

RAP Sheet

The Latest in Disability Research, Advocacy, Policy, and Practice

Spring 2019 Issue

STANDING UP, SPEAKING OUT



LEAVING YOUR COMFORT ZONE

By Darlene Gildersleeve

Welcome to the Spring RAP Sheet where we celebrate the power of advocacy. This year marks the NH RAP Sheet's 15th anniversary. From our very first issue, advocates have been the stars of the show. Whether fighting to end sub-minimum wages for workers with disabilities, attending every planning meeting to ensure a fully accessible Main Street, or persuading legislators to fund the waiting list - advocates have made our state a better place for all of us. This is my last issue as editor. Words cannot express how much this work has meant to me. Thank you to all those who have shared their stories and all the readers who have enjoyed them. It's been a great ride.

SUSAN COVERT, EDITOR

In 2012, my son was diagnosed with a disability. I was in shock and felt scared and alone. Looking for help, I found the Family Voices Facebook page. Immediately, I was connected to a community of parents who understood what I was going through. Through Family Voices I met another mom, who told me about the Institute on Disability's Leadership Series and encouraged me to apply. I was going through a painful divorce and between taking my son to counseling, specialists, and attending stressful IEP meetings, there was no time to do anything for myself.

Fast forward to 2017. My 11 year old daughter had been in the school nurse's office over 20 times in a week. Something was terribly wrong. Twice I requested a Special Education Evaluation and was denied. Then came one of the worst moments of my life. The school called to tell me my daughter was suicidal. I rushed to the school and arrived to see my scared, crying daughter being put in the back of a police car. For three days, she was held like a prisoner in the loud, bright, and scary hospital emergency department. I cried more than I ever have in my life. On my knees I prayed she would get treatment and would live.

With no pediatric mental health beds in New Hampshire, my daughter has been hospitalized six times out of state. When another request for a Special Education Evaluation was met with resistance, I found the strength to be my child's advocate



Darlene Gildersleeve and her daughters arrive at the NH State House for the Budget Hearing.

Photo Credit - Bobbie Erskine

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Jocelyn Marie Curtin, daughter of Marlyn and John Curtin, passed away peacefully on November 19, 2018 at the age of 40. For New Hampshire advocates, Jocelyn was a pivotal figure. Marlyn, who graduated from the New Hampshire Leadership Series in 1988, widely shared her daughter's story. Through Marlyn's connection with the Institute on Disability-UNH, hundreds of educators and school administrators have been inspired by Jocelyn and her family's example of creating a full life in the community.

As Jocelyn got older, she began to tell her own story. Using a communication device, Jocelyn co-taught the courses "Facilitating Friendships" with Dr. Cheryl Jorgensen and "Teaching Exceptional Learners" with Susan Shapiro. Her presence in the classroom and her story influenced so many UNH students as they prepared for their careers. Jocelyn also was the highlight in the IOD film *Voices of Friendship*, which is still being used to teach the value of providing opportunities for real friendships.

Thank you Jocelyn Curtin for being a shining example for inclusive education and full community lives. Within our state and beyond, we are in debt for the lessons that you have taught us. We are grateful to the Curtin family who in their time of loss have generously directed memorial funds to the New Hampshire Leadership Series. To make a donation - <https://iod.unh.edu/projects/nh-leadership/donate>.

(Cover story continued)

and succeeded in getting an IEP in place. It was time to finally apply to the Leadership Series.

I walked into my first Leadership class shaking and nervous. For the first time ever, I was leaving my toddler, pre-teen, and older teenage son overnight. As we shared our stories, I saw others were nervous too. This was about to change. At each monthly training session, with guidance from excellent group leaders, we were being pushed out of our comfort zones and becoming more and more confident.

I found the courage to testify at two public sessions for New Hampshire's 10 Year Mental Health Plan. I advocated for a plan that address children's mental health; something previous plans have not done. I learned about the Children's Behavioral Health Collaborative and signed up for their legislative advocacy training. It was fantastic! This was followed by Leadership's session with state legislators; each class member invited their legislators to attend. I had never made a call to a legislator. When I called Senator Feltes' office, I was trembling. The calls to my representatives were easier.

In February, my daughter Anna and I testified in support of bill which would expand the state's

behavioral health services to include Mobile Crisis Response Services for children. We were interviewed by a reporter following up on the hearing. Our story made the front page of the Concord Monitor! I have testified on other mental health bills and legislation to establish Paid Family Medical Leave, something especially important to me as I was unable to work when my daughter was hospitalized. I wrote my first letter to the editor and it was published. I testified at the State Budget hearing and advocated for full funding of the 10-Year Mental Health Plan. In March I spoke at the State House rally urging the Governor to sign the paid family and medical leave bill that was passed by the legislature. I am currently working with the Hopkinton School District to set up a Parent-School Special Education Partnership Group for our community.

