could support better integration of services for people with disabilities across a range of needs including employment, housing, education, health, transportation, and community engagement.
- Increased awareness and education for the general public could go a long way toward acceptance and services for people who are deaf, deafblind, and hard of hearing.

Weaknesses/Threats

Weaknesses are internal to the system whereas threats are external to the system and largely not controlled by the Collaborative, but both types of issues need to be planned for and addressed in the 5-Year Collaborative Plan. The weaknesses and threats identified by the parents and professionals who were interviewed and/or who participated in a workgroup discussion centered around families' and children's **access to information, resources, and support** across a range of needs, preferences, family types, and locations around Minnesota; **schools' ability to meet students' needs;** and **teachers and interpreter shortages.**

The first thing the doctor said is it's probably a false fail, don't worry about it. That was a mistake. They should treat every fail test the same. All we were told, as we were walking out the door, was she failed a screen in one ear, but it's no big deal, just follow up with her pediatrician. We walked out thinking it wasn't real, and no big deal. It could not have been further from the truth. So the biggest need is to receive correct information, correct advice, and correct direction. We're tired, we're shocked. And they kind of led us down a belief that wasn't accurate at all.

-Parent

You have to be able to figure out each system, and if it's not working for the child, what do you do? How do you help that child without dropping out of the system? Because that's the default. We keep pointing at the young adult and the parent asking, 'why didn't you do anything?' Well they have. It's a box and if they don't fit in the box, they don't get to access it.

-Parent and professional

I think when you're a new parent and you don't know what you don't know, you assume everyone has the best of intentions and things like that. As time went on, there was a period where I didn't feel as supported and you realize it's really about money, even though the schools will never tell you that.

-Parent

The more hearing loss you have, the more support services there are. Kids in the middle get lost. Having a role model program or helping them connect with others is something that needs to be done.

-Professional

I think there are still some issues with school districts equally serving our kids. So many kids now, because of early intervention, tend to not be eligible for special education services, so we fall into a wait-to-fail model, where they have to fail in their school program in order to get services... I'd rather be proactive. I think that school districts tend to over and underestimate what the kids are capable of.

-Parent and professional

There's been discussion of overall licensure for special ed rather than specialization. I think that is a bad idea not only for D/HH kids, but it's bad for everybody. If you're going to work with students who have autism or behavioral issues, you can't lump them together. I hope and pray that does not become the landscape.

-Professional

There are only so many colleges that provide a full four-year degree for ASL interpreting, and if they do it's private, and no one wants to be \$100,000 in debt, so we can only hire people with a two-year degree.

-Parent and Professional

Especially students that are so isolated by geographic area, or they're in a community that might not have enough access, or are able to get peers together, or get adults who are D/HH to be a role model and help them develop that self-esteem. I see a lot of young people struggling, and then when you exacerbate that with isolation, I think that is where things can get really quite desperate for some of our youth.

-Parent

It's a variety of appointments and if their insurance isn't covering it, it adds up quickly. So then it's not only emotional, it's financial. While Minnesota does have a hearing aid mandate for hearing aids, it still means meeting that deductible.

-Professional

- Families may struggle to find out what resources and services are available to them and may need more support in helping them decide what is best for their child.
 - Audiologists, especially in rural areas, and doctors/pediatricians may not have expertise working with DHH children.
- Children who are DHH and their families in Minnesota are increasingly culturally and linguistically diverse, which results in different service needs and preferences.
- Deaf community perspectives (i.e., ASL as primary mode of communication) may not address the needs, preferences, and identity of children who have milder hearing loss and those who choose to not use ASL for any reason.
- Medical professionals and audiologists (who often speak with the parents first after they have learned of their child's hearing loss) may focus on "fixing" the child's hearing loss, which is not always helpful for support. These professionals may emphasize amplification and oral language, and in some cases may even discourage parents from learning and using ASL with their child.
- There are several issues with the ways that schools approach working with and educating kids who are DHH and their families.
 - School systems are not always in tune with the specific needs of DHH kids; they may be making
 decisions based on available resources versus the needs of the DHH student.
 - DHH students may be moved to a 504 plan (which provides monitoring but no additional services) when they may need the services that come with an IEP.
 - Not enough support and trained professionals in schools specifically for deafblind students and students who are deaf+ (DHH with a disability).
 - IDEA pushes students to their neighborhood schools, which may isolate DHH students rather than clustering students within the district and region in one school so they have more access to peers. (The "least restrictive environment (LRE)" for a child who uses American Sign Language as their primary language may not necessarily be their home school district.)
- There are significant teacher shortages and concerns about teacher qualifications.
 - If all special education teachers are lumped together under a non-categorical license (instead of having DHH and other specializations), this could lead to teachers serving students who are DHH (and students with other "low incidence" disabilities) who do not have specialized training or experience.
 - Teachers may not be adequately trained to address the range of communication modes and assistive technologies used by their students; administrators may not understand this when they are deciding about staffing and services for students.

- DHH teachers in rural Minnesota have to travel a lot and have very limited/inadequate time directly serving students and families. (These DHH teachers end up advising the child's classroom teacher rather than providing direct instruction to the child.)
- Teacher training and recruitment programs (e.g., University of Minnesota and Faribault summer program) have been cut or have reduced enrollment, which has resulted in fewer qualified DHH teachers entering the field, and at the same time many existing DHH teachers around MN are approaching retirement.
- There are concerns about educational interpreter qualifications (and shortages of qualified interpreters) and the negative impact that has on students' learning.
 - MDE provided guidance to school districts that they may hire less qualified/uncertified interpreters.
- Also need to increase availability of other professionals (speech language pathologists, audiologists, mental health providers), especially in rural Minnesota.
- Rural Minnesota needs access to better services; the metro is ahead of rural Minnesota in terms of what
 is offered/available.
 - Youth who are DHH in rural Minnesota are isolated; they often don't have DHH peers they can connect with.
- Kids who have milder hearing loss and/or those who do not have IEPs are often left in a "middle ground" with a lack of support but they still struggle to keep up in school.
- Youth who are DHH need more opportunities for career exploration, job training, and work experience.
 - Vocational Rehabilitation services may not be accessible to all students who are DHH and who need these services.
 - Employers may need more training on how to effectively work with employees who are DHH, especially those who are newer to the workforce.
 - Youth who are DHH may need support to self-advocate for workplace accommodations they need and are entitled to.
- Supports that students who are DHH receive through 12th grade may drop off in college, and students and their families may struggle to find out how to get access to needed accommodations and supports.
- Families struggle to pay for the services and technologies their child needs.
- Families struggle to participate in services and activities due to busy work schedules and family life. It is difficult for parents to take extra time off work to go to the audiologist, or coordinate Deaf Mentor program participation with other family activities, etc.

For more information:

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