



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



NH LEADERSHIP

MAKING A DIFFERENCE! NEW HAMPSHIRE CONSUMER AND LEADERSHIP SERIES



NH LEADERSHIP SERIES SURVEY REPORT
SEPTEMBER 2006

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INSTITUTE ON DISABILITY / UCED
UNIVERSITY OF NEW HAMPSHIRE



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UNIVERSITY of NEW HAMPSHIRE

Making a Difference
New Hampshire Consumer and Family Leadership Series
The Institute on Disability/UCE – University of New Hampshire

In 1988 the Institute on Disability/UCE at the University of New Hampshire offered its first Leadership Series to thirty parents of children with disabilities. Today nearly 500 individuals with disabilities or their family members have graduated from the Institute on Disability's (IOD) Consumer and Family Leadership Series. The Series, which consists of seven two-day sessions that occur monthly from September through April, provides participants with information about best practices in education, employment, housing, and community participation. Leadership training also includes an in depth look at issues confronting individuals with disabilities and help in developing strategies to address these issues both on a personal and systemic level. The goal of the Series is to graduate leaders who have a clear vision for the future, knowledge about state-of-the-art supports for individuals with disabilities, and the advocacy skills needed to bring about positive change in their own lives, in their communities, and beyond.

In its work across New Hampshire and through contacts with Leadership graduates, the IOD has seen the tremendous difference that the Leadership Series has made not only in the lives of individual participants, but for the state as a whole. This impact, however, had never been formally documented or quantified. To assess the impact of the Leadership Series, the Institute applied for and was awarded a grant from the New Hampshire Charitable Fund (NHCF). With the support from NHCF, the Institute on Disability surveyed Leadership graduates about the affect participation in the Series had on their personal and family lives and the influence the leadership experience had on their involvement in community, state, and national issues.

Surveying Graduates

In late Fall 2005, the IOD emailed Leadership graduates and invited them to complete the Leadership Survey posted on the Institute's website. (A copy of the survey is included as an addendum to this report.) Unfortunately, there were technical problems with the online survey; if respondents omitted any question their surveys were automatically deleted. In early 2006, after resolving the problem, the IOD again emailed and made personal telephone calls asking graduates to redo the survey; ninety-six individuals completed the survey.

Alumni were asked if, as a result of participating in Leadership, they had made changes in their personal lives and if there had been changes in their children's or families' lives. Graduates were surveyed about whether they now were more involved in their communities, and in work at the state and national level as a result of their Leadership experience. They also were asked to rate the extent to which Leadership directly contributed to their ability to make changes or to be more involved, choosing from one of the following options.

- I could not have made these changes without the benefit of the Leadership experience.
- The Leadership experience was a major contributor. Without it, I would have been much less effective.
- The Leadership experience was a minor contributor. Without it, I would have been slightly less effective.

Additional questions on the Leadership survey included:

- What was the most valuable aspect of the Leadership Series?
- What recommendations do you have for improving the Leadership Series?
- Have you been in contact with other Leadership graduates? If so, for what reason(s)?
- Would you be interested in connecting with other Leadership graduates? If yes, what could the Institute do to help you make these connections?
- What do you believe is *the one most significant change* that has occurred because of your involvement in Leadership?

Respondents

The IOD attempted to contact all leadership alumni from the first series in 1988 through the latest graduating class of 2006; of the 96 who responded, 46% had graduated since 2000. Asked in what capacity they participated in Leadership, 80 (83.3%) were family members of an individual with disabilities, 9 (9.4%) were self-advocates, and 7 (7.3%) were LEND Trainees. The IOD invited self-advocates to participate in the Leadership Series beginning in 1994. Five year later the series was opened to trainees in the Leadership Education in Neurodevelopmental Disabilities (LEND) program. This program prepares graduate students from the University of New Hampshire's School of Health and Human Services and the Department of Education, Dartmouth Medical School students, and health care professionals in the community for leadership positions in health-related services for children with neurodevelopmental disabilities. In addition to participating in Leadership training, LEND trainees intern in an urban health clinic dedicated to serving families living in poverty.

Affect of Leadership Training on Personal Life

An overwhelming number of respondents (83.2%) reported that they had made changes in their personal lives as a result of their participation in Leadership. Graduates reported that Leadership training was an opportunity for tremendous personal growth and led to career changes, continued education, increased civic involvement, and in a profound way, changed their expectations about what was possible for individuals with disabilities.

Asked the extent to which Leadership directly contributed to changes in their personal life, respondents gave the following answers:

- 31.3% - I could not have made these changes without the benefit of the Leadership experience.
- 56.6% - The Leadership experience was a major contributor. Without it, I would have been much less effective.
- 12% - The Leadership experience was a minor contributor. Without it, I would have been slightly less effective.

