

FAMILY SUPPORT MAKES A DIFFERENCE WITH A DEAFBLIND CHILD:

Orion's Journey

By Heather Withrow

Twenty-five weeks into my pregnancy, we learned that our new son's eyes were not developing, a condition called complex bilateral microphthalmia, and that he would be born blind. When Orion arrived on July 19, 2010, indeed his eyes had not developed. Further, there were no responses to the hearing screening tests given at the hospital; a subsequent test showed profound deafness.

While some people feel that an infant who will never see or hear can bring only heartache, we—his deaf parents, hearing sister, and deaf brother—knew differently. My husband and I were aware of how deafness could be perceived as unfortunate, and we did not like the perception. Our lives are full—both professionally and personally—our friendships deep, our children active. After the initial shock and grief of learning Orion's prognosis, we put on our "Deaf Can" lens to appreciate our newborn son. We were overjoyed to meet him and amazed by his beautiful wizard-white hair. We knew he would show us much that we had been missing about deafblind children and about life itself.

The cause of Orion's deafblindness—as well as the cause of deafness for myself, my husband, and Orion's big brother Skyler—is genetic. My husband and I have Waardenburg Syndrome type 2a (WS2a), meaning each of us carries a single copy of a gene that causes a series of factors, including deafness. Orion got a copy of the WS2a gene from each of us, and the most noticeable results are his deafness, blindness, and lack of pigment in the hair. Dr. Brian Brooks at the National Institutes of Health's National Eye Institute, in Bethesda, Maryland, is investigating this condition called COMMAD (or coloboma, osteopetrosis, microphthalmia, macrocephaly, albinism, and deafness). Apparently, it had not been seen or even read about in medical journals prior to Orion's birth.

Deafblindness: An Information-Gathering Disability

Deafblindness is not just about the absence of sight and sound. It is so much more than the sum of these two parts. What one learns from experiencing the collaboration between a teacher of the deaf and a teacher of the visually impaired is that deafblindness

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Clockwise from top

left: Orion's siblings holding him for the first time; with teachers in KDES's PIP classroom; (center) a happy boy at 8 months; with Mommy at 10 months in his PIP classroom; exploring Daddy's face.

Photos courtesy of Heather Withrow



is a unique condition “out on its own,” with separate challenges and intervention needs from either deafness or blindness alone. It is, as Dr. Linda Mamer—a teacher and consultant in the areas of blindness, low vision, deafness, and multiple disabilities—has said, “an information-gathering disability.”

Some deafblind children may have a bit of the senses of vision and hearing, but their primary sense is that of touch, and this sense attains overwhelming importance. Even children who can’t or don’t yet actively use their hands to “look” can feel through the skin all over their body. They can come to know human touch in its gentleness or

intensity, hugs, kisses, and the brush of soft cheeks. They can know the warmth of the sun; the purring of a cat; and the slithering of cold, gooey ice cream as it dribbles down their chest. They can know the textures of their toys, the feel of the toilet lid dropping hard, and other details of their environment.

Information does not flow as quickly through touch as it does through sight. Sighted toddlers identify objects instantaneously. Young and sighted children take in pointed ears, delicate whiskers, tail, and paws, and they know right away the object is a cat. A deafblind child needs the time to touch each of these—ears, nose, whiskers, tail, paws—and to feel the animal purr.

As the child experiences the cat, recognizes the parts as they are consistently found in the same places and the purr as it reoccurs, he or she builds a memory of these shapes and characteristics into the concept of *cat*. Once the child has the concept of what a cat is, he or she can associate this concept, with all its pieces, into first a symbolic and eventually a linguistic representation.

Now as Orion is ready to turn 7 years old, we know that once a deafblind child has a loving family, the top three biggest difference-makers in his or her life are:

- early intervention services,



Left: Orion at 17 months during physical therapy time in KDES's PIP classroom.

blindness are the same for all children, when a child is born deafblind, the impact is unique.

