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

Summer Issue 2010

#### CIVIC ENGAGEMENT



#### **GIVING BACK**

Brittney DeVincenzo, Administrative Support Specialist, UNH/Institute on Disability; YES year 2 participant

I believe that everyone has a responsibility to take action to improve the quality of life in our communities. I was raised to always give back. A community can provide so much – especially in a time of need – and giving back is essential. Taking an active part in a group with a mission has been a very important part of my life.

I am very active in my Church. My son Odin and I attend church at Word of Life Christian Fellowship at least twice a week, and not just for the service – we go early and help set up, and stay late to break down afterwards. And in return, my son got an amazingly cool bike for Christmas! As a single mom I don't have much,

if any, time to myself. Others in my church community take turns caring for my son on Saturdays so I can have some time to myself and he can have new social opportunities.

Currently, I am involved in my son's school. I donate lots of recycling objects to the arts department. I also attend the PTA meetings. I found that some



Brittney DeVincenzo and her son Odin.

advantages of being on the PTA are getting connected, discovering great resources, and tapping into a network. Getting involved in an organization, you can watch yourself grow, witness improvement, and become a role model for others.

(Continued on next page)

includes a willingness to take on civic responsibilities. Whether it's exercising ones right to vote or assuming the lead on a community project, there are opportunities for individuals with disabilities to be involved. In this issue we bear from people who bave stepped up and given of their time and talent to make a positive

Welcome

to the Summer Issue of

the Rap Sheet. Full and

meaningful inclusion

Susan Covert, Editor

difference.

## LESSONS OF A RELUCTANT WARRIOR

By Cathy Spinney

Yes, that's me; a reluctant warrior. Who would've thought it? Me, a civil rights activist. I grew up in the 60's and 70's, so of course I watched Martin Luther King marching peacefully on the evening news. My mother took time to explain to me why these people on TV were doing what they did; how they had to deal with so much injustice. I mostly remember feeling relieved that I never needed to engage in such things. I never had to fight for my rights or dignity. But I did have to wonder, what was driving these people to work so hard, against seemingly insurmountable odds, to have what I had and took for granted?

Fast forward. It's the early eighties. I've been married for three years. Life is still reasonably simple. I work hard at a pretty good job. We own a modest home. In late June, I am blessed to bring Kelly Anne into the world. Those of you who are parents will remember the combination of euphoria and terror that event entails. We are told Kelly is healthy and she has all her parts. Life is moving along as it should.

Then, after one year of "normal" everything, Kelly stops doing what little babies her age are supposed to be doing. The panic sets in. The doctors don't know what's going on. We are told not to worry. Two years of doctors' visits and tests later, we finally know what is "wrong" with Kelly. She has a disability. She will never again be considered "normal" by an often harsh society. We are counseled to be prepared. It will be difficult. There will be disappointments and setbacks. This was the first major lesson of my life. My first real challenge — how to find acceptance in the face of uncertainty.

Fast forward again. Kelly is nine, and has been invited to be one of the first students to be "included" in public school in

our town. The concept of inclusion is a new one, and I am uncertain. But, Kelly's years in public school were mostly pretty good. There was plenty of funding in the budget in those days, and she was offered many opportunities to learn, play and make a few friends. I really didn't need to fight for anything. Can you believe there were ever days like that? And here is where I needed to learn my second major life lesson — how to trust others to do right by Kelly.

When Kelly was 16, I had my first conversation about this thing called a "Waiting List". It was explained to me that without a major paradigm shift, it was likely Kelly would find herself on it at age 21. But that was years away. Surely, any problems would be solved by then. But I was told not to depend on that happening. So, what could be done? I learned about a thing called the "Wait List Oversight Committee" and how they had regular meetings to discuss the status of this list, and to figure out what should be done. I was told I could attend these meetings, and talk with my legislators, and explain to them the many reasons why they needed to solve this problem immediately, or at least by the time Kelly turned 21. Thus was the beginning of my newfound "career" as an advocate.

And you guessed it, here was my opportunity to learn lesson number three – when something important needs to be addressed, do everything you can to affect the outcome.

#### (Cover story continued)

Prior to my son entering public school, he attended Concord Head Start. During that time, I served as the President of the Parent Committee, sat on the Head Start Policy Council, and served as a Board member for the Community Action Program (CAP is the parent organization for Head Start). I think it's really important to take an active role in life and to make sure that the programs that are out there really do meet the needs of my family.

For the past two years I also have been a member of YES (Youth Empowerment Services). This is a program of the Institute on Disability that develops and promotes leadership and self advocacy skills to help young people prepare for their futures.

I have discovered that being a part of a community keeps the fire of life burning in you. When you actively participate in a group with a mission, your "input" actually gets put in.



