

Horizons

A Family Newsletter of Project Reach Deaf-Blind Services

Faith Rosenshein Young, Editor
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Back-to-School Anxiety

Many children, including children with disabilities, have back-to-school jitters. This is true for parents of children with disabilities also. After a year or more of remote or hybrid schooling, returning to in-person schooling full time can be scary for all. How do you help ease anxiety and prepare for the return to school? Jennifer Louie, PhD, a clinical psychologist at the Child Mind Institute and Rachel Busman, PsyD, director for the Anxiety Disorders Center at the Child Mind Institute offers recommendations in “Back-to-School Anxiety During COVID” at <https://childmind.org/article/back-to-school-anxiety-during-covid/>.

Share concerns with each other. Honest and open communication is always best. A conversation about the return to school is a good starting point for allowing your child to express their fears or anxiety and for you to validate them. For older children with proficient communication skills, ask open-ended questions and avoid judging their responses. Try some of the following questions to get the conversation started.

- What excites you about going back to school this year?
- What do you think will happen when you return to school?
- How would you like to prepare for your return to school?
- What are your friends saying about returning to school?

For younger children you might introduce this conversation might be with a video, such as this one (<https://www.youtube.com/watch?v=oap9ssynoxI>) by Belfast Health and Social Care. Good starting questions include

- What did you miss about going to school last year?
- How do you feel about going back to school?
- What will make you feel better about going back to school?

For other students, creating or using a previous a memory box/book, conversation box/book, or an experience story may help guide the conversation. Visit the following for more information about what these tools are, how to use them, and tips for creating them.

- <https://www.pathstoliteracy.org/blog/experience-books-tool-conversation>
- <https://www.tsbvi.edu/203-resources/1316-conversations-without-language-building-quality-interactions-with-children-who-are-deaf-blind>
- <https://www.pathstoliteracy.org/resources/conversation-boxes>
- <https://www.unr.edu/ndsip/english/resources/tips/creating-conversation-boxes>

Review safety measures. Visit your school district’s website for details and information that can answer questions you and your child have about the school day, schedules, masking and other health and safety protocols, and additional student supports to address the impact of the pandemic on learning. Once armed with information, you can set the tone and emphasize safety measures by calmly presenting the known information. If questions arise, make a list, and find the answers together. Social stories (<https://www.special-learning.com/article/what-are-social-stories>, <https://www.pathstoliteracy.org/blog/using-pictello-write-social-stories>,) can also help children learn what to expect and how to manage their feelings. Visit <https://www.autismresourcecentral.org/social-stories-for-young-and-old-on-covid-19/> for some COVID-specific social stories.

Prepare for the transitions. Children who are deafblind often have trouble with transitions and separation. Social stories are useful here also. In addition, cues (<https://www.unr.edu/ndsip/english/resources/tips/how-can-i-help-my-child-understand>, <http://www.cadbs.org/news/a03-touch-cues/>) and transitional objects can help your child understand what’s about to happen and feel connected to you while apart. You can use anything as a transitional object – a bracelet, a piece of a towel, a handkerchief, something lightly sprayed with your perfume for them to smell – it’s just something tangible to make them feel connected to you while apart. For children able to use abstract concepts, a dot on the wrist, a matching ring or bracelet, or matching fidget toy can “invisibly” connect you both.

Get into a routine. Routines provide structure and eliminate anxiety due to anticipation of the unknown. This is especially essential for children with deafblindness. Visit <https://www.nationaldb.org/info-center/educational-practices/routines/> to learn about building routine. Remember to include transition prompts in your routine (see <https://www.pathstoliteracy.org/blog/create-routine-using-tactile-cues> for an example). For those who need it, create a visual or tactile calendar that reflects the routine (see <https://www.tsbvi.edu/let-me-check-my-calendar> and <https://www.nationaldb.org/info-center/educational-practices/calendar-systems/>).

A countdown calendar (<https://www.pathstoliteracy.org/strategies/counting-down-days>) can also help your child recognize when a change will happen.

