



WELCOME!

from Beth Dixon



We welcomed 35 new people this September to participate in the 16th NH Leadership Series. Candidates were chosen from many excellent applicants and will become the class of 2005.

This year's Leadership Series is as exciting as every previous Series has been. No two years have been identical, yet the Series' overall mission is exactly the same:

The goal of the NH Leadership Series is to support self-advocacy and leadership skills for individuals with disabilities and their family members who wish to affect change at a personal, community, and statewide level to support the full inclusion of individuals with disabilities in their schools and communities.

Supporting this goal is an ever-changing list of group leaders who dedicate time to plan, make phone calls to members, and participate in each of the Series' seven sessions.

This year we welcome Frank Sgambati back to the role of group leader after a two-year leave from Leadership, and we are very excited about his return. Sonke Dornblut has participated in Leadership for the past several years and is a group leader for the first time this year. Bonnie Dunham, a 1988 graduate and new group leader, works at the Parent Information Center and will be a valuable resource to everyone. Back again this year are graduates Mary Trinkley, Director of CAUSE; Kathy Bates, statewide advocate; and Janet Williamson of the Institute on Disability to round out this team of group leaders.

As always, this newsletter is one way for Leadership graduates to stay connected and united in our goal to be sure we and our family members are full participants in our schools and communities. Through this publication we can stay in touch with fellow graduates and find out who the new and previous graduates are and what they're involved in.

Don't forget to join the Leadership listserv and send in your updates for the next newsletter!

Until next time, have a wonderful fall!

ANNUAL REUNION

The NH Leadership Series Annual Reunion, originally planned for October 2004, will be rescheduled for:

April 8, 2005

Ashworth by the Sea

Hampton, NH

This year's reunion is set to be held on the last day of the current Series to introduce the graduating class to alums. Connect with new graduates and rekindle past relationships during springtime at the beach!

An announcement with the actual time will be released on the Leadership listserv and on its Web site at:

www.nhleadership.org

GRADUATE UPDATES

KIRSTEN MURPHY ('00)

I am a Leadership graduate from Region 12 (Lebanon). Along with a wonderful group of parents, I have recently founded an organization called ARCH of the Upper Valley. ARCH seeks to improve the availability of resources in our bi-state area that are crucial to families in providing for the care and education of children, teens, and young adults who have a diagnosis of autism spectrum disorder. We can be reached at ARCH@valley.net. Best wishes to all!

ELLEN BENNETT ('04)

My name is Ellen Bennett, and I am now out of the working world and back into school pursuing a master's degree as a physician's assistant, and should be finishing up in December 2006.

LILIA MORALES-HILL ('02)

My name is Lilia Morales-Hill. I attended Leadership when the Positive Behavioral Interventions and Supports initiative was discussed in one of the sessions. I am very happy to inform everyone that Florence Rideout Elementary School in Wilton is participating. We are part of the Cohort#2 and this is the second year. The staff voted to participate on this initiative after the informational session they had with Howard Muscott.

At the start of the school year, Label Arts donated stickers, the school mascot, a bee, great looking posters created by one of the mothers who is a graphic artist and a song composed specially to train the students.

I presented to the Wilton-Lindborough middle and high school School Board during its July 2004 meeting about the program, and its letter of intent to participate was the first one to be received for Cohort #3. Support from all the staff, including the principal, has been incredible.

Both of my children (Stephen, 7, and Bobby, 10) are also participating in the In-Home Waiver, which was one of the presentations during my Leadership session. The program has allowed us to finally make a team of specialists, all communicating to create an intensive and appropriate program for both children. Stephen has gone from suffering panic attacks to being immersed in water to actually receive aquatic therapy. For Robert, the PT worked with the OT

VISIT US ON THE WEB AT
www.nhleadership.org

“ I am very grateful for the experience, for the strength and hope forged within me. I see the lessons I have learned and the connections I have made as forming a reservoir deep within me. I already find myself tapping into it and know I could not sustain my efforts without it. It is so easy to get drained and feel isolated...”

- A recent graduate, summing up her Leadership experience.



NEWS & NOTES

▶ JOIN THE LISTSERV!