Kelly Spinney

Kelly was indeed placed on the Waiting List in 2003. By then I had been traveling for five years back and forth to Concord to beg, coerce, annoy, demand, implore and harass my government into doing the right thing for people with disabilities. Paying privately for Kelly's supports so I could continue to work took a huge toll emotionally, physically, and financially, and she was only on the list for three months. I realized then that advocacy is something we fall or are shoved into. It is born of necessity. It evolves out of something personal, out of our experiences. We become passionate.

After Kelly began receiving services, I knew I needed to do more. I resolved to continue trekking to Concord to try and convince my government to get rid of that darn list. No family should ever have to endure what we endured. But I also became a Board member for my Area Agency where I help guide that organization to better serve individuals with disabilities. I began to use my voice publicly by writing Letters to the Editor and OP-Ed pieces to educate the general public and invite them to be more supportive of our family members. In 2006/2007, I attended

the NH Leadership Series and honed my skills further. After continuing to speak out at every opportunity, New Hampshire finally passed SB138, effectively eliminating that list once and for all (we thought). I was chosen to serve on the SB138 Committee where I helped form recommendations for improving the service delivery system. And here's where life lesson number four came in – persistence pays off. (And having a little bit of attitude when you testify doesn't burt either).

Here we are today. Even with a law against the Waiting List and a mandate to fund services, we still must fight every year for every nickel. We are under constant threat of having services cut or not starting at all. So, I continue to go to Concord, to call and write my representatives, to insist that my government obey its own law. But being a thorn in the side of government isn't the only way to participate. Advocacy has many forms. I also serve on of the newly formed New Hampshire Developmental Disabilities Quality Council where we help review, enhance and recommend the principles that will ensure our family members receive the best supports. I help train and educate other families on how to use any or all of these methods by participating in my Area Agency's advocacy trainings. The only way to have a secure future is to work for it – to fight for it – to create it. It's too important.

And, most importantly, I can finally answer that question I had so long ago after watching Dr. King march. The one about why they were doing it. I know now. It was about equality. About being a full and equal citizen. About demanding the respect that each human earns. And although society still sees Kelly as a disabled person, to us she is just Kelly. She has skills and talents, moods and dislikes, people she likes and those she can do without – just like everyone else. She IS just like everyone else. So, my fifth lesson is that each of us is afforded the right to have life, liberty, and to pursue happiness – it's just that some of us need a little support to enjoy those rights. And it's MY responsibility to fight for those rights on her behalf. Because I love her. Because it's the right thing to do. Because I am a Warrior, reluctant no more.

So, are you a Warrior? Can you afford not to be?



# VOTING ACCESS FOR INDIVIDUALS WITH DISABILITIES: A TRIUMPH FOR FREEDOM

James Fox, Staff Attorney, Disabilities Rights Center

## State and Federal Law Guarantees Voting Access to Individuals with Disabilities.

It has been eight years since Congress passed the Help America Vote Act (HAVA). One of HAVA's goals is to ensure that voting is accessible to individuals with disabilities. This includes accessible voter registration, polling places, and voting equipment. Voters who have disabilities must have the same opportunity to participate in the election process as citizens who do not have a disability.

HAVA's federal standard reinforces the state constitutional guarantee in Article 11 of the New Hampshire Bill of Rights that voting registration and polling places be easily accessible to all persons who are qualified to vote, including individuals with disabilities.

In addition, polling places must meet the "facilities access" standards contained in the federal Americans with Disabilities Act (ADA).

## Working to Ensure Voting Access in New Hampshire.

A variety of organizations including the Disabilities Rights Center, the League of Women Voters, and Granite State Independent Living, along with the New Hampshire Secretary of State's Office, have worked to improve and maintain access to federal, state, and local elections. These organizations have monitored the state's polling places to make sure that they meet the accessibility requirements as laid out in HAVA, the ADA, and our state's Bill of Rights.

#### SO HOW IS NEW HAMPSHIRE DOING?

#### Voter Registration

By law, New Hampshire voters can register at the polls on Election Day. However, many citizens choose to register prior to the election to ensure a smoother voting experience. Voter registration generally entails a trip to city hall or a town office. The Disabilities Rights Center (DRC) has been inspecting town offices throughout New Hampshire to determine their level of access for individuals with disabilities. In doing this assessment, DRC has been applying the ADA facilities standards. The Disabilities Rights Center anticipates completing its statewide inspection of town offices by the fall of 2010.

#### **Auxiliary Aids**

Both polling places and town offices are required by law to provide auxiliary aids to ensure effective communication with voters with disabilities. One of the main auxiliary aids is the accessible voting machine. In New Hampshire, the accessible voting machine includes a phone/fax system. While this machine was developed for individuals with vision impairments, it has been adapted to accommodate individuals with other disabilities. For example, New Hampshire's accessible voting machines include an accessible telephone pad to accommodate individuals who have difficulty with fine motor control.

