

THAT'S HOW I ROLL

THE DIAGNOSIS: TO PROVIDE CONTEXT

- Merosin-Deficient Congenital Muscular Dystrophy
 - A genetic neuromuscular disease
 - Merosin is a protein that keeps muscles stretchy and flexible. I lack this protein, which causes muscles to harden and leads to "muscle wasting"
 - Most common issues include muscle contractures (permanent shortening of muscles or joints), scoliosis (curvature of the spine), feeding issues and respiratory failure
 - Other issues can include facial deformities and eye weakness
 - Diagnosed at 1 year of age

NATURAL SUPPORTS

Extremely supportive family

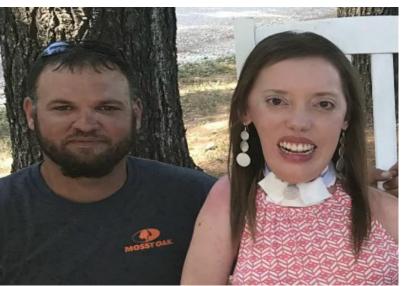
Mom, Dad, older brother, stepparents

Grandparents have always played a huge role in my care

Extended family

Until I went to college, I only utilized natural supports









THE SPECIAL LEARNING CENTER

- Started attending at age 2
- Provided OT/PT/Speech and preschool services
- Very positive atmosphere
- Supported us through some pretty big milestones
 - First wheelchair—age 3
 - Transition to mainstream kindergarten



K-12: SOUTH CALLAWAY

Very supportive and inclusive
OT/PT/Speech services
Full-time Paraprofessional
Always in the mainstream

Assisted with post-high school transition

Introduction to Vocational Rehabilitation

Accommodation Planning

Graduated in 2009

classrooms







COMMUNITY PARTICIPATION

- Muscular Dystrophy Association
 - Labor Day Telethons, Commercials, Radio Interviews, Boot Drives
 - Set the mid-MO record in 2004 for most money raised by a child (\$2400)
- Children's Miracle Network Radiothons—benefitting University of Missouri Children's Hospital
- Various public speaking engagements
 - MO Youth Leadership Forum, Power Up Assistive Technology Conference, LU Spring Institute
- 2015 Recipient of Governor's Council on Disability Youth Leadership Award

LINCOLN UNIVERSITY

- Lived on campus
 - First time utilizing nursing services and navigating a more independent lifestyle
- Started out majoring in social work
 - Knew I wanted to be a social worker since age 13
- Declared 2nd major (psychology) in 2011
- Activities: Student Government Association, Women's Leadership Academy, Alpha Kappa
 Mu Honor Society
 - Through Women's Leadership Academy, I proposed enhancements to accessibility on campus, which were implemented in 2012
- Student editor for a book on counseling with LGBTQ individuals
- Internships: The Special Learning Center, Boys & Girls Club of the Capital City, Missouri Coalition Against Domestic & Sexual Violence
- Graduated Magna Cum Laude in 2015



UNIVERSITY OF MISSOURI SCHOOL OF SOCIAL WORK

- Began the Masters program in January 2016
 - Advanced standing with a concentration in Policy, Planning and Administration
 - Courses included Disability Advocacy, Social Work with Older Adults, and Research Methodology
- Final practicum with Division of Developmental Disabilities, Federal Programs Unit
 - Assisted with HCBS remediation
- Completed MSW program in August 2017—and accepted a position with the Division of Developmental Disabilities, Quality Enhancement Unit



NATIONAL CORE INDICATORS

- National Core Indicators (NCI) Project Coordinator
- NCI is voluntary effort by state DD agencies to measure and track their own performance
 - Coordinated by the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS)
 - Data is collected on the state level using various survey instruments
 - Data is submitted to HSRI, who analyzes the results and produces national and state-specific reports
 - NCI data allows us to track our performance from year to year and compare our performance to other states and the nation
- NCI data helps to inform Division priorities and improve Quality of Life
 - Empowering through Employment Initiative
 - Psychotropic medications
 - Used in the budget and can be used for HCBS waiver assurances
- Stay tuned for some exciting projects to come!

FUN FACTS

- Huge Cardinals fan!!!
- Country music is my favorite!
 - I've had the honor of meeting Martina McBride, Chris Stapleton and Carrie Underwood
- I love to write!
 - Blog: https://accordingtocaitblog.com/
- I'm obsessed with shoes, big earrings, the Eiffel Tower, and dogs
 - Dog Mom to Ruby Rose and Gretchen Louise