Would you like to stay connected with Leadership events and activities? Join our listserv by contacting Beth via e-mail at badixon@cisunix.unh.edu

▶ REQUEST FOR UPDATES

We want to hear from you! Please send updates, news, and stories about how you are using information you learned at the NH Leadership Series to Julie Moser at juliemoser7@designsinaccord.com

▶ DID YOU KNOW?

According to the US Census Bureau, one fifth of Americans (1 in 5) experience a disability, and according to a June 2004 study by the National Organization on Disability, Americans with disabilities are at a critical disadvantage compared to other Americans in 10 key areas of life. For more information, visit www.nod.org

GRADUATE UPDATES, CONTINUED

Sensory Integration and discovered a problem with the curvature of his spine, which explains a lot of his movement limitations and overall functioning, something his pediatrician and neurologist had missed.

During the Legislative session I decided to become an active part of the decision making and the system in charge of supporting my children and my community. My naturalization ceremony took place last February, I am now a citizen of the United States of America. I will be able to vote in the next elections.

Thank you for the opportunity to learn more and enrich my life, the life of my children and my own community.

Laurie A. McCray ('98)

This year I really put the Leadership education I received on community organizing and political involvement into action. As an active volunteer for Senator Edwards' campaign during the primaries, I was fortunate to host a dinner for Elizabeth Edwards with a group of nurses and teachers, and a brunch with Glenn Close for neighbors and friends. After John Kerry selected Edwards as his VP running mate, I created a political listserv to keep people informed of political events happening in and around the Seacoast. During a Lemonade Social in my backyard immediately following the DNC Convention (one of three Kerry/Edwards campaign organized NH events that day), I started my list and today have one general list that goes out to over 250 people plus a second list for healthcare workers. The Lemonade Social brought almost 90 people to my home including several candidates for state rep, State Senate candidate Martha Fuller Clark, 1st District Congressional candidate Justin Nadeau, former Portsmouth Mayor Eileen Foley, and former Gov. Jeanne Shaheen. It was a great opportunity for Portsmouth voters, candidates, and elected officials to meet and talk with each other. And, being the host, I had a chance to educate a captive audience about the real effects of SB 110 and Medicaid "modernization." The best part of hosting the Lemonade Social, though, was that so many folks there that sunny July day became volunteers on various campaigns!

Most recently, I brought State Senate candidate Martha Fuller Clark to meet and have a discussion with parents raising children with special needs that attend UP (United Parents for an Included Community), a group started by Leadership grads Melanie Muns and Kate Portrie. Finally, I am now organizing a local group of nurses and doctors to do an educational campaign to support the Kerry/Edwards health and environmental plans. My "one-on-ones" with all those working with groups such as ACT-NH, MoveOn, Sierra Club, have helped get information to me about important issues that I then pass along to my listserv. As Margaret Mead said, "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."

Linda Steir ('93)

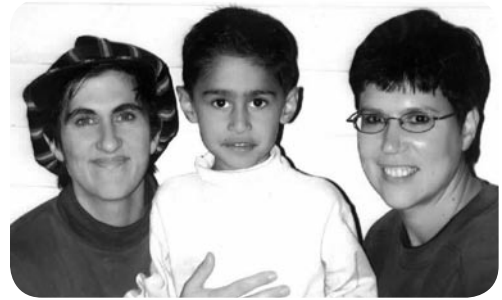
Eagle Tribune staff writer Lois Marchand covered the recent ruling by U.S. Court of Appeals for the First Circuit in Boston against the appeal of a U.S. District Court decision which said Marika Steir could not ask the organization to stop discriminating because she is not currently a member.

Marika, now 18, lost her appeal in a five-year battle with the Girl Scouts over opening up Scout activities to members with disabilities. Linda and Michael Steir have battled the national organization on behalf of their daughter, Marika, a senior at Timberlane High School. Marika was a member of the Girl Scouts until 1998 when she suffered discrimination, was excluded from troop activities because of her disabilities and was not allowed to join another troop in Atkinson. We are disappointed. The courts could have allowed this to move forward. We are avoiding the real issues because of a technicality. We will continue to publicize this in hopes that some other girl will take up the fight to eliminate discrimination from the Girl Scouts.