To use New Hampshire's accessible voting machine, the voter dials into a central computer and is given voice prompts with instructions for casting a ballot, the process is similar to automated voice mail used by companies. Once the voter has cast their vote using a telephone keypad, the ballot is faxed to the voter at the polling place. The voter then submits the ballot.

The main drawback of New Hampshire's accessible voting machine is that it fails to adequately safeguard voter privacy. Because the ballots issued by the accessible voting system are not identical to the standard ballot, poll workers are able to know how a particular group — in this case, individuals with disabilities — voted in their

polling location. In instances where only one individual used the accessible voting machine, poll workers will know how that person voted.

One potential solution to this privacy issue is to have voters who do not have disabilities also use the accessible voting machines. While poll workers have been asked to encourage other voters to the use these machines, no one can be required to use the accessible voting machine. The accessible voting machines also have little appeal to individuals without disabilities as they making voting more time consuming. That said, every citizen who is concerned about disabilities issues should use the accessible voting machine and help to ensure a truly private vote.

Ideally, accessible voting machines would be more user-friendly and have with a broader appeal for all voters.

#### Get Out the Vote

The right to vote is the right from which all others flow. As President Lyndon Johnson noted more than forty-five years ago, the right to vote can be used as an instrument of justice and fulfillment. Since the passage of HAVA in 2002, New Hampshire has made great progress to ensure that polling places are open to all individuals. Now it is up to us to get out to vote. Exercising our right to vote is one of the best ways to advance the interests of individuals with disabilities.



In 2007 the New Hampshire legislature passed SB 138. This bill provided funding for the wait list, increased salaries for certain direct care workers, and established a committee (known as the SB 138 Committee) to address work force issues and to develop a quality assurance enhancement plan. One of the recommendations from the SB 138 Committee was a call to create a Quality Council for Developmental Services. In 2009 the legislature passed and Governor Lynch signed into law HB 483. As stated in the legislation:

This bill establishes the Developmental Services Quality Council to provide leadership for consistent, systemic review and improvement of the developmental disability and acquired brain disorder services provided within New Hampshire's developmental services system. At least 51 per cent of the members of the Council shall be individuals with disabilities served by the system or parents of individuals served by the system.

The Quality Council has been meeting regularly since September 2009. This coming fall the Quality Council will be holding regional meetings throughout the state to provide information about its work and to invite individuals with disabilities, families, service providers, and community members to talk about issues and to share their ideas for improving developmental and acquired brain services in New Hampshire.

To learn more you can sign up for the Quality Council's electronic newsletter by emailing Denise Sleeper at Denise. Sleeper@dhhs.state.nh.us (please put QC Newsletter in the subject line) or by going to http://visitor.constantcontact.com/manage/optin/ea?v=001 WVdpo956d6kpDUo7rllJxw%3D%3D A link to the Quality Council also can be found on the Bureau of Developmental Services website at http://www.dhhs.state.nh.us/DHHS/BDS/qualitycouncil.htm

#### How To Register To Vote

Have you registered to vote yet? If not, NOW is a good time to do it!

Just go to your city/town clerk's office at least 10 days before the election. Bring with you:

- → Proof of your address (driver's license, vehicle registration, Armed Services ID, photo ID issued by the US Government)
- Proof of your age (ID card, driver's license, birth certificate, passport)
- Proof that you are a US citizen (birth certificate, passport, naturalization papers, citizenship affidavit)

You will be given a voter registration form to fill out. You will also be asked if you want to register as a Democrat, Republican, or Undeclared.

You can also register by mail if you have a physical disability that prevents you from registering in person. Call your city/town clerk and ask for an absentee voter registration and affidavit. Make sure to return them to the clerk's office at least 10 days before the election.

If you live in an institution, you are still entitled to vote unless that right has specifically been terminated by law due to criminal conviction or guardianship. Most people with guardians still retain their right to vote.

You can also register at the polls on election day, but we recommend doing it earlier – that way if there is any problem you will still be able to cast your ballot.

If you have any questions or problems registering to vote, call the Disabilities Rights Center at 1-800-834-1721.



"I went to vote for really the first time in two thousand and eight when Obama was elected president. I voted in Greenfield and everyone was very nice. I used facilitated communication and my mother helped me to type. I also voted for New Hampshire candidates." Eric Loening



#### THE PRIVACY OF THE

By Julia Freeman-Woolpert, Disabilities Rights Center

People often say that, in a democracy, decisions are made by a majority of the people. Of course, that is not true. Decisions are made by a majority of those who make themselves heard and who vote - a very different thing.

