

# RAP Sheet

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

Fall Issue 2013

## THE POWER OF SPEAKING OUT



### NEVER GIVE UP

By Julia Freeman-Woolpert, Disabilities Rights Center

*"If you are going through hell, keep going." ~ Winston Churchill*

She has her life back.

It took four long years to regain her freedom, but Michelle Schladenhauffen never gave up. She researched all options, followed every lead, contacted everyone she could think of, including the Governor, and worked with every agency. By the end, she had a state legislator, the Institute on Disability, and the Disabilities Rights Center all standing with her, rooting her on. Michelle's perseverance paid off. In February 2012, she moved into her own apartment.

Michelle never thought she would end up in a nursing home. She had an active, busy life full of family, friends, and activities. She was successfully managing her progressive neuromuscular disease, attending college and working, but in her early thirties her condition worsened. Michelle was forced to check herself into a hospital. From there she was sent to a rehabilitation center and after a year was transferred to a nursing home.

The nursing home stay was intended to be temporary until home health care could be arranged and Michelle could move into her own apartment. It didn't work that way. Getting into the nursing home had been easy, getting out was almost impossible. When she realized that for the foreseeable future she would be in an institution, Michelle said, "I felt like all the air had been sucked out of the room."



*Michelle Schladenhauffen at the May Allies in Self-Advocacy Conference.*

Photographer – Julia Freeman-Woolpert

*Welcome to the Fall 2013 RAP Sheet where we look at the power of advocacy. Learning how to speak up for yourself and to fight for what you need are important life lessons for everyone. For individuals who daily face barriers and challenges that others can't even begin to imagine, knowing how to be a forceful advocate is an essential skill. In this issue we hear from people who have fought against the odds to have their voices heard.*

SUSAN COVERT, EDITOR

*(Continued on next page)*

A COLLABORATIVE EFFORT BY THE

DISABILITIES RIGHTS CENTER, INSTITUTE ON DISABILITY, AND NH COUNCIL ON DEVELOPMENTAL DISABILITIES

*(Cover story continued)*

By far the youngest resident, Michelle had no peers in the nursing home. She became wary of getting close to other residents, because they kept dying. She had no personal space. She shared a bedroom and used a bathroom that wasn't private. It felt degrading. She was isolated. With no transportation or support, Michelle could no longer go out to eat, go shopping, go to the movies, or enjoy any of the community activities she loved.

But she could still use her computer and telephone, and use them she did. Michelle applied to New Hampshire's Choices for Independence Program and was told she wasn't eligible. She contacted home health care organizations and was told over and over again she wasn't eligible. She applied to assisted living facilities and was told she was too young. She got a Section 8 Housing Voucher, only to have it run out before she could put her personal care services in place. She applied to the Rainbow Apartments in Portsmouth and got on the waiting list. She applied to the area agency and after reams of paperwork and eight grueling hours of testing finally was declared eligible for developmental services.

Disabilities Rights Center attorney Rebecca Whitley, who represented Michelle, said, "She's one of the most persistent people I have met. She was amazing. She called everyone and got herself on everyone's radar screen. She never gave up."

After three years on the waiting list, Michelle got a call from the manager at Rainbow Apartments telling her that a unit had opened up. Recounting the conversation, Michelle said, "We both cried."

Even with housing secured, Michelle's need for self-advocacy wasn't over. She negotiated with providers to get services set up the way that would be most effective for her. "It took me a while to get care in place after I moved in," she said. "Once I got care in place and got on a schedule, it was great."

Michelle loves her new home. She has flourished and regained many of the things she had been denied in the nursing home. She now has a cat. She hosted her family for Thanksgiving. She has friends over to visit. She goes out. She has cookouts. She has started applying for jobs.

Michelle wants others to know they too can realize their dreams. "You just need to keep on keeping on," she said. A graduate of the New Hampshire Leadership Series at the UNH Institute on Disability, Michelle is committed to fighting for the rights of people under 60 who have physical disabilities. She has testified before the legislature and taken her story on the road, speaking at conferences and to groups around the state. She has been interviewed on television and is writing about her experiences. She is a force to reckon with.

"I was raised not to give up," Michelle said.

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## ABLE NH – MAKING A DIFFERENCE

The ability to speak up, to take control of your own decisions, is the essence of what it means to be human. But what happens when it seems like no one is listening? How do we develop the power for self-advocacy to become action? That's where ABLE NH comes in.

ABLE NH (Advocates Building Lasting Equality) is New Hampshire's leading grassroots advocacy organization for individuals and families affected by a disability. ABLE advocates for the human and civil rights of all people with disabilities and promotes full participation by improving systems of support, connecting families, inspiring communities, and influencing public policy. ABLE NH is made up of community chapters; the issues we take on come from our membership. We seek out and develop leaders from all across the state. ABLE leaders are individuals with disabilities, family members, and friends. ABLE is made up of people just like you.

