

# RAP Sheet

## BIG DREAMS FOR LITTLE ONES: BIRTH TO THREE



### RIGHT FROM THE START

By Carrie Duran, Policy Chair of the NH Council on Developmental Disabilities

*From the moment of diagnosis, parents of children with disabilities enter a new world of services and supports. In the Fall 2019 issue of the RAP Sheet, we explore the experience of disability for these young children and their families, from diagnosis to age 3, a critical period for learning, growing, and opportunity that will impact long-term health and ability.*

I wasn't prepared for the phone call. I was folding laundry in the living room while my twin four-year-old daughters were playing. It was early evening in South Pasadena, California, just before five o'clock. When I said "hello", the woman on the other end introduced herself as being from the lab and she had the results from my amniocentesis.

Two weeks prior, I had a very scary and painful procedure done to determine if my child had Down syndrome. I was 39 years old and prior bloodwork showed my baby could have Down syndrome. If I had it to do over, I would not have had the procedure. I already knew it made absolutely no difference to me; but I wanted to give peace to those around me, so I went along.

I had not met the woman on the phone. In a single sentence she told me that my otherwise healthy baby girl had Down syndrome. In the next sentence, she realized her mistake in telling me my baby was a girl - we had not asked for that information. Her third sentence was the most troubling: she told me I had one week to decide if I would terminate my pregnancy and then she said she was sorry. The conversation ended and she hung up. I cried for the next two weeks.

During those two weeks I was sad, overwhelmed, scared, and had a lot of questions. I didn't know what to expect or where to turn for answers. The obstetrician who performed the amnio was of not helpful. Upon hearing my decision not to terminate my pregnancy, he told me I was selfish and should think about the burden I was putting on my other children.

*(Continued on next page)*



*Katie takes a turn surfing.*

*(Cover story continued)*

Fortunately, one of my daughter's pre-school teachers had a new grandson with Down syndrome and put me in touch with an organization called Club 21. Club 21 is an organization in Pasadena, California, founded by parents who have children with the extra 21st chromosome, otherwise known as Down syndrome. I reached out and began attending their Mommy and Me classes called First Steps. My young daughters joined me as we sat on the floor and played with babies and toddlers with Down syndrome and talked to parents. My girls were nervous too and I wanted to put them at ease. They were able to make friends with other siblings and share their worries. At Club 21 we met families who had children of all ages with Down syndrome. Along with the First Steps class we attended weekend workshops specialized for various age groups about what to expect along this journey. Club 21 enabled me to dispel the myths of Down syndrome and expect a bright future for my child. I was reassured that anything is possible for my child. I later found out I was the first pregnant parent to attend First Steps and the workshops. I am happy to say this is no longer the case.

Katarina Amalia Duran was born on March 22, 2011. Our little girl, Katie, became the center of our family in more ways than one. She had our hearts from the first moment we saw her, with her full head of black thick hair. Katie made us smile with every interaction. My smiles were always coupled with a twinge of fear and worry. Would she ever walk or talk or reach those milestones reached by my other children? What kind of future would she have? When Katie was home for a few weeks, I changed my mindset. I began to expect she is going to reach those milestones. Perhaps she would take a bit longer than her peers, but it would happen.

Katie was home for a month when someone from a county agency came to visit and assess her. This person spoke of having realistic goals for Katie. When I told her I fully expect my child to go to college and live on her own one day, she looked surprised. She cautioned me to not set my expectations so high. I cautioned her to not underestimate my child or the will of a parent to give her child everything she needs to succeed.

## THANK YOU, SUSAN COVERT

**F**or the life of the RAP Sheet, Susan Covert provided the thread that tied together every word, article, and theme. From coming up with catchy titles and reaching out for content and photos, to expert editing and making sure the articles were accessible and engaging for everyone, Susan ensured that people with disabilities, their families, and the organizations providing support were up-to-date with the information that most mattered to living a life where everyone is welcomed and well supported in their community. We sincerely thank Susan for her efforts, and for challenging members of the IOD, DRC-NH, and DDC to create a publication of which we can all be proud. While Susan may be retiring from this role, we know she will continue her work making the world a better place for all people.

*With sincere gratitude from all of us on the  
RAP Sheet team,*

*Stephanie, Isadora, Déodonné, Mary*



When Katie was a year old, her father and I separated and divorced. When Katie was two years old, her sisters and I moved from California to my childhood home town in New Hampshire. Here we have found a community which embraced my vision for Katie. The support we have received from family, friends, our school district, our town, and our state has been wonderful. I feel that members of our community see past Katie's diagnosis and see just an ordinary child. A child surrounded by people who believe in her, who know she can achieve extraordinary things. And through the years Katie has been fully welcomed and included in her community: in preschool, kindergarten, elementary school, and all kinds of clubs, camps, and activities.

