



A letter

from Beth Dixon



This April, 30 people joined the growing list of Leadership graduates. With their addition, we are all better able to educate communities about the importance of welcoming and including every member. Together we are a force that can affect change at many different levels, public and private, throughout NH.

Graduates participated in issue groups during the series and gave group presentations the last weekend. Each group's assignment was to research a topic, brainstorm possible solutions, and carry out an action related to their issue.

The topics were: accessible playgrounds, transportation issues, voter registration, and workforce shortages for home health care. The groups shared written materials, personal stories, interviews, power point slides, brochures, posters, and videos. We expect this experience to motivate the graduates as they continue the search for information and solutions throughout our lives.

A new topic was added to the Leadership agenda this year. "Working with the Media" was a panel presentation filled with great information about working with the media and effectively getting the message out.

Never before has it been as important to get your message out as it is this year! Every one of us has an obligation to stay informed and to educate others about how the proposed budget cuts and the reorganization at the state level will affect us.

We have all met with legislators at the Leadership Series – it is not hard. Now is the time to invite candidates, friends, and neighbors to your homes for coffee. Contact other Leadership grads from your area. Participate in and learn from the wealth of information available on the Leadership listserve (if you are not on the listserve and are a Leadership Graduate, let me know and I'll add you immediately). Have a discussion about your concerns. Tell your story. Ask questions and make decisions based on the answers you receive. Write letters to elected officials and to the editor of your local paper, AND THEN VOTE in the fall elections!

We are all in this together. It's OUR job. 

Sincerely,

Beth

CALL FOR APPLICATIONS

The Class of 2004 just graduated, and Beth Dixon is already recruiting the Class of 2005. Please encourage the people in your life that you think would be interested in – or benefit from – participation in the Leadership Series to apply. Applications, due to Beth by July 16, are available on the Leadership Web site.

ALUMNI REUNION - SAVE THE DATE

Thursday, October 21st, 2004

6:00 – 8:00 PM

Working with the Media to Organize for Change
(location to be determined)

Connect with old and new friends, share stories, celebrate success, and spark new ideas for the future!

LEADERSHIP GOES GLOBAL ON THE WORLDWIDE WEB

You can now find the NH Leadership Series on the Web at www.nhleadership.org

Check it out for a history of the Leadership Series, profiles of graduates, a description of the Series by weekend topic, information about the Friends of Leadership, helpful links, and an application to the 2004-2005 Leadership Series.

Leave your comments when you visit and tell us what you think!

Authors: Beth Dixon, Betsy McNamara, Mary Schuh

Editor: Julie Moser

THANK YOU!

The NH Leadership Series is made possible through collaboration and financial assistance from a variety of supporters including:

- ▶ The Corporate Fund
- ▶ United Developmental Services
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- ▶ Granite State Independent Living Foundation
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We are grateful to our donors for their generous financial gifts to support the future of the Series. If you would like to become a "Friend of Leadership" and make a tax-deductible financial gift to NH Leadership, visit www.nhleadership.org

If you are a "Friend of Leadership" but are missing from the above list, please contact Beth Dixon at badixon@cisunix.unh.edu

▶ Newsletter available in alternative formats

Institute on Disability/UCED, The Concord Center,
10 Ferry St., Unit 14 (800) 228-2048 (in NH). www.nhleadership.org
www.iod.unh.edu

GRADUATES TALK ABOUT THE IMPACT OF LEADERSHIP

GLEE HOOPER, CLASS OF 1990

PAST PRESIDENT OF THE AUTISM SOCIETY OF NH
WWW.AUTISM-SOCIETY-NH.ORG

Leadership presented Glee Hooper with a new vision for her son, who was four at the time. "Regarding the possibility of a successful life experience - meaningful work, friends, and a place in the community - for my son and others, Jeff Strully was the most inspiring person I had ever heard."

That year's class included several parents of young children with autism. Over coffee breaks and in small groups, parents realized they wanted to sustain the optimism and networks they were developing through Leadership.

At the time the NH Chapter of the Autism Society was mostly dormant. After a period of activity, even the state charter to the national Autism Society had lapsed.

The original group to reorganize the Autism Society was: Ruth and Stu Wallace, Karen Gillespie, Bill White, Mareta Beland (now deceased), Glee Hooper, and Louise and Dave Hackett. Stu Wallace served as the first President.