Orion received home visits every other week from a teacher of the deaf and a teacher of the visually impaired. He also received occupational and physical therapy, and we were able to borrow equipment from the county, including a mobile stander and a gait trainer—devices that would support his being upright and

eventually perhaps learning to walk. This equipment allowed Orion a new experience with gravity and how to use his legs. This was necessary because without vision or hearing, Orion had no access to information about what legs, hands, feet, and arms are for or how they are used. Being held upright gave him the practice of standing and opportunities for keeping his head up.

At 4 months old, Orion had the unique opportunity to experience two early intervention programs at the same time when he started attending the Parent-Infant Program (PIP) at Kendall Demonstration Elementary School (KDES) in Washington, D.C. He already had an Individualized Family Service Plan (IFSP) through our county of residence as entitled by law, and now he had a second IFSP through the school. In both programs, we found incredible individuals who were joyful and skillful in working with our son. Although it was not required, representatives from

each program visited the others' program to coordinate care, an undertaking that was special and deeply appreciated. Each program's IFSP contributed to Orion's growth. While PIP provided language-rich signers who knew how to communicate tactilely, the county program had essential loaner equipment. As a stay-at-home mom with a little more "brain to myself" time than many people, I found it fairly easy to coordinate the schedules.

These programs—and the support of the state's Deaf-Blind Project—enabled Orion to begin his development in communication and physical development early, and the curve of his development was exponential.

State Deaf-Blind Project

Every state has a federally funded Deaf-Blind Project that families and schools can contact for technical assistance and resources. Projects vary from state to state, but they usually include a director and specialists in Birth-to-5 education, family involvement, transition, and K-12 planning.

During the first two years of Orion's life, we connected with Maryland's Deaf-Blind Project called Connections Beyond Sight and Sound. We were delighted that the personnel from this program involved themselves directly in our lives, coming to our home, meeting with Orion's teachers, and offering consultations and coaching. They also provided workshops that enlightened and empowered all of us—family members, professionals, and therapists.

When Orion was 2 years old, we moved to Texas and the services continued. The names and faces were different, but the hearts were equally warm ... and the expertise, support, and resource connections for our family were the same. Training and conferences on topics such as family leadership, communication, and interveners fill our calendar—and their services will continue through Orion's transition to the workplace!

- the Deaf-Blind Project run by every state with its outreach and technical support specialists, and
- interveners who are trained to work one-to-one with deafblind individuals and enable them to explore the world.

Early Intervention

Orion began receiving early intervention services when he was only 3 months old in Prince George's County, Maryland, where we lived. Knowing that early intervention is key for children with disabilities, I had wanted to begin the intake process even before he was born. Our oldest child, Skyler, had received county services related to deafness, but deafblindness was a new sensory disability for us. We felt we needed help—information and resources—so that we could appropriately support Orion at home. We were right. We would soon learn that while the physical and medical aspects of deafness and

Interveners

Anne Sullivan, the famous partner of Helen Keller, might be regarded as the first successful intervener for a deafblind child. Interveners are individuals who have taken intensive training on deafblindness and work to actively assist the deafblind children in their daily lives and learning. In *A Family's Guide to Interveners*, a booklet developed by



Above: Physical therapy service time at TSD.

parents and professionals, the authors note that interveners are critical in the development of deafblind children. They have the important tasks of seeking out opportunities for teaching using otherwise incidental situations, and they must develop a bond of trust with the child that supports a relaxed and nurturing learning environment. Linda Alsop, one of the booklet's authors, notes that the three major roles of an intervener working with deafblind individuals are to facilitate:

- access to the environment,
- access to communication, and

- access to social and emotional development.

Interveners are becoming more common throughout the United States ... however, not quickly enough or in large enough numbers to meet the needs of the nation's 9,574 school-aged deafblind students (National Center on Deaf-Blindness, 2015). Parents need to be aware that life-skills teachers, care providers, and others whom the school may hire to do this work are not interveners; interveners undergo specialized training, and they can be recognized with a national certificate through the National Intervener Certification E-portfolio.

