Pass It On

Winter Edition
January-February 2023

A collaboration of NH Family Voices and the Parent Information Center. Empowering and informing families and professionals caring for children with special health care needs and disabilities from birth to adulthood for over 30 years.

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Transitioning into Adulthood

Deana Taylor, Outreach Coordinator at NHFV recently interviewed Nick Plentzas, regarding his successful transition journey. Read about his experiences, including having learned to manage both his health care needs and independent living, including managing his area agency budget.

Were you involved with your health care decisions growing up?

Always, my parents made a point to show me how to deal with the system and how to advocate for myself by talking to others as best as possible. They would make a point to sit and walk me through: what to say, who to talk to, and what needed to be completed and by when. With my cerebral palsy it was helpful to have guidance so I could really grasp how to deal with the system. Which I am very grateful for in my adulthood.

How did you feel like you were best supported in learning to manage your health care decisions?

Well, my parents always supported me gaining any independence that I could. So, I would say that I was always encouraged to make my own health decisions. I think it’s always challenging to get what you need when it comes to medical treatments or medical supplies, especially in today’s day and age.

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Parent Information Center

Established four decades ago, with the belief that all children can succeed with the right support the NH Coalition for Citizens with Disabilities dba the Parent Information Center (PIC) provides a wealth of services designed to help parents understand their child’s special needs and the laws that govern the early intervention (called Family Centered Early Supports and Services in NH) and special education process. In 1995, PIC expanded its focus to serve all parents, not just parents of children with disabilities. PIC assists families, schools and communities to increase family engagement in children’s learning and development.

PIC is a pioneer in creating family/school/community partnerships that help parents of all children get involved in their children’s learning and development. PIC also offers additional support through workshops and resource and referral. From its inception to the present, the Parent Information Center has demonstrated an ability to identify and respond to the changing needs of children and families in NH.

NH Family Voices

New Hampshire Family Voices is part of a network of families and friends of children and youth with special health care needs/disabilities around the nation. In the early 1990’s, during the health care reform discussions of the Clinton administration, a group of families of children and youth with special health care needs realized that no one was speaking up for the unique concerns of their children. These families contacted other parents they knew around the nation. Families responded enthusiastically and there was an immediate ground swell of support to advocate for better health care for their children. Family Voices was born.

New Hampshire was one of the first Family Voices organizations in the nation to respond to this call. NH Family Voices began in 1994 as a grass roots network of families of children and youth with special health care needs for the purpose of sharing information, resources, health programs and policies.

Today, NHFV continues its work to assist parents and professionals in navigating the systems of care that deliver services. Through the engagement of families across NH, and our partnerships, we participate in program development, implementation and evaluation, sharing families expertise in the formation of policies affecting their children. In addition, NHFV connects families with one another and provides families and professionals information to secure and utilize needed services for children and youth.

New Hampshire Family Voices is administered under a fiscal agreement with New Hampshire Coalition for Citizens with Disabilities Inc., d/b/a/Parent Information Center a 501c3 non-profit organization and is the state affiliate organization of Family Voices National.
Sylvia Pelletier, Associate Director is no stranger to many people familiar with NHFV. Having been with NHFV since 1999 (a life time ago-just kidding) we thought we would take a moment to re-introduce her.

What is your favorite part of your job? Working with families! Prior to coming to work at NH Family Voices my experiences were solidly rooted in the epilepsy and childhood cancer communities, with my lived experiences. Family connection is so important. Through my work at NHFV I came to realize that what really connects us is the experience of parenting, the issues we bump up against. When I realized this, I recognized that my community of support was so much bigger than I originally knew; and that is important, because parenting a child who requires “more” in any way can feel really isolating.

What is one thing have you learned about transition since starting at NHFV? When I started at NHFV, health care transition wasn’t even on my radar. So much of my life was spent managing health or educational needs in the moment. I wasn’t thinking that far ahead. I’ve learned how important it is to plan, not only for access to providers if transitions are going to occur, but also for access to information. Does the youth, or an alternate caregiver, know what needs to be known to support health needs?

Do you have any hidden talents? I am not sure how hidden it is; but baking. I worked as a baker in a restaurant through college.

Heidi Duprey recently celebrated her one year anniversary with the PIC as their Special Education Resource & Training Specialist.

Heidi works on important transition work for youth and their families. She offers a variety of beneficial workshops and trainings at PIC to help families navigate the transition process with their youth.