In that first year, the Society had a strategic planning meeting, crafted a mission statement and action plan, and designed and printed a brochure with Glee's home phone number on it. Glee answered the phone for the society for 5 or 6 years, regularly spending an hour or more on the phone with parents seeking information and support.

"This was before internet access was widespread," says Glee. "Personal contact was the quickest way for parents of newly diagnosed children to obtain information and support."

The revived society also helped develop support groups throughout NH and cultivated a lending library that anyone could borrow from. "Ruth Wallace maintained the library in her home until we donated it to the NH Technical Institute library in Concord," adds Glee. "A year or two after we reorganized, I became the Parent President and that's when Leadership graduates Carole Armstrong, Connie Breen, and Dan Calegari got involved."

Glee says Leadership was one of the most important things she has done in terms of her role as an advocate for her child.

VISIT US ON THE WEB AT
www.nhleadership.org
or
www.iod.unh.edu

Laurie McCray, CLASS OF 1998

1999 MATERNAL CHILD HEALTH/LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES
MEMBER, DEVELOPMENTAL DISABILITIES COUNCIL SINCE 2000
2000 ADVANCED LEADERSHIP/COMMUNITY ORGANIZING
2004 ADVANCED LEADERSHIP/MEDICAID AND MORE



Laurie McCray is profoundly motivated by a quote from Martin Luther King, Jr.: "Our lives begin to end the day we become silent about things that matter."

"I am passionate about civil rights and self-determination for all people, and I am committed to education and advocacy outside the usual disability-related networks," she says. Laurie has used her involvement in Leadership and the Developmental Disabilities Council to make connections and advocate for her son Michael, and for civil rights for all at the state and national levels.

Leadership motivated Laurie to focus her graduate thesis on how self-determination can be applied to administering medication for adults with developmental disabilities. "At the time," Laurie says, "I was working as a RN visiting many former residents of the Laconia State School. I presented my thesis at the annual meeting of the American Association on Mental Retardation and at other national and state meetings of nursing associations...trying to get the message of self-determination out!"

Laurie joined the DD Council to help influence on state policy and practice. This year alone, the council supported grants to the Leadership Series,

McCray Impact, continued on page 4

LEADERSHIP UPDATES (CONT.)

Joyce Ninnis, CLASS OF 2003

Leadership changed my life. I had done so much person centered planning for my daughter, Emma that I thought maybe I could do this for myself too. All too often I never thought of myself - just my children, especially Emma with her disability. Now I realized it is just as important that I take care of myself (I think it was Greg Galuzzo's "harsh" lecture) and that it is so much more than Emma. There are thousands of Emma's in the world that need strong people supporting them!

So, I set some realistic goals:

1. Lose 40 pounds by the end of the year (I have lost 63).
2. Run a 5K race (I didn't run a 5k but I walked two of them. I'm still working on this one!)
3. Finish my master's degree in special education (I graduate this May).
4. Become more active (I am Secretary of the Autism Society of NH).
5. Hike Kearsarge (done!)
6. Grow a vegetable garden (I worked so hard at this and had the best garden, which helped me to lose weight and eat healthier)
7. Become more politically active - I am in frequent contact and have developed a "relationship" with my representative - we talk a lot about issues important to me!

8. Eat healthy and exercise every day (Well again I've lost 63 lbs through eating healthy and running / walking / hiking every day).

9. Include Emma in her community (I was content to avoid places that Emma does not like, but we now have the in-home support waiver and I am learning how to integrate Emma into her community and I'm supported and encouraged to keep trying!)

Sarra Dennehy, CLASS OF 2004

The 2004 Buddy Walk to raise awareness and acceptance of individuals with Down syndrome will be held on October 2nd 2004 at noon in Concord. We will be joined by Chris Burke (star of the hit series "Life Goes On"). Chris will entertain us with his band, and Outback Restaurant will be serving great food! If anyone has any questions, wants to sponsor or volunteer, they can contact me at dennehys@comcast.net or call 715-2450.

Stacey Brooks, CLASS OF 2004

Do you have a child who will be transitioning to Kindergarten next year? Would you be willing to be part of an informal study about the transition process, including your IEP and school experience? There will be a questionnaire and possible follow-up by phone or email. This is not a funded study. It will be used solely to generate a summary of "common experiences" and "how things differ" in school districts. Please contact Stacey Brooks at brooks.stacey@comcast.net.