This has been an exciting year for ABLE. We are gathering incredible momentum! Our leaders have been using their power to bring about changes at the local, state, and national levels. In June ABLE leaders traveled to Washington, DC to speak with our elected officials about ending the use of restraint and seclusion in schools. Teaming up with TASH and other national leaders, our voices were heard loud and clear. We also are working on this issue back at home, talking with local schools,

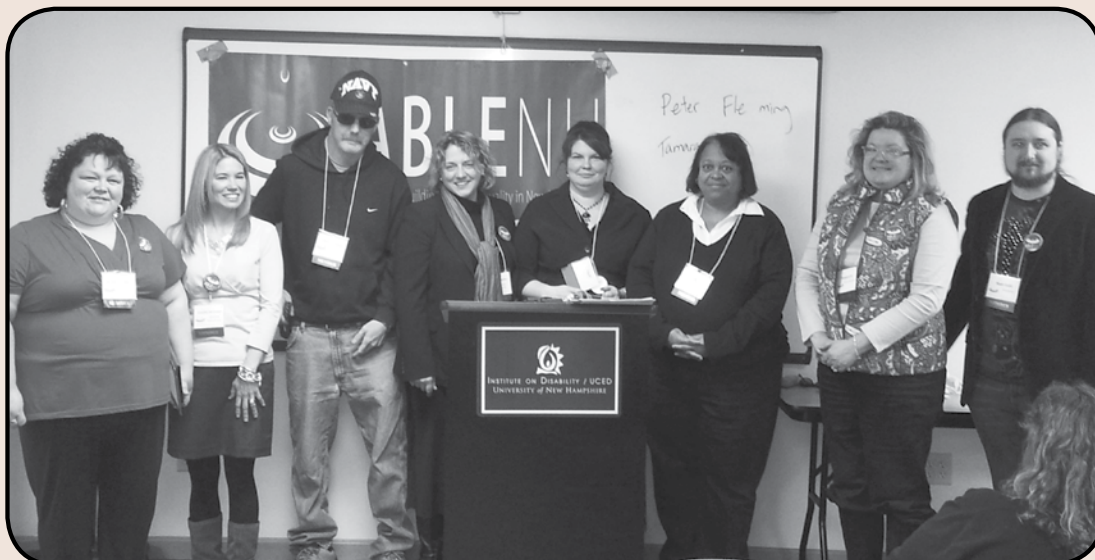
the New Hampshire Association of Special Education Administrators, and State officials. We are committed to ending the practice of restraining and secluding students. We won't take "no" for an answer.

ABLE NH recently hired a community organizer, Amanda Miller Johnson. Amanda brings with her a passion for justice, the will to persevere, and a strong belief in ABLE's mission. She will be supporting ABLE leaders in their work to make a difference. ABLE has the vision and the power to begin important conversations and bring about needed changes in our communities.

So what's next? ABLE NH needs to hear from you. We believe your voice matters. ABLE will meet you where you are and help you to develop the skills you need to become a powerful leader. Granite Staters are known for being strong willed and independent; we want to harness this New Hampshire spirit to make a positive difference for individuals, families, and communities.

Become an ABLE NH member. We invite you to attend a local chapter meeting or to start a chapter in your community. It's time to raise the volume and speak out. We can't wait to have you join us on this incredible journey.

To learn more, visit our website [www.ABLENH.org](http://www.ABLENH.org). For more information email [info@ablenh.org](mailto:info@ablenh.org) or telephone 603-271-2336.



*ABLE NH's newly elected board of directors. From left to right: Wendy Faye Lucier, Jennifer Bertrand, Peter Fleming, Linda Quintanbila, Jennifer Pineo, Deborah Opramolla, Tamara Le, and Matthew Gold*

photographer – Shawn Bertrand

# SELF-ADVOCACY: LEARN IT! LIVE IT! LOVE IT!

On May 10th and 11th over 150 people from all across New Hampshire gathered in Manchester for the Self-Advocacy: Learn it! Live it! Love it! Conference. The conference was the result of a yearlong team effort by self-advocates and allies who are committed to strengthening the self-advocacy movement in New Hampshire. People were inspired by keynote speakers John Fenley,

President of People First of New Hampshire, community organizer Mary Gonzales, and Tracy Thresher, star of the film *Wretches and Jabbers*. In breakout sessions, individuals with disabilities shared their personal stories of how they fought for their rights, stood up to bullies, or helped to organize to bring about changes in their communities.

We hope you'll enjoy Julia Freeman-Woolpert's photos of the conference and what people had to say about their experience.



Planning team for the 2013 Self-Advocacy: Learn it! Live it! Love it! Conference.

*"By working together things happen!"*



*"All the speakers were very passionate and powerful. They lit a fire under me."*



*"It helps to have a voice. We have the power to do things with the legislature."*

*"I loved Mary Gonzales, because she got in everyone's face."*



*"I was inspired by Tracy's story, it brought smiles and tears."*



*"You get to stick up for your rights and tell people what you want."*



*"It was great that people got to network on a statewide level."*



*"Don't let others do your talking for you."*



*"Wonderful. John's clarity and articulation make him a strong speaker. He knows what he wants and is able to help others express their dreams."*



*"Katy's story made me feel more empowered and should become a movie!"*





## PEOPLE FIRST- WEATHERING THE STORM

By John Fenley, President People First of NH

It is hard to embrace change in our personal lives. We are often fearful of deviating from the safe and comfortable path that we have set for ourselves. The same holds true for organizations. In fact, change can be downright overwhelming. As President of People First I found that going through major organizational change was like trying to calm the nerves of your crew while attempting to right your ship in the midst of a storm. Luckily, People First of New Hampshire doesn't hold meetings aboard a ship, so we didn't have crashing waves coming over the bow. Unfortunately, in 2012 we did have to deal with a major cut in State funding that resulted in the loss of our full time advisor of 20 years.

