14th International CHARGE Syndrome Conference
Dallas, Texas • August 2-5, 2019

Saturday, August 3, 2019

Breakout Session A1 • 10:45-11:45am • Grand Ballroom A/B

Days of our Lives - A Snapshot of Adulthood

Sheri Stanger
Djenne-amal N. Morris
Mary Hancock
Tina Steed

Presenter Information

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 2 adult children: Megan, 25 years old with CHARGE syndrome, is doing self-directed services while Matthew, 22 years old, is a senior in college.

Djenne-amal N. Morris, BA, the mother of an amazing son with CHARGE syndrome, brings passion, humor and real-life experience to her role as a national and international parent/professional trainer, facilitator and motivational speaker whose view of the world is not as it is, but as it could be.

Mary Hancock is a parent of a 35 year old son with CHARGE. She has worked in the early childhood field for over 40 years. The resilience her son and family has shown over the years has helped their family survive the challenges of CHARGE. Mary has adapted many early childhood techniques to guide her son throughout the years in the most positive ways possible. She has many adventures to share on how her husband, Phillip's siblings and community worked together.

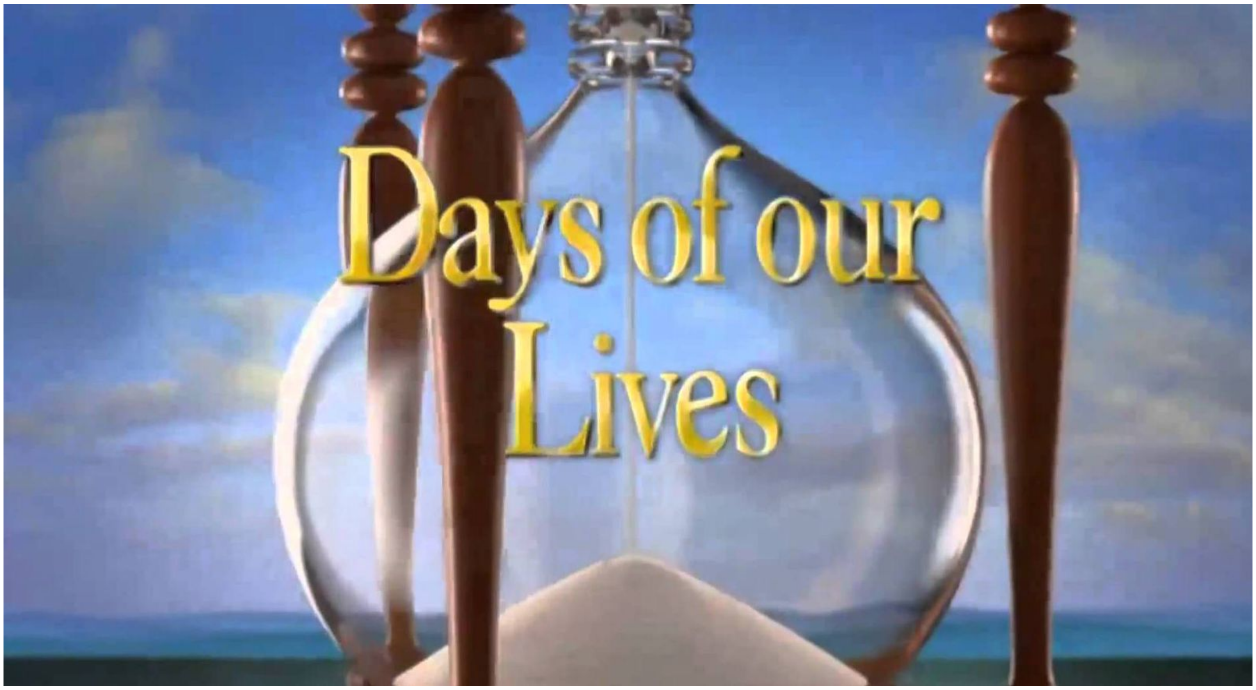
Tina Steed is the mother of Chelsea who was diagnosed with CHARGE at 17 years old. Tina has a BA/MBA from Tarleton State University. She was a Supported Employment Coordinator for 12 years and worked for county and state developmental disability agencies a total of 16 years. She is a Nationally Certified Workforce Development Specialist, Coach, Certified Mentor and continues to assist others (with a variety of disabilities) via the internet and through natural supports.