Partner with teachers. Connect with your child’s teacher(s) and provide them a “cheat sheet” to your child. After a year (or more) of assisting a child with deafblindness during remote or hybrid learning, you have new insights and information to share with your child’s teacher. It can help you, the teacher, and your child to share these insights in a formal or informal way. Both <https://www.texasprojectfirst.org/node/13> and <https://www.laparent.com/special-needs/new-teacher-letter> offer ways to share this information. In addition, “Tips for Partnering with Teachers in the New School Year” at <https://childmind.org/article/tips-for-partnering-with-teachers-in-the-new-school-year/> and a fact sheet from California Deaf-Blind Services (<http://files.cadbs.org/200000132-71ed172e77/28HomeSchoolRel.pdf>) provide strategies for establishing and maintaining a good home-school relationship.

Manage your own anxiety. Dr. Rachel Busman, head of the Anxiety Disorders Center at the Child Mind Institute recommends (https://childmind.org/article/managing-anxiety-during-school-reopening/?utm_source=newsletter&utm_medium=email&utm_content=Managing%20Your%20Own%20Anxiety%20During%20School%20Reopening&utm_campaign=Public-Ed-Newsletter) parents use the following strategies to customize their own approach to managing anxiety.

- Focus on what you can control
- Maintain social connections
- Be transparent about ground rules
- Take breaks when you need them
- Don’t hesitate to seek help

A Day in the Park with Project Reach

On Saturday, August 14, Project Reach families gathered at Maryknoll Park in Glen Ellyn to receive information about deafblind services and support, learn from each other, and have fun. Children made and filled goody bags as parents chatted. Illinois Advocates for the Deafblind (IADB) treated all to a delicious lunch. Everyone had a wonderful time meeting and learning from each other!



Captions (from L to R): 1. Families talk prior to lunch while Eva and Zack Savickas discuss lunch choices. 2. Angela, Brandon and David Walters enjoy lunch with Toni and Elizabeth Kijowski. 3. The Walters family poses for a picture before saying good-bye to Vivian Ong, Josiah Huang, and Joanna Huang.

Back to School in a Mid-COVID World

In this ever-changing pandemic world, practices and policies change rapidly. Last spring, we seemed well on the road to a more normal back-to-school season as vaccinations increased and students left school for the summer. Then came the Delta variant. New Covid hospitalizations and break-through infections are increasing, the Centers for Disease Control (CDC) just authorized a vaccination booster for all people with weakened immune systems extended that starting September 20 to all those fully vaccinated, and mask mandates are back in many stores and towns. As children return to school this year, we need to remain flexible and prepare for possible changes throughout the school year. This month, the Illinois State Board of Education (ISBE) issued *Revised Public Health Guidance for Schools, Part 5 — Supporting the Full Return to In-Person Learning for All Students August 2021* (<https://www.isbe.net/Documents/Updated-Public-Health-School-Guidance.pdf#page=3>). What should you and your child expect in returning to the classroom? The following articles highlight important changes, both Covid and non-Covid related.

Universal Indoor Masking in Schools

On August 4 Governor JB Pritzker issued Executive Order Number 18 (COVID-19 Executive Order No. 85), which requires COVID-19 mitigation measures, including masking. This order applies to all preschool through Grade 12 schools in Illinois (both public and non-public). The order requires masking by all students, staff, and visitors over the age of two, regardless of vaccination status. The Governor included an exclusion for those unable to medically tolerate a face covering, like many of our children who are deafblind. The CDC specifically states masks should not be worn by “[a] person with a disability who cannot wear a mask, or cannot safely wear a mask, for reasons related to the disability.” For more guidance on masking in general and related to children who are deaf/hard of hearing or have a disability, specifically, visit https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/cloth-face-cover-guidance.html#anchor_1619804600020.

In addition, the Governor's order mandates schools put in place "layered prevention strategies," such as social distancing, hand washing, testing, contact tracing, and cleaning and disinfection measures. Visit <https://www.illinois.gov/government/executive-orders/executive-order-executive-order-number-18.2021.html> to read the details of Executive Order Number 18.