Continuing Education

Of those surveyed, 19 individuals have continued with their formal education. Leadership graduates have gone on to complete associate degrees, graduate from college, and earn advanced degrees. Nearly all of these alumni received degrees that are related in some way to the field of disability; areas of study included: special education, learning disabilities, nursing, psychology, non-profit administration, and behavioral science. One self-advocate completed his associate's degree and is currently a part time student working towards a college degree in Human Services. A Leadership graduate who is the parent of a son with Down Syndrome did her thesis for an advanced nursing degree on self-determination for persons with developmental disabilities. Another man, whose brother has significant disabilities, is in the doctoral program in Special Education and Disability Studies at Syracuse University. Two graduates had this to say about their experience since Leadership.

I am taking classes in the Community Service and Leadership Program at the Thompson School (at UNH) to find ways that I could write grants, do fundraising, manage change ... All of these I hope will help me be a better advocate.

My experience in Leadership helped me gain the self-confidence to return to school and obtain a paralegal certificate and an A.S. in General Studies.

Recognizing that many Leadership grads had an interest in continuing their education, in 2000 the IOD arranged for those completing the series to receive nine college credits from the College for Lifelong Learning (recently renamed Granite State College).

Career Changes

Twelve individuals reported that they changed careers after completing their Leadership training. Most of these people now are working in education or human services; this group includes an educational advocate, family support coordinator, inclusion facilitator, paralegal, and policy analyst. The Leadership Series has proven a great vehicle for recruiting staff members for the Institute on Disability. Of the Institute's 41 staff members, seven are graduates of the Leadership Series. One staff member, who had been a small business owner, went on to earn her B.S. in Behavioral Science from the University of New Hampshire and is now the Coordinator of the Leadership Series.

One graduate talked about how the Leadership Series helped tap her creative side, “I wrote and published music and a parent handbook (for parents of children with autism). I have become a public speaker as a result of the popularity of the handbook.” Two individuals reported that they have started their own businesses to help families who have children with disabilities. One of these women expanded on what she learned in Leadership training to help families of young adults who are making the transition from school to the adult service system. She wrote,

I have become a professional advocate and started my own business. I started a non-profit with a partner for the gap closure - where area agencies fall short, schools fall short, and medical professionals fall short. We have helped several dozen families and continue to teach them how navigate the system.

Increased Advocacy

Learning how to be an effective advocate was a theme for many Leadership graduates; asked how Leadership changed their personal life, 23 cited an increased ability to advocate. One family member wrote that since Leadership, she has experienced “a 100% change in parenting and advocating for a child with disabilities.” Another noted, that people in her town now call her a “warrior.” Several leadership graduates wrote about how they have used their advocacy skills to help others.

I enhanced skills I already possessed and have been in a position to help parents new to the process to understand their child's rights, how to prioritize which needs are most immediate and which ones can wait. Leadership strengthened my advocacy skills and the inclusion in our school is more meaningful. We've literally gone outside of the box to develop assessment tools that work for non-verbal learners.

(I am a) better advocate for my child in school, in my work, and for the people I work with who have disabilities. (I am) more aware of what is happening politically around issues that affect people with disabilities. The session with the legislators really changed my perspective and helped open my eyes to what is happening in our state.

I have used information as a school nurse to better advocate for students with special needs.

I started a support group in my town to unite parents of kids with IEP's. I started another support group for parents of children with autism.

I have tried to educate people about disabilities and things such as assistive technology. I have also provided referral and other information resources to those people who have children with disabilities who are not aware of what help is available to them.

Increased Community and Civic Involvement

Since completing the Leadership Series, graduates report that they are more engaged in the lives of their communities and take a more active role on state and national issues. One graduate remarked, "I actually vote now. I am more committed to community involvement." Leadership alumni are active community members volunteering in schools and at food pantries, serving on Family Support Councils and Area Agency Boards of Directors, and working with town recreation departments. Several graduates have become politically active; six have run for School Board and one graduate is currently Chair of the Concord School Board. Several have run for the New Hampshire Legislature; currently three Leadership graduates are State Representatives and one is a State Senator. Graduates have taken on leadership positions in a wide variety of endeavors; many are active in several organizations. The comments from these three graduates are typical of this group.

I am a member of the Watch Me Grow, State Awareness Committee. I volunteer at an elementary school. I am a co-founder of PEP, an on line parent support group. I am also a member of a team school/community playgroup and the press agent for playground and fundraising. For the New Hampshire Collaboration for Autism I am a parent advocate and support contact person.

I have taken many leadership roles in agencies such as the Developmental Disabilities Council, the Real Choice Advisory Council, and Granite State Independent Living.

I became more active in my community. I have served on the school board and other town committees. I also advocate more for my child and have worked with other parents. I also participated on my region's Family Support Council and for five years on the (Family Support) Conference planning committee.

Changes in Perception

One of the most profound personal changes that Leadership graduates talked about was how they perceived disability. For some, the Leadership Series opened up a whole new way of viewing the world. Several self-advocates talked about how the Leadership Series helped them to gain confidence and to become more independent. One self-advocate relayed that participating in Leadership, "enlightened me about not needing to be fixed because I am not broken; disability is a normal and natural part of every society." A parent wrote, "I am prouder of my child with a disability. I am convinced in my deepest soul that my child is a tremendous gift to the world in which he lives." Another talked about how fortunate she felt to have been part of Leadership.