Our Texas Experience

At 2 years old, Orion became the first deafblind student in memory to enroll at the Texas School for the Deaf (TSD). Orion's first TSD teacher in what is now called the Toddler Learning Center had trained as a teacher of the deaf. When she met Orion, however, she became not only interested but enthusiastic in learning about deafblindness and how to work with our precious deafblind boy. Immediately she was on the floor with him, putting her skin against his, communicating through touch. She imitated Orion and she modeled for him. In addition, she attended workshops, took online intervener courses, and studied up on communication and teaching strategies. Orion was very fortunate to have her on his team early on. Further, at TSD Orion joined other deaf babies and toddlers, some with additional

Right: Intervener Nanette signs *finished* while they put Orion's plate in the "finish box."

disabilities. We enjoyed seeing him as he responded positively to his fellow classmates' little hands.

TSD provided a full range of services—an interdisciplinary team of people with specialties in speech-language, occupational therapy, physical therapy, vision, orientation and mobility, and audiology. We also had support from the Blind Children's Vocational Discovery and Development Program, under Texas Health and Human Services, and the Deaf-Blind Project's specialist in children under 5 years old. With so many valuable team members, our meetings—first for the IFSP and then for the Individualized Education Program (IEP)—were major feats.

When Orion turned 3 years old and graduated from the early intervention program, we had the same support services. However, except for the deafblind Birth-to-5 specialist and the blind children's program specialist, these were now provided by TSD. TSD hired Orion's first intervener, an individual with experience in working with deafblind children, who worked with both him and his teacher.

When Orion was 5 years old, he visited the classrooms at the Texas School for the Blind and Visually Impaired (TSBVI) for the first time. He went twice a week for the school day with his TSD interveners and joined in on some class activities, including yoga,





Left: Orion, age 6, with his current teacher, Jenny Otto.

swimming, and cooking. Whether at TSD or TSBVI, he continued to work with his interveners on walking with less support, making requests, and learning about his world. The program was there for him, and we were so grateful to take advantage of it.

Now 6 years old, Orion is enrolled full time in the deafblind program at TSBVI. He rides the local school bus to and from school. At TSBVI, interveners are no longer necessary because everyone possesses intervener skills there and the staff-to-deafblind student ratio is 1:1. Orion has two classmates and a teacher, a teacher aide, and other service providers who provide IEP services and programming activities. Together, they provide a community of teachers and administrators who understand the students' needs and who ensure both that the programming is meaningful for each student and that warmth, companionship, and learning are ongoing throughout the school day ... an ideal world for our deafblind children.

In Home and Community

As Orion has grown, the role of interveners has expanded. As children become bigger, heavier, and more active, it becomes harder to pay attention to

friends' conversations, doctors' explanations, presentations, volleyball games, and church sermons. Orion wants to get up and move around rather than sit submissively in his stroller. Even eating at restaurants is difficult as Orion loves to slither off the dining

benches to lay down on the dirty floor. A community intervener, with the same training as the interveners in schools, becomes essential.

At home, Orion's intervener interacts with him, responds to him, and supports him in getting where he wants to go. The intervener also ensures activities are labeled with tactile signs. She uses "object cues" (e.g., a spoon represents mealtime) to teach and communicate. Our goal is for Orion to learn language and other skills through routines he knows well, including self-care, eating, and playing. Orion leads his intervener along familiar routes inside the home. He knows where he wants to go: to the bed, to the bathtub, to a toy box, or to the kitchen table.

While Orion's intervener is with us, I can focus on being "just Orion's mom" and not Orion's parent/intervener/teacher/physical therapist/occupational therapist. When the intervener is not

Deafblindness: Modules for Learning

We, the families of deafblind children and adults and professionals in the field of deafblindness in the United States, have adopted the Canadian intervener motto: "Do with, not for." This is discussed in one of 27 Open Hands, Open Access DeafBlind Intervener Training Modules.