None of this would have been possible without the knowledge, confidence, and empowerment that the Leadership Series has given me. I am so grateful for this opportunity and encourage others who want to make a difference to apply to the New Hampshire Leadership Series.



THE NH LEADERSHIP SERIES – UNLEASHING THE POWER OF ADVOCACY

By Nancy Glynn, NH Leadership Series Engagement Coordinator, Institute on Disability-UNH

The Institute on Disability's New Hampshire Leadership Series is an intensive, nine college credit, eight-month program that provides leadership and advocacy training for individuals with disabilities and their family members. Since 1988, the program has provided state-of-the-art information and strategies to effect change on disability-related issues locally and across the state. It is recognized as a pivotal change experience for family members and adults with disabilities participating in the program.

As a result of the work of its 1,000 alumni, New Hampshire has achieved national recognition for its innovative approaches to support people with disabilities and their families in their communities.

Alumni of the program hold leadership positions in state and national organizations, have founded advocacy organizations, and are represented at all levels of local, state, and federal government. Following Leadership training, Maggie Hassan was elected to the New Hampshire Senate. She went on to serve two terms as Governor and now represents New Hampshire in the United State Senate.

Recent Leadership graduate Maya Levin's four-year-old son Andy has deep love for horses and all things equestrian. Andy also experiences autism. Since graduating from Leadership in 2018, Maya has worked to expand inclusive opportunities for children and their families in her home community of Derry. Using her personal connections and reaching out through social media, she is organizing parents of children who experience disability. Maya also has worked with her local school board to offer trainings and resources to parents in the district. Trainings have included partnering with the Parent Information Center, A Basic Guide to the IEP Process, and Conflict Resolution in IEP Meetings. She participates in the "Read to Me" program at her son's school, choosing

books that illustrate the value of welcoming and including children who experience disability.

Maya has testified at school board meetings and submitted testimony on bills coming before the New Hampshire Legislature. Maya firmly believes that parents and families should have a voice in the decisions that will affect their children. She is currently working with families to form a Special Education Parent Advisory Committee for the Derry School District. Maya credits the New Hampshire Leadership Series with supporting her growth and leadership as an effective advocate.

To learn more about the Leadership Series, nominate a candidate for Leadership, request an application for the next session, or make a donation to support the Series, go to <https://iod.unh.edu/projects/nh-leadership>.

The NH Leadership Series is a self-funded 501 (c) 3 program of the Institute on Disability at UNH and is only made possible through financial support from our donors and partners.



Photo courtesy of Levin family

NH Leadership graduate Maya Levin with her family.



AS LONG AS IT TAKES

By Regan Burke Lamphier, Kent Street Coalition

New Hampshire has a mental health care problem, and our state does not seem to be able to fix it. Adults and children alike who are experiencing an acute mental health crisis often spend days or even weeks in hospital emergency rooms waiting for a bed in a psychiatric facility to become available. It would be intolerable if a hospital admitted a patient in acute physical pain and then waited days before providing treatment. It should be equally unacceptable when a hospital fails to provide appropriate care for someone in the midst of a mental health crisis.

Kent Street Coalition, a progressive grassroots organization established after the 2016 election, has been working tirelessly to end the emergency boarding room crisis. Kent Street members became aware of the lack of mental health care services only a few months after the group was formed. We were shocked to learn that every day in our state between 20 and 50 adults and children suffering mental health crises in hospitals are going untreated. Being stuck in an emergency room even for a few hours is bad enough; spending days or weeks there is inhumane.

After brainstorming ideas to bring public attention to this crisis, members of Kent Street Coalition came up with an innovative strategy. On a cold morning in

April 2017, legislators arriving at the State House were greeted by a dozen protestors clad in hospital gowns. They carried hand lettered signs like 'Stuck in the ER' and 'I Would be Better Off Having a Heart Attack'. Other signs listed the number of patients – 46 adults and 4 children - who were currently in hospital emergency rooms awaiting appropriate mental health care. The sight stunned legislators and was shocking enough to gain prominent media attention. Significantly, by staging a highly visible event that included a dramatic prop we were able to start a conversation about a systemic problem in our state.

The hospital gown vigil prompted an invitation to meet with Governor Sununu's Policy Advisor. That meeting resulted in Kent Street Coalition being offered a seat on the Governor's Working Group on Mental Health, an advisory group put together to address the state's mental health crisis. In addition, as a result of our work, the New Hampshire Chapter of the National Alliance for the Mentally Ill (NAMI) invited Kent Street to participate in their monthly public policy meetings.