I have met so many parents since that time who did not have that wonderful training, and they have such a different perspective. They have not had the benefit of hearing the points of view of the speakers like Norm Kunc ... So many of them don't see the big picture, often don't know how to navigate the system ... They tend to see their child's disability first, which colors everything they do and every decision they make. I feel so fortunate to have started out on the right foot.

Affect of Leadership Training on Family Life

Leadership had a significant impact on the children and families of those who participated in the Series; 89% of those surveyed said that, as a result of their involvement in Leadership, there have been positive changes in their child's and/or family's life. These changes included better services, supports, and education for family members with disabilities; greater inclusion in school and community; an overall better quality of family life; expanded social networks and personal connections; and increased family involvement in making needed changes in their communities.

Asked the extent to which Leadership directly contributed to changes in their child or family's life, respondents gave the following responses:

- 30.7% - I could not have made these changes without the benefit of the Leadership experience.
- 62.5% - The Leadership experience was a major contributor. Without it, I would have been much less effective.
- 6.8% - The Leadership experience was a minor contributor. Without it, I would have been slightly less effective.

Improved Supports and Services

Leadership graduates reported that learning about exemplary programs and the acquisition of improved advocacy skills enabled them to fight for better supports and services for their family members with disabilities. This parent's observation is typical, "We have advocated very strongly for full inclusion for our son. I believe he wouldn't have the services he has if we hadn't had the leadership skills and knowledge." As a result of Leadership training, families were able to secure home and vehicle modifications, children with disabilities saw improvements in their educational programs, and young people with disabilities were able to make a smoother transition from school to adult life. Respondents had this to say about how the Leadership experience affected their families.

(The changes for my family are) too extensive to list, but we have managed to get all the necessary equipment and supports in school and at home for my two multi-disabled children, (including) home modifications and vehicles for a good quality of life for my children.

We are much better advocates for our son because of Leadership. We gained knowledge of the laws, learned from the experiences of other families, and increased our confidence to advocate with boldness. We were able to secure services through the school department that otherwise we never would have asked for. We understand the importance of the community in our son's life, and are making every effort to help him be a successful member of his community.

We have dared to visualize what we want for our child, and then ask for it. If we didn't know what we wanted we would have accepted what the school could or could not provide for him.

My son has gone from being described by a school principal as being "non-educable" to graduating from high school with a diploma and now at 23 is happy and working and contributing to the community.

Greater Inclusion in School and Community

More than half of those surveyed (47 graduates) credited Leadership with helping their family member with disabilities to be more fully included in school and in their community. Leadership graduates said that because of their participation in Leadership they had a better appreciation of the benefits of inclusion and now demanded that their family members with disabilities be included in the classroom and have the same opportunities as any other citizen to be involved in the life of their community. Leadership gave people the information and tools that they needed to fight for an inclusive education, meaningful employment, and accessible recreational opportunities. Here are some examples of what families have done to ensure that their family members are respected and included members of their schools and communities.

I won't settle for a center-based preschool. I am advocating for my child to be placed in a typical program.

It is really reassuring to know that I am doing the right thing. My philosophy has always been that in order for my daughter to learn from life, she has to live it, and Leadership taught me that I am doing the right thing. I had Frank (Scambati) from the IOD come observe my daughter because Nashua was trying to put her into a special program.

My son and whole family have benefited from the information about best practices in education. We all advocated for full inclusion, high expectations, typical experiences in and out of school, etc. He graduated with his class after twelve years of inclusive education and received support from the school district through his transition years.

She never spent time in the resource room and from what I hear about what goes on in those rooms in our district that's a great thing! Because of Leadership I advocated for Marika to get a standard high school diploma and she was inducted into the National Honor Society. Because of Leadership she is off to college in '06.

Our son was brought back into district from an out of district placement. He was included in general education classes at the high school level. He now has job with natural supports and earns \$9.30 an hour and has had that job for nine years.

Better everything – he went from full segregation to full inclusion, employment, having his own place, own staff, and now his own home and a good life.

Improved Quality of Family Life

Many graduates talked about how taking part in the Leadership Series improved the overall quality of their family's life. A mother said that Leadership taught her how "important it was to preserve me." Another noted that, "Because my son now had adequate support to live and work in his community, I have been able to pursue retirement and my goals." A parent wrote, "Everyone in our family is thriving now. We have time to enjoy one another. We can get a full night's sleep. We can enjoy our child with disabilities."

Working to Improve Communities

The work that Leadership graduates have done around community inclusion has had a significant ripple effect. Many respondents said that one of the changes that occurred as a result of the Leadership experience has been an increased commitment by the entire family to make communities more accessible and inclusive. Those surveyed reported with pride on the work that they are doing.

It has been ten years since I took part (in Leadership), and during that time, I can't count how many times I have drawn on what I learned in those sessions. I have been a better advocate ... I have sought out and supported community activities that add quality to her (daughter's) life, including being part of a group that convinced our recreation department to start a summer day camp.

