



HALEY'S RAYS OF SUNSHINE

**“LIVING INFORMED,
FEELING EMPOWERED!”**

#LIFEConferenceDE2024

HALEY SHIBER

HELLO!

HALEY SHIBER

FOUNDER OF HALEY'S RAYS OF SUNSHINE

- **I AM 27 YEARS YOUNG & LIVE IN SMYRNA, DE**
- **I LOVE TO BE ACTIVE & HEALTHY!**
- **I LOVE SUMMERS AT THE SHORE – THE WILDWOODS, NJ!**
- **I LOVE TO READ!**
- **I LOVE THE PHILADELPHIA PHILLIES!**
- **I LOVE TO LISTEN & DANCE TO MUSIC!**
- **I LOVE TO CREATE ART!**



**I HAVE A RARE
GENETIC
NEUROMUSCULAR
CONDITION
CALLED
PCH TYPE 1B!**



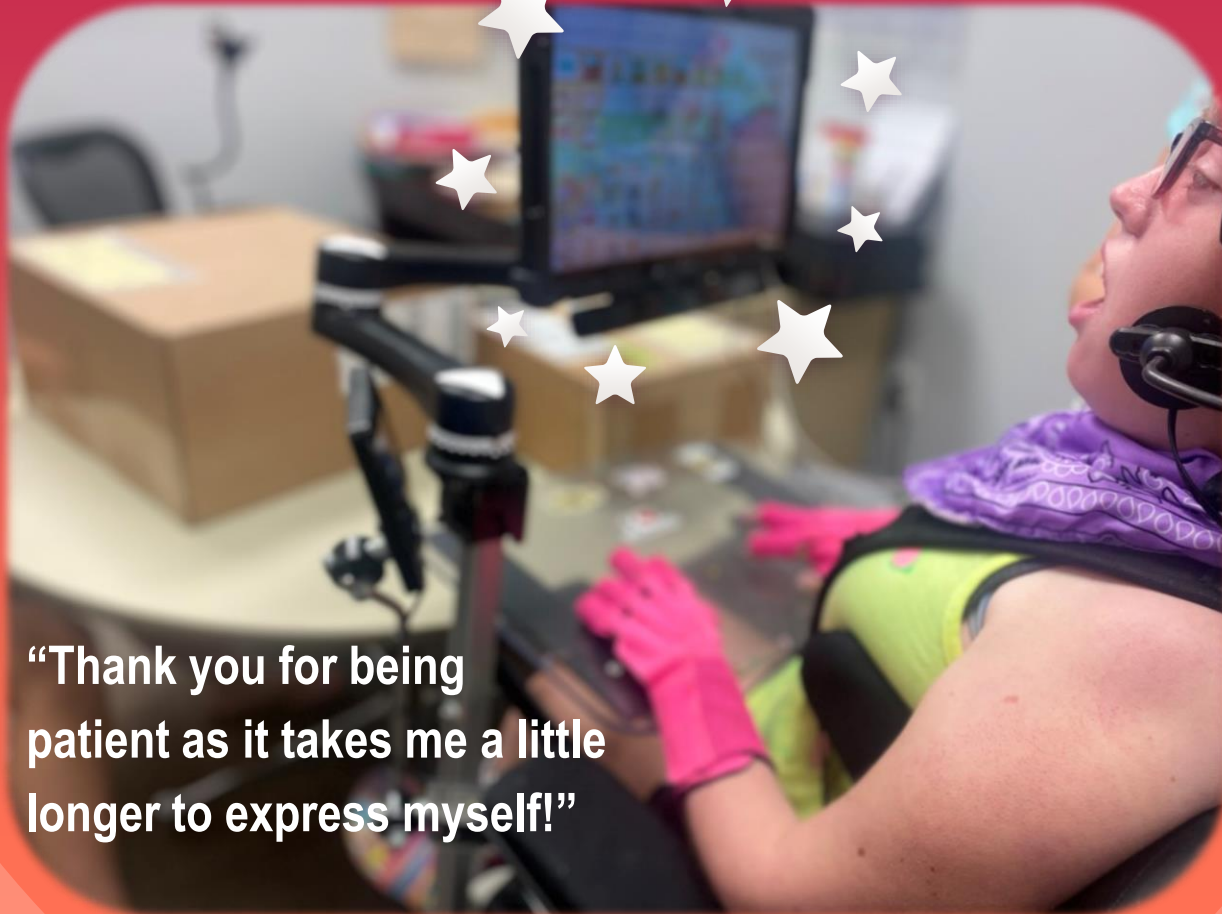
**RARE DISEASE AWARENESS
DAY IS FEBRUARY 29TH!**

PONTOCEREBELLAR HYPOPLASIA (PCH) TYPE 1B




- CEREBRAL PALSY (CP)
- TRACHEOSTOMY
- GTUBE
- LOW VISION
- AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
- POWER WHEELCHAIR
- ADAPTIVE EQUIPMENT
- ASSISTIVE TECHNOLOGY

I USE AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)



“Thank you for being patient as it takes me a little longer to express myself!”



**“OHANA MEANS
FAMILY, & FAMILY
MEANS NOBODY GETS
LEFT BEHIND OR
FORGOTTEN” – LILO & STITCH**

MY FAMILY, MY HEART!