~ Walter H. Judd

Stephanie Hurd, Coordinator of Volunteer Services for the New Hampshire Association for the Blind, believes in the importance of voting. This active Portsmouth resident is a member of the local Lions Club, volunteers in her community, and serves on the Seacoast Advisory Committee for the Association for the Blind, a group working to raise awareness about blindness. While she is a long time voter, Stephanie who is blind has never voted privately or independently. She has always had to rely on the help of a friend or family member. There have been times when she has asked the moderator for assistance in filling out her ballot, even though she would prefer to keep her vote private. The passage of the Help America Vote Act was supposed to change all of this. The act decrees that "The voting system shall...be accessible for individuals with disabilities, including nonvisual accessibility for the blind and visually impaired, in a manner that provides the same opportunity for access and participation (including privacy and independence) as for other voters."

In the last election, Stephanie couldn't wait to try out the accessible phone-fax system. There are a number of options to make voting accessible for those with vision and other disabilities, New Hampshire chose this system - mostly because of its low price. With the phone-fax system, a poll worker dials a number for the voter; the voter hears the ballot read over the phone and votes using a touch tone pad.

Stephanie and her mother drove to the polling place together. A friendly poll worker escorted Stephanie to the accessible booth and explained how the phone-fax system worked. The poll worker dialed the number. Nothing happened. She redialed – still nothing. A second poll worker was called in and the two workers puzzled for a while. Still nothing. Helpers three and four arrived in the booth which now resembled the clown car at the circus. An hour later they still weren't connected. "I never got past step one," Stephanie said. Once again, Stephanie voted with assistance from her mother.

Stephanie's voting experience was not unique. Randy Pierce of Nashua has tried to use the phone-fax system in the last two

#### **VOTING BOOTH**

elections. The first time, the system wasn't even set up. Randy voted with assistance, though this wasn't his preference. The second time Randy tried to vote, the system was set up, but the poll worker was unable to get a dial tone. While the poll worker tried to hunt down someone familiar with the machine, Randy explored the system on his own and discovered the phone wasn't even plugged in. Unfortunately, even after taking care of that detail, the system still didn't work. Again, Randy had to vote without privacy or independence. He told the poll workers, "This is where I live and being able to vote is important to me. If you spent all that money on the system and you don't even know how to use it, what a waste that is."

Larry Ashford of Concord also ended up in a booth full of people scratching their heads, but no working accessible voting system. Larry, a former police officer, once again cast his ballot with the help of a friend. These were not isolated incidents; on Election Day the Disabilities Rights Center received several calls from people across the state who were unable to use the phone/fax machine.

Stephanie, who serves on the Advocacy Committee of the New Hampshire Association for the Blind, brought up her experience to the Committee and learned that most of the of the other committee members also had problems, only two had successfully voted using the phone-fax machine.

"I just want a system that works, that I can do independently," Stephanie said.



Members of the Advocacy Committee discuss the phone-fax voting system.

Pictured, L to R, Leigh Fredericks, Amy Nichols, Guy Woodland,

Stephanie Hurd.Not pictured: Carol Holmes, Marsha Clark.

#### ADVOCACY COMMITTEE – NEW HAMPSHIRE ASSOCIATION FOR THE BLIND

After the last election, the Advocacy Committee of the New Hampshire Association for the Blind met with Tom Manning, Assistant Secretary of State, to discuss the failures of the accessible voting system. The Committee brainstormed ways to improve voter experience in this fall's elections. Their top priorities were poll worker training on use of phone-fax machine and training for blind voters on how to cast their ballot using this system. The Association for the Blind has applied for a grant from the Secretary of State to provide this training. In addition to working on voting issues, the Advocacy Committee has advocated for improved access and safety for blind people. Pedestrian safety is a major concern. The Committee has worked with the Division of Motor Vehicles to educate new drivers about the law that requires cars to

They developed a placard that is given to all new

come to a complete stop when a blind person is crossing.

drivers that explains the law and identifies the symbols of blindness. The Committee also successfully advocated for the inclusion of a question related to blind pedestrians on the driver exam.

Currently, the Advocacy Committee is collaborating with Concord Hospital to produce a training video for hospital staff on how to make medical services accessible for blind patients.

Kids, a mortgage, car payments, taxes to pay...and the list goes on! This describes many of us. With all these obligations tugging at families it is easy to let civic responsibilities drop. It never ceases to amaze me how many people either don't vote or do not fully understand what they are voting for. While there are others who do everything they can to fulfill their civic responsibilities. How do some get so involved? How do they find the time?

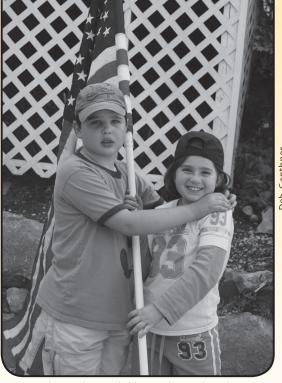
This is my story.