This summer, 8-year-old Katie participated in the Kingswood Children's Summer Theater Program's production of *Beauty and the Beast*. She did this without a paraprofessional and without her mother. She did this without self-doubt and without anyone around her questioning if she could do it. During dress rehearsals and performance days I hung out backstage to offer my support. Katie didn't need it. She did her own makeup right down to the eyeliner and mascara. She was responsible for her own costumes and knowing where to be and when. Whenever I offered her my help, I was met with the profound statement of "I've got this Mom". During her performance, I couldn't stop crying. I cried because I was proud of her. I cried because of the limitations in her abilities others tried to make me accept. And I cried because I know she is going to be just fine.

The road to "I've got this Mom," has been arduous at times. Numerous doctor appointments, medical tests, therapies, medications, chronic illness, and hospital stays have filled up a lot of her 8 years. In my quest to ensure Katie has every opportunity, my daughters and I have also found opportunity. Katie's participation in equine therapy, water therapy, adaptive skiing, surfing, adaptive bike riding, speech therapy, occupational therapy, and physical therapy are just a few of the supports Katie has needed to



*Adaptive bike riding and skiing have allowed Katie the opportunity to grow and enjoy experiences.*

grow. Through Katie's experience, all my girls have learned to ski, swim, and ride horses. Katie's sisters have also learned empathy, compassion, patience, advocacy, and love. I have had the opportunity to learn that I have strength, intelligence, and the heart of an advocate.

As Katie enters the third grade, I can look ahead and clearly imagine dropping her off at college and helping her to set up her first dorm room. I know if she has the right supports, opportunities, and the belief of herself and others in her abilities, her life will continue to be extraordinary!



Join us in showing our appreciation to NH businesses who believe in the power of an inclusive work force!

**October 17, 2019**  
**Holiday Inn, Concord, NH**





## DISABILITY DIAGNOSIS DIALOGUES: SHIFTING THE NARRATIVE

By Susan Zimmermann, PhD, ABLE NH Disability Diagnosis Dialogue Task Force Chair

*"Your son has a 99 percent chance of having Down syndrome..." The doctor laid out our options, concluding with, "don't worry, you don't have to be a hero. If you don't terminate, you can have the baby here, and we can keep him comfortable, but we don't have to do anything drastic to save his life. In plain speak, we could choose to let him die."*

This quotation is from an essay I read on social media about a year ago. While the focus of the essay had a positive upswing – the young mother, Jillian, was passionately promoting social inclusion

in her son's elementary school – I couldn't move beyond her first paragraph where she described the delivery of her son's diagnosis of Down Syndrome. It reminded me of the 1982 case in Bloomington, Indiana in which parents of a baby with Down Syndrome had declined life-saving surgery on their newborn because the family physician convinced them that the infant would have a very poor quality of life. The baby was wheeled to a separate part of the nursery where he was not fed and essentially starved to death. This and a number of other cases involving the deaths of newborns with disabilities where standard medical treatment was withheld, led to the 1984 enactment of the Baby Doe Law which extended the laws defining child abuse to include the withholding of fluids, food, and medically indicated treatment from children with disabilities.

What Jillian's physician offered her in terms of pre-natal "options" seems extreme in this day and age. However, the general assumptions surrounding this discourse are pervasive – that life with a disability is a life not worth living and is full of hardship and suffering. Families beginning their journey in life with a disability continue to report experiencing the delivery of diagnosis in negative terms and life outcomes. For example, after my friend Anna's 11 month-old daughter, Jenny, was diagnosed with Angelman's Syndrome she recalls:



*Susan's son Oliver participating in Concord High School's Marching Band*

*"I remember distinctly when they told me about her diagnosis and they were telling me all the science behind it... Their view of people with Angelman's Syndrome was very bleak... The information out there was absolutely horrific. It portrayed people having Angelman's Syndrome as not being able to be participants in their own lives, in schools, in communities. It never showed anything positive about it... I remember sitting there crying because I thought, "there has to be more that I can do for my daughter than this. This is not going to be her life."*

Despite what Anna was initially told about her daughter's future, Jenny is living a very full and active life: she attends the public middle school where she is completely included in the general educational classroom, she has many friends and participates in several extracurricular activities (including cheerleading!), and has become a pro at using assistive technology in order to communicate.

After my own son, Oliver, was prenatally diagnosed with Down Syndrome, my genetics counselor immediately offered me and my husband an invitation to speak with a father of an adult child with the same diagnosis. The father also happened to be a developmental pediatrician and so had many layers of knowledge about Down Syndrome on both professional and personal levels. After two hours of drilling him with questions about his daughter and their family life, my narrative shifted – I had come into the meeting with fear and uncertainty about my unborn child's future and quality of life, I walked away from the meeting with a newfound hope and excitement about the endless possibilities for my son. After hearing countless negative experiences from parents, I now realize how incredibly fortunate I was to have met with this father.

*(Continued on page 11)*



## KNOW YOUR RIGHTS: EARLY INTERVENTION

By Karen Rosenberg, Senior Staff Attorney at Disability Rights Center - NH

**F**amily-Centered Early Supports and Services (FCESS), or early intervention, provides comprehensive evaluations and services for infants and young children (birth to three years old) with developmental disabilities, including autism, and for infants and children with certain conditions that are likely to result in a developmental delay or who are at risk of a substantial developmental delay. Available services include developmental evaluations, speech therapy, occupational therapy, physical therapy, special instruction, service coordination, parent teaching and assistance with a child's transition to pre-school services. Early intervention services are provided in natural settings, most often the child's home or child care setting.