Hope Shiber
Sister



Haley Shiber
Boss Lady
Founder of HROS



Hilary Shiber
Sister

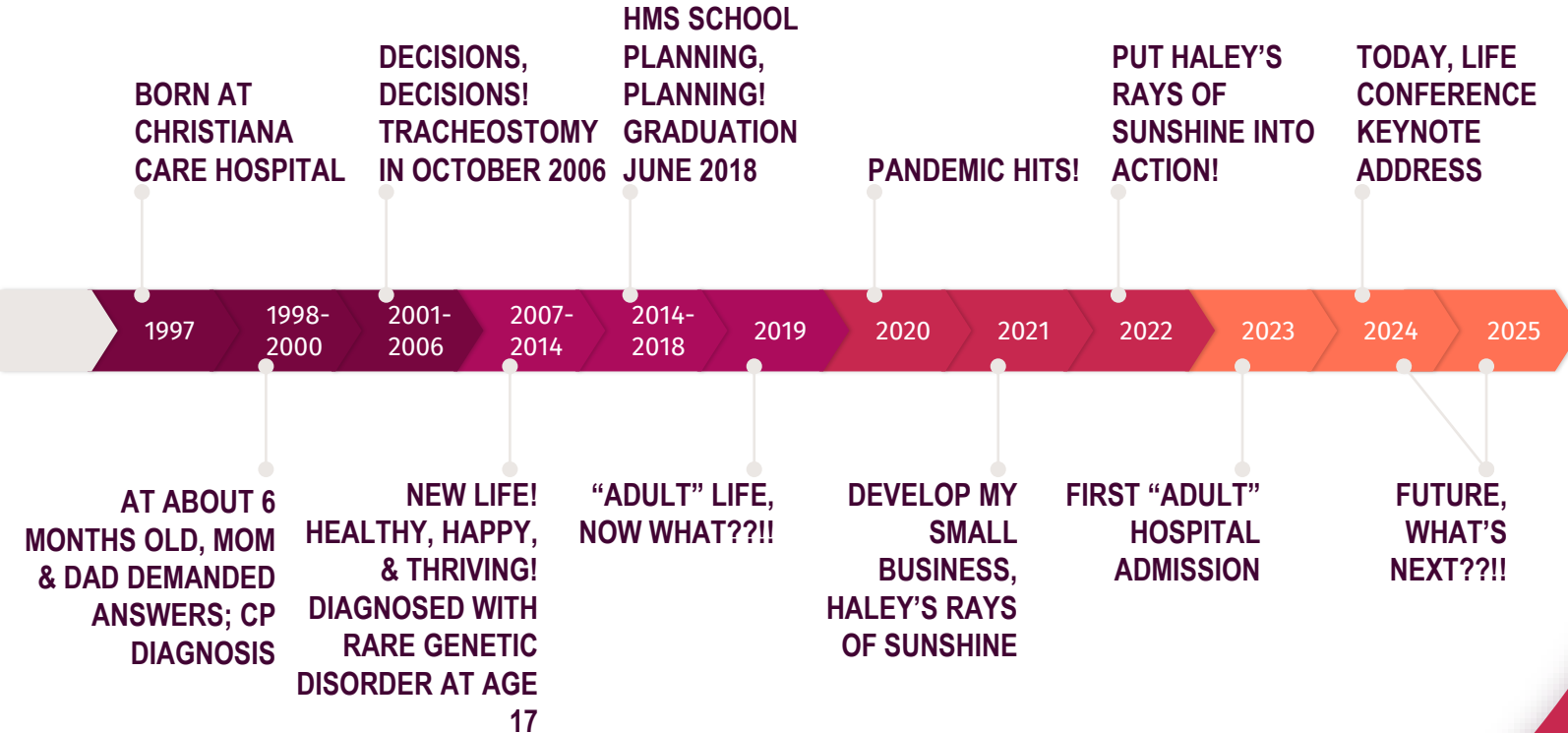


Debbie Shiber
Mom



Howard Shiber
Dad

THROUGH THE YEARS...



WHERE MY STORY BEGINS...



