Tips for the Holidays with a Family Member with Disabilities

With the continuation of the pandemic and the countless festivities associated with Hanukkah, Christmas, Ramadan, and other December events, there are a lot of events where children are expected to be on their best behavior. This holiday event might include wearing a mask, too. The sights, smells, sounds, and expectations can make any child irritable, but it can do that and more for a child with disabilities. While no amount of preparation can make sure everything with the holiday is perfect, there are some things that you can do to make the holiday easier. Here are some tips for your consideration:

- **Maintain routines** as much as possible in the holiday season. Some children have special sensory activities to keep a meltdown from happening.

- **Safe Space** whenever you visit a person’s house or have company at your house, establish a “safe zone” for your child so that the child can retreat and be alone if desired. It may be a room in the house or even a small space.

- **Family Prep** – If you will be visiting family or friends who have not been around your child very much since the pandemic, consider giving them some advice in advance. This advance conversation will help avoid hurt feelings when your little one may not hug Grandma or refuse to eat her Christmas special dish. You might offer alternatives such as your child likes ‘high fives’ or explain that your child is still learning to eat new different foods.

- **Simplify Events** – If there is an activity that will cause frustration for your disabled family member, try to simplify it. For example, suppose it is a fine motor activity such as opening presents that is going to cause anxiety. In that case, you could loosen ribbons, unseal envelopes and minimize tape so your child can feel successful with little frustration.

By adjusting, enlisting at least one other person to help you, and preparing ahead, the holiday should be more enjoyable for everyone.

Source: Pediatric Therapies, 2021
Greetings Friends of West Virginia Parent Training and Information, Inc.,

WVPTI wishes everyone good health, calmness, and peace as we celebrate this holiday season. We understand the holidays will still be different this year due to the viruses. Your family will be together during the holiday, either virtually or in person. The holiday newsletter includes tips and suggestions on making the festivities a merry one including a family member with disabilities. We wish all of you safe and happy celebrations.

To keep you updated in the new year with the latest news, WVPTI social media accounts, emails, and our website will have postings and updates about the status of WVPTI programs and services.

Also, contact us at our main number, 304-472-5697, if you need services or information.

Be well, stay safe, and Happy Holidays!

Brenda Lamkin, Ex. Director of WVPTI
Welcome a New Board Member—Paul Hardesty

West Virginia Board of Education and the West Virginia Department of Education are pleased to announce a new member of the State Board of Education, Paul Hardesty. Governor Jim Justice announced the appointment of Mr. Paul Hardesty. His background includes serving three terms on the Logan Board of Education, vice-chair of the Southern West Virginia Community and Technical College Board of Governors, director of the Office of Coalfield Community Development, and legislative liaison for both governors Bob Wise and Joe Machin III. President Miller Hall of the West Virginia Board of Education will administer the oath of office to Mr. Hardesty at the West Virginia Board of Education meeting on January 12, 2022, in Charleston, West Virginia. West Virginia Parent Training and Information welcomes Mr. Paul Hardesty as the newest member of the West Virginia Board of Education.

The WV 2021 legislative session passed the Hope Scholarship Act, an education savings account that allows eligible parents to receive the average per-pupil funding (approximately $4600 in 2020-21) already set aside for their children’s education onto an electronic, parent-controlled fund for educational expenses. Those expenses can include private tuition, tutoring, credentialing therapies, transportation, and more. Students must have attended public elementary or secondary schools for at least 45 full-time instruction days of school of the school year in which they apply or have enrolled in public schools for the entirety of the previous school year. All kindergarten students are eligible for a Hope Scholarship regardless of previous public school attendance. Later, all k-12 students will be eligible for this program beginning in July 2026, regardless whether they had previously been enrolled in a public school. Parents may renew their children’s Hope scholarships each year after initial approval, up to a student’s high school graduation or when they turn 21 years old.

If you are interested in learning more about this program in which applications are ready to launch no later than March 1, 2022, but could be released earlier, please check out the website West Virginia Hope Scholarship at https://givekidshopewv.com/. You may sign up for regular updates and information to be sent to your email address.
New DRS Director Encourages Higher Expectations!

The West Virginia Division of Rehabilitation Services (DRS) is operating under new leadership.

Pisnu Bua-Iam was appointed Acting Director of DRS, effective August 1, 2021, upon the retirement of Marijane Waldron, who had served in this capacity for nearly five years.

Prior to this appointment, Pisnu served as the DRS Deputy Director, as the Senior Manager of the State Plan and Program Evaluation Unit, and as the Manager of the Program Evaluation Unit when he initially joined DRS 21 years ago. Before coming to DRS, he worked briefly at Westat, a think tank, as a research analyst and at WVU as a research instructor.

Pisnu has more than 34 years of combined experience in the field of vocational rehabilitation. He is also a nationally recognized expert on program evaluation and return-on-investment of public vocational rehabilitation programs, and he has authored numerous journal publications.

In his new role as director, Pisnu has commenced a new initiative, the Systemic Transition Enhancement Project in 2021 (Step 21), which encourages DRS and its partners to “step up” to better serve West Virginians with disabilities.