I think I was a better advocate for my child's needs. This has spread to other children as well. You ought to check out our district's special ed record!

Our town recreation director was discriminating against my child - as well as 6 other children - at the local town run summer camp. By confronting this person with the legal reasons why the situation could not continue and with the help of the Disability Rights Center the situation was rectified.

Leadership was my stepping stone for jumping into my community. Over time, all of the disabled parents in our community have been brought together to brainstorm ideas on how to impact and change our children's educations. We now have a parent council group and web site, www.NHSPED.net. The community is speaking very loud and we are being heard. Keep your eyes on the papers and news in the up coming months for education news in Brookline and Hollis.

LEND trainees found that Leadership gave them the resources and skills not only to help children they see in their professional lives, but also to help family and friends. This comment from a LEND trainee is an example of this, "I have advocated for a friend's child and also have been more comfortable with talking with parents that I am involved

with professionally about best practices. I am more effective in my position serving children with special health care needs.”

A self-advocate said that because of her experience in Leadership she is able to keep her family better informed about disability issues. She commented, “They will talk to their legislators on my behalf. This has been a positive thing.”

Making Connections

People talked about how important Leadership had been for them in making connections both with other families who have children with disabilities and with organizations providing advocacy and support services. Asked to comment about changes in their child or family’s life, one graduate responded, “The most important is feeling part of a community of people around a shared vision of possibility for people with disabilities.” Another family member agreed, “The connections you make during Leadership are essential.”

The exposure Leadership participants had to exemplary programs and practices, and the contacts they made have proven to be invaluable when they went to look for information, resources, or support. One parent wrote about this aspect of Leadership, “I met incredible people at Leadership and as result have gone back to my community to talk about my experience. I also have gotten to know some past participants and that has been awesome! Some of these folks are such great advocates for their children; it inspires me. Also they have been at this longer, so they have more experience, so they serve as good resources for information.”

Increased Community Involvement

In responding to the survey question - Are you more involved in your community because of your participation in Leadership? (volunteering, serving on local boards, running for local offices, working with your faith community, etc.) - 70% of the graduates said yes. Many of those who answered No went on to comment that they have always been active community members and that Leadership gave them tools to be even more effective in this role.

Rating the extent to which Leadership directly contributed to an increased community involvement, respondents gave the following answers.

- 22.8% - I could not have made these changes without the benefit of the Leadership experience.
- 64.6% - The Leadership experience was a major contributor. Without it, I would have been much less effective.
- 12.7% - The Leadership experience was a minor contributor. Without it, I would have been slightly less effective.

The vast majority of alumni reported that not only are they are much more involved in their communities, they also have taken on leadership roles. They serve on Family Support Councils, school boards, town committees, and Area Agency Boards. They are active members of their church or Temple. They are committed volunteers working in local schools, with the Red Cross, at community centers, and in a variety of other capacities to help those in need. Because of Leadership these citizens are better informed about and more active in local politics. They have formed parent support groups, coached soccer teams, and helped make their towns' recreation departments more inclusive. In any number of ways Leadership graduates have helped people in their communities better understand the importance of including individuals with disabilities.

Leadership graduates had this to say about involvement in their communities:

I am now on the board of directors for the Brookline Hollis Youth Soccer League and help parents of disabled children who want to play to have full access.

I attend, on a monthly basis, School Board meetings. Our public input is not always welcomed, but at least we get heard. We volunteer more with our Church.

I have been willing to take on some volunteer roles in helping get more recreational opportunities put into place. I have also recently become involved in the Special Education Parent Advisory Committee of our school district.

I presently work with high school students and have helped to educate them about various disabilities. My experience has also helped my interactions with my boss who is a quadriplegic man with a guide dog.

I feel that I have become a valued resource for my community instead of liability.

I started a "new" mom and dad's local group. I have become a Brownie Girl Scout leader. I have been helping with random acts of kindness. My fiancée and I commit Saturday afternoons to deliver baked goods to the elderly, shop for toys for the poorer kids, bring food to the homeless shelter, etc.

I have been a member of Family Support for 8+ years. I teach at the technical college about including special ed. students using best practices. I began a unified bowling league. ... I participated in Region 4's Inclusion Project Committee.

I think Leadership gave me confidence and knowledge. It inspired me to think outside of the box and envision a much richer life for my daughter. I am now working with the Under One Roof project in Peterborough trying to keep community inclusion at the forefront.

Increased Involvement at the State Level

When asked - Have you been more involved at the state level as a result of your participation in Leadership? (board membership on statewide organizations, testifying at hearings, serving on Task Forces or Commissions, running for the Legislature, etc.) - half of the respondents answered yes.

Those surveyed rated the extent to which Leadership directly contributed to an increased community involvement as follows.

36.7% - I could not have made these changes without the benefit of the Leadership experience.

45% - The Leadership experience was a major contributor. Without it, I would have been much less effective.

18.3% - The Leadership experience was a minor contributor. Without it, I have been slightly less effective.

