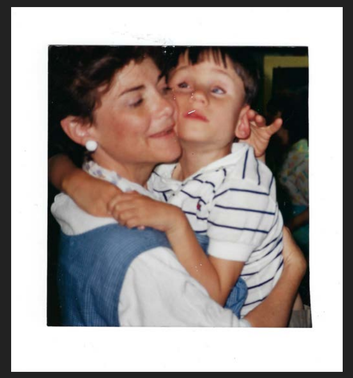
PARENT PERSPECTIVES: MULTIPLE DISABILITIES

# FLORIDA FESTIVAL OF FAMILIES TAKES FLIGHT

WHERE IT ALL BEGAN

# ERIC & BETH

# FROM THEN TO NOW : FAMILY



# JOURNEY TO VISUAL IMPAIRMENT & MULTIPLE DISABILITIES

- Undergraduate: Speech and Language Therapist &
  - Intellectually Impaired Specializations
- First Job: Abilene State School: Therapist for children with intellectual and physical disabilities
- Graduate School: Multiple Disabilities/Deaf-Blind Path, Model Vision Project and Vision Certification

# JOURNEY TO VISUAL IMPAIRMENT & MULTIPLE DISABILITIES

Employment: Kennedy Center: Southeast Regional Deaf-Blind Center

Pinellas County Schools: Resource Teacher for Multiple Disabilities

Pinellas County Schools: Teacher of children 4-14 with visual impairment and other disabilities, including Deaf-Blindness

# ERIC'S DISABILITIES

- Premie (27 weeks gestation): Retinopathy of Prematurity, stage 4. Two failed scleral buckles to reattach Retinas resulting in Calcific band keratopathy in the left eye and removal of lens in the right. He has light perception in the right eye and no vision in the left.

- Cerebral Palsy: low tone
- Seizure disorder
- Scoliosis
- Vaso-vagal syncope
- Non-verbal
- Profoundly cognitively impaired
- Requires support to walk and uses wheelchair in crowds and in situations in which he has to walk for long lengths of time
- Developmentally, functions within a 15 to 18 month old range
- Reflux

# CHALLENGES

- Cannot “typically” communicate his needs or wants
- CANNOT tell me if and where he is hurting
- Becomes upset  and anxious when familiar routines are interrupted
- Eating: struggles to coordinate breathing with intake of food
- EXTREMLY COMBATIVE WITH ANYTHING MEDICAL
-

# SCHOOL: IT TAKES A VILLAGE!

- FIRST AND FOREMOST: ONLY YOU (and perhaps a few special people in your circle of family and friends/therapists) KNOW WHAT MAKES YOUR CHILD TICK!
- WHILE teachers and therapists have a unique set of skills, they may not know or appreciate how to apply/adapt them for your child to address his/her abilities, needs, preferences, joys, and fears.
- Establish an Ally who knows and understands your child's needs within a school setting

# SCHOOL: IT TAKES A VILLAGE

- Before your child attends any educational setting, share with the teacher(s) your expertise about your child:
    - What makes him/her happy, joyful, upset, fearful, angry, non-compliant
    - How should your child be positioned in the classroom and what type of equipment does he/she use; what is his/her mobility level
    - What motivates your child (clapping hands, Eric Clapton, silly sounds, time with a preferred toy or game

# SCHOOL

- How does your child function visually within different contexts: what dampens/enhances their use of vision, if any functional sight
- How does your child communicate?  If nonverbal, make a list of gestures, body movements, sounds, behaviors that have communicative meaning
- What have you found to be successful if your child becomes overwhelmed, non-compliant, fearful, over stimulated
- How /what does your child eat (manage utensils, textures of foods, amount consumed in a setting, any atypical feeding strategies you use)

# YOU CAN'T MAKE THIS STUFF UP!

- GOAL for middle school child with total blindness:  "Stack 10 one inch square blocks"
- Parent GOAL: middle school aged child with total blindness: "open doors independently and safely". Therapist inquired, "Which door?"
- GOAL: Transitional age youth with total blindness and severe cognitive deficits: Will accurately complete an 81 step utensil sorting activity.