Despite increased attention to this issue by the Governor and the legislature we have yet to see any measurable progress in the mental health boarding crisis. It has been two years since the first State House

vigil and there are still scores of adults and children languishing in hospital emergency rooms awaiting appropriate placement for mental health care. Amid frustration at the lack of action, Kent Street Coalition continues to show up, speak out, don our hospital gowns, and wield our signs. In November 2018 Kent Street member turned out in force at the public hearing for New Hampshire's proposed 10-year mental health plan. Giving public testimony dressed in a hospital gown ensured that the mental health crises in emergency rooms was well covered by the media.

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Kent Street Coalition members in the halls of the legislature.

Photo courtesy of Kent Street Coalition



ABLE NH

By Lisa Beaudoin, Director, ABLE NH

ABLE NH (Advocates Building Lasting Equality in NH) is a grassroots, member-driven organization whose mission is to advocate for the civil and human rights of children and adults with disabilities. Founded in 2009, ABLE NH promotes the full participation of individuals with disabilities by improving systems of support, connecting families, inspiring communities, and influencing public policy. ABLE NH is the Granite State's only disability justice organization that is free from public funding. As an independent non-profit organization, ABLE NH has the freedom to engage in courageous conversations and actions and challenges discriminatory practices without fear of losing funds.

Over the course of its ten year history, ABLE NH has been a key player in bringing about positive changes in our state. In 2012, while still an all-volunteer organization, members of ABLE NH advocated for and secured an additional \$3 million for the Developmental Disability Wait List. This resulted in an additional 70 New Hampshire families receiving Medicaid funding for community based services for their adult family members who experience disabilities.

In 2014, ABLE NH initiated and organized a statewide effort to ban the payment of sub-minimum wages to people with disabilities, a legal practice which dated back to the 1938 Fair Wages Act. Working in partnership with families and disability advocacy organizations, ABLE NH worked for the passage of Senate Bill 47, making New Hampshire the first state in the nation to ban the payment of sub-minimum wages to workers solely on the basis of their disability.

For six long years, ABLE NH members and disability coalition partners waged war against the takeover of community based developmental services by corporate managed care organizations (MCOs). ABLE NH organized its members - individuals who experience disabilities and their families - to save New Hampshire's community based, person-centered system of long-term care. This sustained effort resulted in the 2018

passage of legislation that eliminated the plan to shift the State's responsibility for long-term supports and services for people with disabilities to MCOs. ABLE NH will continue to fiercely defend New Hampshire's community-based system of services, one that is overseen by families and has earned our state the 3rd highest rating in the nation in the quality of life for people with disabilities.

Most recently, ABLE NH is leading a statewide effort to have oral health care covered under Medicaid. We are excited to have strong leaders in ABLE NH's Nashua Chapter who are focusing on this issue and working tirelessly to support the passage of House Bill 692 which would amend state Medicaid policy to include dental care. For a complete list of ABLE NH accomplishments: <https://www.ablenh.org/wins-successes/>

ABLE NH is growing and we'd love you to join the team! Across NH, ABLE chapters are working to create more inclusive communities by removing barriers and fixing the small "system" problems that keep individuals who experience disability from being fully included. Typically, these are short-term campaigns focused on local issues impacting education, employment, health care, accessibility, and community engagement. At the state level, ABLE NH has three task forces - Inclusive Education, Transition to Employment, and Disability Diagnosis Dialogues – addressing statewide issues that require a longer, sustained campaign to affect change.

Throughout the year, ABLE NH offers a variety of trainings on community organizing to provide individuals with the advocacy skills necessary to bring about positive change. We are building of an army of Love. ABLE NH is working to advance equity, opportunity, and inclusion for all regardless of ability. We are breaking down barriers in the lives of people with disabilities by organizing ordinary people to become extraordinary leaders. To learn more please visit our website www.ablenh.org or email lisab@ablenh.org.



OVERCOMING ADVERSITY TO FIND STRENGTH IN ADVOCACY

By Isadora Rodriguez-Legendre, Executive Director, NH Council on Developmental Disabilities

We cannot talk about advocacy in New Hampshire without talking about Roberta Gallant. When Roberta tells her story, she often says that she found her strength in advocacy because of her experiences living in an institution. In 1956 when she was five years old, her parents admitted Roberta and her four-year old sister Jocelyn to the Laconia State School and Training Center. While they continued to have some connection with their family, like most institutional residents, Roberta and Jocelyn spent their childhood isolated from family and their community. While they were at the State School, both sisters suffered significant abuse.

Roberta says her independence and ability to advocate for herself began with her fight to learn how to read. "I saw the other students read books in the classrooms at the State School. I started asking people at Laconia State School to teach me how to read and write. I was persistent. I refused to stop begging them until they finally agreed to teach me."