Leadership graduates are active in a variety of statewide organizations, often in leadership capacities. They are members of the Governor's Commission on Disability, the New Hampshire Developmental Disabilities Council, People First of New Hampshire, CAUSE, the New Hampshire Mental Health Commission, the Interagency Coordinating Council, the New Hampshire Autism Society, the Governor's Commission on Child Care, the Disabilities Rights Center's Board of Directors, the Statewide Family Support Council, the State Advisory Council for Special Education, the Real Choice Advisory Committee, Future Planning Networks of New Hampshire, and the Institute on Disability's Consumer Advisory Council.

Many of those surveyed have become politically active; they have worked on election campaigns and run for office themselves. One of New Hampshire's State Senators is a Leadership graduate and three are in the New Hampshire House of Representatives. One graduate talked about how she has included her teenage son in her political work, "I organized nurses (for Senator John Edwards) during the Presidential campaign. I attended town halls (meetings) with congressmen and taught my son to advocate for himself. I included my son during campaigns of city council, state rep, state senator, Congress, the US Senate, and the presidential campaigns. I was active in all races."

An important goal of the Leadership Series is educating participants about how the political process works; the Series includes an opportunity to meet with members of the New Hampshire Legislature. With a better understanding of the legislature's role in setting policies that affect individuals with disabilities and their families, graduates have taken seriously the charge to educate their representatives. Leadership graduates have hosted legislative coffees, called their representatives about pending bills, and testified at legislative hearings.

Here are what some alumni had to say about their involvement at the state level.

I met a State Senator and worked with him on a Legislative Study Group to try and improve the quality of the Katie Beckett funds.

I have hosted legislative coffees. I have testified at budget hearings. I have had the Commissioner of Health and Human Services in my living room avoiding direct answers to families' questions about proposed changes in Medicaid. Hopefully, my active voice will help change some very long held misconceptions.

I serve on four non-profit boards. All were formed to assist people with disabilities. I have done letter writing workshops with adult consumers to teach and assist them in contacting their legislators on issues that would have an impact on them. This is most rewarding to help them have a voice.

I am testifying (at the legislature) and training other parents how to lobby their legislators. I am working with legislators to craft and sponsor needed legislation.

I wrote letters to my State Reps a few times. I understand my civic duties; I had no foundation before Leadership.

Increased Involvement at the National Level

Almost half (48.9%) of those who completed the Leadership Survey reported that, as a result of Leadership, they have expanded their involvement beyond New Hampshire. Asked the extent to which Leadership directly contributed to becoming more involved on national issues, respondents gave the following answers.

30.9% - I could not have made these changes without the benefit of the Leadership experience.

41.8% - The Leadership experience was a major contributor. Without it, I would have been much less effective.

27.3% - The Leadership experience was a minor contributor. Without it, I would have been slightly less effective.

Twenty-seven graduates reported that they now regularly write or call their United States Senators and Representatives about issues coming before Congress. A few people have traveled to Washington to meet personally with their Representatives. Several individuals serve on the boards of national organizations. Many have attended national conferences on disability related issues and a few alumni have been presenters at national conferences. One graduate, a refugee from Rwanda, is taking what he learned in the Leadership Series to help him in his international work with the Organization for Peace, Justice, and Development in Rwanda.

Here are what Leadership graduates had to say about their involvement at the national level.

I testify on a regular basis and speak to my legislators often. As a result of my work on the DD council and being able to go to Capital Hill, I have been able to advocate on a national level.

I am on two national organizations ... (one) helps to establish basic criteria needed for special ed advocacy training. I'm thrilled I was picked from hundreds of applicants for this first of its kind course in this country.

I served as the NH representative in Washington DC during the Fragile X Syndrome Conference. We spoke as advocates to our home state legislators and senators to ask for increased awareness of Fragile X Syndrome and funding for research at NIH. We received assistance with our bill and up to \$5million over the next three years.

I write to my Senators and Congressmen often, whenever necessary. I am in touch with several national organizations and on their mailing lists for legislative updates as they occur. I have applied for the Kennedy Family Policy Fellowship to work in a Senate or congressional office for a year. I have been interviewed, (but) not accepted yet.

My daughter and I have become active with both the NH Department of Education and the US Department of Education regarding high school transition.

I write many letters to state, national and world organizations. I am pleased with my knowledge and hope to make Leadership 2005 proud.

The Most Valuable Aspect of Leadership

Those surveyed were asked what was the most valuable aspect of the Leadership Series. In responding, most graduates were unable to confine their answers to just one aspect of the Series; their responses typically included several reasons why participating in Leadership had been a valuable experience. One family member wrote, "All of it (was valuable). I don't think that I would have understood the meaning of the word leadership without the whole thing."

Leadership graduates found the following aspects of Leadership most valuable to them.

Personal Empowerment	36 responses
Increased Awareness	35 responses
Networking /Personal Connections	31 Responses
Changed Perceptions of Disability	10 Responses

Personal Empowerment

More than a third (37%) of those surveyed said that the Leadership Series provided them with advocacy skills and helped them to realize that they had the power to make a positive difference in the world. People reported that they were inspired by the personal stories that they heard and were motivated to become more involved in any number of areas. Asked about the most valuable aspect of Leadership, here are what some graduates had to say:

(Leadership) Changed my thinking. Gave me hope. Taught me how to advocate. I believe if it weren't for influence of the Leadership Series and IOD, my son would not be the happy, productive person he is today.