# SCHOOL AND COMMUNITY EXPECTATIONS

- What do you want your child to work towards accomplishing?
  - Goals and activities, whether in the early or transitional years, should be focused on improving quality of life, functional behaviors that lead to the most independence possible, communication, social interaction, and sensory skills that will help the child understand what is happening, where they are, safety, mobility, and integration in their communities.
  - What types of skills and activities will facilitate your child demonstrating her competence within community settings

# EXPECTATIONS FOR YOUR CHILD/YOUTH

- If there is a task that you would like your child to do:
  - Physically guide your child through the parts that he/she can't accomplish independently and allow him/her to do the parts she/he can
  - Keep your expectations HIGH! If you don't expect, your child may not achieve
  - Don't give up on your expectation: modify it so that your child can achieve some form of success
  - How can you facilitate your child or youth to demonstrate some level of competence?

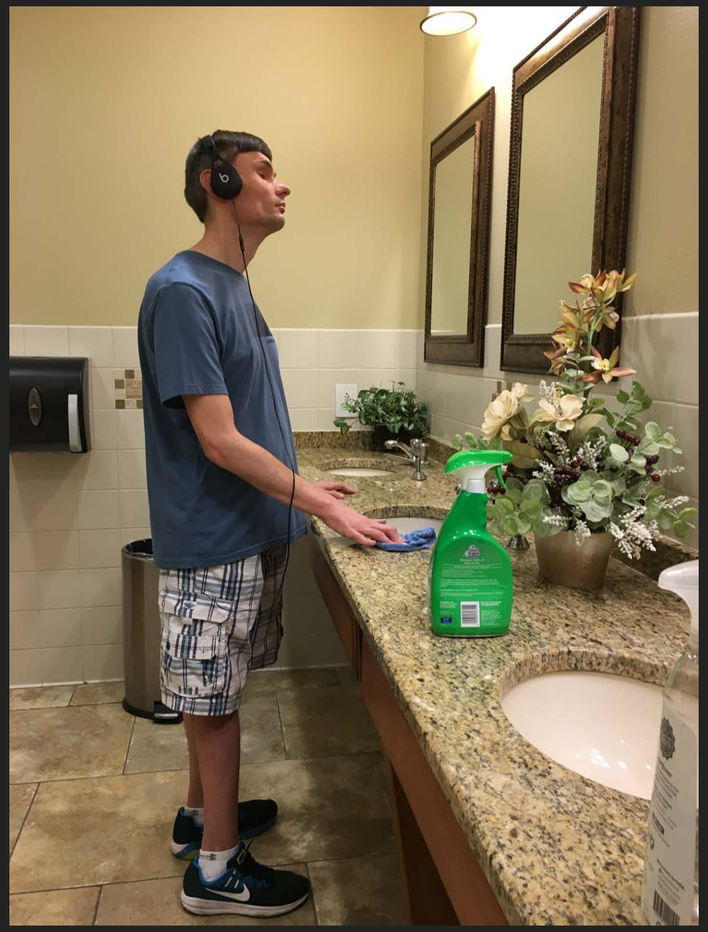
# TRANSITION AND COMMUNITY

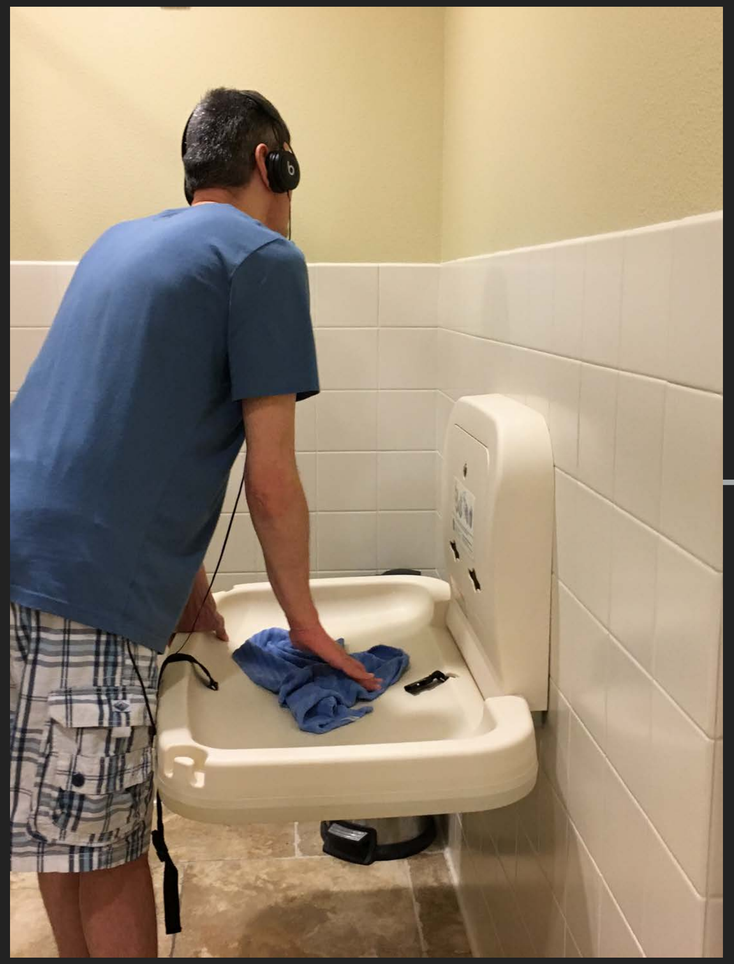
- Is there something your child/youth really likes to do (shred paper, turn on and listen to radio, throw objects, etc.)