In 1981, after twenty five years living in the institution, Roberta left the State School. (Jocelyn had moved to Henniker in 1979.) Roberta settled in Laconia where her housing, healthcare, and employment services were provided through the Area Agency. Roberta continued her education and became a student at the Adult Basic Education Program at Laconia High School. Living in the community, Roberta advocated for the rights to education for adults with disabilities who had been denied a public education as children. She received The Arc of NH Citizenship Award for her work and in 1992, the Martin Luther King Jr. Coalition recognized Roberta for her advocacy on behalf of individuals with disabilities.

In 1999, Roberta moved into her own apartment in Concord. "I wanted to live alone. Living alone did not make me feel lonely. I made some new friends. I am so proud of myself for my accomplishments."

Roberta continued to harness the power of her story and used it to advocate for people with disabilities. In 2007 she was appointed to the New Hampshire Council on Developmental Disabilities. As a Council member she helped to educate legislators and members of the community about her experiences in the State institution.

Roberta is an active member in a number of advocacy organizations including: People First of New Hampshire, Capitol City Self-Advocates, Self-Advocates Leadership Team (SALT), North East Advocates Together (NEAT), and Advocates Building Lasting Equality (ABLE) NH. After taking three years off, she is once again a member of the DD Council. Through her work on legislative issues, Roberta is well known at the State House and has developed relationships with many long-time legislators. She continues to call on legislators to take the actions that are needed to improve the lives of citizens with disabilities.



Photo courtesy of the NH Council on Developmental Disabilities

Roberta Gallant and Senator Maggie Hassan

In sharing her story, Roberta has been a voice for deinstitutionalization and community inclusion in the Granite State and beyond. She is a regular presenter at the New Hampshire Leadership Series and the annual New Hampshire Family Support Conference where she has spoken about how her experiences led to advocacy. She was a New Hampshire representative at the national Self-Advocates Becoming Empowered (SABE) conferences in 2008 and again in 2018. She also recently attended the National Councils on Developmental Disabilities' annual conference in Washington, DC.

In addition to her advocacy, it is important to note that from 2008 until her retirement in February 2019, Roberta worked at the Bureau of Developmental Services. Roberta was a valued team member, who was paid a fair wage for her work, and very proud of the job she did. Colleagues and friends filled the room at her retirement party. Co-workers and others whose lives she had touched talked about what Roberta meant to them and wished her well.

We thank Roberta Gallant for making a difference. Through her tireless advocacy, she has fought for the rights of people with disabilities and has worked to ensure that in New Hampshire they are welcomed and included. As Roberta says in her presentation about Laconia State School, "Living in the past, takes away the present and the future... I will always advocate to go forward and let go of the past. The present is a wonderful place to be."



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Recent signs offer some hope moving forward. Governor Sununu's 2019 budget includes improvements to the mental health care network. In January 2019 the Governor and the New Hampshire Department of Health and Human Services released the 10-Year Mental Health Plan calling for a statewide mental health system that provides access to a full continuum of care. This includes crisis supports and services, with specific recommendations for increased numbers of psychiatric beds and emergency department reforms to eliminate long wait times for psychiatric hospitalization.

Kent Street Coalition is committed to seeing this through. With hospital gowns and signs at the ready, we will continue to keep the focus on improving mental health services in our state. How long do we plan to keep this up? As long as it takes.

To learn more about Kent Street Coalition -
<http://www.kentstreetcoalition.org/index.html>



ADVOCATING FOR ORAL HEALTH

By Vanessa Blais, Project Assistant and Isadora Rodriguez-Legendre, Executive Director NH Council on Developmental Disabilities

Kelly Ehrhart knows that having a tooth ache is painful in more ways than one. Kelly requires medication that has the unfortunate side effect of causing dental problems. She has had to miss work because of extreme tooth pain. Kelly, whose health care is covered through Medicaid, is frustrated that Medicaid will pay to have her tooth pulled, but will not pay for the cost of a filling or root canal that could save the tooth. To prevent tooth decay, Kelly needs to have her teeth cleaned four times a year. With preventative oral health care not covered by Medicaid, Kelly pays out of pocket for these cleanings. This is a significant annual expense for someone who is on a fixed income.

In 2018, Kelly was accepted into the Institute on Disability's New Hampshire Leadership Series, an intensive program that provides leadership and advocacy training for individuals with disabilities and their families. After participating in a training session focused on Medicaid, Kelly and fellow Leadership



Kelly Ehrhart founding member of ABLE NH's Nashua Chapter.



Danielle Poirier testifies at the House Committee hearing on HB 692.

classmate Danielle Poirier teamed up to take on the challenge of expanding Medicaid coverage to include oral health care for adults with disabilities. Kelly and Danielle, who are both from Nashua, worked with ABLE NH Director Lisa Beaudoin to organize an ABLE chapter in Nashua. The Nashua chapter's primary focus has been to advocate for changes in Medicaid policy to provide coverage of preventative oral health care for individuals with disabilities.