DRS helps people with disabilities (ages 14 and up) prepare for, secure, regain, retain or advance in employment. DRS’ vocational rehabilitation counselors help consumers assess interests and abilities and explore career options to develop employment plans that will empower each person to meet individualized employment goals.

Through STEP 21, DRS and partner agencies are stepping up to increase coordination and cooperation to expand access and opportunities for individuals, especially students, with disabilities to participate and succeed in education and training programs that will lead to high-quality employment outcomes. DRS is setting higher expectations for itself, its partner agencies and for its consumers.

STEP 21 goals include:

- Evaluating the vocational rehabilitation system, which involves the macroanalysis of DRS partnerships at the state level and the microanalysis of DRS’ internal operations to effectively and efficiently expand vocational services throughout West Virginia.
- Expanding coordination and outreach efforts with DRS partners including Special Education, Career Technical Education, local schools and their administrators, community service providers and other partners to further enhance relationships and increase buy-in that will facilitate systemic change and a systematic approach to jointly support students with disabilities in maximizing their potential.
Step 21 Goals from the Pisnu Bua-Iam, Acting Director of WV Division of Rehabilitation Services (continued)

- Focusing on early intervention, beginning when students are in the eighth grade, to increase awareness and expectations among students, parents, family members, middle school and high school teachers, guidance counselors, and classroom aides to ensure that students with disabilities enter the vocational rehabilitation program at the age of 14 or older to strengthen their participation in career exploration activities (Pre-Employment Transition Services) and other support services to better prepare them for future training, educational and employment opportunities.
- Encouraging students with disabilities to aspire to pursue careers in the areas of science, technology, engineering, arts and math (STEAM) and assisting those who are interested to access education, training and support to succeed in these high-demand occupations.
- Promoting effective teamwork among DRS partners, especially high schools and teachers, to eliminate access barriers to STEAM educational programs for students with disabilities by supplementing services, such as tutoring, mentoring and assistive technology for participating students as needed and when determined necessary by our local education or school partners.
- Enhancing cooperation and coordination among essential partners, including the West Virginia Department of Education’s Office of Special Education and local Career Technical Education (CTE) centers to better prepare students with disabilities for CTE training and to expand training opportunities to these students through assistive technology and other resources, whenever possible.
- Fostering awareness of the availability of a continuum of services to meet the various work-related needs and career goals of individuals with disabilities throughout their lifetime.

Individuals interested in vocational services through DRS can call 1-800-642-8207 or email DRSQuestions@wv.gov or visit wvdrs.org for more information.

Note: The source of the photo of Mr. Pisnu Bua-Iam is the WV Division of Rehabilitation website, 2021.

Research Opportunity for Families with Disabled Children
From Children and Youth with Special Health Care Needs Research

A phone survey is being sponsored by Children and Youth with Special Health Needs Research for additional participants to find information about your child’s healthcare during the pandemic. Here is the information from the sponsors:

Help us understand how your child’s healthcare changed during the COVID pandemic!
We are recruiting caregivers of children up to age 17 with special health care needs for phone interviews. We expect the interview will be 45-60 minutes. You will receive a $50 Amazon gift card for your time. The IRB number for the study is IRB-P00036588.

Please copy and paste the survey link below if you would like to participate:

English survey: https://redcap.tch.harvard.edu/redcap_edc/surveys/?s=LPPAFP37NCRKY4DT
Any questions? Please email Arda Hotz (arda.hotz@childrens.harvard.edu) or Kathleen Conroy (Kathleen.Conroy@childrens.harvard.edu)

SPANISH
¡Ayúdenos a comprender cómo cambió la atención médica de su hijo/a durante la pandemia de COVID!
Estamos reclutando cuidadores de niños/as de hasta 17 años con necesidades especiales de atención médica para entrevista por teléfono.
Esperamos que la entrevista sea de 45 a 60 minutos. Recibirás una tarjeta de regalo de Amazon de $50 por tu tiempo.
Haga clic en el enlace de la encuesta si te gustaría participar:
Spanish survey: https://redcap.tch.harvard.edu/redcap_edc/surveys/?s=YFLAQXTMA4NYLYA
¿Alguna pregunta? Envíe un correo electrónico a Arda Hotz (arda.hotz@childrens.harvard.edu) o Kathle-leen Conroy (Kathleen.Conroy@childrens.harvard.edu)
West Virginia Parent Training and Information, Inc. (WVPTI) is a non-profit agency that operates the statewide federally funded Parent Training and is the Family Voices State Affiliate Organization for West Virginia.

The programs and services of WVPTI, Inc. are based on the concept of parents helping parents. Our mission is to empower parents of children and youth with disabilities in their roles as parents, decision makers, and advocates for their children and to promote partnerships among parents and professionals.

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**Self—Advocacy is our strength!**

- Speaking up for yourself,
- Asking for what you need,
- Negotiating for yourself (working with others to reach an agreement that will meet your needs),
- Knowing your rights and responsibilities,
- Using the resources that are available to you,
- Being able to explain your disability either by the use of written words, pictures.
- Being able to explain your disability either by the use of written words, pictures or gestures.


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