- Make sure that you have a school TEAM of people join in the planning of a solid goal that your child/youth has a decent chance of being able to accomplish in the community: whether a paid or volunteer position.  Involve PT, OT, Classroom Teacher, Teacher of the visually and/or hearing impaired.  Design a concise, attainable, and replicable skill.

# IN THE COMMUNITY

- Whenever in any community setting, demonstrate your child's competence, even if you support and guide him/her through it!
- **ROUTINES, ROUTINES, ROUTINES!!!!!!**

# CLEANING CHANGING TABLES/SINKS AT CHURCH





# PARISHIONER WORK DAYS

# VOLUNTEERING @ CLOTHES TO KIDS

# FUNDRAISING

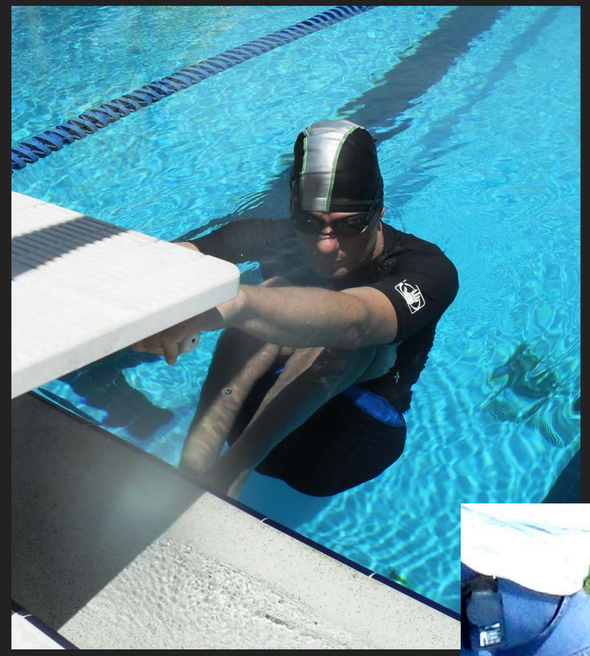
## TD BANK, RED ROBIN

## TECH DATA

# FRIENDS & SPORTS

speedo

# FRIENDS & SPORTS



# WHAT WORRIES ME

- GETTING APPROPRIATE AND COMPASSIONATE MEDICAL CARE FOR ERIC
- CONCERNS THAT ERIC WILL NOT BE MISTREATED WHEN I AM NOT PRESENT
- CONCERNS THAT FUTURE CAREGIVERS WILL CONTINUE TO LOVE ERIC, HAVE PATIENCE WITH HIM, PROVIDE HIM MEALS THAT WILL ENSURE HE WILL EAT, AND CONTINUE TO CARRY OUT BEDTIME ROUTINES OF PRAYING AND READING
- THAT CAREGIVERS WILL TRANSPORT HIM TO MASS ON A REGULAR BASIS
- THAT SUFFICIENT FUNDS WILL BE AVAILABLE FOR ERIC'S NEEDS AND FAVORITE ACTIVITIES

# AND NOW: AN ONGOING WORK IN PROGRESS!

# THANK YOU FOR FOLLOWING OUR JOURNEY