In October 2018, as part of their campaign to improve access to dental care, Kelly, Danielle, and Lisa appeared on Gate City Chronicles, a Nashua Community Access television program produced and hosted by former Senator Kevin Avard. They discussed the struggles that Medicaid recipients have with oral health and the secondary diseases that often occur due to lack of preventative oral health care. (To view the program - <https://www.youtube.com/watch?v=eDsQkvRQEDU>)

When the New Hampshire legislative session began in January, ABLE New Hampshire joined disability advocates from around the state to fight for the passage of House Bill 692 amending New Hampshire's Medicaid

policy to include dental care. The Nashua Chapter of ABLE created and distributed a flyer on oral health care, solicited personal stories to share with legislators, and organized turn out for the bill's hearing.

Kelly and Danielle emphasized that they wanted legislators to know that preventative oral health care would result in significant cost-savings. Heart disease, strokes, and other illnesses can be linked to poor oral health. By providing adults with preventative oral health care coverage, Medicaid would see reduced treatment costs for these secondary diseases, fewer number of emergency room visits, and a decrease in medications. Equally important, having access to dental care improves quality of life, increases self-confidence, expands employment opportunities, and supports community engagement for individuals with disabilities.

While HB 692 is still working its way through the legislature, things are moving in the right direction. There was huge supporter turnout at the House Health, Human Services, and Elder Affairs Committee's hearing on the bill. HB 692 came out of the Committee with an Ought to Pass recommendation and has been passed New Hampshire House of Representatives. It now goes on to the Senate.

YOUTH LEADERSHIP IN NH

By Heidi Cloutier, IOD-UNH Project Director and Hannah Raiche, Youth MOVE NH Program Coordinator

In the wake of school violence, the "Me Too" movement and widespread behavioral health issues, youth all across America are stepping up demanding change. Their leadership is creating a cultural shift. Instead of adults making decisions for youth, youth are now being engaged as equal partners to address issues and bring about lasting change. For youth to have a meaningful role in transforming schools and our larger communities, they must not only be at the table, but share equally in decision making.

By moving away from adult-directed initiatives and embracing shared partnerships with youth, organizations evolve and grow and youth leaders flourish. In our work, we have seen organizations move from surveying youth for their ideas and input, to recognizing youth leaders as experts on their school and community's culture. Working in partnership, they have identified challenges, set goals, and developed action plans for implementing positive changes.

The Institute on Disability-UNH and Youth Move NH have been working collaboratively since 2008 to provide education, leadership training, and technical assistance to elevate youth voice in New Hampshire. This effort has included peer support, school based youth leadership teams, youth advocacy training, and convening youth organizations from around the state to collaborate and share resources. NH Youth Leadership has trained over 200 youth leaders who are committed to sharing their lived experiences, ideas, energy, and expertise to bring about positive changes not only in their own lives, but in their communities and in our state.

To learn more about Youth Move NH, visit their website <http://www.youthmovenh.org/>. For more information about NH's Youth Engagement Project, check out <https://iod.unh.edu/projects/youth-engagement-project>. If you are interested in joining YEP's monthly online conversation (every 3rd Wednesday at 4:00 PM), please email heidi.cloutier@unh.edu.



ART AS ADVOCACY

By Heather Stockwell, Rights & Democracy NH

Throughout history art has helped us to celebrate the things we value, as well as contemplate perspectives different than our own. Art provides an opportunity to dive into a topic we are unfamiliar with and to be open to new ideas. In the past art was reserved for the rich and the royal. Today art is for everyone and made by everyone.

New Year's 2018 I made a resolution to paint more. The beginning of the year started out great and then I started a job as a grassroots organizer with Rights & Democracy. I began spending more time advocating and teaching others to advocate for themselves. My personal journey got put on the back burner for a while. Once again, I resolved to "paint more" and used my time off to escape into my own creative world. What I found happening was my advocacy world was colliding with my art world.

I began reflecting on how artists have affected social change through their work. I thought about the power of Norman Rockwell's painting "The Problem We All Live With (Ruby Bridges)" that depicted a the first black child to attend an all white elementary school. I thought about the murals of Diego Rivera and Pablo Picasso with their message about social injustice and war. I recalled the "Rosie the Riveter" image from World War II and Shepard Fairey's Obama/Hope poster and how they became icons of their eras. When I was in college, the Guerilla Girls, an anonymous group of female artists, were bringing gender and racial inequality into focus. Today graffiti artist Banksy is putting his political message out onto the street, bypassing galleries altogether.

