Six Strategies to Ease Holiday Stress

Developed from the webinar “Identifying Target Behaviors and Implementation Strategies for Home Use” by Kari Taylor, Illinois Service Resource Center (ISRC)

1. Keep it cool. Body temperature greatly impacts emotional regulation. Lower the thermostat if you are having people over or if visiting others, dress your child in layers. Layers allow you or your child to add or remove clothing to ensure their ideal body temperature.

2. Eat and drink. Avoid the hangries by serving your child a hearty snack or light meal before any gathering or event. While gatherings and events will likely include snacks and meals, the excitement often reduces a child’s appetite. It’s better for them to eat something nutritious in advance and eat lightly at the event than for them to experience regulation issues due to hunger and thirst.

3. Stick to a schedule. Pay attention to event times. Only attend events if the timing matches your family schedule. For example, opting to skip an event that occurs too close to bedtime helps prevent overstimulation.

4. Set expectations. Proximity to many other family members or event attendees can increase anxiety or other issues that impact behavior. Set expectations (yours and theirs) in advance by discussing event activities, desired behaviors, and adaptive plans with all immediate family members prior to the event.

5. Get some R&R. While our loved ones enjoy seeing relatives and joining in holiday traditions and events, it can be taxing. Plan plenty of rest times. For example, plan an activity day followed by a day of rest and relaxation. If you go to an event or activity, look for rooms/places your children can go to relax from the stimulation and excitement.

6. Pack a bag. Don’t leave the house without a bag of tricks to help ease overstimulation or anxiety. Include fidget toys, comfort items, ear buds/noise cancelling headphones, products with calming scents, snacks, water, and a light blanket or sweater.
MTI 2022 SustainABE-L Futures a Huge Success!
By Michelle Clyne, Project Reach Coordinator

The 2022 DeafBlind Midwest Transition Institute (MTI) was a success! Some activities (a Talent Show, student work on a transition portfolio, a seminar by Olaya Landa-Vialard and George Stern on “Informational Interviews,” and a Services and Technology Fair) were completed virtually. The in-person MTI was on August 5 – 8, 2022 in Woodstock, Illinois at the Loyola University of Chicago Retreat and Ecology Campus. With nine other partner states and two national agencies, young adults, mentors, and parents of young adults met to share experiences that support youth transition plans as outlined in individual youth portfolios.

Activities for young adults included:
- Mentor led sessions and panels on topics like “My Transition from School to Adult Life” and “Tips for Leading Your Portfolio Meeting.”
- Yoga, a trip to North Wall Rock Climbing, and casual games into the night (including photo booth fun!).

Sessions for parents included:
- “A Child-Parent Retrospective: Transition from High School to College & Work” by a DeafBlind college student and his mother and “Letting Go: Specific Strategies to Let Your Child Take Charge.”
- A trip to a speak-easy and making doggie snuffle pads to donate to Leader Dogs for the Blind.

Young adults all agreed that the information they learned was useful, and that they learned something they will use at home or school (such as learning about magnifiers, live stream captioning, trying a guide dog, using kitchen tools and gadgets designed for people with visual impairments, learning sign language, working with anxiety, and speaking up for themselves). Parent evaluations noted all parents strongly agreed or agreed that MTI was relevant to their family, and 100% strongly agreed that their young adult will benefit from attending. Parents said they planned to follow up on referral to vocational services, different tips about transition to college, things to help with vision changes, requesting live captioning for classes, accessible pharmacy options, and allowing their child to self-advocate.

Soon there will be recorded sessions to view – check the “What’s New” section of the Project Reach website for updates. Next year MTI will be at Webster University in St. Louis, MO from July 13-17, 2023. If your young adult and family would benefit from attending, please contact Project Reach!

Enjoy these candid photos from this year’s MTI!
Important News about Illinois Support Waiver Services

On November 3, 2022, the Department of Human Services, Division of Developmental Disabilities (DDD) released details of a policy change to the Children’s Support Waiver (CSW). The new policy, effective January 1, 2023, allows a parent (biological or adoptive) or guardian of a young adult who is 18 years of age or older to provide Personal Support Worker (PSW) services under the CSW. If your child is under the age of 18, the policy remains that a parent cannot provide PSW supports to them. If you have any questions regarding this change or actions you need to take to take advantage of this policy change, please email Derek Hedges at derek.hedges@illinois.gov.