New Hampshire's local area agencies are responsible for administering New Hampshire's early intervention services. Anyone who has a concern about a child's development can make a referral to early intervention including, and most-importantly, the parent. If you have questions or concerns about your child's progress in meeting developmental milestones such as crawling, making eye contact or talking, you may want to speak with your child's pediatrician or contact your local area agency to refer your child for early intervention.

After you (or another person, such as the child's pediatrician) contact the area agency to make a referral, the area agency has 45 days to complete an evaluation (with your permission), determine eligibility and, if your child is eligible, develop an Individualized Family Support Plan (IFSP). During this time, the area agency's Intake Coordinator will hold a meeting with a team of professionals to determine what assessments and evaluations need to be conducted to identify your child's developmental needs in the following areas: cognitive development, physical development (including hearing and vision), communication, social and emotional development and adaptive development. The parent is a critical member of the child's early intervention team and should be actively involved in the evaluation process and, if the child is eligible, in developing the child's IFSP.

The IFSP outlines the child's goals and strategies for attaining those goals. It should reflect the family's and child's strengths, needs and priorities. Early Supports and Services are available at no cost to families. However, if authorized by the parent, private and/or public insurance may be used to cover the cost of medical services provided through early intervention.

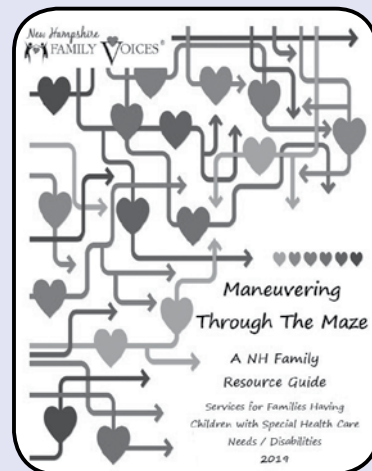
## MANEUVERING THROUGH THE MAZE

By Terry Ohlson-Martin, Co-Director, NH Family Voices

NH Family Voices has released a newly updated *Maneuvering Through the Maze*, A Family resource Guide for families having children with Special Health Care Needs/Disabilities. It is also now available in Spanish: **Maniobras a través del laberinto** **Guía de recursos de NH Family Servicios para familias de niños con necesidades especiales de atención médica o discapacidades 2019.**

The guidebook is formatted to take the user from birth to adolescents transitioning into adulthood. Listings include state health and human services agencies, educational resources, private associations and organizations that serve people with physical, developmental, mental health, and chronic health conditions and their families. Also listed are organizations and services that can be accessed by all state residents (housing, childcare, etc.). If you view the document online, hyperlinks are used for easy access.

*If you prefer a hard copy of the resource guide call (603) 271-4525 or Email to [nhfamilyvoices@nhfv.org](mailto:nhfamilyvoices@nhfv.org). The resource guide is free to families but to offset printing and postage, we ask that you consider a donation of \$15.*





## NEW TO NEWBORN SCREENING

By Déodonné Dustin Bhattarai, Communications Specialist, Disability Rights Center – NH  
with support from Cristle Gordon, School Counselor, Pembroke Elementary

I didn't give newborn screening a second thought. It seemed rather cruel to prick my newborn's perfect little baby toe hours after his birth, but it wasn't something that really registered given everything else that was going on.

I didn't worry about the results. My pregnancy was routine and my baby was healthy. When all the results came back negative, I shrugged the screening off as a non-event in what would clearly be the long and healthy life of my firstborn child.

Now I know better. Eight months later, our son began to miss key gross motor milestones like rolling over and crawling.

For four months, we met with medical experts throughout the state. Our infant son had so many tests and evaluations, we lost count. He slowly began to lose strength in his neck and core and sitting up for extended periods of time was a challenge. We felt helpless; no one knew what was causing the muscle loss.

It was devastating. Confusion, terror, isolation, and despair took hold of our family for months.

Finally, we were referred to a neuromuscular specialist in Boston who diagnosed our son within a matter of minutes. A simple blood test confirmed the diagnosis:

Spinal Muscular Atrophy (SMA-Type II). It was one month after his first birthday.

SMA is the leading genetic cause of death for children under age two and one in 50 Americans is a genetic carrier for SMA. Spinal Muscular Atrophy is a disease that robs people of physical strength by affecting the motor nerve cells in the spinal cord, taking away a child's ability to walk, crawl, eat, and breathe.

On December 23, 2016, the FDA approved the first-ever treatment for SMA and in May 2019, it approved a second treatment. Unfortunately, the drugs' effectiveness is closely linked to early treatment. Infants who receive treatment before the onset of symptoms achieve unprecedented gross motor milestones including sitting, standing, and walking – some remain virtually asymptomatic.

Unfortunately, our son, like all newborns in New Hampshire, was not tested for SMA at birth. His diagnosis and treatment were subsequently and unnecessarily delayed until months after symptom onset.

