
Living With a Disability

— Clerkship Led by Linda Long-Bellil Ph.D., J.D. —
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Our Prior Exposure to Disability

Elisha, NP student

Has a cousin with cerebral palsy and interned at the Perkin School with students who were deaf, visually impaired, or on autistic spectrum.

Clare, NP student

Worked with a student with intellectual and developmental disability while he was high-school aged and worked with other individuals with disability at camps, has a brother with Type 1 Diabetes

Tammy, MS2

Had little experience with individuals with disability prior to medical school

Vanessa, MS2

Had little experience with individuals with disability except for a family member with epilepsy

Zak, MS2

Worked as a PCA prior to starting medical school and has a sister with cerebral palsy

Olivia, MS2

Worked as a research assistant in a pediatric epilepsy department with individuals with intellectual and developmental disability prior to starting medical school

Assistive Technology

Assistive technology (AT): an umbrella term that includes assistive, adaptive, and rehabilitative devices for people with disabilities or elderly population while also including the process used in selecting, locating, and using them.

Resources for AT that the clerkship visited:

- Easter Seals
 - LIVE
 - LEARN
 - PLAY
 - WORK
- Mass Rehab
- REquipment Center
- CC's Workshop



EASTER SEALS
MASSACHUSETTS

LEARN

CREATES LOANABLE
ASSISTIVE TECH KITS
FOR PUBLIC LIBRARIES

CC's Workshop



WPS Transition Program

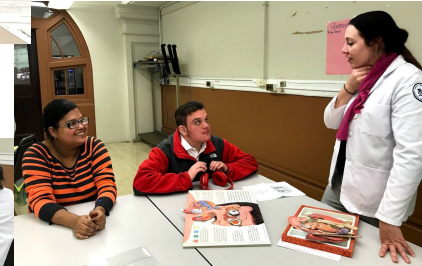


Individualized curriculum designed to help students with disabilities ages 18-22 develop personal and social skills necessary in transitioning into adult life.

- Promote independence
- Encourage goal setting
- High school diploma or equivalent
- Vocational training programs and entry into the workforce

Service Learning

- Young adults with disabilities have rarely visited a doctor's office on their own and thus have limited understanding of their own health information and body functions
- We conducted stations surrounding various health topics for WPS Transition students
- Goals:
 - Introduce students to aspects of a doctor's visit and encourage independence in managing their own health
 - Gain experience in working with a patient population that we may come across as medical professionals



The People We've Met: Cindy Purcell

- Spinal cord injury in 1977 at age 18
- Full-time Massachusetts Rehabilitation Commission employee
- Discussed dating, sexuality, and parenting with a disability
- Showed us tools that have helped her live independently



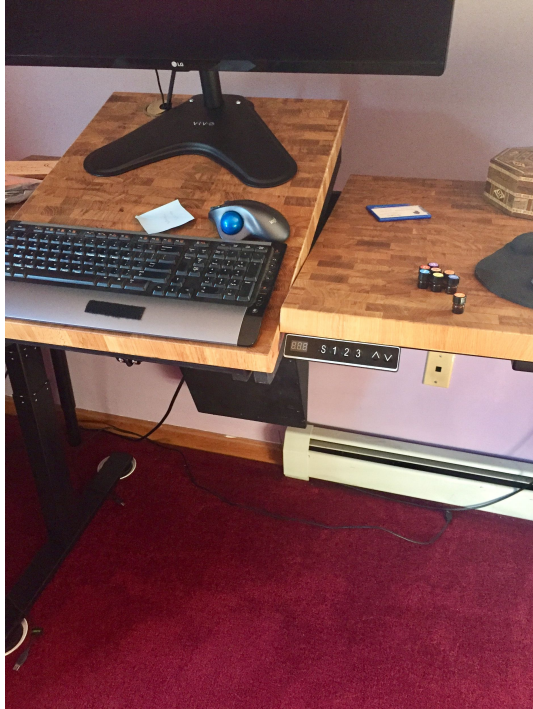
Cindy advocating for higher wages for home care workers in 2015. Photo from the Telegram & Gazette.

The People We've Met: Tammy Rayess

- Diagnosed at birth with Cerebral Palsy (CP)
- Worked as a Licensed Occupational Therapist (OT)
- Organizes Power Soccer for Central MA
- Works as a Cancer Care Minister
- Has a husband and 2 daughters
- Travels frequently
- Discussed diagnosis, treatment, challenges with aging, and assistive technology



Tammy Rayess Continued...



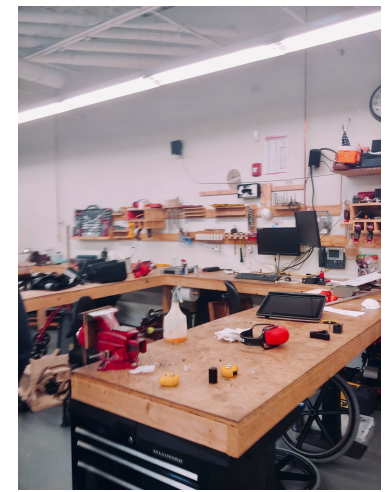
Tammy's desk is custom-made and has rotating capabilities. It was made by her husband who is an electrical engineer.



Tammy, along with her husband and 2 daughters, went on a road trip across the country. She succeeded in escalating (part of) Devil's Tower!

Community Resources

- Massachusetts Rehab Commission (MRC)
- REquipment
- Easter Seals
- Massachusetts Department of Developmental Services (DDS)
- Massachusetts Commission for the Deaf and Hard of Hearing
- Para-sport options--Wheelchair Rugby, Power Soccer
- Awareness Societies/Groups: The Epilepsy Foundation, Marfan Foundation, Ehlers-Danlos MA/New England Support Group, United Spinal Association
- Worcester Public Schools Transition Program
- Center for Living and Working
- Disabled Persons Protection Commission



Conclusions

- Many disparities continue to exist:
 - Health:
 - Poor access to routine health services
 - Lack of provider training
 - Environmental:
 - Lack of accessibility: Exam tables, scales, offices...etc.
 - Economic:
 - Lower employment rates and higher poverty rate
 - Social:
 - Less emotional/social support
 - Prejudices/stereotypes

Take Away Points

- Provider focus must shift:
 - Cure ⇒ Perspective that maximizes an individuals' well-being, functioning and independence.
- Impairments are not 'one size fits all'
- ASK! Most individuals are experts in their abilities and great partnership can be achieved through collaboration.
- Admit when you don't have the answers but be open to searching for the right resources to help the patient get the help they need.