I am married with two kids, a mortgage, and a car payment and yes we also pay taxes! When our children came along I changed job titles going from manager to stay-at-home Mom. Whenever I begin something new I immerse myself; I learn as much as possible, get to know new people, and find ways to get involved. As a new mom, I organized playgroups, frequented local playgrounds, and read everything I could about raising children. When our three year old son was diagnosed with autism my life was again shaken up. New books were read, workshops attended, and I joined the PTA and the Autism Society of New Hampshire.

When I learned about the Institute on Disability's New Hampshire Leadership Series from a fellow workshop attendee I had to find out more. In 2005 I attended and graduated from the Leadership Series. Leadership gives you tools to become a better advocate for yourself and your loved ones with disabilities. In Leadership I learned about the history of disabilities in New Hampshire, best practices in education, community organizing, the legislative process, and how to have the good life for all. I was inspired. As I went through the Series, I wondered how can I be a better advocate for my son, as well as for my daughter? Being informed and getting involved that is how! In addition to the seven Leadership sessions, the fieldwork assignments provided valuable opportunities for growth. We were asked to learn about our town government by meeting with local officials and attending a meeting of a town board. I met with Heidi Carlson, Freemont's amazing Town Administrator and asked questions about how our town offices function. She encouraged me to serve on the town's Parks and Recreation Commission. As a member of this commission I learned about the town's budget process and got to know many hardworking town employees. In an effort to gain a better understanding of how our school system is managed, I also attended School Board meetings. At graduation, Leadership participants are asked to state their future goals. I thought how could I make a difference? What did I want to do next? I decided that my long-term goal was to become a School Board member.

Getting involved in my community was another beginning for me. The more I learned, the more I was

> concerned for our children's future. While the economic crisis has been a challenge, I believe where there is a will there is a way... determination and persistence makes the difference. In 2007, one of the School Board members asked me to consider running for an open seat on the Board. I was intrigued, but nervous. While I am passionate about the education and future of all children, I thought my goal of serving on the School Board would be a few years down the road. However, with encouragement from my husband I decided to run. (Continued on page 10)



Deb Genthner's children, Alex and Jackie, showing their patriotism.



### **REFLECTIONS ON LEADERSHIP**

Dennis Powers, Executive Director, Community Support Network, Inc.

When I moved to New Hampshire twenty years ago, I discovered a very curious thing. In other states where I had worked, families and individuals with disabilities had very little say in how the system operated. That was left to bureaucrats like me. Any family member who spoke out did so at the risk of being labeled "difficult" or "unreasonable."

What I found here was something quite different. Families had not only been instrumental in closing the state institution, but a new generation was shaping the way local school districts and area agencies provided supports to their kids. As I got to know some of these families, I realized that they shared certain characteristics. They were passionate, articulate, informed, politically

connected, and willing to do whatever it took to build a life for their loved ones. They also had one other thing in common – they were invariably graduates of the New Hampshire Leadership Series, a program developed by the Institute on Disability at the University of New Hampshire.

Through the years as more and more people graduated, they brought their new-found leadership skills to the board of directors, family support councils, and local school boards, as well as assumed critical staff roles at the agency. I often heard them describe their Leadership experience as "life changing." On a broader scale, they were also changing the system.

It was around this time that my own personal involvement with the Leadership Series began. At first it involved an annual Friday afternoon visit for a 15-minute welcome and overview of the system. I was always struck by the level of energy and excitement in the room—certainly not a result of my presentation! Then one afternoon a few years ago I got a call from Frank Sgambati on my cell phone as I was driving down I-93. In his own unique style, he asked if I would be a group leader for the next session and rattled off a series of dates and topics. He ended the conversation by saying "Don't worry, you'll love it!" Three years later, I can honestly say he was right.



New Hampshire Leadership Series 2010 Graduating Class

These past three years have given me the opportunity to work with as talented and committed a group of people as I've ever known including Beth Dixon, Janet Williamson, Frank Sgambati, Kathy Bates, Sönke Dornblut, and now Gordon Dubois. They put in countless hours, making every session a positive experience for each participant. In their spare time they are out scrounging for every nickel to keep the Series going.

I have also had the opportunity to meet and listen to the hopes and dreams of many emerging leaders as they travel down their unique paths of discovery. To me there is nothing more rewarding than watching someone struggle to define their vision and then go out and make it a reality.

Many people my age worry about where the new leadership will come from when we retire. I don't.

It's already here.

If you would like more information about the New Hampshire Leadership Series visit their website at www.nhleadership.org or contact Beth Dixon at 603.228.2084 or email Beth.Dixon@unh.edu

NEWS YOU CAN USE

#### KNOW YOUR RIGHTS WHEN APPLYING FOR AND

By: The Disabilities Rights Center, Inc.