Presentation Abstract

Are you the family member/caregiver of an adult child or a child in transition to adulthood? Ever wonder what happens after your child leaves the education system? Come hear a panel of parents of adult children with CHARGE syndrome share their unique and diverse experiences on the evolution of creating a fulfilling adult life for their child. Each panelist will share their successes and challenges on their journey to navigating the adult world.

Learning Objectives

- Panelists will share their personal stories about options for adult life to increase knowledge about choices available to families and individuals with CHARGE syndrome.
- Panelists will share their decision making process to demonstrate the different paths available to reaching your adulthood goals
- Participants will gain insight into the social-emotional journey of adult life planning.



A Snapshot of Adulthood

Panelist Family Stories

Sheri & Megan Stanger

Djenne-amal & Malik Morris

Tina & Chelsea Steed

Mary & Phillip Hancock

14th International CHARGE Syndrome Conference - Dallas, TX 2019

My name is Sheri Stanger and many people know me as the Director of Outreach for the CHARGE Syndrome Foundation. What you may not know is that I am a Certified School Counselor and worked in the disability field – specifically in blindness and deaf-blindness before my daughter, Megan, was born in 1993. I continued to work part time until my son, Matthew, was born in 1997. I stayed involved in the field by joining the Board of Directors for the National Family Association for Deaf-Blind (NFADB) in 1998 and continued to volunteer for that organization for the next 18 years as a board member, president and special advisor. NFADB is where I gathered more knowledge, leadership and advocacy skills and truly learned the importance of family connections. As my kids got older, I was ready to return to work and in November 2010 I began to work part-time for the CHARGE Syndrome Foundation.

Megan was born after an uncomplicated pregnancy and was not clinically diagnosed with CHARGE syndrome until 10 months of age. Her medical history is not as involved as some people with CHARGE syndrome but she is visually impaired, hearing impaired, had many developmental delays, severe food allergies and difficulty with swallowing. She attended a school for the blind for EI and Pre-School followed by special education programs, inclusive education settings and Perkins School for the Blind's Deaf-Blind Program as a residential student for her last 5 years of school until she graduated in 2014 with an IEP diploma. Megan is ambulatory, can read print and is verbal. She is extremely social but we struggle with behavioral challenges despite her high level of communication skills.

Our family includes myself, my husband Neal (a 22 year board member and past president of the CHARGE Syndrome Foundation), Matthew (age 22 and recent college graduate in May 2019) and Megan (age 25), a very fluffy dog, Sophie and our new fluffy puppy, Ginny. We live in Hastings-on-Hudson, NY. We have supportive extended family and we receive a lot of help from my parents.

Megan currently lives at home with Neal and I. She is registered with NY State's Office for People with Developmental Disabilities (OPWDD) and receives a budget from the state to do Self Directed Services. She has a full time Community Habilitation Worker with her from 9am-5pm Monday-Friday to support her at home and in the community and to facilitate communication, social interactions, self care skills, work and recreation. Megan has 2 volunteer jobs, is currently working on Supported Employment with a job coach, continues her education with a special college program mentor, exercises at our local JCC, takes drum lessons and belongs to two special recreation programs where she is a member of a swim team, does Zumba, attends a music class, attends dances and also plays Challenger Basketball in the winter. Megan is part of the decision making process as we strive to provide her with meaningful activities where she feels valued, happy and successful.

For further information please contact:
Sheri Stanger
Sheri@chargesyndrome.org

Hi, I am Djenne-amal Morris. I currently live in North Carolina where I wear several different hats. The most important one is the wife to my husband, Michael of 27 years and mother to our 3 incredible children. Imani, 24, lives is Austin, Texas where she is a nanny and works for a non-profit organization. Malik, 23 has CHARGE syndrome and lives on his own in Fayetteville, NC. Zakiya-mali will be a pre-med major at UNC Chapel Hill in August 2019. My other hats include being a Parent Educator at BEGINNINGS for Parents, an NC agency that provides education and support to parents of children with who are deaf, hard of hearing, deafblind. I am also the Family Faculty Advisor for the LEND(Leadership Education in Neurodevelopmental Disorders) at UNC-Chapel Hill and serve as the Board president for Hands & Voices HQ. I have written a book on parent-professional collaboration in the world of disability and do consulting to both families, professionals and organizations.