Missing from the photo are: Sara Edgerly, Emily Edgerly, and Emily Bennett.

Class of 2004

JIM TOBIN, CLASS OF 1998

I have an update on my life. Since 1998, I have been going to the College for LifeLong Learning in Conway, NH and I am proud to say that after a very long haul, I am going to end my schooling in December 2004 and I graduate in 2005. I wanted this for myself to see if there was more that I could do since I left high school. I am going after my Associate's degree.

The teachers are not only teaching me, but I am teaching them as well. Along the way, I have met a lot of my fellow classmates that at first had a hard time warming up to me and talking to me. Once they warmed up to me and me to them, it was very easy to strike up a good conversation with them. Now, the teachers and students alike can not get enough of me. I feel strongly, if I did not go to Leadership or have my friends behind me, I would not have done this.

MICHELLE CATANZARO, CLASS OF 2001

Since my graduating Leadership, many changes have occurred. To others I look like the same person, I may even act like the same person. But something or someone has drastically changed my outlook.

When I was at Leadership I struggled with some moral issues I was having and how I was going to come to terms with it I wasn't so sure. I had always been the black sheep of our family, but not for the reasons you might have expected. I wasn't the "bad one" but the good one; always wanting to make my life better, and make my mother proud of her daughter. I went to college, got married, had a son, and then gave birth to a daughter.

This is when my life changed, not for the worse but it was something I was going to struggle with for the rest of my life. You see, I wanted to have that mother-daughter relationship that I did not have with my mother. I wanted to share everything with this little girl. As I fell in love with my daughter, I soon found out that I was also going to struggle with even a more emotional issue than raising a little girl with Down syndrome. I would be taking care of my mother who was very sick at the time and had developed mid-stages of Alzheimer's. I knew it would only be time before my mother had slipped from me, as I had been slipping away from my daughter as I fell deeper and deeper into depression.

Believe it or not, my mother getting Alzheimer's was the light I needed to show me all I would be missing with my daughter if I didn't turn things around. Leadership was a way for me to get close to many people with disabilities. I learned much in the way of advocacy, tools to use, and strength in each of us. But most importantly I got to look inside myself and really change what I wanted. I had for so long only done things to make my daughter progress.

I always used her disability as an excuse as to why I was so depressed. I finally realized that it was my expectations of my life that was doing it. I had such high dreams for my life and how "perfect I was supposed to be" as the 'good one'. As I worked to make my daughter independent, I struggled so hard as I saw my mother lose those same skills. I had no mother to turn to when I was happy, proud of my daughter, sad, or frustrated. Wasn't she supposed to be there for me? Now I was the one caring for her.

Over the next two years after leadership my mom would get much weaker. But there was something getting stronger: a relationship between a mother and a daughter. I was the lucky person to become the mother I had hoped to be and the daughter I always knew I was! You never know when you will be living both sides of the spectrum.

HEATHER OLDS, CLASS OF 2002

I have gone to work for NH-ATEC, a division of ATECH Services as a Speech Language Pathologist specializing in Augmentative Communication (AAC). Would readers be interested in more information on augmentative communication or assistive technology? I have many families who I'm sure if I asked would love to share their stories about how much a loved one has benefited from having a communication device.

MARIANNE WHIPPLE, CLASS OF 2002

On December 1, 2003 John (Class of 2002) was called for active duty with his reserve unit. He is now in Iraq. Polly and I are doing well and miss him every much. If people would like to write him we ask that they send only positive and not negative things as our views on the war are not needed.

John E Whipple Jr.
LSA Anaconda
HHD-7th Tran/744th TC
APO-AE 09391

We were told not to put rank on the letters.
Bless you all!

KAT MACK, CLASS OF 2003

I will be freelancing my design work under "Midnight Boos Design." Please be aware that I would be happy to do any Leadership graduate's work for free. If you are interested in free design work for your group, organization, or yourself please contact me at this email address: midnightboos@comcast.net. A Web site is pending; for now you can view some of my work at: <http://midnightboos.deviantart.com>. This is not design per se, but it is a small showcase of works I have put up for display.

Updates, continued next page

LEADERSHIP IMPACT (CONT.)