Depending on the type of SMA, diagnosis may not occur until a child's first or second year, well after SMA has started to rob them of abilities. Although treatment at any age is critical in stopping the degenerative progression of SMA, it is likely less effective than treatment as a newborn. So, in May 2018, I joined forces with another SMA mom to testify in front of the New Hampshire Newborn Screening Advisory Committee. We described how, despite SMA, our children are spunky, smart, funny, and loving. But because of SMA, they use wheelchairs to explore their environments and they will most likely predecease us, their parents, their siblings, and their friends, by decades.

We asked that SMA be added to the state's Newborn Screening Panel. We made the case that SMA qualifies under state law and that no other family should be put through what ours were, given the ease of diagnosis and availability of effective treatment. Even though it was too late for our babies to benefit, we asked the Committee to



*Cristle Gordon and Deodonne Bhattarai with Advisory Committee member and fellow SMA parent, Bill Morin, after testifying.*

act quickly, but there were not enough Committee members present to vote. In October, we testified again. During that meeting, the Committee voted unanimously to recommend that SMA be added to New Hampshire's Newborn Screening Panel. Shortly after, the Committee's recommendation was approved by DHHS Commissioner Meyers. We were so excited.

Our excitement was short-lived. Nearly a year has gone by and newborns born in the Granite State are still not being screened for SMA. As part of the implementation process, the contract between the State of NH and the Massachusetts-based lab which conducts NH's newborn screenings had to be amended. Once amended, the contract will have to be presented to Governor Sununu and the Executive Council for approval. Via email, Patricia Tilley, Deputy Director of the New Hampshire Division of Public Health Services at DHHS stated that the amended contract was "currently anticipated to be presented for approval by [Governor and Council] on August 28, 2019.... If all goes as planned ... SMA screening will be initiated the beginning of September 2019."

Unfortunately, August came and went and no vote was taken. Babies are born every day. None are screened for SMA. We continue to wait.

In a follow-up email, Courtney Keane, the Newborn Screening Program Manager at DHHS stated that they "expect that [SMA] will be on the [October 2nd Governor & Council] agenda." If this happens, it will have taken almost exactly a year to implement one new screening to our existing panel of thirty-four conditions. Although this seems excessive, we choose to focus on the positive; a future when babies in New Hampshire will finally receive timely diagnosis and life saving treatment for SMA.

## WHAT IS NEWBORN SCREENING?

By Déodonné Bhattarai, Communications Specialist,  
Disability Rights Center - NH

Within 24-72 hours of birth, your baby likely had their toe pricked and a blood sample taken to screen them for thirty-four different genetic conditions where early diagnosis is critical. This screen is performed at no cost to the young patient or its parents.

In New Hampshire, our newborn screening program is housed in the Maternal & Child Health Section of the Department of Health and Human Services. The program is informed by the recommendations of the Newborn Screening Advisory Committee. The Committee is made up of medical providers, researchers, genetic counselors, industry administrators, and a parent of a child with a genetic condition to provide the family perspective.

When considering whether to add a condition to the panel, Committee members consider four key factors: how common the condition is (incidence), its severity (morbidity and mortality), whether screening is possible, and the availability of effective treatment.

If a screening indicates that your baby may have a genetic condition, you will be contacted and diagnostic testing will be conducted to confirm or rule out the genetic condition. Although the Newborn Screening Program has information and resources, your child's physician will be an important resource for you during this time and during any treatment or additional follow-up.

New Hampshire's Newborn Screening Program provides critical information to families, leading to early diagnosis and treatment of dozens of conditions, and changing health outcomes and the quality of life for our children. For more information on New Hampshire's Newborn Screening Program visit: <https://www.dhhs.nh.gov/dphs/bchs/mch/newborn.htm>





## IS ASSISTIVE TECHNOLOGY FOR INFANTS?

By Jennifer Stylianos M.S., OTR/L, ATP, Gray Consulting & Therapy, LLC

**W**hat is Assistive Technology (AT) anyway? AT is defined as any item that helps a person with a disability increase, maintain, or improve function. This means that technology makes tasks and activities which are difficult or impossible, *possible*. For example, gluing small drawer knobs on to a wooden puzzle can make it possible for a child who struggles to pick up flat puzzle pieces to play with it. Possibility is powerful, but the real power of Assistive Technology is access. Access to play, access to communication, access to movement, and access to independence.

Assistive Technology devices can be complicated and expensive, a tablet that allows a child to communicate with a glance of his eyes or a power wheelchair that allows her to race across the playground with the press of a button, but it doesn't have to be. Most AT for infants and toddlers would not even be considered technology; things like pointing to photographs of farm animals to sing Old MacDonald, or spoons with bent handles for eating pudding are AT.

Assistive Technology is **not** just things. It is also a service which helps the child and his family in the selection, acquisition, or use of appropriate technology. These services include evaluation and training in how to use the technology. Most people who provide



*All AT evaluations are unique.*

AT services are knowledgeable in a particular area of AT such as Augmentative and Alternative Communication (AAC) or seating and mobility.