Since then, members of People First have worked hard to get back on course. I am proud to say that we have taken a number of steps to regroup and have come out stronger than ever. Our statewide People First team is working well together and members have taken on more responsibility for getting things done. We have a great new part time advisor and facilitator for our meetings

and we are looking to bring in new members. What's even more exciting is we now have invited liaisons from the Disabilities Rights Center, the New Hampshire Council on Developmental Disabilities, and the New Hampshire Bureau of Developmental Services to our monthly meetings. The liaisons are not voting members of People First, they are there to hear about the issues affecting our membership and to help support the work we are doing. Having these kind and dedicated folks present at our meetings has strengthened our communication and collaboration with the key service and advocacy organizations in our state. Finally, we have launched an exciting new rebranding campaign for People First of New Hampshire. We are designing a new logo and have plans to spice up our website with a new look and more interactive options.

We have set our course for an exciting new future and rest assured, we have big plans for New Hampshire.

Change is in the wind! If you would like to be part of it, give John Fenley a call at (603)-727-9198.

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- Reduce costs
- Be more environmentally friendly

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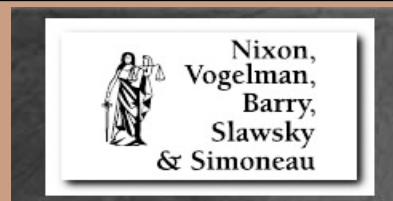
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For more information, see <http://www.davenixonlaw.com>.



## PEER SUPPORT

By Damien Licata, Executive Director Monadnock Area Peer Support Agency

*Peer support is a system of giving and receiving help founded on the key principles of respect, shared responsibility, and mutual agreement of what is helpful.*

In the world of peer support and recovery, we often hear about self-advocacy and empowerment, but it is not always clear what is meant by these terms. What does it mean to embody such qualities? How can we be sufficiently "empowered" to advocate effectively for ourselves? Many of us believe that for us - persons with disabilities, educational, economic, and/or emotional challenges - such terms simply do not apply.

I would like to share my perspective about what self-advocacy and empowerment look like at Monadnock Area Peer Support Agency (MPS), which I've had the privilege to direct over the last five years. Located in Keene, MPS is one of ten peer support agencies in New Hampshire that offer support services for adults with mental illness.

Typically, an individual who first comes through our doors has experienced years of being the recipient of services from therapists, case managers, psychiatrists, and governmental programs like Social Security, local housing authorities, and the state Department of Health and Human Services. Decisions about the nature and extent of medical and psychiatric treatment (including hospitalization), where to live, and even one's daily schedule are made with very little input from the individual. It's not

surprising, that many of us have never felt that we had the ability or the power to say what it is that we want or need. We have not had the opportunity to make our own decisions and to take control of our lives.

What happens in a peer-run organization is very different. All MPS members and staff, and at least 51% of our Board of Directors are mental health consumers. Decisions about the day-to-day operation at MPS, including programming and support services, are made collectively. Those who are directly affected have a say in the decision-making process. This experience challenges our assumption that we don't have the ability or power to direct our own lives. At MPS we are supported to develop relationships with our peers where we can express our perspective. By listening to others and sharing our respective needs, we take on a mutual responsibility for relationships.

Others cannot give us personal power - it is something that we must assert for ourselves. The experience of mutually supportive relationships, where taking risks and speaking truthfully are encouraged, reinforces our self-image as someone who has the right and the ability to advocate for her or himself. To develop effective communication skills, at MPS we practice conversations with healthcare and other service providers and support each other at appointments. As our voices become stronger, we are able to insist on taking an active role in decisions that affect us and by doing so take control of our relationships and our lives. In my time at MPS I have seen peers transform themselves from someone who believes they are at the mercy of others to strong independent individuals who are capable of effectively advocating for themselves and others. That's what we mean by self-advocacy and empowerment.

To find the Peer Support Agency nearest you, see the Department of Health and Human Services website at - <http://www.dbhs.nh.gov/dcbcs/bbh/peer.htm>



*Damien Licata preps Thanksgiving dinner with two MPS members.*



## SAIL: ADVOCACY ON THE SEACOAST

By Julia Freeman-Woolpert, Disabilities Rights Center

Seacoast Advocates for Independent Living - SAIL - is a fitting acronym for this small group of determined advocates.

The group, which meets monthly, has been going strong for decades. They began as a social gathering and over the years have evolved into an active advocacy group. Together, members identify local barriers to accessibility they want to challenge. They take on projects individually and support each other to see them through. Shellie Lemelin, a lifelong resident of Dover who has been involved in SAIL for 28 years, said, "Transportation is a big priority for the group."