For more information, visit www.diversityingirlscouts.org

PLANTING SEEDS OF HOPE *by Karen Turner*

It wasn't until the last day at graduation that I understood how last year's Leadership experience changed the landscape of my life. There it was before me, a community of people and my family had a home in it. How alone I had been! Early on in Leadership I wrote a poem with the line: "The pain of invisibility does not cease / and neither does this yearning." Leadership helped me transform this yearning into strength, this pain into possibility.



KAREN, NIKHIL AND KATHY

My heart had been telling the truth all along: The landscape before me became rich not only with possibility but with the tools to fulfill that promise. From that point, the steps I have taken to ensure my son is a full member of our community have been more confident and powerful. Leadership helped me decide that if being powerful means I can be a part of making our community a better place, then I'm all over that. I sought and found partners along the way, including many wonderful people from the Leadership Series and in my own community. Our family is no longer alone.

In our town of Newmarket, we developed a collaborative project in which my understanding of community was realized. The school district, recreation department, and parents implemented an innovative inclusive summer camp. We created a grant-funded position of friendship facilitator and this person focused on building bridges between children in order to create avenues for friendships. Children with disabilities, including my son, attended camp with other children in town. At the end of camp, another child referred to my son as his "best friend." Through this project, our community learned that inclusive change comes not at the expense of other children, but rather enhances all children's experiences. And by focusing on positive interactions, discipline problems were down overall at camp by over 50 percent.

The recreation department was so inspired by this project that it has included the position of friendship facilitator in its budget for next year. Armed with this success, we are working to make next year's summer camp experience even better. The strong partnership we have built serves as a platform for other efforts such as educational workshops for families and school staff and joint projects with the public library. Let this web grow wider and stronger!

I joined the board of directors for our local area agency, which I would never have done were it not for Leadership. I have become a public speaker in order to share my views of possibilities with others, yet I realize that my voice is only possible because of the community that buoys me. Whenever I feel depleted, Leadership is there again with wonderful, passionate, talented people to replenish me and restore my hope. A community. Our community. And I am off again.

One day, in rare quiet moment, I remembered another lesson of Leadership - the most revolutionary for me. How would I forge a vision for myself as ferociously as I do for my son? I created a vision for myself in which my advocacy work comes not at my expense but rather expands my life. My goal is to do this work professionally. This semester I am co-teaching an interdisciplinary class on autism at the University of New Hampshire, and I am currently applying to a doctoral program at the University of New Hampshire in the field of education. The landscape is rich with possibility.

Leadership was one of those rare turning-point experiences in my life, and I am grateful to every person with whom our family shares this journey, planting and fertilizing seeds of hope at every step along the way.

THE UNKNOWN

- By Jim Tobin, 1997 NH Leadership Graduate

In summer I paint.

Surrounding nature allows my mind to process,
take a visual snapshot

Imagination begins, permitting me to pick up
the paintbrush with ease.

The flowing of the paint can take my imagination anywhere

Although it may not be a true reflection,
in my mind it is what I want it to be.

The mind sees one way, the hand another
Signals cross unconsciously

Beauty of color combination can trigger awareness of an
Unknown deity that one can relate to.

The outcome of the painting may be better than the
original thought.

The result is a mystery of the intention.

As a good poem inspires you

So will a good painting

It can be breathtaking

Perhaps bringing you closer to the unknown.

As a good poem inspires you, so will a good painting. If
you read a good poem or visualize a good painting it can
be breathtaking.

How breathtaking it is! With beauty, colors, personal trigger,
relate to - It's what inspires you. It's a little like poetry. A good
poem will inspire you. Not all poems or paintings will be right
for all people. You may not keep with one particular theme.

CONGRATULATIONS!



Patricia Vincent and Jim Piet are the first couple
to meet at Leadership and get married.

In fall 2001 Jim Piet, a public relations specialist
with New Hampshire Vocational Rehabilitation,
talked to Leadership participants about his life
growing up in Crotched Mountain Rehabilitation
Facility, his struggle – and triumph – to become
the first member of his family to earn a college
degree, and his work to achieve his master's
degree.

Patricia, Leadership '02, was wowed by
his presentation and made sure to say “hi”
afterwards.

Then, she says, “I tracked him down a few
months later at the Access Expo.” They’ve been
dating ever since and were married September
3, 2004.

