



Poster Presentation

Partnering to Give Parents a Voice

Megan Cote, National Center on Deaf-Blindness
Sheri Stanger, CHARGE Syndrome Foundation
Melanie Knapp, NFADB

Presenter Information

Megan Cote is the Initiative Lead at the National Center on Deaf-Blindness (NCDB) for Family Engagement. In her 26-year career in special education, she has been a classroom teacher, educational consultant, director of the Kansas Deaf-Blind Project, and has worked on multiple grant projects. Megan earned her Master's degree at the University of Kansas in Special Education. As a board member for the CHARGE Syndrome Foundation, she has worked to expand and shape the CHARGE State Liaison program and the outreach services they provide to families.

Sheri Stanger, MA, EdM, has worked in the disability field for 28 years and is currently the Director of Outreach for the CHARGE Syndrome Foundation. She also runs a national CHARGE tele-support group. Sheri received her Master's Degrees from Teachers College, Columbia University in Psychological Counseling. Prior to becoming Director of Outreach for the Foundation, she worked as a rehabilitation counselor, school counselor for children with vision and hearing loss and as a consultant for the NY State Deaf-Blind Collaborative. She is a past president for the National Family Association for Deaf-Blind, was a board member for 18 years and started the agency's Affiliate Network. Sheri is the mother of two adult children: Megan, 25 years old with CHARGE syndrome, is doing self-directed services while Matthew, 22 years old, just graduated from college.

Melanie Knapp is a board member of NFADB who has spent over 20 years advocating for the needs of individuals with deaf-blindness and their families. Prior to serving in this role, she spent 14 years on the board of The Deaf-Blind Multihandicapped Association of Texas (DBMAT).

Presentation Abstract

We will explain the distinct roles of the National Center on Deaf-Blindness, the CHARGE Syndrome Foundation, and the National Family Association for Deaf-Blind and describe how work conducted by the three organizations supports families to access the knowledge and services they need to promote better outcomes for their children and family members who are deaf-blind. Attendees will learn what each organization offers and how to take part in the training and connections they provide.

NATIONAL FAMILY ASSOCIATION FOR DEAF-BLIND

- Nonprofit organization empowering families to advocate for individuals who are deaf-blind
- Connects families through Facebook, webinars (in English and Spanish), and a toll-free number.

NFADB.ORG

CHARGE SYNDROME FOUNDATION

- Nonprofit organization that partners with families and professionals to improve the lives of people with CHARGE syndrome through outreach, education, and research
- Supports families via a director of outreach, webinars, a provider database, extensive online resources, and an international conference every two years

CHARGESYNDROME.ORG

NATIONAL DEAF-BLIND TECHNICAL ASSISTANCE NETWORK

- Funded by the U.S. Department of Education and consists of the National Center on Deaf-Blindness (NCDB) and a deaf-blind project in every state
- NCDB provides online information about all aspects of deaf-blindness
- The state projects offer personalized advice, information, and support to families

NATIONALDB.ORG

WORKING FOR FAMILIES

COMMUNITY - LEARNING - ADVOCACY