Last year COAST transportation system reduced bus service to Dover. This year, COAST plans to completely eliminate service to the area where Shellie lives. Without the bus, Shellie won't be able to get into town to shop or take care of other business. A strong advocate, she began a petition to protest COAST's decision. Foster's Daily Democrat picked up the story and featured her in both an article and editorial. Shellie also voiced her concerns in an open forum at Dover City Hall. Ellie Kimball, another SAIL member, offered moral support and went with her to the forum. The Deputy Mayor listened and agreed something should be done. Shellie is waiting.

Ellie has taken up the crusade for accessible parking. She has fought to make sure her apartment complex keeps the accessible spaces maintained and clear of snow. The apartment's maintenance man habitually parked his truck in an accessible space, until Ellie gave him an earful. He found a new parking place. "If I have something to say, I don't hold back," she said.

Ellie also got involved when a neighbor was threatened with eviction. The man, who has a brain injury, says whatever is on his mind without considering the consequences. He was given seven days to move after he lost his temper with a maintenance man who had thrown sand and salt on his car. Ellie researched fair housing rights and called New Hampshire Legal Assistance on his

behalf. Legal Assistance got involved, and her neighbor was able to stay in his apartment.

Matt Greenwood is working for better pedestrian access and safety in Dover. Like Ellie, he isn't shy about speaking up for himself. "I'm sticky, loud, and persistent," he said. He wants Dover to put in accessible curb cuts and audible signaling at crosswalks. One audible signal near his home has been installed and he expects more to follow. Matt went to the city to complain about an unplowed stretch of sidewalk near the hospital that was forcing pedestrians into the street. It took a discussion with the city manager and a meeting with the city council, but eventually the city started clearing the area. Matt also convinced the city to take down trees that were blocking driver visibility and endangering pedestrians.

SAIL member John VanBuskirk enjoys going into Portsmouth, but without public transportation his trips are limited to when he can catch a ride on the GSIL van. Once in Portsmouth John encounters problems with accessibility. Restaurants frequently put chairs and tables on the sidewalk, blocking the path for people using wheelchairs. There are a number of inaccessible establishments, including the Press Room, a pub with live music. John, a jazz aficionado, would love to hang out there, but he can't get in. "It's a big problem for me," he said. SAIL has started discussing the lack of accessibility in Portsmouth and will decide whether to take on this issue.

GSIL's Advocacy Director, Jeff Dickinson and Regional Advocacy Facilitator, Jen Decker, help to support the group. Jen facilitates SAIL meetings and Jeff provides technical support including workshops on advocacy and the legislative process. He explained, "We're there to help folks get more confident doing systems advocacy."

Jeff speaks highly of SAIL, "They identify things they want to improve and take it on. Even if they aren't sure where to start, they start anyway and figure it out as they go." He hopes to see other local advocacy groups start up around the state. When they do, GSIL will be ready to support their efforts.

*(Continued on page 11)*



# NHLS GRADUATES TALK ABOUT ADVOCACY

Tamara Le asked three New Hampshire Leadership Series (NHLS) graduates who experience disabilities to share their thoughts on advocacy.

## Jennifer Decker, 2010 NHLS Graduate

"To be an effective advocate, I need to keep up the effort. Even when I'm getting nowhere, it's my responsibility to teach what it's really like to live with a disability, while continually educating myself."

Decker said, "Before Leadership, I never thought I'd do public speaking, let alone relay stories and experiences to others on how to advocate."

At the May Allies in Self Advocacy statewide conference, Decker was a panelist on a breakout session about the NH Leadership Series. She told conference goers that there were two aspects of the Leadership curriculum that were key to her development as an advocate, "(In) the session about the history of Laconia State School and subsequent organization of the New Hampshire disability community, I gained a foundation for understanding why it is essential that people with disabilities advocate for themselves. We have come so far from Laconia, but have a long way to go. The Legislative Advocacy session gave me skills I needed to take on employment issues. Now that I'm working for Granite State Independent Living and the Brain Injury Association of NH, I'm putting my passions into practice."

Utilizing her advocacy skills, Decker secured a grant from the Challenged Athletes' Foundation ([challengedathletes.org](http://challengedathletes.org)) for personal sports equipment and through the Chanda Plan Foundation ([thechandaplanfoundation.org](http://thechandaplanfoundation.org)) she accessed funds for alternative therapies that were not covered by her insurance.



Photographer - Margaret Moloney

Jennifer Decker

## Galen Spiegler, 2010 NHLS Graduate

"My vision, as a self advocate, is simply to fight for the support I need to live the life I want to lead. In my case that means finishing school, finding work, marrying, and starting a family."

Only a senior in high school when he went through Leadership, 2013 NHLS class members tapped Spiegler to give the keynote address at graduation. He delivered his speech- in a British accent no less - using his augmentative communication device.

Now attending college in Dayton, Ohio, Spiegler talked about his plans for the future. "When I started at Wright State University, I wanted to go into architecture, but soon realized my math skills were not quite sharp enough. At the same time I was taking psychology 101. I fell in love with it." Spiegler remained uncertain about how he wanted to put his education to use until he took a course on human sexuality. "With my masters or doctorate in psychology and sexology, I'll work as a psycho therapist helping people living with physical disabilities break down barriers that interfere with the expression of their sexuality."