Belief. I know that my actions, individual and collaborative make a difference. I can organize and I am more motivated.

The courage to speak up. One day during Leadership we got face to face with legislators - teaching them things and they taught us. It was a great experience.

It has given me the knowledge and the spark to be a change agent, and not just a follower of changes that affect my family.

The push! I always knew this stuff was important - but Leadership made me realize it is important now!

The vision that though we are individuals, alone at times, together we can affect great changes.

Increased Awareness

The Leadership Series brings in nationally recognized experts as presenters on inclusion, community organizing, governmental policies, and state-of-the-art services and supports for individuals with disabilities. Series presentations include ample time for discussions and questions and answers. In their homework assignments and working in Action Groups, participants have opportunities to put what they learn into practice. Graduates valued this hands-on approach to education; for many this was one of the most valuable aspects of Leadership. Here are some comments from graduates about what this learning experience meant to them.

For me the inclusion piece was most valuable. I went to the table for team meetings with many proposals for how my son and other developmentally challenged students can more fully participate in the overall school setting. Thinking outside of the box has proven to be a wonderful approach for all of the students.

I feel like the Leadership Series empowered me in so many ways. It didn't make my problems disappear, but it showed me resources that were available.

Heightened awareness of issues facing people in NH who have disabilities. Resources and networking. Creative problem solving around all aspects of ensuring that people with disabilities have an equal and enriched life.

Focusing on thinking outside the box. Being creative. Not settling for what the mainstream provides. Not seeing disability first.

Personal Connections

For many, the best thing about participating in the Leadership Series was the opportunity to get to know other people who are facing similar challenges. As one parent put it, the most valuable part of the Leadership experience was “knowing you are not alone on this extremely challenging journey.” Another family member commented the most valuable aspect was “feeling connected to a larger community across the state that can sustain me through hard times.” People reported that through Leadership they made important personal connections and, in some cases, lifelong friendships. People also noted that the contacts they made with IOD staff and those who presented at the Series have proven invaluable for networking and problem solving. Talking about what was most valuable, other Leadership graduates said:

Two equally valuable aspects: The first is being able to network with people who understand and value the challenges I face daily. Secondly, was finding out that the resources I had always been told locally do not exist, and how to access those resources.

Realizing you are not alone and can reach out to others for guidance. Realizing that you can make a difference in the lives of people with disabilities through awareness and becoming politically active.

Realizing we are part of a large, powerful community. Hearing stories, especially success stories. Learning that planning ahead makes a huge difference.

The most valuable aspect of the Leadership Series was mostly just meeting other parents and self advocates. Having this exposure to people who shared my issues. It was empowering to meet so many people who wanted to make a better world for their child or themselves.

Changed Perceptions of Disabilities

Ten of those who were surveyed said for them the most valuable aspect of Leadership was the change in how they now viewed disabilities. Self-advocates, LEND trainees, and family members, all said that taking part in the Series opened their eyes to a whole new world of possibilities for those who have disabilities. A self-advocate wrote she no longer felt “broken” and LEND trainees said they were inspired by the presenters who have disabilities. One parent said that being part of Leadership gave “me back my ability to dream about my son's future, to embrace his disabilities and not continue to expect him to change, but to expect the world to change.” Echoing this thought another parent

commented that because of Leadership, “(I am) really thinking about a different life for my child.” Another parent said that the most valuable aspect of the Leadership was “the understanding that my son is not a victim and does not have to be treated as such and that we have much more control than I thought we did over the choices in his life.”

One mother summed up the feelings of many parents when she wrote:

You educated me so that I can be, not only a good advocate for my daughter, but a good parent for my daughter. You taught me how to see my child as a person first, and a person with a disability second. You taught me to have dreams for my child, just as I had for my other children. You taught me not to be afraid -- not to be afraid of the future, not to be afraid to be an advocate, not to be afraid to learn and become a part of the community of families of kids with disabilities. You taught me that disability is a normal part of society and that mindset has changed everything. You taught me these things through a combination of fabulous guest speakers -- all of them had an impact on me.

Recommendations for Improving the Leadership Series

Asked what recommendations they had to improve the Leadership Series, a number of graduates reported that they were very happy with the way the Series was organized and did not see a need for any changes. One participant who had no recommendations for improvements wrote, “It was an incredibly powerful experience. Intense. I was completely saturated, exhausted, and energized ... (I am) still reflecting about all that was shared.” Others suggested ways Leadership participants could connect better with one another, recommended additional topics for the Series, and proposed some changes in structure. There were many who wanted to see the Leadership experience expanded to accommodate more participants.