Medicaid Waiver programs are designed to provide essential supports and services to individuals with disabilities that allow them to remain in their homes rather than being required to enter an institution in order to receive needed services. The Disabilities Rights Center (DRC) recently learned that some New Hampshire residents are not receiving adequate and timely notice either when applying for Waiver services or when their existing Waiver services are discontinued, suspended, terminated, or reduced. It is important that individuals who are applying for and receiving the essential supports and services funded through the Medicaid Waiver programs understand their rights.

#### What Are Waiver Programs?

Medicaid Home and Community-Based Care Waivers (sometimes called a "Community Care Waiver") are programs that allow certain Medicaid rules to be waived so that services that Medicaid would normally only pay for in institutions or intermediate care facilities can be provided in community settings and covered under Medicaid. New Hampshire has four separate Waiver programs for specific groups of people: elderly and chronically ill (ECI Waiver or CFI "Choices for Independence" Program), people with developmental disabilities (DD Waiver), people with acquired brain disorders (ABD Waiver), and certain children from birth to age 21 receiving in home supports (IHS Waiver).

## What are my rights when applying for Waiver Services?

While you are not permitted, under federal law, to be on more than one Waiver at a time, you may be eligible for more than one program. You have the right to apply for any Waiver program and even may chose to apply for all Waiver programs. Deciding which Waiver programs you want to apply for is *your* decision. You have the right to have your Waiver application(s) formally reviewed for eligibility. If you are deemed eligible for more than one Waiver, it is your right to determine which Waiver you would like to be

served under. In New Hampshire, the state's Department of Health and Human Services (DHHS) is responsible for reviewing applications and determining eligibility for all the Waiver programs.

Federal law requires that DHHS make a decision on eligibility and notify you within 90 days of your application for medical assistance on the basis of disability. DHHS must determine eligibility within this 90 day time period except in "unusual circumstances" and must document the reasons for any delay in your case record.

When you apply for the ECI Waiver/CFI Program, you may also request that DHHS make a presumptive eligibility determination. If you qualify for presumptive eligibility, you will receive Waiver services until DHHS makes a final determination regarding your eligibility.

## What are my rights when I am denied eligibility for a Waiver Program?

If you are denied eligibility for a Waiver program, DHHS must provide you with written notice of this decision. The written notice must contain a statement of the intended action, reasons for the denial, specific legal support for the denial, and an explanation of your hearing rights, rights to representation and to continued benefits, if applicable. You have the right to appeal an eligibility determination and to have a fair hearing in front of the DHHS Administrative Appeals Unit.

## What are my rights when my Waiver Services are discontinued, terminated, suspended, or reduced?

Once you are found eligible for a Waiver program, you have a right to receive those services with "reasonable promptness". If you are already part of a Waiver program and DHHS decides to deny coverage for a Waiver service or decides to discontinue, terminate, suspend, or reduce *any* Waiver service, DHHS must provide you with written notice of this decision. DHHS must mail a written notice to you at least 10 days before it intends to take the action.

#### RECEIVING MEDICAID WAIVER SERVICES

The written notice must contain a statement of the intended action, reasons for the action, specific legal support for the action, and an explanation of your hearing rights, rights to representation and to continued benefits, if applicable. You have the right to appeal *any* decision regarding *any* Waiver Service and to have a fair hearing in front of the State.

If you are told verbally that you cannot apply for a particular Waiver Program or if you are told verbally that you are not eligible for a Waiver Program you should request written notice of this decision.

If someone asks you to discontinue, terminate, suspend, or reduce your Waiver services, you do not need to agree to this decision. You have a right to written notice of the action and have the right to appeal any decision related to your Waiver services.

The Bureau of Elderly and Adult Services (BEAS) within DHHS manages the ECI Waiver/CFI Program. You can

apply for this Waiver by contacting DHHS directly or contacting the regional ServiceLink Resource Center in your area. DHHS's Bureau of Developmental Services (BDS) manages the ABD and DD Waivers. You can apply for these Waivers by contacting the Area Agency in your region. Information on the locations of Area Agency or ServiceLink offices in your area can be found on the DHHS website at www.dhhs.state.nh.us.

If you would like more information regarding your rights to Waiver services or if you have submitted an application for a Waiver and have not received an eligibility determination within 90 days or if you have had your Waiver services discontinued, terminated, suspended, or reduced and you did not receive adequate written notice, please contact Cindy Robertson or Rebecca Whitley at the Disabilities Rights Center, Inc. at 1-800-834-1721 (voice or TTY). For more information you can also visit our website at www.drcnh.org.



#### (Continued from page 8)

I was elected and in my first term learned that public education is a complicated process. The public school system is legally responsible for educating everyone – students with disabilities, those labeled exceptional, and everyone in between. All children deserve to receive the best education we can afford. As a Board member I have come to appreciate just how vital it is that voters understand that every vote is important, one vote can make a difference in keeping a program

or teacher or a sports team. We all need to educate ourselves, become informed, and get involved.