Congratulations, Jim and Pat!

ANNIE FORTS "UP" SYNDROME FUND

During her work to remind people about the "UP" side of Down syndrome, Ann Forts never forgets her past paths.

The NH Leadership Series proudly includes Ann on its list of past Leadership graduates, and was recently the recipient of a financial donation on behalf of Ann's organization established in 1990, the Annie Forts "UP" Syndrome Fund.

Ann is a nationally recognized motivational speaker and advocate for the needs and rights of individuals with disabilities. Her speeches focus primarily on her concept of "UP" syndrome, which focuses on the "up" side of Down syndrome and redefines - in a positive way - the image of disability in culture. By focusing on the "up" side of her life, Ann highlights "ability."

Ann, who was appointed by President Clinton to the President's Committee on Retardation, has extensive experience serving on NH and national committees and associations.

The youngest of four children, Ann draws from her professional experiences when delivering speeches. She travels more than 20,000 miles each year and speaks to about 5,000 people at state, regional, and national conferences.

She recently wrote the foreword to a new parents' guide entitled "Babies with Down Syndrome," and is the author of the article "My Keys to Opening Doors to Successful Community Inclusion and Self-Advocacy."

Ann started the "UP" Syndrome Fund to benefit the National Down Syndrome Congress, and has donated more than \$20,000 from sales of items such as T-shirts, caps and sweatshirts using her "UP Syndrome logo."



The Leadership Series would like to thank Ann Forts for her recent contribution as a "Friend of Leadership." Each tax-deductible gift ensures the Series will continue for future graduates and alumni.

"You must make things happen - don't wait around for someone else to make things happen for you. While you are waiting, you will be missing out on some great things that you could have made happen for yourself."

The Annie Forts "UP" Syndrome Fund works to:

Educate and assist people with Down Syndrome so those individuals may realize their full potential to live independently, contribute to their communities and to society at large.

Encourage a better understanding about Down Syndrome and support of the study of the treatment and rehabilitation of individuals with disabilities.

In 1997 Ann started a new fund with a \$1 million goal, of which more than \$200,000 has been received in donations to date. The interest earned has made it possible for the fund to provide more than \$50,000 toward enrichment opportunities to individuals with Down syndrome and to provide scholarships to those interested in pursuing special education careers.

By donating many of her speaking fees and awards, Ann is the largest contributor to the "UP" Fund.

For more information about Ann or the Annie Forts "UP" Syndrome Fund, visit:

www.anniefortsupfund.org

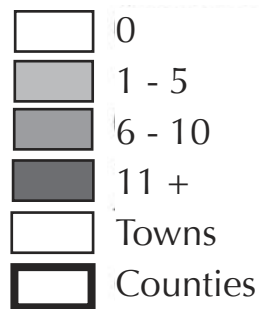
THE FACE OF NH LEADERSHIP

New community leaders for individuals with disabilities and their families 1988-2004