### **Common myths that prevent appropriate AT services include:**

**Myth:** The use of an AT device can act as a deterrent to a child's ability to develop typical skills.

**Fact:** Research shows the opposite to be true.

**Myth:** Infants and toddlers are either too young to benefit from AT or need certain "readiness skills" before they can use it.

**Fact:** Very young children can benefit from AT that is properly matched to their needs and abilities with no prerequisite skills.

**Myth:** AT is a magic bullet.

**Fact:** There are no magic bullets. AT, like other interventions, is an ongoing process in which the child will progress, learn, change, and grow.

Assistive Technology evaluations are not like other evaluations that the child might participate in. Rather than obtaining standardized measures, the focus of an AT evaluation is exploring potential solutions to meet a specific functional need. In this process, the child's abilities, environment, and the family's input are carefully matched with potential solutions. The child may test the equipment or have a short-term equipment trial. Once an appropriate AT solution is identified and obtained, continued evaluations are recommended as the child grows and learns because changes may need to be made to the equipment in order to meet the child's needs at any given time.

Every evaluation process is unique. I met Johnny when he was two. Any purposeful movement caused his entire body to become painfully tense and sweat to bead up on his skin. It was clear by his quick smile and mischie-



vous look that he had a lot to say. His family, an AAC specialist, physical therapist, and I worked collaboratively to trial a variety of eye-gaze solutions from low-tech plastic frames to high-tech eye-gaze communication devices. Johnny was immediately able to select from an array of four choices. He and his family chose a device to trial during which time Johnny received training and support from the AAC specialist and myself. Following his trial period, Johnny was able to put together simple sentences with his eyes from pages with an array of fifteen buttons. When he entered preschool, he was using thirty-six buttons per page. By using the eye-gaze, Johnny was able to say “hi”, label all of his shapes, request his favorite books, and yell at his little brother. Johnny is entering middle school now and is using his latest communication device to read, write, and access the curriculum. He also can say several phrases verbally.



*AT for summer fun.*



*Knobs on a puzzle increases a child's access to toys.*

Given the appropriate assistive technology, infants and toddlers

experience more access to and control over their environment. This can reduce frustration and improve their self-esteem and cognitive development. While there is a growing awareness of AT, it is underutilized. Nationally, only 3.1% of individual family service plans (IFSP) include the use of assistive technology. Although assistive technology does not replace traditional therapies or prevent/delay a child's ability to develop typical skills, there is no reason to wait to begin implementing AT services and strategies to expand the world for young children.



## PARTNERS IN HEALTH

By Janice Boudreau, Partners in Health Family Support Coordinator for Region 4 Waypoint

Partners in Health (PIH) is a statewide community-based program that provides support to families of children (birth to 21) with chronic health conditions, regardless of income.

PIH assists in getting necessary care and services for its clients as well as setting health care goals and collaborating with other community organizations to help achieve those goals. PIH also arranges inclusive community events and trips for its client families. Partners in Health is one of the programs available through Special Medical Services for children and youth with special health care needs and their families.

For more information and eligibility criteria, visit the Partners in Health webpage at

<https://www.dhhs.nh.gov/dcbcs/bds/sms/pih/index.htm>



## LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL AND RELATED DISABILITIES (LEND)

By Betsy P. Humphreys, PhD, Research Assistant Professor & Interim Director of NH-ME LEND Program

There are 52 LEND programs in the United States and they all have the same goal: To improve the clinical expertise and leadership skills of professionals and family members who are caring for children and youth with neurodevelopmental disabilities. Each year there are about 1,500 trainees in LEND programs across the US. LEND programs are funded through the Autism Collaboration, Accountability, Research, Education and Support Act of 2014 – also known as Autism CARES. LEND programs must provide training that 1) increases awareness of autism spectrum disorder (ASD) and developmental disabilities (DD); 2) increases the number of clinicians who are able to screen, rule out, and/or diagnose ASD/DD, and 3) provide evidence-based interventions for children and youth with a diagnosis of ASD/DD. Early screening, diagnosis, and intervention provides children with the supports they need to develop to their full potential.

The NH-ME LEND program is a two-state collaboration between Dartmouth Hitchcock Medical Center, the Institute on Disability at the University of New Hampshire, and the Center for Community Inclusion and Disability Studies at the University of Maine.

There are 24 trainees each year; trainees can be professionals, students, family members, or self-advocates. The program works hard to make sure that training goals are met. For example, trainees complete a course where early screening, diagnosis and intervention is studied alongside the LEND faculty. All trainees visit clinics around New Hampshire and Maine to learn more about diagnosis and intervention for children and youth with ASD/DD. Sometimes trainees travel with NH Family Centered Early Supports and Services staff to visit children and families in their homes. All trainees complete leadership projects with community partners related to early screening, diagnosis and interventions. All trainees learn about systems and policies that support children and youth with ASD/DD. A smaller group of trainees each year complete specialized training on screening and diagnostic tools so they can use the tools in their clinical practices. The NH-ME LEND Program is lucky to have many partners across NH and ME who support trainees in their learning.