Making and Keeping Personal Connections

Participants in the Series wanted to ensure that making personal connections would continue to be an important component of Leadership. They had ideas for fostering relationships during the Series and for maintaining them after people graduate. Several people wanted more opportunities early on to get to know other participants. They recommended additional team building exercises, assigned seating at meals that ensured participants didn’t just sit with the people they already knew, and rotating roommate assignments. Two graduates suggested creating a mentor program where new participants are connected to past graduates and where they in turn agree to be a Leadership mentor once they have become established as effective leaders and advocates. Other recommendations included:

A registry for all Leadership grads that has name, address, phone numbers, specific talents, interests, and organizations that they belong to. This could help if people are working on projects and need resources or assistance of any kind.

More connection to people's communities - some way to keep it ongoing for alumni.

Continue with the ListServ.

“After You Finish Leadership” – a next steps with wrap-up information.

Get parents/guardians of kids in the developmental disability community together in some way to voice their opinions; do something, even just on a yearly basis.

Additional Topics

Graduates recommended a number of additional topics that they would like to see covered during the Leadership Series. These included: effective communication skills, how to form friendship circles, 504 plans and how they relate to special education, more detailed information on pending legislation, how to be more effective working with schools, and how to meet the needs of families caring for family members with complex medical issues. A few people commented that much of Leadership was directed to families who have younger children; they wanted to see a Series that addressed the transition from school to adulthood and looked at issues confronting adults with disabilities. One parent wrote, “I personally had one adult child out of the school system and one on the way out, so it wasn't geared towards my personal situation, but I was thrilled with the legislative part of it as well as the guests who spoke about community involvement, state involvement.” Finally, one graduate said she wished the Series “included more ideas on how to take care of yourself while leading!”

Changes in Structure and Approach

A number of Leadership graduates proposed changes to the current structure and the approach of the Series. Suggested logistical changes included making meeting three days a month rather than two, adding an additional weekend to make sure all the information gets covered, and offering the Series in different parts of the state. A graduate who had a long commute said a later starting time on Friday night, or a location nearer her home, would have been easier for her.

Two people commented on the need to set a positive tone. A LEND trainee wrote, “Make it more real. Be more practical. Set the expectations to the parents before they start the Leadership Series. For most of them it seems like a nice weekend off with lots of complaining about everything. It has to be more positive.” Another graduate, who noted that some of the presentations were negative and boring, wanted more positive, energetic speakers. One participant asked for more emphasis on political advocacy; another thought the Series was “a little too political.” One person praised Greg Galluzzo (Leadership presenter); another thought he was unprofessional and should be replaced. One person suggested bringing in speakers who live in the region as a way to save Leadership operating expenses.

There were several suggestions that had to do with the Action Work Groups. People asked for more time to organize, help arranging specific times and places for Action

Group meetings, collection of written homework, and increased involvement from the IOD group leaders during the Action Group process.

Many said that they wanted to see an increased commitment on the part of graduates to be more actively involved and to assume leadership roles. One graduate wrote, “We have to figure out a way to create a united force in this state.” Another stated, “We need to figure out how to impart the message that this is an expectation of all graduates - that they will all get and stay involved at the local, state, and national levels.” Another individual wanted to find a way for graduates to continue the Leadership experience at the local level.

A LEND trainee asked that the Leadership Series be more cognizant of the role of professionals and find a way to better incorporate the trainees into the teaching process. “What I walked away with was the necessity of incorporating the trainees better - so much focus is on parents and not enough on trainees/professionals. We can't ignore that professionals are needed; incorporate professional piece because we are in it together.”

A family member made this recommendation to improve the Series, “Sometimes the inclusion or nothing mission/attitude turns people off. It scares them away or leaves them feeling guilty and/or not good enough as a parent or advocate. Reminding participants that social movements are not an easy, fast process might help ease some of the resistance, inadequacy, or guilt.”

Expanding the Series

Many of those surveyed wanted to see the Leadership Series expanded to accommodate increased numbers of participants. Some wanted more self-advocates and family members to graduate from Leadership each year, others suggested expanding the scope of Leadership to include providers, administrators, regular education teachers, and principals. One graduate wished that the IOD could “address how to provide a forum for recreation directors, scout leaders, sports coaches etc. (to) access training that would allow differently abled children to more readily participate in programs that are otherwise not an option.”

Several people wanted the Institute to do more to promote Leadership, including doing a better job of getting out the word in the North Country. One graduate, who saw the need to broaden the diversity of Leadership participants, recommended, “Increased presence of people from low SES (socioeconomic status) families, single parent and alternative families, immigrant families are essential. Perhaps, a concerted effort to get out information on Leadership to those families and more support to allow them to participate. Bringing in families of children with mental health needs under this umbrella, as they are VERY marginalized.”

Contact with Leadership Graduates

Those surveyed were asked if they are in contact with Leadership graduates, if they would be interested in connecting with other graduates, and what the IOD could do help them make connections. Nearly 75% of those surveyed are in contact with other Leadership participants. People reported that they serve on committees and boards of directors with other graduates, have close friends from Leadership, work with alumni on community projects, see Leadership graduates at conferences and trainings, volunteer together on political campaigns, call each other for support and advice, and see fellow graduates daily at their workplace. Here are what some participants had to say about their contact with Leadership alumni:

Two of my best friends came from Leadership, so we talk often. My State Rep introduced me to two other Leadership grads in my area. Reason: Leadership grads have the knowledge to move mountains and be strong leaders. What's better than having one Leadership grad in a community project? Three!