HMS SCHOOL FOR CHILDREN WITH CEREBRAL PALSY & SMYRNA HIGH SCHOOL



**“LIVING INFORMED,
FEELING EMPOWERED!”**



HALEY'S RAYS OF SUNSHINE



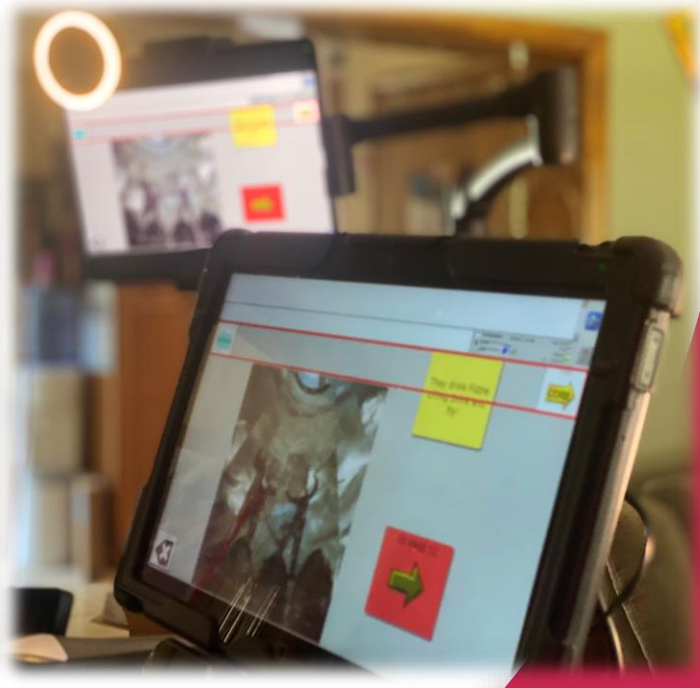
LITERACY, AAC, ADVOCACY, ART, COMMUNITY



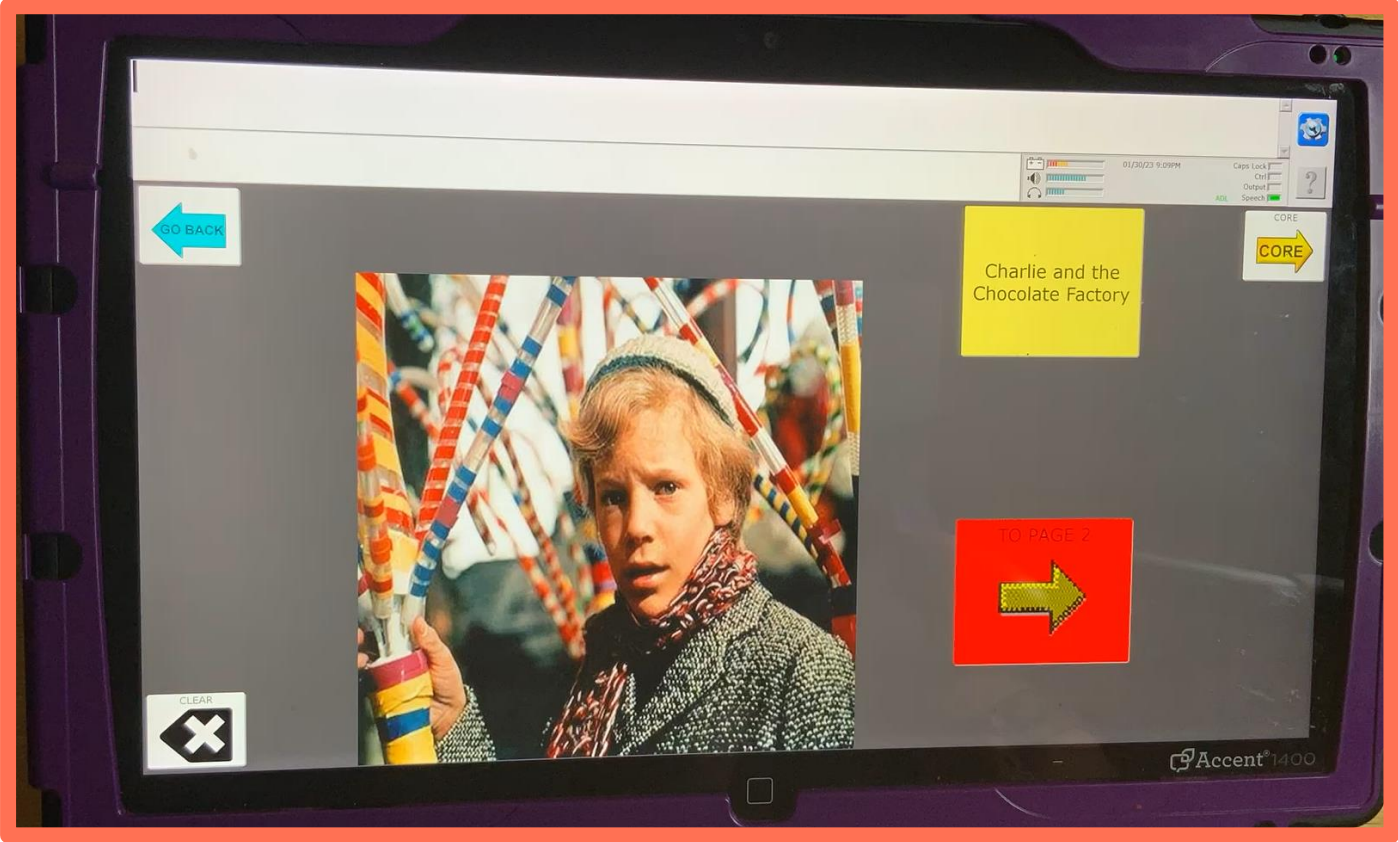
