

NDVS/SB OUTREACH NEWSLETTER

NDVS/SB provides individualized services and resources to infants, children, and adults with visual impairment to empower them in achieving their goals.



Presley with her husband Charles and their daughters, Rose (left), Maria (center), and Nora (on lap).

The Way "Forward": Advice from ND's @prevailandbraillemama

about how sad and tragic their lives (and mine) must be. However, it's so far from the truth. I try to convey that on my page. I want to be a place to bring hope and connection to other parents of kids who have visual impairments. I also try to address misconceptions that many have.

You have a huge following on Instagram. Why do you think that is?

Originally, I shared a lot of videos featuring my daughters, showing their current developmental stage or how typical some aspects of our life are despite two children being blind. I think most people have minimal exposure to blindness and are suckers for cute kid content. Many videos have reached hundreds of thousands of views, and many of those viewers have turned into followers. Partly because of the massive following, I've recently decided to basically remove my kids from my content. I don't feel comfortable sharing them online. Therefore, now I'm trying to focus more on my experiences as a parent of blind children.

What advice would you offer a parent who just found out their child has a visual impairment?

First, check to see if your child qualifies for early intervention. If they qualify, there is no cost to you and the therapists come right to your home (or wherever your child is during the day). I didn't understand this when it was first suggested to us for Rose, and I was hesitant because I didn't think we could commit to the travel and cost. Come to find out, those should not have been concerns! Early intervention connected us with our first TVI, who was so educational. Plus, having someone track your child's development weekly is extremely helpful, especially if you can attend many of the meetings as well.

Secondly, learn the stories of successful people who are blind. I think it's crucial for parents to believe their kids can achieve anything. Learning about real people who have accomplished great things has been very helpful to me.

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After her daughter Nora was born in 2021, Presley Forward began writing a blog to help educate the people in her small community in North Dakota about blindness. Nora and her oldest daughter Rose had both been born with Peter's Anomaly and microphthalmia and were blind. "I really disliked talking to others about Rose's visual impairment in front of her like, 'Hi. Meet Rose. She's blind.' I detested the idea of her blindness being her main identifier because that's just a small piece of her. So I wrote a post on tips for interacting with her that I shared online. That way, people could better accommodate her without it constantly being brought up in front of Rose." Soon, Presley started an Instagram page to direct people to her blog, and now, @prevailandbraillemama has close to 200,000 followers. On it, she shares what family life is like with her three daughters, Rose (5), Maria (3), who is fully sighted, and Nora (1). Read on to find out more about Presley and her family.

What services have you received from NDVS/SB?

We've worked with TVIs since Rose and Nora were babies. Especially because I had no experience with visual impairments when Rose was born, I gained so much knowledge from her TVI each month. She always left me feeling more confident in my abilities to teach and accommodate Rose. The girls also both receive O&M services through NDVS/SB. Nora started taking her first steps at the end of October when she was 19 months old, so I'm looking forward to seeing how she takes to her cane.

Tell us about your Instagram page, @prevailandbraillemama.

Rose is the first blind person I ever met. I think society has a pretty negative view of disabilities, blindness included. This idea is reinforced in comments I often get on my page

The Way "Forward," continued from page 1...

What do you wish educators knew about vision loss?

People with vision loss can live independently, and parents and educators have the opportunity to teach and encourage those independent living skills. Educators may feel like they are helping by doing tasks for a visually impaired student, but what's more helpful is supporting skill development. Also, encourage students to be independent as much as possible and to advocate for their own needs.

Also, accommodations help students access their education. They must have an accessible way to learn and show mastery. It is crucial. (This still applies for a child who doesn't "appear" to have a visual impairment

or who "seems to get around just fine." If it's in the IEP, provide the accommodation.)

Why did you attend Family Weekend in 2022?

Mostly, I want to connect with other parents! We share a very unique experience, and it's a great opportunity for us to get together. I also love meeting blind adults and hearing their stories. I only have had second-hand experience with blindness for five years. There is so much to learn from adults with lived experience that will help shape how I raise my kids.

Do you plan to attend in 2023?

Definitely! I connect with many parents of blind children online, but there is something so special about real life, face-to-face connections with people in your area.



THE BEST OF ME IN 2023!

**Family Weekend
March 31 - April 1
Bismarck, ND**

Speakers include Richard Crawford and Robbin Clark! Meet, connect, and learn from other families who are raising children with vision loss.



Resource Spotlight

**American Printing House
for the Blind**
aph.org

The American Printing House for the Blind is the world's largest nonprofit organization creating accessible learning experiences through educational, workplace, and independent living products and services for people who are blind or visually impaired. It was founded in 1858 after a blind man from Mississippi convinced his state to charter a publishing house to print books in raised letters, located in Louisville, Kentucky.

Each year, NDVS/SB receives federal funding to purchase textbooks and accessible materials for the students and adults they serve. Anyone can order materials directly from APH, but reach out to your Regional Coordinator, APH Coordinator Lilly Mankie (lmankie@nd.gov, 701-795-2732), or APH EOT Emily Stenberg Brown (estenber@nd.gov, 701-795-2709) for more information.

APH.org is more than just a shopping website. It has information for educators, parents, and families. Here are a few spots that we recommend you check out. Click on each heading to go to the website.

[Find Holiday Gift Ideas for Everyone on Your List](#)

[Connect and learn from other families on Family Connect](#)

[Learn more about Cortical Visual Impairment: CVI: The Conversation Continues](#)



[Download, browse, or order APH Catalogs](#)

[VisionAware helps adults with visual impairment lead more independent lives](#)