What is one thing you have learned about transition since starting at PIC? I was not aware of all the organizations that support families in transition.

As a kid, what did you want to be when you grew up? A teacher (makes perfect sense as training specialist).

What is your favorite winter activity? I play Unturned and Minecraft with Jay, my teenager.

Do you have any hidden talents? I like photography.

Family Voices Acknowledges Senator Maggie Hassan Advocacy Work

Family Voices each year holds an annual national conference. The conference provides the opportunity for affiliate members from across the country to gather, network, and learn from one another. At this annual conference, those who not only advocate for families but help to impact national policies to support families with disabilities and chronic health needs are acknowledged.

On October 18, 2022, Senator Maggie Hassan of New Hampshire was one of these recipients. Sen. Maggie Hassan was elected to the Senate in 2016 and currently serves on the Senate Committee on Health, Education, Labor and Pensions, including as a member of its Primary Health and Retirement Security Subcommittee and its Children...
Special Education Eligibility Extended until Age 22

Joanne Grobecker of the Parent Information Center asked Diane Andrews, Parent; Daniel Alexander, Assistant Director of Special Education for Nashua School District; and Mindy Huckins, Senior Director of Family and Participant Directed Services at Gateways Community Services to share their perspectives to the extension of special education until the age of 22.

The transition from high school can be an emotional time for families of children with disabilities. Caregivers are hopeful the skills learned in the school setting will enable students to live in adulthood as independently as possible. In a recent change to state law, students with disabilities will now have an additional year of school-based supports and services to help them prepare for their transition into adulthood. This allows students who have not yet earned a regular high school diploma the opportunity to remain in school until the day before they turn twenty-two.

According to Disabilities Rights Center – NH, this change now brings NH into compliance with federal law. Previously, NH law ended eligibility for special education upon a student’s 21st birthday. This left the decision regarding continuation of programming until the end of the traditional school year to individual districts, creating different standards across the state. Originally the bill was sponsored by State Representative Nancy Murphy so that all NH students could access an education until 22 years old, regardless of the town in which they live. “This benefits students all over the state, and removes confusion among administrators, so all students can access the services they need.” State Representative Bill Boyd who sponsored the bill that became law said “It is a question of equity so all the children who have IEPs would be on par with every student in the United States.”

Not only does the additional time create equity, it has the potential to have a tremendous positive impact on the lives of students with disabilities. This additional year of transition brings benefits and opportunities for students with disabilities, families, school districts, area agencies and other community providers.

A Family Perspective: Diane Andrews

Diane’s son Ryan is 17 years old and has Autism Spectrum Disorder. This extra year in the transition process is life changing for their family. Diane was emphatic when speaking about students who benefit from this transition law saying “That year can make such a huge difference for their development and maturity.” Ryan is continually making gains and this additional year will be a huge benefit to him academically and socially. Ryan is placed by his NH school district at a school that can meet his needs in Massachusetts. This law aligns Ryan’s NH IEP transition plan to the MA law which eliminates confusion and gives him full access to programs that can benefit his transition to adulthood as a NH resident.

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Diane is navigating this transition process on top of all the responsibilities that come with having a child with special needs. She is managing his health services, social security disability, health insurance, guardianship, school, and other services on top of being a mom. The list of responsibilities on a parent is a lot to navigate alone.

Diane said that that “There is no road map and you are left to figure it out yourself as a parent.” Having additional time to get these services in place before transition from school is a huge relief for Diane.

The COVID pandemic was a huge disrupter in Ryan’s transition plan. Relationships Diane had built with staff at various agencies changed with staffing turnover due to the pandemic. Diane is working on building new relationships and feels that this extra year came at a perfect time for families where services were disrupted for so many families with disabilities during Covid. This additional year gives her time to rebuild relationships and navigate all the systems that come with Ryan becoming an adult.

Diane expressed her gratitude for this law that will give Ryan an extra year at school. This extra year will give him time to mature socially and make gains at school academically. Diane was filled with relief when the law passed. “My son needs that time. I was so happy when the law finally went through. I couldn’t be happier!”