The U.S. Office of Special Education Programs designated the National Center on DeafBlindness to develop modules based on the Council for Exceptional Children's competency standards for interveners for individuals with deafblindness. The last of the modules was completed in October 2016 after four years of development and collaboration among interveners, family members, deafblind individuals, interpreters, teachers, state deafblind project personnel, and deafblind consultants.

These modules are a rich resource for families, administrators, teachers, and providers of support services. In fact, they are helpful to anyone who is involved in a deafblind child's life.

For more information, visit <http://moodle.nationaldb.org>.

there, this all-in-one superhuman combo is what my husband and I try out of necessity to become. Our time out together in the community is rare because one of us is usually home with Orion meeting his needs unless we have a community intervener present.

The needs of a deafblind child do not stop with the child. They radiate through the family. Our other children need nurturing, too. We celebrate all our children's successes. For our older children, this means the celebration of mostly A's on report cards, receiving outstanding citizenship awards, or making it through multiple rounds at the spelling bee. For Orion, it means signing *shoe* and *diaper* and getting on his hands and knees independently. The birth of Orion has caused us to make sacrifices. Still, we are rewarded with smiles, laughter, and accomplishments of every kind that make all those sacrifices worthwhile.

The progress made by Orion and other deafblind children is not a miracle. It is the result of the informed efforts and abilities of the children's families as well as those of qualified interveners and teachers. I wish that every deafblind child had services and access to interveners and teachers of the deafblind as soon as he or she was evaluated. We were very fortunate that this occurred with Orion. The professionals—teachers, interveners, and therapists—who have blessed Orion's life have blessed our lives, too.

Reference

National Center on Deaf-Blindness. (2015). *National deaf-blind child count*. Monmouth, OR: The Research Institute, Western Oregon University. Retrieved October 11, 2016, from <https://nationaldb.org/pages/show/2015-national-deaf-blind-child-count/overall-population-demographics>.

Helpful Resources Related to Deafblindness

Many of the following resources have proved helpful to us on our journey with Orion. Included as well are resources that may be helpful to those individuals interested in learning more about educational programs for interveners.

- **Anne Sullivan**, Perkins School for the Blind, www.perkins.org/history/people/anne-sullivan
- **Deafblind Intervener Training**, Utah State University, <https://online.usu.edu/deafblindness-cert>
- **ECU Certificate in Deafblindness**, East Carolina University, www.ecu.edu
- **A Family's Guide to Interveners for Children with Combined Vision and Hearing Loss** (by Linda Alsop and others), SKI-HI Institute, <http://intervener.org>
- **Helen Keller**, Perkins School for the Blind, www.perkins.org/history/people/helen-keller
- **Interveners & Intervention**, Provincial Outreach Program for Students with Deafblindness, <http://popdb.sd38.bc.ca/>
- **Laura Bridgman**, Perkins School for the Blind, www.perkins.org/history/people/laura-bridgman
- **Microphthalmia**, Wikipedia, <https://en.wikipedia.org/wiki/Microphthalmia>
- **A Parent's Guide to Services at TSBVI**, www.tsbvi.edu/parent-s-guide-to-tsbvi-services
- **Special Education—Dual Sensory Impairments (MEd)**, Texas Tech University, www.depts.ttu.edu/education/graduate/psychology-and-leadership/special_education_dual_sensory_impairments.php
- **Teachers of Students with DeafBlindness Pilot, Part II**, Chris Montgomery, Texas SENSE Abilities, www.tsbvi.edu/spring-2016-newsletter/5007-tdb-pilot-part-2
- **Undergraduate Certificate (Deafblind Intervener)**, Central Michigan University, www.cmich.edu
- **What is an Intervener?** Interveners, <http://intervener.org>
- **What is NICE?** National Center on Deaf-Blindness, <https://nationaldb.org>