## Kathy Bates, 1998 NHLS Graduate

Since Leadership, Bates has started her own business, *Wings and Wheels Consultant Services*, and taken on several leadership roles with state boards and committees. For 15 years she has been a NHLS group leader. She has been an advisor to People First of New Hampshire and facilitates the newly formed SALT Team (Self Advocates Leading Together). This fall she will be a trainee in the New Hampshire Leadership in Neurodevelopmental Disabilities Program (LEND) at UNH.

Bates said honoring her own self-interest was key to her development as an advocate. "It taught me to think about what was really important for me. I realized my possibilities were limitless. NHLS presenter Norman Kunc taught me that *I do not need to be fixed*. That disability really was natural. And, Jeff Strully? He taught me advocacy is telling my story. My vision as Kathy Bates, leader, is for people with disabilities to stop being seen as a drain on society. We are talented citizens who can contribute in major ways."

"I have to say, the term 'self-advocate' is just another way to single out people with disabilities. Since we all are self-advocates we all need to learn the skills to make the changes we wish to see in the world. Everyone's voice needs to be heard. I would like to stop being called a self-advocate because we all can stand up for ourselves. Everyone just calls *you by your first name, right?*"

Right, Kathy.



Photographer – Julia Freeman-Woolpert

Kathy Bates



Photographer – John Wesley Lee

Galen Spiegler and Selina Lee



*The New Hampshire Leadership Series (NHLS) is a powerful training series that supports people who have disabilities and family members to develop advocacy skills to create changes in their lives, communities, and service systems. NHLS graduates have gone on to run for local and state offices; they are represented on local school boards, city councils, and the state legislature. New Hampshire Governor Maggie Hassan is a Leadership graduate. As part of the Institute on Disability at UNH, the NHLS has been operating since 1988 and over 800 graduates have taken part in the Series. To learn more about the NHLS, visit <http://www.nhleadership.org>.*



## SELF-ADVOCACY LEADERSHIP TEAM (SALT)

By Katherine Epstein, Member of the NH Council on Developmental Disabilities and NH Leadership Series Intern

The self-advocacy movement seeks to reduce the isolation that people with disabilities face by giving us the tools and experiences to have greater control of our lives. The New Hampshire Council on Developmental Disabilities (NHCDD), in keeping with its mission to support equal opportunities and full participation for all New Hampshire citizens with developmental disabilities, brought together self-advocacy leaders from across the state to work with the Council on issues facing people with disabilities. The Self-Advocacy Leadership Team (SALT) not only advises the Council, it also serves as consultants to New Hampshire policy makers and other advocacy groups in the state.

SALT members are talented citizens who want to bring about positive systemic changes in New Hampshire. The majority of members are graduates of the UNH Institute on Disabilities Leadership Series. Seasoned self-advocates, SALT members include the President of People First of New Hampshire, Advocacy Coordinator for Granite State Independent Living, past Co-chair of the NHCDD and longtime volunteer with the Best Buddy Program, and a recipient of the Martin Luther King Jr. Coalition award for advocacy.

SALT is committed to supporting people who experience disabilities by tackling issues that keep them from living

quality lives in their communities. SALT is focusing on access to transportation, meaningful career opportunities, abuse prevention, and increased self-advocacy awareness for young adults with disabilities. Currently SALT is writing a position paper on the inadequacy of New Hampshire's transportation system; lack of transportation is a problem for everyone, not just people with disabilities.

As a member of the NHDCC, I was thrilled when I learned the Council was forming a group comprised of only people who experience disabilities. I jumped at the chance to be part of it. There is something magical about discussing the issues that affect your life with people who face the same challenges. When you are the only one in your family or circle of friends who experiences a disability, it is nice to be able to connect with people who get it. Since joining SALT, I have had a chance to meet with our elected officials in Washington, DC and to speak out publicly about issues confronting New Hampshire citizens with disabilities.

SALT meets every third Thursday of the month at the Walker Building, 21 South Fruit Street, Suite 22 in Concord. If you are a self-advocacy leader and interested in making a difference, please contact me (Katherine Epstein) at [Katkmepestein@aol.com](mailto:Katkmepestein@aol.com) or our facilitator Kathy Bates at [wngsandwheels@comcast.net](mailto:wngsandwheels@comcast.net) for more information.



Photographer – Carol Stamatakis

SALT members (from left to right) Katherine Epstein, Susie Conlon, Roberta Gallant, John Fenley, Peter Fleming, Sarah Cooley, and facilitator, Kathy Bates



## WALQ (Working Alliance for Language Quality)

What's that... "WALK"??! WALQ is the Working Alliance for Language Quality, a group of unaffiliated Deaf community advocates and allies working to improve services and opportunities for New Hampshire's Deaf community. WALQ was founded in April 2013 following a workshop taught by two Deaf advocates from Facundo Element, an organization that actively works to remove oppression and misrepresentation of Deaf people (<http://facundoelement.com>). They spoke about power and privilege and helped us examine an experience that we in the Deaf community call "audism". Audism is the notion that one is superior based on one's ability to hear or to behave in the manner of one who hears and that hearing loss is a tragedy and life without hearing is futile.

with developmental disabilities, mental health care, and communication with DHHS. WALQ is exploring how state resources can be tapped to make New Hampshire a place where Deaf people can work, grow, and thrive. We are building a new understanding about the needs of the Deaf community among State agency personnel and our legislators. Through WALQ we are becoming empowered and finding our "voice".