A School District’s Perspective: Daniel Alexander

As the Assistant Director of Special Education for the Nashua School District, Daniel Alexander sees what goes into a meaningful transition plan. “The extra year allowed students a little more time for that planning.” Families were excited students had the opportunity for an additional year. While it is a positive change it was still an adjustment for students. His staff worked hard to help students understand and process why they were still in a school environment, or returning to a school environment, after they had celebrated graduation and said their goodbyes. Daniel is excited for the opportunities that exist for schools and area agencies to work together for a year to enable a smooth transition for students. Collaboration between schools and area agencies can happen in a new way and that is exciting for Daniel. His staff has worked closely with families around this new law to ensure that students are best supported. Daniel respects that first and foremost “This is a family-based decision.” Keeping the focus on families during this time has made all the difference.

An Area Agency’s Perspective: Mindy Huckins

As the Senior Director of Family and Participant Directed Services at Gateways Community Services Mindy Huckins sees the direct impact of extending the transition age by a year. Mindy expressed that “The best practice is to use the person-centered planning process to define the vision, goals, and skills the individual wants for their life.” The extra year means that students can have a smoother transition. Students will still begin adult services at age 21 and will have those while they receive school services until the day before a student’s 22nd birthday when school services end. The overlap in services means that the final year is really the careful handoff for individuals as they move from a school setting to adulthood. It can be a true collaboration to benefit individuals with disabilities. The pandemic impacted staffing and having an extra year has been helpful. To Mindy, there are clear benefits to having an extra year. Gateways is making the most of this extra year to partner with families while individuals are still in school.

Everyone interviewed was clear, this extra year can have a positive impact on students transitioning from school. Regardless of what age students’ transition, every student is unique and every transition plan will look different. With the right supports and collaboration, transition can be an exciting time of opportunity.

Resources

Are you interested in learning more? Head to www.picnh.org and choose the Resources Tab for the Planning for Life After High School section of the website. The Transition Toolkit is a print kit of information to read as well as the Time for Transition videos available for viewing.
VR New Hampshire: Assisting Students with Disabilities to Take it to the Next Level

On November 4, 2022, over 60 students representing ten high schools throughout the state, participated in the first annual Level Up! College and Career Fair sponsored by VR New Hampshire and NHTI – Concord’s Community College. The half-day event, hosted at NHTI, was packed with activities seeking to expose the students to a college campus, introduce them to businesses throughout the area that are hiring, familiarize them with organizations that can help to support their goals both in and out of high school and educate them on some of the tools and skills necessary to prepare for the workforce.

Throughout the event, students had the opportunity to connect with The United States Postal Service, Visiting Angels, Nylon Corporation of America, North and South Construction Services, WIN Waste Innovations, Johnson and Jordan, Five Guys, CVS Health, Rangam SourceAbled and Amazon. Participating students further expanded their network of resources by connections made with The Parent Information Center, Granite State Independent Living, Accessibility Services at NHTI, Easter Seals, New Hampshire Employment Security, New Hampshire Federal Credit Union, New Hampshire Apprenticeship – High School and New Hampshire Higher Education Assistance Foundation. This connection resulted in one of the event’s exhibitors stating, “It was an excellent opportunity to reach an important population.”

In addition to making so many worthwhile connections with employers and organizations, students were wowed by the Mobile Access to Possibilities (MAPs) RV. Parked behind NHTI’s Student Center, the MAPs RV is the New Hampshire Education Department’s Recreational Vehicle, which promotes Career and Technical Education programs throughout the state. Students got the chance to receive hands on experience with modern technology such as drones, an air simulator, CPR manikins, a blood-drawing phlebotomy practice arm, cosmetology training heads and zSpace computers with virtual and augmented reality – all designed to introduce students to 3-D technology, welding, automotive, healthcare, machine shop programs and more.

Students also spent time discovering in a couple of the NHTI classrooms, learning about career assessment tool options at the post-secondary level, as well as today’s landscape of the New Hampshire workforce.

As a result of the overall event, students and educators alike shared, “thank you for a great event! If you decide to put another on, we will definitely come back.”

VR New Hampshire will look to host similar events in the future across the state and is a statewide resource available to assist individuals with disabilities to enter into, maintain or regain employment. For more information, please visit Bureau of Vocational Rehabilitation | Department of Education (nh.gov) or feel free to contact Tina Greco at betina.m.greco@doe.nh.gov or (603) 271-3993.
**Tips for Preparing Your Youth with a Chronic Health Condition for College**

1. **Have them connect with their doctor (primary and specialist)** in advance of leaving for college. Make sure your youth has a full understanding of their condition and medications. Have them ask questions on how to alter their medication regimen if a problem or need arises. Suggest they pre-schedule doctor appointments in advance for when they are home on break.