Additionally, the Home-Based Support Services Program (HBS) announced increases to the monthly and annual maximum amounts for HBS programs. Effective January 1, 2023, children and young adults up to the age of 22 who are enrolled in a special education program will receive a monthly service allotment of $1,828. If you use the flexible spending amount option under the CSW, the new monthly maximum will be $3,656, with an annual maximum of $21,936. You will need to update your service plans and service agreements with ACES$ Illinois to use the additional funds. For questions or more information, contact ACES$ Illinois at 1-877-223-7781 or SupportIL@mycil.org.

In a final bit of good news, ACES$ Illinois announced the ACES$ “Cost to You” rate will decrease from 8% to 7% starting January 1, 2023.

If you have questions about Illinois Waiver Services or the children or adult PUNS process, please email or call Faith Young at FRYoung@philiprockcenter.org or 630-568-8720. She’s happy to help you figure it all out.

Gwynnie-Gwyn-Gwyn Releases App for Marvin Fans

Gwyn McCormack of Positive Eye, Ltd recently released the free app, Positive Looking To Go. You may know Gwyn from the Marvin Adventures series. Positive Looking To Go contains a collection of skills, activities and resources for educators and families. These resources will help educate adults how to develop skills in children and young learners with vision loss and special educational/additional learning needs. Gwyn intends to update the content regularly with new resources, activities, and Marvin Adventures! The app is available for Apple devices in the App Store and for Android devices in Google Play. To learn more about the app visit https://positiveeye.co.uk/positive-looking-to-go/.

Introducing USH Ambassador of Illinois

By Heather Clark, Usher Syndrome Coalition Ambassador of Illinois, ambassador.il@usher-syndrome.org

My name is Heather Clark, and I am a volunteer Ambassador of Illinois for the Usher Syndrome Coalition. Usher Syndrome is the most common genetic cause of combined vision and hearing loss. Balance can also be affected over time. As a volunteer Ambassador, I serve as a local resource to individuals in Illinois with Usher Syndrome, their families, and the organizations that serve the community.

I am from Central Illinois. I was born profoundly Deaf and was diagnosed with Usher Syndrome type 1D during my adolescent years. I use American Sign Language to communicate, and I use Cochlear Implants to hear the sounds of the environment around me.
I graduated with a bachelor’s degree in Recreational Therapy from Illinois State University. In addition, I completed two internships within local Healthcare facilities, including a nursing home and a hospital. Following graduation, I worked as an Activities Director within the Healthcare field for a period of eight years. Currently, I am a stay-at-home mom for my two children.

The Usher Syndrome Coalition is the only organization in the world to find and support every individual with Usher Syndrome. Our mission is to raise awareness and to accelerate research while providing information and support to individuals and families affected by Usher Syndrome. We provide information, resources and support. We are working on building the bridge between the research community and the Usher Syndrome community.

Here are some of our many resources that may be of interest to you.

- Usher Syndrome Coalition: [https://www.usher-syndrome.org/](https://www.usher-syndrome.org/)
- The USH Trust Registry: [https://www.usher-registry.org/](https://www.usher-registry.org/)
- The USH Blue Book Online Forum is a private email group for the Usher community to share information and support: [https://www.usher-registry.org/en/network_members/new](https://www.usher-registry.org/en/network_members/new)

**Illinois EDHI Introduces New Sound Beginnings Website!**

What is Illinois Early Hearing Detection & Intervention (EDHI)? If you are the parent of a young child with combined vision/hearing loss, you are probably already familiar with newborn hearing screening given to babies before they leave the hospital. This screening is provided as part of the EDHI program, which works to ensure families of babies and children who are deaf or hard of hearing receive appropriate and timely services.

What is Illinois Sound Beginnings? It’s a partnership between Illinois EDHI program and Illinois Hands & Voices Guide By Your Side (ILHV GBYS) in which both entities work seamlessly to address the hearing screening and follow-up needs of all Illinois infants and their families. Their family-focused activities help families follow-up on initial hearing screenings, begin early intervention services, and receive parent-to-parent support.

The Illinois Sound Beginnings website ([https://www.illinoissoundbeginnings.org](https://www.illinoissoundbeginnings.org)) is a reliable source for all parents of children with hearing loss seeking information, programs, referral, and parent education. Check it out!