"The connections with people, hearing about great things happening in New Hampshire, and seeing people with disabilities involved as known, loved, and respected members of the community – well, it looked like what I wanted to have for my son."

"It didn't stop with that year, either," adds Glee. "My relationship with the Institute on Disability and the incredible people there helped me both personally and professionally. They were a great resource for me in my role on the board of the Autism Society of NH."

These days Glee is past president of the society, and finds herself more involved in other ventures. "My children are older now; we're looking at colleges. I have noticed I'm less interested in doing work with the Autism Society. After 10 years I'm glad that there are new Leadership graduates to continue and build upon our work."

“Our lives begin to end the day we
become silent about things that matter.”

- Martin Luther King, Jr.

STACEY SHANNON, CLASS OF 2003

CURRENT PRESIDENT OF THE AUTISM SOCIETY OF NH

Stacey Shannon started Leadership one month before she took over as President of the Autism Society. "Leadership gave me a great base of contacts to call on and provided me with the leadership tools to be successful in this role."

Leadership's influence was so strong that the summer after she graduated she opted to go to a week-long training put on by Greg Galuzzo of the Gamaliel Foundation, instead of the Autism Society of America's national conference.

"Leadership affirmed and strengthened my belief in inclusion," said Stacey. "The Autism Society of NH is careful not to tell families what path to follow; our goal is to educate them about various resources and interventions available – including the benefits of inclusion – and then let each family decide for themselves what works in their situation."

These days, in addition to working full-time, Stacey presents to college and graduate students on acceptance and appreciation of all students, especially those with autism. Recent Autism Society events include a Free Jazz Concert to celebrate Autism Awareness Month, the first-ever Autism Awareness Nature Walk at the Massabesic Audubon Center, and the 7th annual Autism Golf Tournament at Stonebridge Country Club.

Upcoming events include a collaborative effort with the NH chapter of the Asperger's Association to bring Dennis Debbaudt back to NH in October and also to participate this summer in a post-conference day on autism at the Franklin Pierce Law School conference held in Portland, Maine.

"Three new board members came out of my Leadership class, and right away they took on leadership roles within the organization," says Stacey. "The contacts we developed and knowledge we gained through Leadership are helping us build upon the great work done by the previous directors. It's been energizing and gratifying to see the momentum and excitement grow. We recently held a strategic planning session, and will be working on our business plan. Our next big goal is to open an Autism Resource Center in the state."



LEADERSHIP IMPACT (CONT.)

Future Planning Networks of NH (started by Leadership grads Mary Beshta, Marlyn Curtin, and Ann Dillon), the Disabilities Rights Center and Family Voices, and helped send many folks to educational conferences.

As a council member Laurie presented at the annual meeting of PlusTime NH (a statewide after-school nonprofit) on how to build inclusion into after-school programs. "Again," Laurie says, "trying to get the message of civil rights and self-determination out."

Laurie's commitment motivated her to campaign in the 2004 presidential primaries. "This was the first time I took advocacy and activism to a national level. I also volunteered with the Disabilities Rights Center to conduct voting accessibility surveys at local polling places."

Laurie is currently advocating for her son Michael's transition from middle to high school. "I've let people know that we want to plan for the post-secondary transition now, as Michael's 9th grade curriculum and IEP are developed. But the reaction from high school staff so far is that post-secondary planning is 'not typically started until 11th grade.'"

Laurie sought advice from parents and Leadership and DD Council contacts. "Everything I have heard and read about best practices for transition planning can be summed up in two words: Start early." Laurie now conducts one-on-one meetings (remember those, Leadership grads?) with key players who will have a say in Michael's high school experience.

"Michael wants to work, and we want him to have relevant work experience by the time he graduates from high school. So, the conversations have started, seeds have been planted and expectations identified." Laurie concluded "Stay tuned. This story will be continued." 



VISIT US ON THE WEB AT
www.nhleadership.org
or
www.i.od.unh.edu

LEADERSHIP UPDATES

This is a forum for Leadership Graduates to provide updates on their lives. Submit your update anytime to Betsy McNamara at bmcnamaragrants@comcast.net for inclusion in the fall newsletter.

