

Usher Syndrome Coalition | Overview of the National Center on Deaf-Blindness (NCDB)

Hello. My name is Megan Cote, and I am the initiative lead for Family Engagement and Early Identification and Referral at the National Center on Deaf-Blindness, also known as NCDB. I want to thank you for listening to my brief overview on the National Center, and hope to help you understand what we have to offer to parents, and ways in which you can connect to resources and support. So let me start by explaining what NCDB is.

We are a technical assistance center funded by the Federal Department of Education. The term "technical assistance" is used in education to mean consultation or help. So NCDB works with state deaf-blind projects and national family organizations to help improve quality of life for children who are deaf-blind, and their families.

At NCDB we have six initiatives or areas where we focus our work. They are, one, Early Identification and Referral, which involves working to find the children as early as possible and get them referred to their state deaf-blind project if a dual loss is suspected.

The second is Family Engagement, specifically how we can more effectively connect parents to resources and support. The third is Interveners and Qualified Personnel, and the work of this initiative centers around increasing the number of qualified personnel who can support the educational development of kids with deaf-blindness. Our fourth is Literacy, which focuses on how to assess reading readiness and potential needed modifications of support.

The National Child Count is our fifth initiative, which helps us know how many kids have been identified birth through 21, where they're located, and their ages and their primary etiologies. And the last and sixth initiative is Transition, and much of the work in this area focuses on planning for the transition to adult life, specifically what parents need to do to attempt to ensure that appropriate supports are in place for their child after graduating from the educational system.

So let me explain a little bit more about the National Deaf-Blind Child Count. Annually, each state deaf-blind project conducts a census of children and youth who are deaf-blind, birth through age 21. Then the information from all the states gets sent to the National Center and compiled into a report called the National Child Count of Children and Youth Who Are Deaf-Blind. To find out if your child is eligible for services through your state deaf-blind project, contact them directly, as each state deaf-blind project has their own certification process.

So here's a few interesting pieces of data for you from the 2015 National Deaf-Blind Child Count. There were 9,574 children, birth through 21, on the 2015 National Child Count, and of those 9,574 children, 295 have been diagnosed with Usher syndrome, and over 2/3 are between the ages of 12 and 22, which accounts for 68.5% of the children diagnosed with Usher syndrome on the National Child Count, and approximately 10% of those kids

are under the age of 6.

So as a parent, what resources does NCDB have for you? Well, you could create a profile and join initiatives that are of interest to you on our website. You can also learn about upcoming trainings across the nation on our website. You can browse our resource library, which also includes an advanced search feature. You can visit our For Families section of our website, which has information directed specifically to families, and view on that page the Family Matters stories, which are stories collected from families across the network where they talk about the experiences that they've had in raising their children. You can find the contact information for your state deaf-blind project, and you can also follow us on Facebook and Twitter.

So now let me show you how to create a profile on our site. On this slide, you'll see a screenshot of the home page of the NCDB website, and on the lower left corner, you can see the red arrow that says Make a Profile. When you go there, it will lead you through a few simple steps to help you create a profile on our site. Once your profile is made, you can then select initiatives that are of interest to you and join them so you can receive email notifications to let you know when something has been added to a group. This will be an easy and simple way of keeping you up to date with opportunities for you to get involved in, and also engage in discussions.

I want to make sure, though, that you know that creating a profile is not required for you to use our website. You're more than welcome to explore without one. We've just added that feature in the event that you are interested in receiving updates from us about the work being done across the network.

This next slide gives you information about how to do an advanced library search on our website, and on this slide there's a screenshot of the library page of the NCDB website. And on the top toolbar, there is a burgundy-colored strip, and you'll see that the third item from the left says Library. When you click on that, a drop-down menu will appear, and you can then click on Advanced Search. Once you're there, it will direct you to a page that allows you to search by topic of interest. You will hopefully find this feature to be a huge benefit for narrowing your search of materials and information about selected topics that interest you, as there's so much information available to us now that searching can sometimes be overwhelming. So we hope that this will be of assistance to you.

This next slide shows you a little bit of information about how you can locate your state deaf-blind project on the National Center website. So when you go to the landing page of the NCDB website, if you scroll down a bit, on the right you'll notice a United States map with the state that you are in highlighted, and your project contact information for that state. But you can also go to the link listed on this page and get a listing of all the state deaf-blind projects, including a link to their project website and contact information for the folks who work at that project.

So you may be asking yourself, why should I connect with my state deaf-blind project, and what can they do for

me? Well, the answer varies from state project to state project in terms of the specific services they can provide, but all projects offer local training and support as well as a connection to other families in your area. They also have specific knowledge to help you navigate the various systems in your state, which as a parent can be extremely invaluable.

An additional resource is the Open Hands, Open Access, also known as OHOA, learning modules. These are free, self-paced modules that were created to increase awareness, knowledge, and skills related to the process of intervention for students who are deaf-blind. As a parent, these are a great resource for you to build your knowledge about deaf-blindness and also to share with providers who work with your child. And for more information about them, you can go to the link listed on this slide, which is nationaldb.org/ohoamoodle/.

An additional resource is the National Family Association for Deaf-Blind, also known as NFADB. And they are a nonprofit organization that has served families of individuals who are deaf-blind since 1994, and they offer family members chances for advocacy for families of persons who are deaf-blind. They connect families to information and resources, they provide training and support, and they also bring families together for trainings. And they're a lifetime support for families, which is a distinction that's unique to the National Family Association. Where the NCDB focuses on servicing of children birth through 21, NFADB is a lifetime continuum of support for families.

An additional family resource is Family-to-Family Connections. This is a collaborative project amongst state deaf-blind projects, NFADB and NCDB, where families meet monthly via phone or computer to discuss topics of interest, share their knowledge, and offer support to one another. An enrollment typically occurs in the fall, and it is free. If you are interested, you need to contact Carol Darrah, and I've provided her email address here, which is cdarrah@uga.edu.

The second resource listed on this slide is information about state and local parent centers. Every state has at least one federally funded parent center, which provides parents of children with disabilities information about local and educational services, and their child's rights under IDEA. Visit this site to find out about your local parent centers and browse general resources about special education.

Two additional family resources that we thought would be of benefit to you are iCanConnect, which is a federally funded program that provides free distance communication technology to people with combined vision and hearing loss, and their website is <http://www.icanconnect.org>. And an additional one is Helen Keller National Center for deaf-blind youth and adults. And they provide individualized residential training for teens and adults on their campus in New York, and information about local resources and services via their regional representatives throughout the country. And their website is <https://www.hellenkeller.org/hknc>.

This final slide is a resource that I want to share, which is a blog written by a lovely woman named Patti McGowan

called *Paths to Transition*. This is a blog written by a mother of a young woman who has Usher type 2, and her son Hunter has also written some posts for the site. So if you are a family that's interested in watching another family's journey of having a child with Usher, I strongly recommend that you check this out. And the web site is also included here, which is <http://www.perkinselearning.org/users/patti-mcgowan>.

So I sincerely hope that I've convinced you all to make connection with your state deaf-blind project, investigate becoming a member of NFADB, and connect to knowledge and training through the resources at NCDB. Please don't hesitate to contact me or any of the other NCDB staff members if we can be of assistance to you and your family, and thanks so much for your interest and time. I hope you have a great day.