In a letter to all superintendents, Dr. Carmen I. Ayala, State Superintendent of Education, affirmed on August 11 that all schools, public and non-public, must comply with Governor Pritzker's order. She stated she understood the pressures some school districts face, "However, noncompliance is not an option. I will not compromise the health and safety of students or staff, nor will I risk even one child's life." Dr. Ayala went on to stress school districts could face legal liability and loss of State recognition if they ignore Governor Pritzker's order. For the full text of Dr. Ayala's letter, go to <https://www.isbe.net/Documents/Enforcement-Universal-Indoor-Masking-Requirement.pdf>.

Extended School Services for Students who Turned 22 During 2020-2021 School Year

Public Act 102-0173 (HB 2748) amends The Illinois School Code to make students with disabilities who turned 22 years old during the time of remote education due to the COVID-19 pandemic eligible for services during the 2021-2022 school year. To qualify, the student's in-person instruction, services, or activities must have been suspended for a minimum of three months during the 2020-2021 school year due to the pandemic and the student must still live in the school district. This law does not apply to therapeutic day school or residential program students if the student aged out of the program or the funding for the placement is no longer available. For the full text of the Act, visit <https://www.ilga.gov/legislation/publicacts/102/PDF/102-0173.pdf>.

Additional School Legislative Changes of Importance

Section 10 of Public Act 102-0339, effective starting August 13, 2021, amends The School Code to further restrict the use of time out and physical restraint in Illinois schools, special education cooperatives, and therapeutic day schools with the requirement to eliminate these practices within three years. Nora Collins-Mandeville, Director of Systems Reform Policy, ACLU of Illinois released a statement after passage of HB 219 (the bill which became Public Act 102-0339) on May 30, 2021, which states in part, "The passage of House Bill 219 is a huge win for students across the State of Illinois. The measure was advanced after media reports indicated that schools regularly used restraint and seclusion practices. More alarming, these harmful practices were used most often against youth of color and youth with disabilities.

Per this Act, "Isolated time out, time out, and physical restraint, other than prone physical restraint, may be used ONLY (emphasis added) if:

- the student's behavior presents imminent danger of serious physical harm to the student or others;
- other less restrictive and intrusive measures have been tried and have proven to be ineffective in stopping the imminent danger of serious physical harm;
- there is no known medical contraindication to its use on the student; AND (emphasis added)
- the school staff member or members applying the use of time out, isolated time out, or physical restraint on a student have been trained in its safe application, as established by rule by the State Board of Education."

The Act also requires schools take active steps to eliminate the use of isolated time out, time out, and physical restraint within three years.

Prone physical restraint is prohibited under the bill except under one set of very specific conditions for the 2021-2022 school year. Prone physical restraint is defined as "a physical restraint in which the student is held

face down on the floor or other surface and physical pressure is applied to the student's body to keep the student in the prone position." After this school year, prone physical restraint will be prohibited under any circumstance. For the full text of the Act, visit <https://www.ilga.gov/legislation/publicacts/102/PDF/102-0339.pdf>.

Public Act 102-0172 (HB 40) amends The School Code to allow children with disabilities receiving special education services to continue receiving those services through the end of the school year if their 22nd birthday falls during the school year. A school year is defined by a particular school's public calendar and does not include summer programming or extended school year services. Prior to the law's effective date of July 28, 2021, students with disabilities turning 22 during the school year were only able to attend school until the day before their 22nd birthday. For the full text of the Act, visit <https://www.ilga.gov/legislation/publicacts/102/PDF/102-0172.pdf>.

Public Act 102-0357 (SB 654) amends The School Code to provide daily recess time for students in kindergarten through grade 5 and dictates the allotment of time based on the length of the school day. While it's encouraged that this unstructured, yet supervised, child-directed play time occur outside, it is permitted to hold this time indoors. The Act permits organized games, but prohibits the use of computers, tablets, phones, or videos. For students with disabilities, recess time must comply with the student's IEP or Section 504 plan. For the full text of the Act, visit <https://www.ilga.gov/legislation/publicacts/102/PDF/102-0357.pdf>.