MARY BESHTA (1996), ANN DILLON (1988), MARLYN CURTIN (1988) AND MICKEY SHOEMAKER

Founded an organization called Future Planning Networks of NH to assist families to provide a safe and secure future for their relative with a disability. This is accomplished by creating a personal support network made up of people from the local community who are committed to enhancing the quality of life for your loved one now and in the future when their families may not be around to advocate and care for them. The approach FPNNH takes to help people with disabilities have a good life with genuine relationships is one that honors the gifts and contributions of each individual person. To learn more about Future Planning Networks of NH, and how to become a member, you can call Barbara Teittinen at 271-8948.

DEBRA FOSTER, CLASS OF 1988

I am a graduate of the very first Leadership series course (with Beth Dixon and Ann Dillon) and have a son with severe, multiple disabilities and medical needs who is almost 19 and going through transition from school to adult services. The update I want to share is that I was just elected to the Dunbarton School Board!! I plan to bring a balance to the board with my background as a former high school science teacher, my leadership training in disabilities, my parental experience with special needs and IEPs, and my current training as a government science agency communicator. As I recall, this was one of the assignments we had from the leadership series to help improve attitudes and behaviors toward special education. It took me a few years, but my time has come and I am ready for the challenge.

The other news is that my son will graduate from high school this June with a real diploma! His path has taken a different route than most kids like him in that he was at Cedarcrest for many years and did not attend a public school. He did, however, attend a Montessori pre-school and kindergarten-3rd grade and has attended a public high school for the last 3 years. Despite the fact that he has not lived at home full time with us since he was 3, has extensive medical needs, and uses a wheelchair, he has had a full, high quality of life and over the years has enjoyed many, many normal activities with his family such as meeting President Clinton and his family, riding ferry boats and the mail boat to the Isle of Shoals, vacationing at the beach in Maine, Cape Cod, Martha's Vineyard, and the White Mountains, shopping in Boston, marching in a parade, riding ski lifts, and enjoying all holiday family gatherings and traditions to name a few (the van is full of equipment and supplies when we go on trips). He is loved by many and has a personality and smile that draws people to him without speaking. The theme of my story is that parents need options and it is possible to balance family life when one family member requires 24-7 total nursing care by having that member be cared for in a nurturing environment. We were able to raise our older daughter, keep our family together, and be there for, and include, our son every step of the way. Even though he has had multiple hospitalizations and surgeries and other continuing medical issues, we have been able to give him everything a child needs for thriving within a family, including time at home. He really needs a village to help him grow and the many "villages" that we have found to help with his care have allowed him and our family to thrive and advocate for him. The scary part now comes with transition and adult services on the horizon (which, as usual, has no book to follow).

PAT BOLIEAU, CLASS OF 1995

I want everyone to know that I'm still working on getting a home of my own.

LAURIE MCCRAY, CLASS OF 1998

I would love to hear from other parents and/or students about what their post-secondary transition IEP goals are/were, specifically as they relate to jobs. I'm very curious as to how those goals are/were written into the IEP. My son, Michael, is now 14, and I want goals written and implemented as he enters ninth grade in the fall. Michael wants to work now and I want him to have a wealth of work-related experiences by the age of eighteen. I would be happy to include in the newsletter our experiences with how both the school system and the community do in helping Michael meet those goals.

CORPORATE CONTRIBUTOR:



When Linda Steir sat down to ask Mark Lore for a matching contribution from his company, Ride-Away Handicap Equipment Corporation, she was nervous.

But, she was armed with a combined commitment from herself and three other folks, all graduates of the NH Leadership Series and customers of Ride-Away Corp. Her plan: to approach Mark and appeal to his charitable nature by describing the impact of the Leadership Series on her; then, aim for his business sense with the list of customers who were asking him to match their gift.

"Before I could get a word out, Mark offered to make a contribution that exceeded our combined gifts," Linda reported.

He was pleasantly surprised to see that many of his customers were Leadership graduates, and was quite willing to support an organization so important to us."



Mark started Ride-Away in 1986. Before then, adapting vehicles for accessibility was a sideline for most providers in the region.

Ride-Away was the first to make it their primary business. Since then, Ride-Away has become the Northeast's largest supplier of handicap-modified vehicles.

"I got into this line of work because I wanted to have a business that would be successful AND do good work in the community," says Lore.

"That feeling is also why we support so many organizations – it makes our work even more fulfilling."

"We have great company morale," adds Lore, "and I believe that it is because we're always giving back to the communities we serve." 