LITERACY

I LOVE TO *READ!*

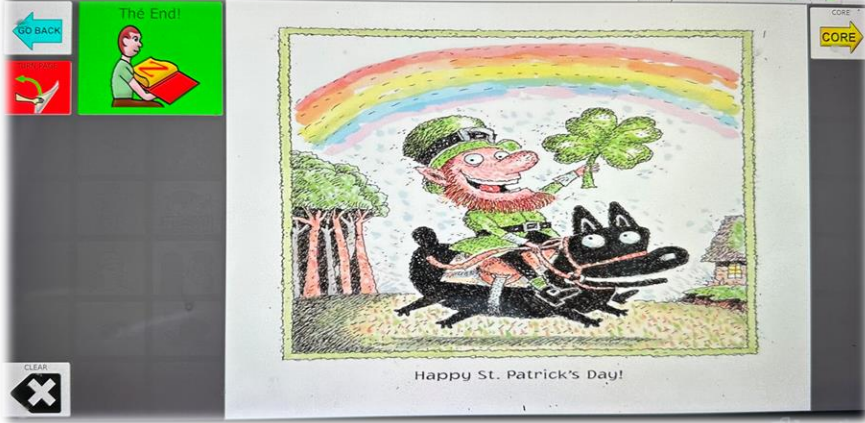
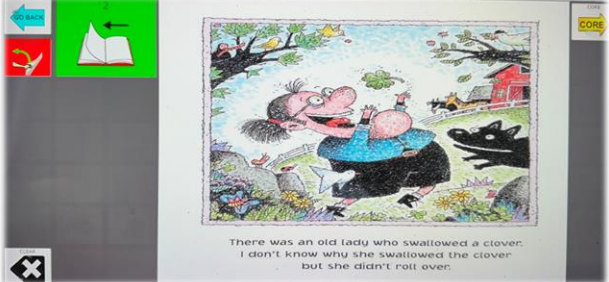
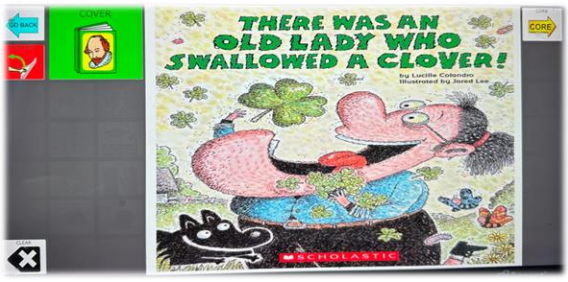
READING *CHARLIE & THE CHOCOLATE FACTORY* TO STUDENTS AT DOVER HIGH SCHOOL IN DOVER, DELAWARE