Malik-asante Lamar was born on March 3, 1996. Within the first year of life he was diagnosed with Tracheoesophageal Fistula, blindness due to colobomas,GERD, failure to thrive, profound deafness and undescended testes and cognitive/developmental delays. He had numerous surgeries in his young life. At 3 years old, he was diagnosed with CHARGE syndrome. Malik attended the Deafblind program at Perkins School for the Blind in Watertown, MA until he was 8. At that time we decided to move to North Carolina due to the harshness of weather that was having an adverse effect on Malik's health. He was only 35 pounds and constantly battling illnesses.

In NC, Malik attended the Eastern North Carolina School for the Deaf for 14 years where he thrived under the care of deafblind interveners and a great medical staff. As an ENCSD residential student, Malik was able to have access to communication in ASL and instruction from trained deafblind interveners who are deaf adults. He graduated in June of 2018.

Malik has a wonderful sense of humor, is obsessed with water bottles and lights, can problem solve and loves to work. During summers and breaks from school, Malik worked at local stores, washed cars, learned to walk our dog, Boston, learned to cook with minimal assistance and does chores around the house and school. His favorite thing to do is go on adventures that include food and drink.

Prior to graduation, we spent several years preparing for transition to adulthood. Through the Person Centered Plan and a few close advisors, we knew Malik would be happiest in an independent living environment with 24 hour supervised care. It was a frightening time, because we knew the choices were very limited given his needs and group home availability. Early 2018, 6 months before graduation, we found Serenity Therapeutic Services Inc. that provides both group homes and a day program. The owner offered to have one of his group homes serve young men who are Deaf. He hired Deaf staff and provided the hearing staff with classes in ASL. We are collaborating to make the home deafblind accessible. Malik attends the day program, the YMCA and volunteers in community activities. It is obviously a work in progress getting employment and other activities set up for Malik but he is happy and content.

For further information:
Djenne-amal Morris
djennemorris@gmail.com
www.todaywithdjenne.com

My name is Tina Steed. I worked for 12 years as a Supported Employment Coordinator for people with developmental and mental health disabilities in the community. I was a Residential Trainer/Therapist Technician for four years for the State of Texas working in a residential and facility-like community. I am a national certified Workforce Development Specialist. I have worked as a coach and am also a coach for Toastmasters International. I am a Certified Mentor. I continue to be able to use Natural Supports to help people with disabilities to keep their jobs and cope with difficult situations. My husband Bobby was also a Residential Trainer/Therapist Technician for several years. Chelsea was born in 1993. She was diagnosed with CHARGE syndrome when she was 17 years old. Some of her major health issues (associated with CHARGE) are as follows: C-Coloboma-Chelsea possibly has a small coloboma; however, she has not had good eye exams to see it; H-Heart: Birth-Atrial Septal Defect, Ventricular Septal Defect and Open PDA-repaired with open heart surgery at 3 weeks; Current-Long QT Syndrome; R-Retardation of Growth and/or Development-Chelsea was very tiny as a young child. She was even diagnosed as *failure to thrive* at one point. She has caught up nicely. Development-Chelsea graduated from high school in 2013. She was mainstreamed from the time she started Kindergarten. She was in PPCD (preschool for developmental reasons) from age 3-5. She had a 1:1 aide throughout her entire education to assist with both school work, speech, hearing and her mobility issues. She also has significant speech issues. G-Genito-Urinary -Missing organs-no uterus and missing an ovary and her gallbladder. E-Ear-Bilateral Profound Hearing Loss-She has worn hearing aids since she was five years old. Chelsea was extremely floppy as an infant. She did not sit up independently until she was about 2 years old. She did not walk until about 2 ½ years old. Chelsea has always been a happy child. In school, she was voted Class Favorite all through high school. She was named Homecoming Duchess and then Homecoming Queen her Senior year. The kids in her class said the following about her: “When they said she could not talk, she talked. When they said she could not walk, she walked. When they said she could not live, she lived. We want her to be our Queen”. When asked what she would do when she graduates, she often said, “Have surgery”. She has had three reconstructive surgeries since graduation and still needs one more. That will be scheduled later.