2. **Know what health resources are available on campus from health care centers to accommodations.** No two health care centers are the same. Things to consider: are the hours of operations, access, and type of providers on-site, do they offer walk-in options, and can they treat your child’s condition. Consider asking your youth’s provider to prepare information for the school especially if accommodations need to be made.

3. **Decide what pharmacy to use:** will you need to find a new pharmacy closer to the campus or can you continue using your current pharmacy.

4. **Make sure they have a copy of their insurance card and know their medical background (allergies to medications, surgeries).** It will be important to find out if the health care center, providers, and hospital near the college are in your network especially for those students going out of state or further away from home. They should know the list of their current providers.

5. **Create an emergency plan should an unexpected medical emergency arise.** It is not only a good idea to know the hours of the college’s health center but a secondary medical location should they need treatment after hours. Have them share with someone they can trust such as close friend about their health condition and how they can help should an emergency arise.

6. **Secure medication.** Discuss with your student the importance of keeping medications secured from others as some medications are highly sought after on campuses.

7. **Finally, don’t forget to take care of themselves.** College life can be an adjustment and campus life can be busy.

To learn more about preparing youth to transition from pediatric care to adult care and tools surrounding healthcare transition visit NHFV website: [https://nhfv.org/projectsinitiatives/health-care-transition/](https://nhfv.org/projectsinitiatives/health-care-transition/)

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**Time For Transition**

*a family to family chat*

**DISABILITY BENEFIT OPTIONS**

February 23rd @ 6pm


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Do you want to know more about disability benefits? Join us for this chat to hear Ashley Palma from Granite State Independent Living tell us about the types of benefits, what the process is when you or the youth should apply and who you should contact if you or the youth would like to apply for benefits.

This event is being sponsored by the Parent Information Center on Thursday, February 23rd from 6:00 p.m. to 7:00 p.m. To see their on-going event calendar visit: [https://picnh.org/events/](https://picnh.org/events/)
Check out our rich selection of books written for children, teens, parents, and professionals providing a positive, affirmative approach to learning about transition

**Promoting Health Care Transitions for Adolescents with Special Health Care Needs**

*By: Cecily L Betz, & Wendy M. Nehring*

This book provides professionals from both health care and educational backgrounds with comprehensive information about the health-care related aspects of transition planning for adolescents with special health care needs and/or disabilities.

The book is divided into three parts. The first part focuses on what is currently considered best practice in health care transition planning, including legal and ethical issues, health insurance options, long-term care, and accommodations in educational and work settings. The second part provides practical information about assessing, developing, and determining outcomes for health care transitions. The third part concentrates on coordination between health care and non-health care professionals in the areas of education, rehabilitation, and employment services.

**Caregivers And Personal Assistants: How To Find, Hire And Manage The People Who Help You (Or Your Loved One!)

*By: Alfred Degraff*

A comprehensive reference. Step by step strategies for recruiting, interviewing, screening, hiring, training, managing and parting ways with paid help providers. Great guide for help recipients, of all ages, as well as family caregivers and paid aides.

**Essentials of Transition Planning**

*By: Paul Wehman*

For young people with disabilities crossing the bridge to adulthood will be empowering instead of intimidating—when their support teams know the essentials of effective transition planning. Now all the fundamentals of well-crafted transition plans are collected in one concise quick-guide, straight from one of the top authorities on helping young people live fulfilling adult lives.
The book is divided into three parts. The first part focuses on what is currently considered best practice in health care transition planning. The second part provides practical information about assessing, developing, and determining outcomes for health care needs and/or disabilities. The third part concentrates on coordination between health care and care transitions.

Autism Speaks: Transition Tool Kit

Available as download on NHFV website under the lending library.

This tool kit will serve as a guide that can provide you with options to think about and explore as you and your adolescent with autism begin to plan for adulthood. The guiding principle used in developing this kit is that all individuals with autism, regardless of the level of support needed, should be able to live lives filled with purpose, dignity, choices, and happiness. With this in mind, the development of self-help and self-advocacy skills is highlighted throughout this kit. The kit has been broken down into different sections including timelines for each state, with state agency information that may be helpful to you throughout this process.