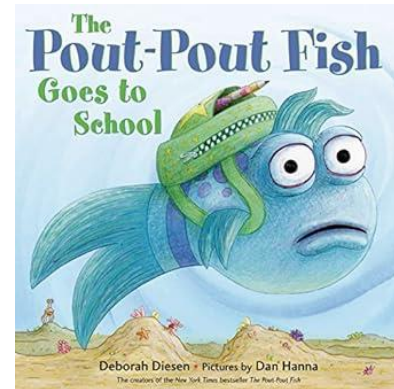
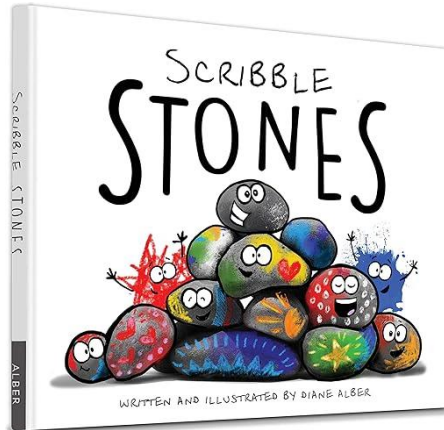
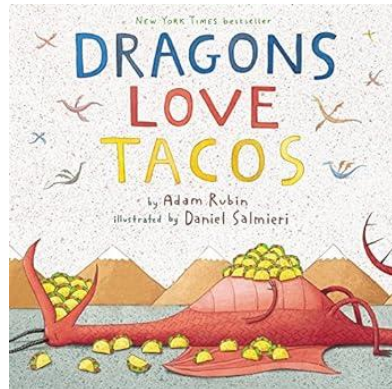
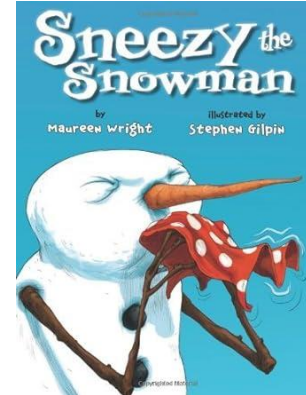
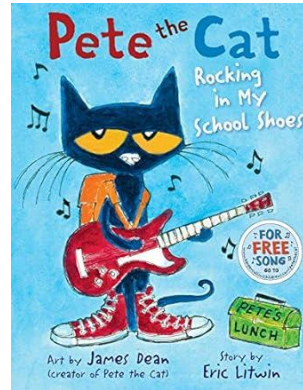
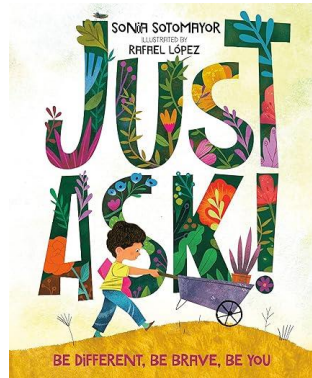
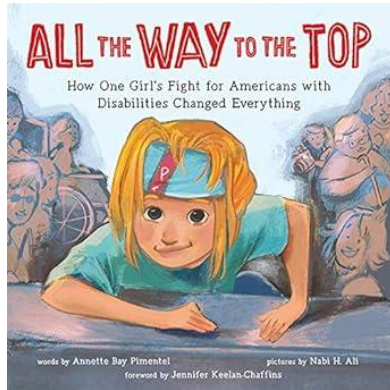
CHARLIE & THE CHOCOLATE FACTORY



READING *THERE WAS AN OLD LADY WHO SWALLOWED A CLOVER* TO STUDENTS AT KCCS IN DOVER, DELAWARE



BOOKS, BOOKS, & MORE BOOKS!