I recently began my second term on the School Board. I have continued to learn and to be an advocate for all children. I truly believe that the inclusion of all children in our schools will lead to the inclusion and acceptance of all adults in our communities. What more could we want or need in this world?



#### CHANGING HOW WE THINK ABOUT DISABILITY

Nick Holzthum, graduate White Mountain School

During my senior year at the White Mountain School I organized a *Multi-ability Awareness Day*. I wanted to create a cultural shift in how we think about people with disabilities; I focused on the idea that disability is a natural occurrence in life. In my project I explored the social, cultural, and political aspects of people with different disabilities. I organized small groups with guiding questions to provided opportunities for lively student discussions. To increase awareness about the challenges of integrating people with disabilities as equal and fully contributing members of society, I invited film producer, Dan Habib to screen his documentary, *Including Samuel*, and speak to students and faculty at the school.

My primary goal was to create a dialogue about disability as a civil rights issue. My hope was that our school community would gain a deeper understanding of the impacts of disability on society and society on those who have disabilities. Long-term, I hoped that this event would lead to future activities at the school, inclusion of disability issues in the curriculum, some type of activism on campus, and ultimately, the enrollment of students with greater levels of disabilities at White Mountain School.

I believe that *Multi-ability Awareness Day* achieved its main goal of arousing curiosity and creating an open dialogue about disability as a social issue. I began the day by showing a video clip of Martin Luther King's "I Have a Dream" speech at the morning meeting. I wanted to catch students off guard and to set the tone for the day. During the morning there were small group discussions where we looked at disability from multiple perspectives.

In the afternoon Dan Habib screened his film *Including Samuel*. Afterwards he led a dynamic discussion about what it is like living with a disability. The discussion raised some tough points about inclusion at our own school. One of the more heated debates was whether our school is fit for a person with a moderate to severe disability. Dan, along with many students, challenged people to think about alternative activities or slight adaptations that would make inclusion possible. The biggest hurdle that Dan and the student body identified was the physical inaccessibility of the buildings on campus.



Nick Holzthum (far left) sharing ideas at the 2010 National Youth Inclusion Summit in Washington, DC.

#### IDEAS FOR HOW YOU IN YOUR SCHOOL

- ◆ Stop using the R word and other derogatory comments about persons with disabilities
- ◆ Invite someone with a disability who is sitting alone to join you. Ask about their interests and get to know them. Don't just try to be nice!
- ◆ Organize a club that promotes disability awareness.

Over all I would say that this day was the most successful event I ever worked on. I would like to refine it further and spread it to other schools.

An unexpected outcome of my project was the opportunity to participate in the National Youth Inclusion Summit in Washington DC in January 2010. At the Summit, twenty teenage activists from around the country worked to develop a national advocacy campaign to build awareness and support for inclusion. In less than 48 hours we created two public service announcement videos. Following the Summit I built my own website the flipsideofdisability.org The website includes information about *Multi-Ability Awareness Day* and a collection of ideas and thoughts about disability issues.

Nick Holzthum will be attending the University of New Hampshire where he plans to major in philosophy and disability studies.

## CAN INFLUENCE CHANGE COMMUNITY:

- ◆ Create your own Multi-Ability Awareness Day for your school (visit flipsideofdisability.org for ideas)
- ◆ Screen the film *Including Samuel* and organize student discussions about the film.
- ♦ Write an Op-Ed piece for your local newspaper to educate the public about disability rights

# ABLE-NH – AN INDEPENDENT VOICE

Jan Larsen, ABLE-NH founder and Board member, NH Challenge, writer and advertising manager and Susan Covert

ABLE NH stands for Advocates Building Lasting Equality in New Hampshire. This statewide advocacy group is made up of individuals with disabilities, parents, family members, and others who are seeking to improve the quality of life for individuals with developmental disabilities and acquired brain disorders. ABLE NH is the result of a collaborative effort by the Institute on Disabilities, the Council on Developmental Disabilities, and the Disability Rights Center. In early 2007 these organizations brought together individuals with disabilities, family members, and advocates from across the state to discuss the need for an independent organization — one not tied to state agencies — that could effectively advocate for individuals with disabilities and their families.

In earlier years the state chapter of the Arc was the primary independent advocacy organization for those with developmental disabilities and provided the leadership that led to the closing of the Laconia State School. (With this mission accomplished, the Arc disbanded several years ago.) Initially, the planning group looked into reinstating a state chapter of the national Arc, however, after much consideration they made the decision that an independent New Hampshire-based organization made the most sense. ABLE NH was created and the following mission statement was adopted.

ABLE NH advocates for the civil and human rights of all children and adults with disabilities and promotes full participation by: improving systems of supports, connecting families, inspiring communities, and influencing public policy.

ABLE NH is incorporated as a nonprofit organization. The three founding organizations have representatives on the Board of Directors; the majority of the board is comprised of individuals with a disabilities and family members.