Whose Life Is It Anyway? Subtitle: How One Teenager, Her Parents, and Her Teacher View the Transition Process for a Young Person with Disabilities

Available as download on NHFV website under the lending library.

Profiles five points in the transition process (from the beginning of the senior year to one year post graduation) at each point in time we see the unique perspectives of the youth, the parent and the professional. Includes discussion questions and resources.

Life After High School Transition Tool Kit: Strategies, Tools and Resources For Families of Youth with Disabilities to Assist in Creating Successful Transition Plans

Available as download on NHFV website under the lending library.

Put together by NH’s Parent Information Center, this toolkit was developed to help families and youth learn about transition planning during the IEP process. It provides an overview of the laws, as well as specific tools to assist with this process.

Give us a call or search our catalog by subject online. Books are sent free of charge through the mail with a postage paid return envelope.

To borrow a book call 603-271-4525 or visit www.nhfv.org
Life After High School: The Importance of IEP Transition Goals

Terry Ohlson-Martin, Director at NHFV recently interviewed Keagan Watson regarding his experience transitioning from high school to life after high school. He obtained his bachelor’s degree at Keene State College and is currently a grad student at Plymouth State College. We also look forward to hearing more from him as a contributor to one of our future podcasts.

In what ways did your high school IEP Transition planning and goals help prepare you for college/life after high school?

First of all, as people know or may not know, when people go to college the IEP (Individual Educational Plan) goes away. You either go onto a 504 plan or go on to deal with life. This is important for youth and their families to know and understand. I mention this because I knew I wanted to go to college, and this can be a hurdle for some.

My transition plan was to investigate the resources at my disposal for when I graduated high school at either the age of 18 or 21. These goals were to visit colleges, gather financial information, and information about how to access public transportation. I wanted to learn to be independent as much as possible so when I went to college it wasn’t such a big shock.

Those things make sense to me – definitely all the things you need to do. But, what did you learn during that transition process that would have been more helpful or things you wish you had known?

More time. I wish I had started the process earlier than 15 to help gather more information. The transition plan changes as your plans change and shift. For instance, I did not start looking at colleges until junior/senior year of high school.

If you plan on going to college, I want to stress the importance of going to the college and touring it. Especially, individuals with a disability of any kind or use wheelchair or any other implement. What I learned is that what they deem as accessible may not be truly accessible from the person with the disabilities standpoint. For example, I toured a private college and found it wasn’t really accessible. The handicap buttons didn’t work properly or at all (Keagan uses a motorized wheelchair). Instead of being concerned, they said not to worry someone would help open the doors for me. That’s not feasible to be waiting outside waiting for someone to be around to open a door.

I ended up choosing Keene State were I earned my bachelor’s degree. They were willing to work with me. As you know, Keene State campus is fairly flat, making it more accessible for a motorized wheelchair which are not great in the snow. There were still some challenges but they were willing to work with me.

My point is you would hate to get to the college only to find it is not accessible as you thought or were as told. It would end up being a waste of your money. I also want to note as I was applying to Keene State, I spoke to the disability coordinator. They told me it looked like I was missing a few things so they wanted to meet with my IEP team. Some of the things that came up were kind of expected but others were shocking. This is why more time would have benefited me.

Tell us more about your transition process from high school to college? Your actual experience: what challenges did you face, what went well and resources helped you?

I knew it was coming. But, when you get there it is a different animal. It is one of those things that until you experience it you aren’t really going to know what to expect.

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For instance, one of the challenges I experienced is the need to prove myself, that I belonged on the campus of Keene State. So many people were waiting for me to fail and find a reason to send me home because they didn’t think I could be successful. My disability coordinator one day told me “if I get any lip from anyone that you are being unsafe, I can make you be a home student.” Typically, college students aren’t given a onetime deal to succeed or fail “for instance the safety factor”. Thankfully, I had a strong family support system helping me get to college and moving me in and encouraging me that I could do it. After some time, I proved I could do it, and the coordinator relaxed. While that was a negative experience I believe it was directly related to that person and thankfully they are no longer there.

I learned to navigate systems around the school, vendors like my wheelchair vendor, and others necessary for my independence and success including using Aspire and the disability services on campus.

**There is definitely an added layer to you being a student.**

Yes. A lot of my friends didn’t get that I had to do certain things and I had to rely on my PCA or needed extra time due to my disability. It is just part of who I am.