GOALS
FOR
2024



AAC

I HAVE A VOICE!





- **MAKES ME “MISS INDEPENDENT”!**
- **COMMUNICATE MY WANTS, NEEDS, THOUGHTS, WISHES, EMOTIONS, & VOICE MY OPINION!**
- **HELPS ME BE AN ADVOCATE, NOT ONLY FOR MYSELF BUT, FOR OTHERS TOO!**

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)

**PRC-SALTILLO
ACCENT 1400**

**UNITY 84 SEQUENCED
SWITCH SCAN
HEAD TRACKING**





- HELPS ME LIVE MY BEST LIFE AS A SOCIAL BUTTERFLY (SOCIAL MEDIA, EMAIL, TEXT)
- I ALSO COMMUNICATE WITH MY FACIAL EXPRESSIONS, BODY LANGUAGE, AND RAISE MY EYEBROWS TO INDICATE “YES”!

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)

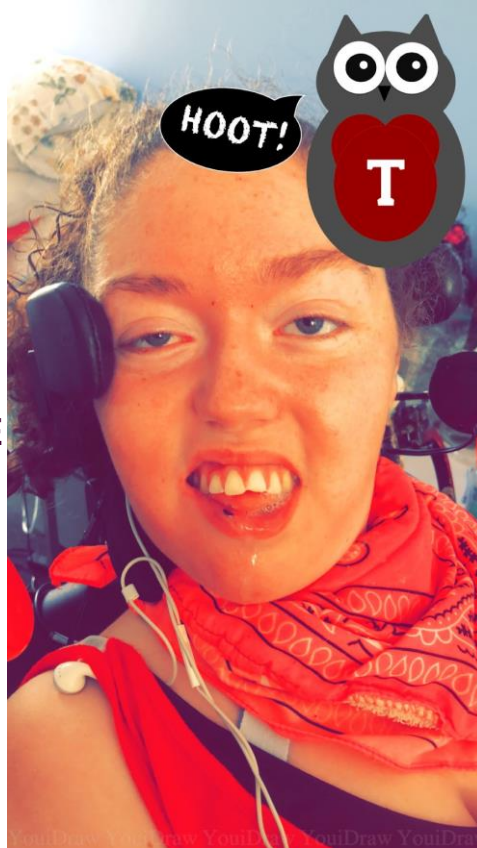
TEMPLE UNIVERSITY - TECHOWL

AUGMENTATIVE COMMUNICATION EMPOWERMENT AND SUPPORTS (ACES)

- TWO WEEK PROGRAM
- LIVED IN DORM ON CAMPUS WITH ROOMMATE
- TOURED THE CITY

A.T. CHAMPIONS

- MULTI-STATE
- AWARENESS
- COLLAB WITH UD CDS DATI



UNIVERSITY OF DELAWARE

CENTER FOR DISABILITIES STUDIES (CDS)

DELAWARE ASSISTIVE TECHNOLOGY INITIATIVE (D.A.T.I.)



COMBATING SOCIAL ISOLATION (CSI) GRANT

- MACBOOK, CABLES & ADAPTERS, MOBILE TV STAND, BEATS HEADPHONES

A.T. CHAMPIONS

- 6 MONTH PROGRAM, PAID
- MONTHLY AWARENESS PROJECTS
- COLLAB WITH MID-ATLANTIC REGION

LENDING LIBRARY

- IDENTIFY, FIND, & BORROW A.T.





WREX ARMS

- “A FUNCTIONAL UPPER LIMB ORTHOSIS DESIGNED TO ENHANCE MOVEMENT FOR INDIVIDUALS WITH NEUROMUSCULAR DISABILITIES”
- JAECO WILMINGTON ROBOTIC EXOSKELETON (WREX) ARMS





OBI

- “ADAPTIVE EATING DEVICE FOR INDIVIDUALS WITH UPPER EXTREMITY STRENGTH & MOBILITY LIMITATIONS”
- DATI LENDING LIBRARY





ADVOCACY

I *SPEAK* UP
FOR MYSELF & OTHERS!