My own perception of what art could be was changing. I thought about how it

could be used to help heal us and bring us together in times where so many people are struggling to understand what is happening to our country. I believe that we are at the tipping point of a change. The more that we the people confront the problems facing us and use our voices and lift up the voices of all of those around us, the more change we will begin to see. As the end of the year approached, I finished a series of graphic images to accompany Rights & Democracy's project the "People's Platform". My worlds of art and advocacy had merged.

During this past year I've realized how isolated you can feel as an artist. I began to reach out to other artists who are interested in social justice to explore the idea of showing work as a collective. As we have thought about this, we made the decision to expand our reach beyond the visual arts to include music, dance, theater, video, and performance based works. We have started a New Hampshire Social Justice Artists Facebook page and plan to have a first meeting soon. We'd love to have you join us in building a network of artists creating change across the Granite State.

For more information - [New Hampshire Social Justice Artists Facebook Page](#)



Rights & Democracy NH press conference at the NH Legislative Office Building. Poster images by Heather Stockwell.

Photo courtesy of Rights & Democracy NH



SELF-ADVOCACY IS FOR EVERYONE

By Kathy Bates

I've been advocating for myself and others with disabilities since I was in grade school. This was before the passage of the *Education of All Handicapped Children Act* in 1975 and there weren't many kids who had obvious disabilities in public school during the late sixties and early seventies. I learned how to advocate for myself by watching my parents fight for me to have typical learning experiences.

Advocacy has always been a natural fit for me. Over the course of my career, I have had years of experience working with children and adults with disabilities. Helping others to find their voices and advocate for themselves is a passion of mine. Advocacy is about self-awareness, understanding your needs, and being able to ask for the help you need to achieve your goals.

I am currently the facilitator and a member of the Self-Advocacy Leadership Team (SALT). Originally a task force of the New Hampshire Council on Developmental Disabilities, SALT now consults with other advocacy organizations as well. In our most recent project, we helped to rewrite New Hampshire's Adult Protective Services laws to make them easier for everyone to read and understand. We also created a brochure to educate the public about this project. SALT has chosen to work on issues that are important to the wider community, not just those that concern people with disabilities.

Given my personal history and work with SALT it might surprise you to know that I really don't like the term self-advocate and how it has become synonymous with the word disabled. For example, if I am at a conference, I'm labeled a self-advocate along with every other person with a disability who is in attendance. The rest of the people at the conference are referred to as participants. Aren't we all participants? Here's the kicker, this isn't just something that happens at conference or an event, I am forever labeled a self-advocate. I think that's strange because people without disabilities advocate for themselves all the time, yet they are never called self-advocates. Self-advocacy skills are very important for everyone to learn and disability should have nothing to do with it.

*I learned a long time ago the wisest thing
I can do is be on my side, be an advocate
for myself and others like me.*

~ Maya Angelou



Photo courtesy of NH Council on Developmental Disabilities

SALT members getting down to work.

There is nothing wrong with having a disability. I use a wheelchair to get around and I'm not embarrassed by it at all. I also understand that there are times when labels are necessary. A diagnosis of a disability is a label that provides access to the equipment and services I need. My label of Cerebral Palsy gives me the right to have my really cool powerchair, my adjustable bed, and my accessible house. It also lets me take advantage of personal care services and physical therapy. I could not imagine my life without these tools; they are critical to my ability to live as independently as possible.

The funny thing about a label – whether it is a disability diagnosis or the term self-advocate - is that it doesn't tell you anything about the person who has been labeled. If there are fifty people in a room who have CP or who are labeled self-advocates, their strengths and challenges will all be different. For me, I would rather be known as Kathy the blond chick who gets around in really cool wheelchair! We don't need another word that is code for disabled. It really is okay to have a disability. It's the only minority that anyone can join at any time. Maybe, I could just be known as Kathy Bates, the writer who likes to give people something to think about.



ADVOCATE NH

By Members of the Advocate NH Planning Team

“Advocacy is important to help others who might not be able to help themselves.”

“No one knows your story better than you.”

“Advocacy is important to tell others what you think. It makes your interactions stronger.”

These are all answers to the question, Why is it important to be an advocate? Advocacy for people with disabilities, led by people with disabilities, is critical to the success of any disability advocacy movement. Advocate NH is committed to helping people with disabilities gain the skills they need to become effective advocates.

Originally known as NH Allies in Self-Advocacy, the group first came together in 2011 as part of a national initiative under the US Administration on Developmental Disabilities (ADD). In March of 2012, the New Hampshire team joined advocates from around the country at the National Advocacy Summit in Washington, DC. Members left the Summit with an appreciation of how important it is for advocates to share their stories, identify issues, and learn from one another. The group wanted to bring this experience back to New Hampshire. After a year of planning, in 2013 the group hosted the state’s first *Advocate: Learn it! Live it! Love it! Conference*.