**In what ways did the university ensure you received the accommodations you needed? How were the professors, and how did they accommodate you?**

As long as you have a documented something, they are pretty flexible. This is where the 504 comes in handy. I did have a few professors that I had to spell out every single accommodation, “that was just because of who they were”. If it wasn’t on the list, I wasn’t getting it, while other professors used logic.

For instance, I needed a word processor not only for tests and exams but to process individual assignments. Another instance, I had a professor who got a table from another room because I needed a higher table because of my chair. It wasn’t on the paper but it made sense to her.

Overall, I found I had a good relationship with my professors and fortunately had some of the same ones several times because of the size of the campus.

**If you were still in high school, what is some takeaways you would pass on to others? Like how does somebody know what they should be working on before leaving high school? Or what things should they be making sure happens before transitioning out of high school?**

Like I said, it comes very fast. Know what feels right for yourself. For instance, I knew I was ready to leave high school and the additional years and services didn’t make sense for me.

Additionally, you really need to sit down and have in-depth conversations with family, resources such as NHFV, and disabilities services to be prepared to hit ready set go. This includes considering having an AT assessment to have things in place when the time comes.

I was taken by surprise when I turned 18 by some things: the need for me to advertise and hire my own PCAs; all the Medicaid rules that you try not to violate; and the IEP ends after high school and there are no para educators in college.

Finally, don’t be afraid to speak up and ask for help; this includes signing appropriate paperwork that allows your parents/caregivers to step-in and help when necessary. The laws change at 18. You are now an adult. Parents do not have easy access to records. You must give the school/medical practice permission. Also, self-discipline is important. Be prepared for nay sayers and push back but know you can do it! Wishing everyone luck in their endeavors.
Meet the YEAH Council

The Youth Education Advocacy and Health (YEAH) Council is a youth lead organization that prompts advocacy and leadership to help enhance the lives of youth with disabilities and special health conditions. This council meets monthly to discuss topics surrounding employment, education, finance, and healthcare while prompting self-advocacy for youth 14+.

Some things the YEAH Council are currently busy working on are:

- Preparing for their annual conference for youth with disabilities and special health care needs.
- Podcast on hot topics such as transitioning and healthcare

To learn more about joining the YEAH Council, visit their website https://yeahnh.org/ or find them social media.

Emergency Room Preparedness Brochure

How well prepared do you think your youth is if they need to go to the emergency room – without you? Things happen whether we want them to or not. Unfortunately, we can not bubble wrap our youth. Helping prepare them to navigate healthcare including visits to the Emergency Room (ER) is one step towards building their capacity in navigating the world around them.

Meet another valuable staff member: Tracey Walbridge. She is currently the Training Coordinator and Youth Coordinator of the YEAH Council. Read on to learn more about her time with NHFV and more.

What have you learned about transition since starting at NHFV that you were not aware of prior? No one talks about the importance of a child graduating with a diploma versus a modified diploma/certificate of completion/ages out vs. Hiset. How the different ways that schools offer students to exit impacts their long term choices and quality of life; continued education, employment, military, etc.

As a kid, what did you want to be when you grew Up? Happy no matter what.

What is your favorite winter pastime? Counting down the days until spring.

Do you have any hidden talents? I can think of a song to fit any situation. (What a great hidden talent!)
YEAH Council
Service Award

On October 27, 2022, Karen Steel was awarded the YEAH Council Award for Service by Terry Ohlson-Martin, Director of NHFV. This award acknowledges Karen’s dedication and service as a long time member of the YEAH Council from 2013 to 2019.

Shout Out to YEAH Council Member

Abby Bohannon, a current member of the YEAH Council, has stepped up in a supportive role within the YEAH Council. Her active participation has been invaluable following the departure of long term and beloved facilitator Karin Harvey-Olson and the departure of long standing members to college. Abby has taken on the responsibility for minutes at the meetings, and assumed a leadership role, representing the YEAH Council and providing a youth voice at the Healthcare Transition Advisory Project meetings.

(Continued from Emergency Room Preparedness on page 12)

Last year, the YEAH Council took on a project to create a brochure with the goal to teach other young adults how to prepare for and navigate an emergency room visit.