Joint Finance Hearing Room

I AM AN ADVOCATE!

- JOINT FINANCE COMMITTEE (JFC)
- HEARTS 4 HOMECARE (H4HC)
- HOME & COMMUNITY BASED SERVICES (HCBS)

JFC IN PERSON & VIRTUALLY





I AM AN ADVOCATE!

- HUMAN RIGHTS COMMITTEE (HRC) for DDDS
- TRANSITION CONFERENCE
- LIFE CONFERENCE
- CAREGIVER TASK FORCE
- &&& MORE!

LOOKING FOR WAYS TO
ADVOCATE IN DE, TRY
REACHING OUT TO THE DDC!



Are YOU a nurse (RN or LPN)?

Come hang with me!! 🥳



I LOVE TO KEEP ACTIVE. BE A SOCIAL BUTTERFLY. WATCH MOVIES. READ BOOKS. & BAKE!



I USE A SPEECH DEVICE & MY EYEBROWS TO COMMUNICATE

I HAVE A TRACH/VENT, GTUBE, USE POWER WHEELCHAIR & HAVE CEILING LIFT!



MY FAMILY IS SUPER HELPFUL!

SHIFTS 8+HRS: DAYS, NIGHTS, & WEEKENDS

WORK ONE SHIFT A MONTH OR WEEK OR COME ON BOARD TO WORK FILL INS AND RESPITE AS NEEDED!

MY AGENCIES ARE:

AVEANNA

&

BAYADA

MESSAGE ME! &&& SHARE!

I AM AN ADVOCATE!

- SOCIAL MEDIA AWARENESS



MAKE YOUR VOICE HEARD, BE LOUD!



 Haley Shiber is with Debbie Shiber and Howard Shiber.
Nov 6, 2018 · 🌐
I voted.... did you???? #govote #itmatters 🇺🇸 🇬🇧 🇫🇷 🇮🇹



YOUR VOTE COUNTS! BE PROUD TO VOTE!



ART
I *CREATE* ART!



HMS SCHOOL FOR CHILDREN WITH CEREBRAL PALSY



ART CLASS WEEKLY

**TEACHER EIKO HELPED ME PAINT
WITH MY HEAD MOVEMENTS**





ART THERAPY EXPRESS



ART STUDIO SESSIONS, FIELD TRIPS, ART SHOWS,
& MORE!

WEEKLY WITH LISA BARTOLI





ART THERAPY EXPRESS





MASTERPIECES CREATED WITH ART THERAPY EXPRESS

COMMUNITY

I AM A *PART* OF MY COMMUNITY!





MOVE 2 INCLUDE



DUO TEAM RACES WITH FRIENDS



MOVE 2 INCLUDE



FIRST PLACE!!!!

ENDLESS POSSIBILITIES IN THE COMMUNITY (EPIC) AT YMCA



ENDLESS POSSIBILITIES IN THE COMMUNITY (EPIC) AT YMCA



L.I.F.E. CLASS



MOTOMED



MARY CAMPBELL CENTER

CHILDREN & YOUTH PROGRAM
PLUS PROGRAM



WEEKLY VIRTUAL & IN PERSON
ACTIVITIES

- GAMES, COOKING, READING, & MORE!

“SO WHEN THEY SEE YOUR
NAME, OR SEE YOU
ROLLING, STROLLING,
PATROLLING AROUND,
THEY KNOW, *OH THEY
KNOW...YOU MEAN
BUSINESS!”*

“I want to see a feisty
group of disabled
people around the
world...if you don't
respect yourself and
if you don't demand
what you believe in
for yourself, you're
not gonna get it.”

**JUDY
HEUMANN**

Disability Rights Activist



QUESTIONS?

I AM HAPPY TO ANSWER YOUR
QUESTIONS, MY SUPPORTS MAY
HELP ME, IF NEEDED!

THANK YOU FOR BEING PATIENT AS
IT MAY TAKE ME A LITTLE LONGER
TO EXPRESS MYSELF!



THANK YOU, THANK YOU!



HALEYSHIBER.COM



Haley's Rays of Sunshine



haleys_rays_of_sunshine



haleys_rays_of_sunshine