I stay in touch with some of the Leadership grads. As issues around the state come up, you are always bumping into someone who had graduated, or you are recommending this terrific program to them.

It is nice to be able to contact those who have had the Leadership experience for advice and ideas when issues concerning my son arise.

More than half of respondents (62.2%) said they would be interested in connecting with other graduates and suggested a number of ways the IOD could facilitate this. Their recommendations included

- Create an on-line Leadership directory with emails, phone numbers, and areas of expertise and experience
- Continue holding Leadership Reunions (chose central locations, bring in a well known speakers)
- Host regional meetings of Leadership graduates
- Develop issue specific Action Groups for graduates
- Hold a Leadership gathering (wine and cheese or special breakfast) at the annual Family Support Conference
- Offer graduates refresher courses and workshops on timely topics
- Do an annual Alumni roundtable
- During each series invite past graduates to a workshop or presentation
- Continue getting out information through the ListServ
- Help connect graduates who have common interests
- Provide financial assistance for Leadership graduates to attend conferences

The Most Significant Change

The final question on the Leadership Survey was – What do you believe is *the one most significant change* that has occurred because of your involvement in Leadership?

Five graduates said the most significant change for them was increased personal connections and support and five cited an increased awareness of disability issues and the value of community inclusion. For everyone else, the significant changes they reported were connected in some way to their ability to be effective advocates. Graduate after graduate reported that they are no longer afraid to speak up or to fight for what they believe is right. People said that they now had the skills and the confidence to make a difference; these graduates wrote about their most significant change.

The strength of commitment I have to making sure that my son has a vision for his life and has choices at every step of the way. The pressure on families to conform and do what we are told to do, from the medical, educational, and policy arenas, is intense. It takes a great deal of commitment to keep to our goal of making sure our son lives a full life.

I am more confident to handle whatever is dealt to us. I'm not as frustrated to believe the first, "No" I get. I find another way. I'm not sure that this would have been possible before.

Before Leadership I had some tools. After Leadership I have more tools, self-determination, and self esteem to use them. From the bottom of my heart, from my family to yours, THANK YOU!"

Parents reported that because of their participation in Leadership their sons and daughters had a higher quality and more inclusive education. One parent wrote that her daughter's "bright future is in large part due to YOUR efforts to educate me." Leadership alumni said that they now "dare to dream" about a positive future for their children who have disabilities. One parent wrote, "I believe my son's life has been a lot fuller and exciting because of Leadership." This was echoed by another who observed, "My daughter's life has been richer and our personal lives as family members enriched." Here are what other family members said about the impact of the Leadership experience:

My son's life being so meaningful. My daughter is becoming a special educator specializing in inclusion for students with disabilities.

Empowered me to be more hopeful. The education that I want for my children can and should happen.

The most significant change is my son. Over the last 15 years, I have seen him mature into a young man, having had the supports that I deemed necessary for him to achieve his highest potential.

Graduates said that they have used the lessons they learned in Leadership not only to advocate for themselves and their families, but also to fight for the rights of those who don't have a voice. One graduate reported, "We felt empowered as a family to take on Medicaid and their policy on adult diapers." Another wrote that Leadership "strengthened my conviction to be the best advocate I can be for my child and for other

members of the NH community with disabilities.” Here are what others said Leadership accomplished for them:

I am in a Ph.D. program that is designed to prepare me to be a national leader in the area of educating children with ASD (autism spectrum disorders). I would not be there were it not for the Leadership Series.

My self-confidence. Believe it or not, when things are going really bad, I always say to myself, ‘What would Greg. G. from the Gamaliel Foundation do?’ I just have to picture him standing there and that gets my feet moving.

For me, this was an awakening. Finding out who I was, and what I wanted to do. I graduated Leadership feeling almost like I had been re-born. A whole new me was about to emerge like a butterfly and I had been no moth before! It helped me to re-evaluate the direction in which I wanted my life to go in and I couldn't be happier! I'm on several committees at my area agency, as well as the Board of Directors. I testify in Concord whenever I get the opportunity and continue to advocate in my community!

My advocating for changes globally. I believe that “NO” is not an acceptable answer. I, with a team, have submitted a proposal to VR (Vocational Rehabilitation) for Consumer Directed Employment. We will see where it goes.

For many, the Leadership experience marked a pivotal point in their lives. Over and over again graduates commented on how meaningful this training had been for them and thanked the Institute on Disability for the opportunity to participate in the series. This parent's reflections captured the value of the Leadership experience; “I feel that the education you provided me resulted in a complete change in my attitude, point of view, approach to education, and feelings about Carly's future. It was nothing less than what happens when you turn on a light in a dark room. You gave me the eyes to see disability in a new way, the knowledge to feel confident going forward, and the courage to face the future. I can never thank you enough.”