The statewide conference is now an annual event. In 2018, over 100 people gathered in Concord for Advocate NH’s sixth conference, *Lights, Camera, Advocacy!* focused on helping people learn the advocacy skills they need to live their best life. Conference Spotlight Sessions included: Staying Safe in Your Community, Exercising Your Right to Vote, and Getting Involved with a Self-Advocacy Group. Talking about the event, one participant said, “The conference far exceeded my expectations!”

Advocate NH is now hard at work planning their seventh annual conference, *The Future of Advocacy*. It will be held on Friday, September 27, 2019 at the

Grappone Center in Concord. Sessions about assistive technology, health and fitness, dating and relationships, and employment are in the works. Why should you attend? It’s a great opportunity to meet other strong advocates and hear their stories. You will learn new things, and gain confidence in your ability to advocate.



Advocate NH’s 2018 Conference – Lights, Camera, Advocacy!



Advocate NH is always looking for more members to help plan the conference and talk about advocacy. If you are interested in joining, please contact Cat Jones at **603-228-2084** or email **contact.iod@unh.edu**. The group meets the second Tuesday of every month from 2:00–4:00 in Concord. You can attend in person or on-line via Zoom.

Get out your calendars now and save the date - September 27, 2019 – for the 7th Annual Advocate NH Conference!



ALLIES IN THE AISLES - NH BIPARTISAN LEGISLATIVE DISABILITY CAUCUS

By Representative Tamara Le, Rockingham District 31

“How can I help?” This is often the beginning of the conversation when I approach a colleague about legislation involving persons with disabilities.

Along with over 100 legislators, I am a member of the NH Legislative Bipartisan Disability Caucus. Now in its second term, the caucus was born out of a need to educate newly elected legislators and keep veteran legislators up to date on disability-related issues. The caucus is not a formal body with bylaws or regularly scheduled meetings. As a legislator, one quickly learns that in order to get real support on something, you stop to chat in the elevator and corridors. You make allies in the aisles and find teammates in the tunnel.

Showing respect *and building relationships* are fundamental to long-term advocacy and organizing. Most legislators are not immune to the emotions triggered when confronted with examples of discrimination or unfairness and are not shy about expressing their anger when needed. However, caucus members understand that we can be most effective in advocating for disability-related legislation by being a consistent presence in the legislature and a constant voice of truth.

Helping others to understand and share our vision is key. Taking a multi-pronged approach and casting a wide net helps to gain credibility. As caucus members we realize we need to connect not only with elected officials, but also with industry leaders, citizen advocacy groups, professionals, lobbyists, and anyone who has a stake in the issue. Having conversations with those who are in opposition can also be helpful. We are looking to answer questions, solicit ideas, address concerns, and build support. Our most important job - *to listen*. Listen to others' experiences. Listen to their feedback. Does their perspective offer insight in how or why we might or might not be successful?

In working together as a caucus, common sense and basic humanity are reliable guard rails. There are certain bills my most ardent philosophical opponents will support and others that kindred spirits will dismiss. As an example, members of the caucus were divided on school choice legislation. As someone whose



NH State Representative Tamara Le

commitment to inclusion and accessibility is unwavering, I could not bring myself to support any bill that was exclusionary. Many very compassionate and reasonable legislators in our caucus supported school “choice” for their own reasons and their own constituents. You learn to never take things personally, because right after one bill flies or dies, you find you are working on ten more.

In this session, the New Hampshire House passed bills that formerly lacked adequate bipartisan support. Legislation to establish a Deaf Child’s Bill of Rights and an Advisory Council on the Education of Deaf Children and a bill to establish a registry for the deaf, hard of hearing, and deaf/blind were voted through the Health Human Services and Elderly Affairs Committee unanimously and were passed by the full House with no floor debate. It was significant that these bills had bipartisan sponsors that included House and Senate leadership and newly appointed members of the New Hampshire Commission on Deafness and Hearing Loss.

When a piece of legislation that would improve the lives of people with disabilities does not move forward, the reason is most often lack of funding. In and of itself, this is not all bad news. New Hampshire is fortunate to have significant bipartisan support on disability-related issues.

When thanking a caucus member or colleague for their input and support on a bill, it is not surprising to get the response, “Glad I could help.”

I know they mean it.



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 offers a live broadcast via Zoom Webinar to share the results of the latest nTIDE findings, provide updates from the field of Disability Employment, and hosts an invited guest to discuss current disability-related findings and events.