For more information about the NH-ME LEND Program please visit our website: [www.mchlend.unh.edu](http://www.mchlend.unh.edu)



## FINANCIAL PLANNING IN A WORLD OF GO FUND ME

By John Kitchen

One of the many things to think about following a diagnosis is financial planning. What disability-related expenses will you face? Will you need to take unexpected time off from work? Will you need to make your home accessible or incur medically-related travel expenses? What won't be covered by health insurance? How will you cover these expenses?

It's never too soon to think about financial planning for your child and family. For children with disabilities, regular savings accounts, 529 college savings plans, a fundraiser, or a Go Fund Me or other crowd funding site can impact eligibility for needs-based public disability-related benefits.

Public benefits, like Medicaid, may have financial eligibility requirements. This means that raising money

in your child's name could result in them losing their services. However, with some thoughtful planning and the use of ABLE accounts and Special Needs Trusts, unintentional outcomes can be avoided.

What is an ABLE account? It's like a 529 college savings plan account (and can be used for education) but it also includes other disability related purchases. For more information about ABLE, check out [www.stablenh.com](http://www.stablenh.com), New Hampshire's ABLE account program.

What is a Special Needs Trust? It's a trust that is allowed for people with disabilities receiving Medicaid and other public benefits. It can be a savings account and can also make purchases. For more information, check out [www.elonh.org](http://www.elonh.org), a non-profit pooled trust program in New Hampshire.



## AN INTERVIEW WITH LEND TRAINEE JULIA PHEIFER MS OTR/L

***What inspired you to apply to the LEND program? Did the LEND program influence your decision to work in early intervention? If so, how?***

When I was a freshman in high school, my parents decided to become a foster family and we cared and loved for babies one at a time, most of them born addicted to drugs. I was very interested in the occupational therapists that came to our home to provide therapy services. This sparked my interest to apply to the OT program at UNH. I always knew I loved playing and working with children between the ages of 0-3 but LEND definitely influenced my decision to work in early intervention. Through LEND, I was given the opportunity to work with Healthy Families NH and observed home visits from a case manager perspective. I was also able to observe the NICU at Dartmouth-Hitchcock and was provided with valuable resources throughout my LEND year that have helped me in my career now. For example, I learned about resources such as “Zero to Three” and took a continuing education course about the effects of substance abuse on young children. Overall, LEND provided me with a foundation of resources and connections that I will forever be grateful for!

***As an early intervention provider, how did your LEND experience influence how you approach your work? How did it influence the ways you work with children and families?***

LEND taught me that in order to be successful as an OT, I need to provide support to the entire family, not just the client. I need to encourage and support the parents’ role in their interactions with their child and need to meet each individual parent at the skill level they are at in order to promote successful carryover of suggestions and recommendations given during therapy.

***What tips do you have for families who are transitioning their children into inclusive childcare and preschool settings?***

Through LEND, I witnessed that the parents with positive relationships with their child’s teachers were those who were not afraid to ask questions and be open to teachers’ recommendations. I would tell parents whose children are transitioning into an inclusive program that this relationship is a partnership. Furthermore, I would share that this transition is a positive milestone in a child’s life, even though it may be scary for the parent. During this time, their child will continue to develop skills, especially social skills, as they interact and learn from their peers.

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ABLE NH’s Disability Diagnosis Dialogues Task Force aims to collaborate with medical teams to present a more balanced and accurate narrative about life with a disability. We believe that by developing mutually beneficial partnerships, healthcare professionals and disability rights advocates can work together to effectively transform NH’s healthcare system into one which embraces the vision that with the right supports, people who experience disabilities can and do lead fulfilling and meaningful lives.

To learn more about our mission and our current projects, please visit us at <https://www.ablenh.org/our-work/disability-diagnosis-dialogues/>.





## NERGN – SUPPORTING CONNECTIONS TO GENETICS CARE

By Karen Volle, Project Coordinator, NERGN

The New England Regional Genetics Network, or NERGN, aims to improve the health and social well-being of individuals with genetic conditions and their families. Its primary goal is to connect families from underserved communities (including those from rural areas and immigrants) who are in need of services, with a geneticist or genetic counselor. However, scarce resources and long waiting lists for services can make this process challenging. Fortunately, with funding from the Genetic Services Branch in the Department of Health and Human Services, NERGN works with regional partners and a national network made up of healthcare providers, public health, family organizations, and researchers to better meet the needs of families.

As part of this work, NERGN hosts a website called Genetics Education Materials for School Success, or GEMSS. The aim of GEMSS is to assure all children with genetic health conditions succeed in school-life. It provides a family-friendly starting point to help family members learn more about genetic conditions and offer ideas to encourage inclusion and participation in the classroom. To learn more about GEMSS visit: [www.gemssforschools.org](http://www.gemssforschools.org).

NERGN also works to increase services for families by teaching primary care providers about issues related to genetics including how to inform and make timely referrals to genetic specialists. A recent webinar, co-presented by Dr. Leah Burke from Vermont and Hibo Omer from the New Mainers Public Health Initiative focused on genetic considerations for immigrants and refugees.