WALQ is committed to action. In our short history, we have hosted two public forums that were well attended by State legislators and representatives from service agencies. We also have established communication networks via emails, video messaging, and Facebook, (<https://www.facebook.com/WALQ.WalkingAllianceForLanguageQuality>). We

are holding bi-weekly planning meetings to discuss what we can do to create a positive future for Deaf people. We have high aspirations that New Hampshire will become known as a state that is a great place for Deaf people to live.

WALQ has no official membership. Anyone and everyone who uses ASL are welcome at our meetings. We will arrange for interpreters for those who want to support our work. To learn more about WALQ and to get a meeting schedule please email [WALQaction@gmail.com](mailto:WALQaction@gmail.com) attention Thomas Minch.



WALQ members at their July 10, 2013 meeting.

Of all the lessons we learned, the most important one was that liberation from oppression happens best through action. And we are taking ACTION. Within a week of the workshop, an active and growing community was formed to create opportunities for Deaf people to have a voice in getting the services we need.

Our initial goal was to ask for changes in the way interpreter services were being provided by the state's Department of Health and Human Services (DHHS). This request created an opportunity for us to be heard at the highest levels of DHHS. We are pursuing other initiatives for improving early intervention programming, services to Deaf people

*(Continued from page 7)*

SAIL welcomes new members. Shellie is especially interested in reaching out to recent high school graduates with disabilities to offer support as they start negotiating the challenges of adult life. Ellie agrees, "It's a terrific way to get with other people who face similar problems, and problems you haven't even thought of yet."

For more information about SAIL or to get involved, contact Jen Decker at GSIL at 228-9680 or email [jdecker@gsil.org](mailto:jdecker@gsil.org).

Photographer - Rachel Farrell

# 10 TIPS TO SUPERCHARGE YOUR ADVOCACY GROUP

By Kathy Bates, owner Wings and Wheels Consulting Services

I don't like the term self-advocate very much. It's just another one of the gazillion ways a person who experiences a disability can be referred to. However, learning to advocate for oneself is extremely important and anyone can learn how to do it.

Advocating for what you want is all about self-awareness. You have to know what is important to you and how you can use your gifts to achieve your goals. Awareness also is a critical feature of an advocacy group. Members decide on the goals for their group and look for ways that individuals can contribute to the success of the group.

I have been facilitating advocacy groups for many years and have found that the following tips can help supercharge a group, keep things running smoothly, and maximize chances for success.

- 1) **Find common ground** – If a group is going to be successful, it is critical that members agree on why they are meeting. While advocacy groups can be somewhat social in nature, members are coming together for a deeper purpose. As the facilitator, I help members develop a mission statement that outlines the purpose of their group.
- 2) **Get to know each other** – Good communication is key, it is important that people have time to get to know each other. Everyone should feel comfortable discussing issues and bringing up whatever is on their mind. I always start meetings with something called "What's Up?" This icebreaker gives members a few minutes to talk about what is going on in their lives.
- 3) **Agree on basic rules** – In order for meetings to run smoothly, the group needs to agree on some basic principles. For example, only having one conversation at a time during the meeting. The group also needs to learn some practical rules about how meetings are run; things like how to make a motion to bring an issue up for a vote.
- 4) **Share the air** – As the facilitator, it is my job to make sure that everyone's voice is heard. If one person is dominating the conversation, I may ask members who have been quiet to share their opinions. If everyone has something to say about the topic, I may ask people to raise their hand if they still want to speak. This helps me to keep track of the conversation and to make sure everyone gets a chance to participate.
- 5) **Respect others' opinions** – While it is important for the group to come up with common goals, it

is inevitable that members will have different ideas about what is most important and how things should be done. Opinions are going to differ and that is a good thing. We all benefit from looking at issues from different angles.

- 6) **Keep it confidential** – Sometimes discussions in advocacy groups can become very personal. It is important that everyone understands the importance of respecting each other's privacy. Whatever comes up in the group stays in the group.
- 7) **Support productive participation** – There is a risk that an advocacy group can become one big complaint session. When an issue is brought up, I always ask, "How are you going to fix it?" Meetings can be a productive place for brainstorming solutions. It is important to know what skills and talents people bring to the group. Having this information makes it easier to help match people's talents with the work that needs to be done.
- 8) **Break it down** – The challenges that people who experience disabilities deal with on a daily basis – lack of transportation, discrimination in the workplace, inaccessibility, and educational barriers – can be overwhelming. When a group decides to take on an issue, it is extremely important to break things down into concrete action steps.
- 9) **Hold everyone accountable** – As the facilitator this is usually my job. At the end of each meeting, action steps are reviewed and members volunteer to take on specific tasks. These assignments are included in the meeting minutes. I also send out emails or make phone calls to remind members of their assignments.
- 10) **Have fun and celebrate victories** – While the issues they take on can be very serious, effective advocacy groups take time to have fun and celebrate their accomplishments. Making time for celebrations helps to keep the group energized and moving forward.