- Dates:** First Friday of each Month
- Time:** 12:00 pm EST
- Location:** www.researchondisability.org/ntide

Responsive Practice Training

Responsive Practice enhances health care providers' ability to deliver disability-competent care to people with intellectual, mobility, and other disabilities. Training includes strategies and approaches to identify, address, and help remove barriers to care. There are trainings on *Providing Health Care & Screenings to Individuals with Disabilities* and *Providing Mammography to Women with Disabilities*. CEU's are available.

- Date:** Available On Demand
- Location:** www.nhdisabilityhealth.org
- Cost:** Free

INTELLIGENT LIVES

INTELLIGENT LIVES stars three pioneering young Americans with intellectual disabilities – Micah, Naieer, and Naomie – who challenge perceptions of intelligence as they navigate high school, college, and the workforce. Academy Award-winning actor Chris Cooper narrates the film and shares his emotional personal story of his son Jesse. Intelligent Lives unpacks the shameful and ongoing track record of intelligence testing in the U.S.

- Date:** Ongoing
- Website:** www.intelligentlives.org
- Location:** Across NH and USA
- Cost:** Vary

2019-2020 NH Leadership Series

The NH Leadership Series is an innovative annual training program that provides participants with information and strategies to effectively impact organizations and policies on issues related to disabilities. Applications for the 2019-2020 Series will be accepted on a rolling basis during Spring/Summer 2019.

- Date:** Monthly Starting in September 2019
- Location:** Across NH
- Website:** www.nhleadership.org

2019 START National Training Institute

This year's program, Value in Us All: Advancing Inclusive Practices, focuses on the dignity and inclusion of service recipients and their families. Inclusive practices value the unique cultural identities, positive characteristics, and the dreams of individuals and their families. The training will include 2 keynote presentations, 3 panel presentations, a research poster session, and 20 breakout sessions from 5 content strands: Strength-Based Approaches; Psychiatry and Integrated Health; START Best Practices and New Strategies; Crisis Response; and Policy, Practices, and Community Inclusion.

- Date:** May 6 - 8, 2019
- Time:** 9:00 a.m. – 5:00 p.m.
- Location:** Crystal Gateway Marriott, Arlington, VA

Using the Science of Implementation to Make Long-Lasting Change

A 2-day forum for individuals and teams responsible for implementing practices and/or supporting large-scale initiatives. Teams will learn how to implement a new practice, project, or framework by drawing on proven implementation strategies. Each team will learn to improve fidelity of implementation, enhance the sustainability of implementation efforts, and scale-up successful programs and practices.

- Date:** May 8-9, 2019
- Time:** 9:00 a.m. - 4:00 p.m.
- Location:** Grappone Conference Center, Concord, NH
- Cost:** \$599 per attendee

The New England Regional Genetics Network Annual Meeting

Join the New England Regional Genetics Network (NERGN) at their Annual Meeting to receive updates on research and projects taking place around the region.

Date: May 16 & 17, 2019

Time: 9:00 a.m. - 4:00 p.m.

Location: Portsmouth, NH

Effects of Substance Abuse on Young Children

Join the NH-ME LEND program and Dartmouth Hitchcock Medical Center's Department of Psychiatry for their Spring Conference. This year the conference will look at the effects of substance abuse on young children.

Date: May 17, 2019

Time: 8:30 a.m. - 4:00 p.m.

Location: Grappone Conference Center,
Concord, NH

3 EASY WAYS TO REGISTER!



online

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
56 OLD SUNCOOK ROAD, SUITE 2
CONCORD, NH 03301

Institute on Disability/UCED



University of
New Hampshire

2019 RAP SHEET SURVEY

Please let us know what you think about the RAP Sheet by answering our 4 question survey at

<https://sites.google.com/view/2019rapshetsurvey/home>

or calling NHCDD at 603-271-7046.

- What do you like about the RAP Sheet?
- What can be done to improve the RAP Sheet?
- How do you find out when a new issue of the RAP Sheet is available?
- Other suggestions?

Deadline: June 30, 2019



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.

Apply now at www.nhleadership.org

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

Learn. Lead. Create Change.

RAP Sheet

NH COUNCIL ON DEVELOPMENTAL DISABILITIES

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

RETURN SERVICE REQUESTED

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DISABILITY RIGHTS CENTER - NH

64 North Main Street, Suite 2, 3rd 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 ◆ Website: 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

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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

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Phone: (603) 271-3236 ◆ TTY/TDD: 1-800-735-2964 ◆ Website: www.nhddc.org

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

This publication was supported solely by federal funding from grants from the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, Administration for Community Living/ Administration on Intellectual and Developmental Disabilities, U.S. Department of Education, Department of Rehabilitation Services, Social Security Administration, and a grant from the New Hampshire Bar Foundation.

The contents are solely the responsibility of the grantees and do not necessarily represent the official views of the federal grantors.