HB 3849, sent to Governor Pritzker on June 29, 2021, creates the Supported Decision-Making Agreement Act. This Bill authorizes the creation of supported decision-making agreements as an alternative to adult guardianship, establishes the rules and definitions of terms for such an agreement, the roles and responsibilities of parties to the agreement, and the qualifications and disqualifications of parties to the agreement. HB 3849 presumes competence by stating, "all adults are presumed to be capable of making decisions regarding daily living and to have capacity unless otherwise determined by a court." Supported Decision-Making Agreements Act will become effective six months after it is signed into law by the Governor. For the full text of the Bill, visit <https://www.ilga.gov/legislation/102/HB/PDF/10200HB3849lv.pdf>.

New from Deafblind International Youth Network



On July 5, Deafblind International Youth Network (DbIYN) released a new publication, *A Glimpse of our Covid World, Stories of resilience from young deafblind people during a global pandemic*. The publication, a collection of stories from around the world, provides a unique insight into how young people who are deafblind have lived their lives in this new, unpredictable pandemic world. The publication is available for download in a PDF format at <http://dbiyn.deafblindinternational.org/publications/>.

DbI Youth Network is currently planning their next publication, a collection of international recipes from youth network members. Have a recipe you would like to include in this new publication? Submit your original or family recipe to simon.allison@sense.org.uk by September 1, 2021.

DbIYN provides a global platform from which young people who are deafblind can form peer group friendships by experiencing events such as holidays, exchange visits, and participating in conferences. Membership is free and open to all young people between the ages of 14 and 28 years old who are deafblind. If you are a person who supports young people who are deafblind or are interested in the issues important to young people who are deafblind, you are eligible for an associate membership, which is also free.

Dinner in the Dark

By Krista Bohl

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It had been two months of constant frustration by my DeafBlind junior high daughter. Why were people forgetting to use her microphone? Why didn't others understand that she needed to sit in the middle of the friend group in order to be a part of the conversation? Why would people always say "never mind" after she needed them to repeat a comment a second time? The lack of other's willingness to accommodate and understand her needs was wearing her down. Being DeafBlind in junior high is overwhelming. The nuances of social interactions, mood swings, on again/off again friendships, is hard enough to navigate in junior high – add to that a dual sensory loss and one fills like the deck is stacked against them. I didn't want my daughter traveling through her school years with others who didn't understand her situation. I wanted them to put themselves in her shoes at an early age, so that maybe, just maybe, they would choose different responses. I warned her that we were working with middle schoolers. We lowered our expectations when it came to empathy and attention span and got to work!

My daughter made up a catchy party phrase on text. "Have you ever wondered what it is like to have low vision and a hearing impairment? Come experience the first annual Dinner in the Dark!" I told her to invite anyone she interacted with on a regular basis. The RSVPs were coming in minutes after sending the text. They seemed excited and intrigued.

I spent the next week making individual masks out of packing bubble. This seemed to be the best representation of how she sees the world. With the mask on, I couldn't see details of others in front of me – just an outline of their body. I definitely couldn't read normal size print. We also gathered together ear plugs and noise blocking earmuffs, to help one experience what it is like to be hearing impaired.

The day of the party arrived. My daughter would be in charge; I wanted her to own this experience. Her friends arrived one by one. We made them stay in the front room so that they would not receive any visual cues as to what was being served for dinner. Masks were given out with ear plugs. They were encouraged to wear them as long as they could. They then entered the dark dining room. The excitement was growing. We explained that we would start a plate at one end, and they would pass it around. We would not be telling them what was being served. As we started the dinner the girls were already saying "what?" due to the ear plugs in their ears. Many were quiet, intently trying to figure out what food was in front of them. Others were sniffing the food and taking it or passing it on. Still others were yelling "Ew!" when they realized what they thought was a grape was really a tomato. I started hearing them say things to my daughter like, "You're amazing. How do you do this?" One friend on the end of the table did not say anything the entire dinner. She didn't know what was going on because she couldn't see or hear well enough. She later told the group that they needed to let my daughter sit in the middle of the group at lunch, because now she knew how it felt.