**We’re Listening**

Project Reach needs your opinion to set priorities for communication systems and technology for the upcoming years. Could you please help us by taking this four-question survey ([https://www.surveymonkey.com/r/8Y26KW7](https://www.surveymonkey.com/r/8Y26KW7))?
Grabbing Equestrian Gold

Who doesn’t like to win? Certainly not Project Reach’s very own David who signed “medals” in response to a question about his favorite part of competition. David grabbed two medals on Saturday, October 22, 2022, at the Illinois Special Olympics State Games at BraveHearts’ Bergmann Centre in Poplar Grove, Illinois. David, one of 50 equestrians competing, received a gold medal for his program in the Stock Seat Pattern and a bronze medal for his program in Working Trail Pattern. He competes as the part of the Holistic Riding and Equestrian Therapy equestrian team.

David also shared he loves riding horses. Of course, riding horses and competing is not all fun and games. But the hard work is worth it when you love what you do, which David does. His mom shared David “was beyond excited and so proud of himself! He worked really hard for this, and his efforts paid off.”

During competitions, David wears a green arm band to notify the judge he has hearing and vision accommodations. David’s accommodations include his mother signing the judge’s directions, alerting David to where he is in the arena/where the obstacles are, and giving him number cues to signal he is in the right place in the arena to complete the next skill in the pattern.

Transition Across the Lifespan

The Illinois Family Leaders Collaboration will present “Transition Across the Lifespan” at the 16th Annual Family Conference for Families of Children with Disabilities on Saturday, April 29, 2023, from 9 a.m. until 3 p.m. at the Spaulding Pastoral Center in Peoria, Illinois. This year’s keynote presenters are Daniel and Samuel Habib who will share how to create a disability roadmap. In the afternoon, families will break into two groups based on child age. The early childhood/elementary school age group will explore how inclusion helps students gain social/emotional skills that prepare them for integrated work settings. The middle school/high school group will work on transition and self-advocacy issues.

Due to the importance of the topic this year, the collaboration is inviting high school students with disabilities to join their parent or guardian for the conference. More information including conference fee and registration details will be available in March. Project Reach will share the conference information on their website under the What’s New section (https://www.philprockcenter.org/whats_new) and on their Facebook page (https://www.facebook.com/Project-Reach-Illinois-Deaf-Blind-Services-150957798289173).

This will be the first in-person Family Leaders Collaboration conference since 2019. In 2020, the group cancelled the conference due to the Covid-19 pandemic. During 2021 and 2022, the group offered free virtual conference sessions.
Stipends to Help Families Attend Trainings & Conferences

Wish you could attend a training or conference to help develop your skills or increase your knowledge about supporting your loved one, but you can’t afford the cost? Several stipend programs are available to help you.

**Project Reach** offers stipends for Project Reach families to learn how to better serve their child with combined vision/hearing loss and their unique needs. For more information, email Michelle Clyne, MClyne@philiprockcenter.org.

**The Arc of Illinois** offers two stipend programs. Through a grant from the Illinois Council on Developmental Disabilities, The Arc offers consumer stipend funds ($450/person per 12-month period or $750/family per 12-month period) to people with developmental disabilities and their family members to attend conferences directly related to developmental disability issues. For more information and to apply visit [https://www.thearcofil.org/about-us/programs/financial-assistance-for-trainings/](https://www.thearcofil.org/about-us/programs/financial-assistance-for-trainings/). The Family-to-Family Health Information Center offers conference stipends to individuals and families of individuals up to age 22 with any type of disability, chronic illness, and/or special health care need. Training events must take place in Illinois (in-person or virtual) and be targeted to disabling conditions and/or chronic illnesses of children/youth. Proof of registration is required. Stipends (based on F2F budget and usually limited to $100 per family) cannot be combined with other stipends. For more information or to apply email mary@thearcofil.org.

Each **StarNet Region** offers training/event fellowships for family members of a child aged 2 to 6 who receives Early Intervention or Early Childhood Special Education Services. For more information and to apply, visit your region’s website—[StarNet Regions I & III](https://www.starinet.info/region1 REGION3), [StarNet Region II](https://www.starinet.info/region2), [StarNet Region IV](https://www.starinet.info/region4), [StarNet Region V](https://www.starinet.info/region5), or [StarNet Region VI](https://www.starinet.info/region6).

**News You Can Use**


**Complete Training Modules to Earn Amazon Gift Cards.** The Illinois Service Resource Center (ISRC) Parent University helps families further develop ideas and supports in raising a child with hearing and/or vision loss. ISRC learning modules include a video, article, or other material along with a quiz. Complete a module and return the quiz to receive an Amazon gift card. You can earn a maximum of a $20 gift card every three months. To learn more about this program and the training topics visit [https://www.isrc.us/parents](https://www.isrc.us/parents).