CELEBRATING DATA POINTS

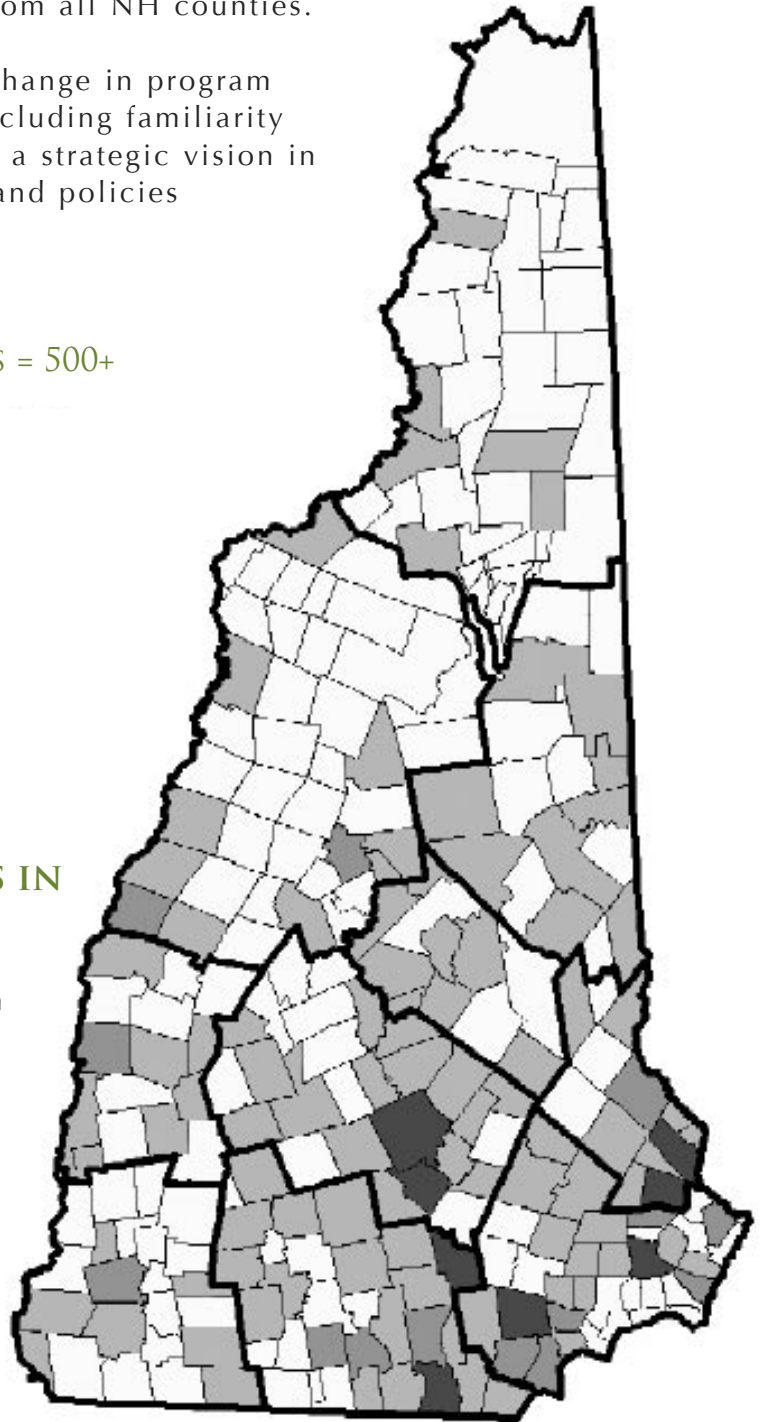
- ▶ Since 1988, more than 500 community participants have graduated from the NH Leadership Series.
- ▶ Past participants include representatives from all NH counties.
- ▶ During the past year, significant positive change in program outcomes was documented in 15 areas, including familiarity with key issues and being able to develop a strategic vision in area such as career, social relationships, and policies reflecting quality inclusive lives.

PARTICIPANT NUMBERS = 500+



CHARACTERISTICS OF PARTICIPANTS IN THE 2005 NH LEADERSHIP SERIES

- ▶ Most are parents who care for a child with a disability.
- ▶ About half are from small towns with fewer than 1,000 residents.
- ▶ About 50 percent are from southern NH, with the remainder coming from the western, central and northern regions of the state.



NH LEADERSHIP SERIES

Institute on Disability/UCED
University of New Hampshire
10 West Edge Drive, Suite 101
Durham, NH 03824-3522



NH LEADERSHIP SERIES NEWSLETTER

FALL 2004

PLEASE SUPPORT THE NH LEADERSHIP SERIES

Please make a contribution to the NH Leadership Series. Your gift supports the Series' dedication to present promising practices, policies, and advocacy training to emerging leaders throughout NH. Your gift will be directed to the NH Leadership Series and will help pay for speaker fees, transportation costs, lodging, and food. Please use the enclosed envelope to send your gift today.

THANK YOU PROVIDIAN NATIONAL BANK!

The NH Leadership Series would like to thank Providian National Bank for its generous donation to "help people with disabilities and their families develop self-advocacy and leadership skills, which are critical if they are to successfully achieve change at the personal, community, and statewide level."

Katharine Bogle Shields, Vice President of Community Development, stated "We applaud your goals of full inclusion and full economic participation for persons with disabilities in our communities."

For a complete list of donors who make up the "Friends of Leadership," visit the Series' Web site at www.nhleadership.org

► *Newsletter available in alternative formats*

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