I really love advocacy work! I have been advocating for myself and for others since I was a little kid. That is not to say it has always been easy and I know it is something that I will have to do for the rest of my life. But because of advocacy, my life is full of choices. For me, that is the definition of a good life – having a life that I choose. My favorite part about being a facilitator is helping others learn how to be more effective advocates. Joining an advocacy group gives people who experience disabilities the opportunity to grow as individuals and to use their talents to make a real difference in the world.

# Resources

## **ABLE NH**

*Advocates Building Lasting Equality* advocates for the human and civil rights of all children and adults with disabilities and promotes full participation by improving systems of supports, connecting families, inspiring communities, and influencing public policy.

21 South Fruit Street, Suite 22  
Concord, NH 03301  
(603) 271-2336  
[info@ablenh.org](mailto:info@ablenh.org)  
<http://www.ablenh.org/>

## **Advocate NH**

*Advocate NH* is a network of advocacy groups and statewide organizations brought together to strengthen and enhance self advocacy.

<http://www.drcnh.org/AlliesinSelfAdvocacy/AlliesinSA.html>

## **Autistic Self Advocacy Network**

*ASAN* was created to provide support and services to individuals on the autism spectrum while working to educate communities and improve public perceptions of autism.

PO Box 66122  
Washington, DC 20035  
(202) 596-1056  
[info@autisticadvocacy.org](mailto:info@autisticadvocacy.org)  
<http://autisticadvocacy.org/>

## **Disabilities Rights Center**

*DRC* provides information, referral, advice, and legal representation to individuals with disabilities on a wide range of disability-related problems. *DRC* advocates for legal rights in the areas of: education, employment, housing, assistive technology, access to services, elimination of barriers in public accommodations, access to voting and other civil rights, and freedom from abuse, neglect, and restraint and seclusion.

18 Low Avenue  
Concord, NH 03301  
(603) 228-0432 or toll free 1- 800-834-1721  
V/TTY –fax: (603) 225-2077  
[advocacy@drcnh.org](mailto:advocacy@drcnh.org)  
<http://www.drcnh.org>

## **Granite State Independent Living**

New Hampshire's Center for Independent Living  
21 Chenell Drive  
Concord, NH 03301  
(603) 228-9680  
[info@gsil.org](mailto:info@gsil.org)  
<http://www.gsil.org/>

## **LifeArt Community Resource Center**

A Keene Community resource center where everyone is welcome!

25 Roxbury St, Suite A  
Keene, NH 03431  
603-357-1456  
<http://www.lifeartkeene.org/>

## **NH Bureau of Developmental Services – Complaint Process**

*Individuals who receive services in the developmental services system have the right to be free from abuse, neglect, and exploitation. They also have the right to be treated with dignity and respect at all times. If you receive services and believe your rights have been violated, you have the right to file a complaint. Staff and others who work with individuals receiving services in the developmental services system must file a complaint whenever they have reason to suspect that an individual has been subjected to abuse, neglect, exploitation, or a rights violation by an employee of, or a contractor, consultant, or volunteer for an area agency or program.*

To file a complaint, please call this toll free number at any time: 1-855-450-3593

## **NH Leadership Series**

A project of the Institute on Disability, this 7-session series provides training on how to impact change and organize communities to support inclusion.

<http://nhleadership.org/>

## **Peer Support Agencies**

Peer support services are provided by and for people with mental illness and are designed to assist people with their recovery. To find the Peer Support Agency nearest you, visit the NH Department of Health and Human Services website at <http://www.dhhs.nh.gov/dcbcs/bbh/peer.htm>

## **People First of NH**

Statewide self-advocacy organization led by people with disabilities

<http://www.peoplefirstofnh.org/>  
Contact: John Fenley (603) 727-9198

## **Seacoast Advocates for Independent Living**

Peer support group for individuals with disabilities living on the Seacoast

Contact: Jen Decker at GSIL 228-9680 or  
[jdecker@gsil.org](mailto:jdecker@gsil.org)

## **Working Alliance for Language Quality**

*WALQ* is a group of NH citizens from all walks of life striving to achieve Deaf social justice in New Hampshire.

[WALQaction@gmail.com](mailto:WALQaction@gmail.com), attention Thomas Minch.

# IOD TRAINING &

## **Apps to Support Individuals Who Experience Neurobehavioral Disabilities**

Learn about iPad and iPhone apps that assist in: prompting/remembering important tasks; self-regulation; reducing anxiety or depression; task transitioning; time management; increasing focus, attention, and task completion; and helping to reduce cognitive fatigue associated with reading, writing, or task sequencing.