NERGN also recently completed a brochure: ***A Few Things to Know About Your Child's Visit to the Genetics Clinic.*** Drawing on previous work by the Heartland

Regional Genetics Network as well as feedback from local partners, this resource provides basic information on genes and genetic conditions, offers resources, and answers these questions:

- ◆ Why was my child referred to the genetics clinic?
- ◆ Why see a geneticist as opposed to her regular doctor?
- ◆ What can I do while we wait for the appointment?
  - This is seen as very important, as the wait can be quite long and quite stressful. This is an ideal time to talk to other parents who have been through similar circumstances; to write down questions; and to check with your insurance plan to see if they cover genetic testing.
- ◆ What will happen at the visit itself?
- ◆ Will my child get a diagnosis at the first appointment?
- ◆ What happens next?

You can find the brochure along with many other resources in NERGN's Resource Library at [www.negenetics.org](http://www.negenetics.org)

***Please feel free to contact Karen Volle at [karen.volle@unh.edu](mailto:karen.volle@unh.edu) about NERGN's work and resources.***



*Hibo Omer and Leah Burke, MD*



*The New Hampshire Council on Developmental Disabilities offers a variety of grants for community projects, educational programs, leadership development, and demonstration programs that will increase quality of life for people with developmental disabilities through systems change.*

**Recent grants include:**

- ◆ \$50,000 to Center for Life Management and Community Crossroads for a project to Implement New Strategies that Address the Needs of Individuals with a Dual Diagnosis of Intellectual/Developmental Disabilities and Mental Health Needs. This will include training to increase capacity in the system and data collection in hopes of expanding this innovative service approach throughout the state of New Hampshire.
- ◆ \$50,000 to University of New Hampshire to help providing Post-Secondary Educational Opportunities for Individuals with Intellectual Disabilities. The UNH-4U pilot project will aid in the developmental and implementation of Think College National Standards for a cohort of individuals with labels of intellectual disability.
- ◆ \$40,000 to Refurbished Equipment Marketplace (REM) for assisting individuals with intellectual and developmental disabilities in purchasing, servicing, and in the delivery of REM equipment. With this grant, Refurbished Equipment Marketplace will be able to continue to assist individuals with I/DD in obtaining and sustaining necessary devices and equipment that will further their independence and quality of life.

*Please contact the NHCDD for information on grant opportunities. You can also see our grant applications on our website [www.nhcdd.org](http://www.nhcdd.org). We are glad to assist in filling out grant forms!*



*DD Council members and staff.*



*Left: Jason Alexander Smith, facilitator of People First of NH, and NH Advocate, Katie Epstein.*



*Right: NHCDD Executive Director, Isadora Rodriguez-Legendre, presenting NH Senator Dan Feltes with the Legislator of the Year Award.*

## NHCDD WINTER AWARDS CEREMONY

**DECEMBER 12, 2019**

Grappone Center  
Concord, NH

The Council will be presenting our

Legislator of the Year Award

Virginia Bowden Advocate of  
the Year Award

and the first annual  
Smile Award  
celebrating accessible recreation

Everyone is Welcome!  
Refreshments will be served.

# TRAINING & EVENTS

## nTIDE Lunch & Learn Webinar Series

On the first Friday of every month, corresponding with the Bureau of Labor Statistics jobs report, the Employment Policy and Measurement Rehabilitation and Research Training Center will be offering a live broadcast via Zoom Webinar to share the results of the latest nTIDE findings. In addition, we will provide news and updates from the field of Disability Employment, as well as host an invited panelist who will discuss current disability-related findings and events.

**Upcoming:** First Friday of the Month  
**Time:** 12:00 - 1:00 pm EST  
**Location:** Webinar Online  
**Cost:** Free  
**Register:** [www.researchondisability.org/ntide](http://www.researchondisability.org/ntide)

## Multi-Tiered Systems of Support for Behavioral Health & Wellness Coach Training

Effective team leadership and facilitation have proven to be key in implementing Multi-Tiered Systems of Supports with fidelity. This two-day training is designed for internal school coaches of Tier 1 (Universal), Tier 2 (Targeted), or Tier 3 (Intensive) teams. Participants will learn about best practices for supporting teams to use data-based decision making, establish buy-in, and ensure fidelity of MTSS-B implementation.

**Dates:** November 18, January 15, March 18  
**Location:** Grappone Conference Center, Concord, NH  
**Cost:** \$400  
**Register:** <https://iod.unh.edu/event/multi-tiered-systems-support-behavioral-health-wellness-coach-training>

## Assistive Technology Makers' Fair 2020

The third annual Assistive Technology Makers' Fair will inspire participants to become creative problem solvers, bringing together makers of all abilities to share ideas, develop new skills and enhance innovations for persons with disabilities. The Fair will empower individuals with the methods, materials, and know-how needed to efficiently create everyday just-in-time devices and technologies. Join us! Novice to veteran makers of all ages and abilities are welcome.