**Free Family Membership to Described and Captioned Media Program (DCMP).** Families and educators with at least one student with a disability can register for a free membership to DCMP that allows access to thousands of accessible, educational videos. Register at [https://dcmp.org/](https://dcmp.org/).

**Illinois 988 Myth Busters Fact Sheet.** While most information online and in the news has shared the helpful and life-saving aspects of the new 988 Suicide and Crisis Lifeline, there has also been some incorrect information being shared. Illinois Department of Human Services, Division of Mental Health released an Illinois fact sheet ([https://www.dhs.state.il.us/page.aspx?item=146358](https://www.dhs.state.il.us/page.aspx?item=146358)) with some of the myths that have been circulating on social media about 988, along with correct information. For information about 988 resources, please visit: [IDHS: 988 Suicide & Crisis Lifeline (state.il.us)](https://www.dhs.state.il.us/page.aspx?item=146358). To ask a question about 988, please complete and submit this request from to the Division of Mental Health: [https://forms.office.com/g/K82GhbRgKJ](https://forms.office.com/g/K82GhbRgKJ).
Important Legislative Information

**Illinois Public Act 102-0841.** Signed into law on May 13, 2022, this act changes the Illinois School Code to require school districts to give families information about the Achieving a Better Life Experience (ABLE) account program at the student’s annual individualized education program (IEP) meeting starting with the 2023-2024 school year. ABLE accounts help persons with disabilities save money without losing public benefits. To learn more about this act, visit [https://www.ilga.gov/legislation/publicacts/fulltext.asp?Name=102-0841&GA=102](https://www.ilga.gov/legislation/publicacts/fulltext.asp?Name=102-0841&GA=102). To learn more about ABLE accounts visit [https://www.ablenrc.org/](https://www.ablenrc.org/).

**Words Matter Act of 2022 (H.R. 8863).** Introduced in the U.S. House of Representatives on September 15, 2022, if passed, this bill would replace the outdated terms “mentally retarded” and “mental retardation,” which still exist in many federal laws, with the words “intellectual disability” or “intellectual disabilities.” To learn more about this bill including co-sponsors and how to contact your member of Congress, visit [https://www.congress.gov/bill/117th-congress/house-bill/8863](https://www.congress.gov/bill/117th-congress/house-bill/8863).

**SSI Savings Penalty Elimination Act (S.4102).** This bill would increase the resource limits used to determine eligibility for the Supplemental Security Income (SSI) program. SSI provides people with disabilities and limited income and resources a monthly payment to help afford necessities, like food and rent. Resources include money in bank accounts, retirement accounts, and savings. The resource limit (currently $2,000 for individuals and $3,000 for married couples) was set in 1989. This bill would raise the resource limit to $10,000 for individuals and $20,000 for married couples and increase these limits every year for inflation. To learn more about this bill including co-sponsors and how to contact your member of Congress, visit [https://www.congress.gov/bill/117th-congress/senate-bill/4102](https://www.congress.gov/bill/117th-congress/senate-bill/4102).

Upcoming Events

- **February 2023 – Project Reach Family Directory Invitation.** Mailed in February with responses due in April. Each year you must submit a new form to be in that year’s directory.


- **April 29, 2023 – Family Leaders Conference – Transition Across the Lifespan, Peoria, IL.**

- **July 13-17, 2023 – Midwest Transition Institute, St. Louis, MO.** Contact Michelle (MClyne@philiprockcenter.org) or Faith Young (FYoung@philiprockcenter.org) if you have a transition age young adult interested in attending.


- **2023 – Project Reach Vocational Webinars.** Watch for coming announcements & details.
  - Customized Employment
  - Department of Rehabilitation Services (DRS) & Bureau of Blind Services (BBS) Supports
  - Preemployment Training Services & IL’s HKNC Youth Services Coordinator, McKenna Liesman
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Please return the following information to Philip J. Rock Center and School

_____ Please make no changes to my address and keep me on your mailing list
_____ Please take my name off the mailing list.
_____ Please mail me a large print edition of the newsletter.
_____ Please mail me a Braille edition of the newsletter.
_____ Please make the following changes on my mailing address label:

Name: ___________________________ Parent? _________ Educator? _______________
Address: __________________________________________________________________________________
Email: _________________________________________________________________________________