**Date:** Tuesday, September 17, 2013  
**Presenter:** Therese Willkomm, Ph.D., ATP  
**Time:** 3:30pm - 5:00pm  
**Location:** Online  
**Cost:** \$59

## **RENEW Facilitator Training Institute**

An in-depth training about the RENEW (Rehabilitation for Empowerment, Natural supports, Education, and Work) model and process

**Date:** Tuesday, September 17 - Wednesday, September 18, 2013  
**Presenters:** Jonathon Drake, MSW, Heidi Cloutier, MSW, and Kathy Francoeuer, B.A.  
**Time:** 8:30am - 4:00pm  
**Location:** Holiday Inn, 172 North Main Street, Concord, NH  
**Cost:** \$349

## **Introductory Training for Facilitated Communication**

An overview of Facilitated Communication (FC), a method of augmentative and alternative communication used by people who have limited speaking abilities and motor planning challenges

**Date:** Thursday, October 10, 2013  
**Presenter:** Pascal Cheng, M.Ed., C.A.S.  
**Time:** 9:00am - 3:30pm  
**Location:** Institute on Disability Professional Development Center, 56 Old Suncook Road, Concord, NH  
**Cost:** \$125

## **Navigating Choice & Change in Later Life**

An introductory workshop on person-centered planning for adults, including an overview of the person-centered system of care

**Date:** Thursday, October 17, 2013  
**Presenter:** Susan Fox, M.Ed., MA, Patty Cotton, M.Ed., Kate Crary  
**Time:** 9:00 am – 4:00 pm  
**Location:** Institute on Disability Professional Development Center, 56 Old Suncook Road, Concord, NH  
**Cost:** \$90

## **PBIS Universal Team Training Retreats**

The Fall retreat provides an overview of PBIS Universal level systems. Teams will 1) identify their PBIS implementation status, 2) plan for the school year, 3) analyze their school-wide data, and 4) develop new or revise their existing systems, including the school-wide behavior expectations matrix, behavior definitions table, screening system, the office discipline referral form and flow chart, and teaching tools for specific school-wide roll out activities.

**Date:** Friday, November 1, 2013 and Thursday, March 27, 2014  
**Presenter:** JoAnne Malloy, Ph.D.  
**Time:** 8:30 a.m. – 2:30 p.m.  
**Location:** Holiday Inn, 172 N. Main Street, Concord, NH  
**Cost:** \$119 per session – \$99 per session for a member of a group of 3 or more

## **Taking Control: Advanced Tools for Person-Centered Decision Making**

Gain advanced skills in person-centered planning to design person-centered routines and responsive support networks with a focus on tools for decision-making

**Date:** Thursday, November 14, 2013  
**Presenter:** Patty Cotton, M.Ed.  
**Time:** 9:00 a.m. – 4:00 p.m.  
**Location:** Institute on Disability Professional Development Center, 56 Old Suncook Road, Concord, NH  
**Cost:** \$75

# EVENTS







INSTITUTE ON DISABILITY / UCED  
A University Center for Excellence on Disability

## NH Transition Community of Practice Summit VII - Navigating the Transition Road Map: Which Exit Do I Take?

The only statewide conference for training, collaboration, networking, and information focused on post-secondary outcomes for students.

**Date:** Tuesday, November 19, 2013  
**Time:** 8:00 a.m. – 3:00 p.m.  
**Location:** Grappone Conference Center, Concord, NH  
**Cost:** \$70

### 4 EASY WAYS TO REGISTER!

-  online  
**WWW.IOD.UNH.EDU**
-  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**
-  fax a completed registration form  
**603.228.3270**

## Visit the Institute on Disability Bookstore <http://www.iodbookstore.com>

The leading resource for products that support community inclusion and individual excellence.

### Featured Resource:

Assistive Technology Solutions in Minutes II:  
Ordinary Items, Extraordinary Solutions  
By: Therese Willkomm, PhD  
Price: \$50.00  
Copyright: 2013  
236 pages

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# RAP Sheet

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

Fall Issue 2013

## NH COUNCIL ON DEVELOPMENTAL DISABILITIES

21 South Fruit Street, Suite 22, Room 290

Concord, NH 03301-2451

**RETURN SERVICE REQUESTED**

## INSIDE THIS ISSUE

- ◆ *ABLE NH*
- ◆ *Peer Support*
- ◆ *NH Leadership Series*
- ◆ *Personal Stories*

◆ **The RAP Sheet Has Gone Electronic** - see inside for details on how to subscribe ◆

### DISABILITIES RIGHTS CENTER, INC.

18 Low Avenue, Concord, NH 03301-4971

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: [advocacy@drcnh.org](mailto:advocacy@drcnh.org) ◆ Website: [www.drcnh.org](http://www.drcnh.org)

*"Protection and Advocacy System for New Hampshire"*

*The Disabilities 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 – UNIVERSITY OF NH

10 West Edge Drive, Suite 101, Durham, NH 03824-3522

Phone (Tel/TTY): (603) 862-4320 ◆ Fax: (603) 862-0555 ◆ Website: [www.iod.unh.edu](http://www.iod.unh.edu)

### Institute on Disability/UNH – Concord

56 Old Suncook Road, Suite 2

Concord, NH 03301

Phone (Tel/TTY): (603) 228-2084

*The Institute on Disability advances policies and systems changes, promising practices, education and research that strengthen communities and ensure full access, equal opportunities, and participation for all persons.*

### NH COUNCIL ON DEVELOPMENTAL DISABILITIES

21 South Fruit Street, Suite 22, Room 290

Concord, NH 03301-2451

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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