**Date:** Saturday, October 24, 2020  
**Time:** 9:00 am - 4:00 pm  
**Location:** Grappone Conference Center  
 Concord, NH 03301

## The IOD Bookstore

TO PLACE AN ORDER OR  
TO BROWSE THE COMPLETE  
IOD BOOKSTORE CATALOG, VISIT:

[www.iodbookstore.org](http://www.iodbookstore.org)  
or call (800) 378-0386

### 3 EASY WAYS TO REGISTER!



online  
[WWW.IOD.UNH.EDU/Events](http://WWW.IOD.UNH.EDU/Events)



call to register or to request a  
registration form  
603.228.2084



mail a completed registration form  
INSTITUTE ON DISABILITY  
57 REGIONAL DRIVE, UNIT 8  
CONCORD, NH 03301



### NH LEADERSHIP SERIES

Partner with others who are passionate about supporting people with disabilities and family members within their communities. The NH Leadership Series is committed to building a culturally diverse class and encourages applications from people of color, individuals with disabilities, and veterans.

Learn more at [www.nhleadership.org](http://www.nhleadership.org)

- Develop leadership skills
- Build networking skills
- Identify your strengths
- Learn to advocate
- Connect with resources

**Learn. Lead. Create Change.**





# DISABILITY RIGHTS CENTER - NH

DRC-NH is dedicated to eliminating barriers for people with disabilities across the state. Contact us to schedule a free consultation on a disability discrimination issue with an experienced attorney.

## KNOW YOUR RIGHTS: ISSUE AREA SPOTLIGHTS



### **Access to Services Clarified for People with Developmental Disabilities Ages 18-21**

If otherwise eligible, individuals with developmental disabilities who are not yet 21 but who have graduated or exited school, should receive funding for a full range of developmental disability services, including home and community-based services. These services are administered through their area agency. More info at <https://drcnh.org/press-releases/access-to-services-clarified-for-people-with-developmental-disabilities-ages-18-21/>.



### **Voting Rights and the 2020 Elections**

The 2020 presidential primary season is in full swing here in New Hampshire and we are talking with the candidates about disability, inclusion, and accessibility. Check out our Disability Unscripted video series as well as candidate responses to the 2020 Presidential Primary Candidate Survey on Disability at <https://drcnh.org/voting-rights-2020-election/>.



### **Learn About Your Child's Rights**

Children with disabilities may be entitled to special education, related services, reasonable accommodations and modifications to enable them to receive a free appropriate education in the least restrictive environment. Some children may be eligible for Medicaid. For more information about these and other related topics, visit our Children's Issues page at <https://drcnh.org/issue-areas/childrens-issues/>.

**Abuse and Neglect • Access and Accomodation • Children's Issues  
Special Education • Employment • Housing • Medicaid and Healthcare  
Mental Health • Traumatic Brain Injury • Voting**

**(603) 228-0432 • [drcnh.org](https://drcnh.org)**

# RAP Sheet

## NH COUNCIL ON DEVELOPMENTAL DISABILITIES

2½ Beacon Street, Suite 10  
Concord, NH 03301-4447

**RETURN SERVICE REQUESTED**

## INSIDE THIS ISSUE

- ◆ *Know Your Rights:  
Early Intervention*
- ◆ *LEND Program*
- ◆ *Newborn Screening*
- ◆ *Personal Stories*

## DISABILITY RIGHTS CENTER - NH

64 North Main Street, Suite 2, 3<sup>rd</sup> Floor, Concord, NH 03301-4913  
Voice and TDD: (603) 228-0432 ◆ 1-800-834-1721 ◆ FAX: (603) 225-2077  
TDD access also through NH Relay Service: 1-800-735-2964 (Voice and TDD)  
E-mail: [mail@drcnh.org](mailto:mail@drcnh.org) ◆ Website: [www.drcnh.org](http://www.drcnh.org)  
"Protection and Advocacy System for New Hampshire"

*The Disability Rights Center is dedicated to eliminating barriers to the full and equal enjoyment of civil and other legal rights for people with disabilities.*

## INSTITUTE ON DISABILITY/UCED AT THE UNIVERSITY OF NEW HAMPSHIRE

[www.iod.unh.edu](http://www.iod.unh.edu) | [facebook.com/instituteondisability](https://facebook.com/instituteondisability) | [twitter.com/unhiod](https://twitter.com/unhiod) | [youtube.com/unhiod](https://youtube.com/unhiod)  
Durham Office:  
10 West Edge Drive, Suite 101 | Durham, NH 03824  
Phone: 603.862.1769 | Relay: 711 | Fax: 603.862.0555

Concord Office:  
57 Regional Drive, Unit 8 | Concord, NH 03301  
Phone: 603.228.2084 | Relay: 711 | Fax: 603.228.3270

*The IOD promotes full access, equal opportunities, and participation for all persons by strengthening communities and advancing policy and systems change, promising practices, education, and research.*

## NH COUNCIL ON DEVELOPMENTAL DISABILITIES

2½ Beacon Street, Suite 10  
Concord, NH 03301-4447  
Phone: (603) 271-3236 ◆ TTY/TDD: 1-800-735-2964 ◆ Website: [www.nhddc.org](http://www.nhddc.org)

*Dignity, full rights of citizenship, equal opportunity, and full participation for all New Hampshire citizens with developmental disabilities.*

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