They then moved on to games. They started with ping pong. It got a little crazy, but I think they got the point. My daughter then handed out questions from the game Would You Rather that were printed on a piece of paper. The girls were supposed to respond to the questions they received. After struggling for a few minutes, they started asking my daughter for the devices they see her use at school. One ran to the office where her CCTV was set up.

Eventually it was time for dessert. We had chosen sundaes. Everything was out of its original packaging and placed in separate bowls, to make it more visually challenging. I even got out my most busy tablecloth. It got extremely messy. Everyone was concentrating very hard as they bent down as close as possible to the bowl, hoping not to spill.

Later that evening, my daughter opened it up to questions. She said they could ask her anything. To my surprise, they sat around and talked about their experiences and asked her questions for 45 minutes. When the parents showed up, the girls were still reflecting on the evening.

As we were picking up after the party, I could tell my daughter felt empowered and excited. I severely underestimated this age group. They asked questions they had never dared to ask in the past. I heard them ask my daughter personal questions like “Are you upset you were born with vision and hearing loss?” This was hard to hear. But that type of question helps everyone grow and reflect, even the person being asked. Many of the girls had been in classes with her for 6 years. Tonight, they finally felt the freedom to ask what they had been wondering.

Things have not been perfect since that evening. They still forget to pass her microphone or leave her sitting on the outside of the group. But seeds were planted. Understanding was sewn. And hopefully, from this moment forward, when they see someone with a vision or hearing impairment, all the feelings they experienced tonight will come flooding back. For inclusion goes beyond allowing those with disabilities to be a part of mainstream activities. It means befriending them, understanding their needs, and inviting them into your life as an equal.



Helping Households Connect During the Pandemic

The Federal Communications Commission has launched a temporary program to help families and households struggling to afford Internet service during the COVID-19 pandemic. The Emergency Broadband Benefit provides a discount of up to \$50 per month toward broadband service for eligible households and up to \$75 per month for households on qualifying Tribal lands. Eligible households can also receive a one-time discount of up to \$100 to purchase a laptop, desktop computer, or tablet from participating providers.

Eligible households can enroll through a participating provider at <https://www.fcc.gov/emergency-broadband-benefit-providers> or directly with the Universal Service Administrative Company (USAC) using an online (<http://getemergencybroadband.org/>) or mail in application.

You can learn more about the benefit, including eligibility and enrollment information, by visiting www.fcc.gov/broadbandbenefit, or by calling 833-511-0311.



A Special Live Story Time Show: Marvin’s Seaside Adventure and the Rescue of Super Sparkle

Join storyteller Gwyn McCormack on August 30 at 3 p.m. CST for a lively, enthusiastic, and colorful one-hour Marvin Story Time Show. Gwynnie-Gwyn-Gwyn, as she refers to herself in the show, will tell the story of Marvin’s Seaside Adventure and the Rescue of Super Sparkle with rainbow spins, cheers, fun songs, and a sprinkling of glitter! This special, live broadcast presented by HABA Toy Company USA is free for all families to enjoy. For more information and to register for this special event, visit <https://www.habausa.com/story-time/>.

Upcoming Events

- **August 30 – Marvin’s Seaside Adventure and the Rescue of Super Sparkle** – See description above
- **September 22 – NFADB 5th Annual Evening of Deaf-Blind Experience** – <https://nfadb.org/event-4447554>
- **October – Illinois Families Together Parent Zoom** – Topic: Helping Our Children Develop Friendships
- **April 22-24, 2022 – Project Reach Weekend at Illinois Family Leaders Conference, Peoria, Illinois**



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