Kaley, a YEAH council member shared her thoughts on the project and the purpose behind it. “Many of us youth find it anxiety-inducing to enter a new setting or situation without prior experience, and often outright avoid new settings or opt to not attempt entering new situations at all as a result of this anxiety. The YEAH council thought it would be beneficial to provide a resource for other youth to alleviate some of that anxiety. We specifically focused on emergency room (ER) scenarios and preparedness because in our experiences, the ER in particular can be an overwhelming and stressful setting. By providing informative content about ER experiences, we aimed to encourage youth to feel more comfortable and prepared in an ER setting so that they may better care for their needs.”

Were there any specific challenges that you had to overcome that you would find helpful to share with other youth?

The most challenging thing is having to push prior authorizations and grievances to no end to get appropriate services/medical equipment. Often times you need to be really persistent to get the best care, and I think that is a good message for others. Never settle for less than you need.

Looking back, what are some of the resources or supports that you wish you would have known about when you began to take over your own healthcare decisions?

I was lucky enough to have great parents who basically showed me the ropes from a very young age so when it was time to manage my own healthcare it was a very natural transition. I was well versed in self-advocacy, how to navigate systems, and things like that. So, I consider myself lucky in that regard.

You’ve also been successful at transitioning to manage your own budget with your area agency. What are some of the things that have been helpful in doing this on your own, and some challenges you have run into managing your own budget?

I would say I don’t really have many struggles with my budget because I made sure I was signed up for the appropriate services to aid me in independent living before I moved out on my own. But, you have to be mindful of what you’re spending and making sure any assistance programs are renewed timely. Also don’t be afraid to ask for help with any paperwork needed.

Nick, would you like to give any final advice to others who are transitioning into adulthood, and learning to navigate complex systems?

Yes, don’t be afraid to call people, make connections and develop your own personal support system, your health is the most important thing and a lot of things can be rectified with just a little push. It can be a headache but it’s always worth it in the end.
Online Subscription

NHFV and PIC are striving to deliver valuable information and resources to families and the professionals that work with them through a variety of outreach tools. The paper copy of Pass It On serves many purposes and is one of our most valued resources. But reality is... many do their reading and sharing online. The webpage pdf of Pass It On contains live links so that readers may click and get to more in depth information in seconds. We would like to encourage those who are receiving a hard copy to think about this alternative and feel free to switch to the web page newsletter. This is easy to do, just follow these steps!

• Go to www.nhfv.org and click on Membership.
• Fill out the form as if you were a new member (please include address information).
• Add nhfamilyvoices@nhfv.org to your email safe senders list, address book or contact list so that an email notice of a new newsletter is not blocked or filtered into your spam folder.

This free resource is intended for sharing so please continue to “Pass It On” to friends, family and professionals you think might find it useful.

Preparing for Transition

Turning 18 is a milestone where suddenly your child is deemed an adult. This comes with legal implications, new rights, and responsibilities. These changes often take people by surprise. Don’t let this happen to you and your child. Begin planning early for this transition as early as 14 years old to provide enough time to gather resources and information. Here are a few things to consider:

● When a child turns 18, even if they have a disability, still live at home, or don’t have the capacity to make their own decisions, parents can no longer legally make decisions on their behalf. In the school setting, Parents will no longer be invited to the IEP meeting unless the youth approves. In the medical setting, proof of guardianship or power of attorney for medical decisions will need to be in place.

● Social Security Income (SSI) requirements change at 18. For instance, your youth may have qualified for SSI benefits as a child but the “test” used to determine disability changes at 18. It is important to re-apply prior to turning 18 to ensure they qualify and continue receiving benefits.
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I am a  ❑ Parent / Family member of a child/teen/adult (circle) with a:   ❑ chronic health condition   ❑ physical disability

❑ learning disability               ❑ developmental disability             ❑ behavioral challenges

❑ I am interested in materials relating to: ______________________________________________________________________

I am a  ❑ Professional working with families and/or children/adolescents/adults (circle) with:   ❑ chronic health conditions

❑ physical disabilities       ❑ learning disabilities       ❑ developmental disabilities         ❑ behavioral challenges

❑ I am interested in material relating to: ______________________________________________________________________

I am a Professional in  ❑ Education (circle one), EI, Head-Start, Pre-school, Elementary, Middle, High school, Residential setting.  ❑ Health Care Field (circle one), Community clinic, Hospital, VNA, Physician, Family Practitioner, Nurse.

❑ Human Services (explain) __________________________________________ Other:________________________________

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