Chelsea lives at home with her Dad and Mom. Because of the surgeries after high school, Chelsea has not started any outside activities. Chelsea does not work due to her various medical and communication issues. She would like to volunteer, possibly at my work, when she finishes with all her surgeries. We do not see her living in a community type setting. Bobby and I are both trained to teach her the community living skills that she needs to communicate and associate in her community. She is starting to work out at the gym. Her favorite activity at the gym is the recumbent bicycle. Chelsea loves shopping, makeup, jewelry and clothes. She loves playing games on her various electronic devices. She also loves putting anything together and taking it apart (stacking blocks, perler beads, making jewelry). Although she is friendly to wave or say hello to people, she is not comfortable enough to be safe in the community by herself and hold full conversations with people. She is not in any programs through the state and we do not have extended family to assist with her. She enjoys Facetiming with her sister and nephew in California.

Please remember that no matter what your situation or your family member’s situation, you know what is best. My situation may not work for you, but maybe you can learn something from what I do. Always keep an open mind to learning more to help with your child/family member. CHARGE On, My Friends!

For further information please contact:Tina Steed STEED_1@msn.com

My name is Mary Hancock. I am a parent of three children, Rick 39, Keleigh 30 and Phillip is 35 years old with CHARGE. I have a Degree in Education and my husband, Richard has a degree in sociology. My husband, myself and Phillip's two siblings also have had extensive training in Positive Behavior Supports including strategies to support children with challenging behaviors. We own and operate two Private Nationally Accredited Preschools. Phillip's brother is a graduate of the University of Florida and Keleigh is a graduate of Hofstra University.

Phillip was born in 1983 and was unofficially diagnosed with CHARGE a year later. Phillip's CHARGE diagnosis was confirmed at the CHARGE conference in Houston in 1999. We attended the first CHARGE conference in 1993 and have been to 10 more including one in Australia.

Phillip was born after an uncomplicated pregnancy, weighing 7.8 pounds. He was born with Colobomas, Tetralogy of Fallot, Deafness, and underdeveloped genitalia. He had difficulty gaining weight and only weighed 15 pounds at 15 months of age. He has had challenging behaviors for most of his life but these have usually been contributed to his medical issues including a lifelong history of constipation, his inability to communicate and teachers who were unfamiliar with teaching techniques and strategies to work with a deaf-blind child.

Phillip is legally blind, profoundly deaf, socially and mentally immature. He had a complete repair of Tetralogy of Fallot (15 months old) and valve replacement(heart)(22 years old), detached retinas, cornea transplants and glaucoma. He exhibits unusual fears, poor communication skills, can read at a first grade level and has digestive difficulties

We always had a goal for Phillip to become as independent as he feels comfortable. . Phillip attended the Helen Keller National Center in 2005 and 2006. Phillip was very successful at age 22 upon completing the program at HKNC. We attempted a group home for 1 month when he came back to Florida but was unsuccessful in having the agency buy into the resources with which HKNC had trained him. We then bought him a private home within the same deaf community across the street from a typical day program. He had a very nice elderly man After his primary caregiver retired he began to deteriorate emotionally and then physically. Up until age 33 when he lost most of his vision, he worked in the community with a deaf companion, was an avid bike rider and loved to jog around the community. He enjoys electronics. He was able to go shopping using a list for large quantities of items needed for the two preschools we own. He also worked in three preschools one hour/week cleaning the computer areas. Phillip currently lives with his 30 year old sister at night and has an interpreter who assists him with menu and meal planning and grocery shopping every Wednesday. He is responsible for our family dinner every Wednesday night. Phillip has leisurely days in our home with his father. Phillip has separate living quarters in both his daytime and nighttime homes.

We have a large support system for Phillip. He adores his six year old nephew and five year old niece. He enjoys our large family events which include over 20 cousins and 12 aunt and uncles at least 4 times per year.

For further information please contact:
Mary Hancock
Marygoround25@aol.com