Since its inception, ABLE NH has taken an active role in the state. Members of ABLE have testified before the legislature, a representative of ABLE NH serves on the New Hampshire Developmental Services Quality Council. The organization has conducted an Advanced Leadership workshop and hosted a presentation at the New Hampshire Family Support conference.

ABLE NH is a membership organization and invites individuals with disabilities, family members, and anyone who cares about its mission to join. To learn more and to become a member, visit the organization's website at albenh.org.

Jan Larsen can be reached at askjannhchallenge@msn.com

#### ♦ ♦ ♦ WAYS TO MAKE A DIFFERENCE ♦ ♦ ♦

- ◆ VOTE!
- → Encourage your friends and family to vote.
- Make sure your kids who are away at college vote absentee or register to vote where they are going to school (if this allowed in that state).
- Near Election Day, post a notice on your apartment bulletin board or near mailboxes with the voting times and the polling place for your neighborhood.
- → Go to Town Meeting and School District Meeting speak up about issues that are important to you.
- Go to City Council, Board of Selectmen, and School Board meetings.
- ◆ Commit to really getting to know one of your state representatives. Build a relationship, keep in touch, and share your positions on key issues.
- Add your legislators' email addresses and telephone numbers to your address book. When you need to ask for their vote, you won't need to research their contact information.
- Attend legislative hearings and speak up on issues you care about or provide written or provide written testimony.
- ◆ Thank your legislators when they vote the right way.
- Join your Area Agency Board of Directors, Family Support Council or agency sub-committees.
- Participate in your Area Agency events donate raffle items, sell tickets, serve on an organizing committee, and attend fundraising and recognition events.
- ♦ Write a letter to the editor about an issue you care about.
- Write a letter to the editor about something positive that has happened in your town.
- + Run for office.
- → Campaign for a candidate you believe in.
- → Hold a sign for a candidate on Election Day.
- → Put a candidate's sign on your lawn.

- → Volunteer with an organization whose mission you believe in.
- ♦ Share your wisdom, especially if you're a Leadership graduate. Put that expensive training to good use.
- Join your town's Recreation Committee and work for inclusion and accessibility.
- → Volunteer to serve on your community's Zoning Board and advocate for accessibility.
- ◆ Write for your local newspaper; editors are always looking for people to cover school board meetings and local events. This is a good way to empower yourself – ask questions about resources, access, and services for people with disabilities..
- Wherever you volunteer raise awareness about the need for inclusion and accessibility.
- ◆ Start, foster, and sustain a support group around an issue you care about.
- → Become a facilitator for friendship groups.
- → Participate in Walks or Fun Runs for a cause.
- → Go to parades.
- → Organize or join a group around a personal interest bike riding, crafting, gardening.
- → Host a neighborhood potluck.
- → Organize a summer block party.
- → Scouts have over 140 merit badges; contact a troop to teach a topic you're an expert in.
- ◆ Do a presentation for your school district on the topic of civil rights for all.
- ◆ Join the PTA.
- → Run for School Board help to insure that your district supports inclusion, hires teachers and administrators who care about disability issues, and complies with special education laws.
- Attend concerts, plays, Celebration of the Arts, and other school events.
- → Volunteer to listen to elementary students read.

- → Be a fan support your town's local sports teams.
- ◆ Visit a nursing home. If you can't visit, call and ask if there is a resident who would enjoy receiving mail or e-mail.
- → Get a library card. Check out library programs and activities. Be a library volunteer.
- → Respond to telephone surveys and polls.
- → Volunteer to serve on a State Board or Commission there is often a "public member" seat.
- → Shop local support Main Street businesses, be a regular at the Farmers' Market.
- → Be informed about issues in your community.
- ♦ Attend public hearings about issues that affect your community.
- ◆ Attend a variety of community activities to learn about potential volunteer opportunities.
- → Reach out to a refugee family.
- ♦ Bring a meal to an older neighbor or to a friend who is sick.
- → Don't wait to be asked to participate.
- → Introduce yourself (to almost everyone!).
- → Reach out to people who may feel left out and invite them to be part of something.
- → Pick up litter.
- + Share a ride.
- → Volunteer at your local food pantry or soup kitchen.
- → Cultivate a plot in a community garden.
- → Recycle.
- ◆ Do a neighborhood food collection for the local food pantry.
- → Say Thank You.
- ◆ SHOW UP As Woody Allen noted, "80% of success is showing up."

Thanks to – Kathy Bates, Robin Carlson, Gina Colantuoni, Bonnie Dunham, Jocelyn Gallant, Nathan Gams, Susan Gunther, Lorna Landry, Jim Latouche, Tamara Le, Marie Primeau, Chrissy Shaffer, Cathy Spinney, Maureen Tracy, Kathryn Wallenstein, Miriam West, and Jeff Williamson



Michael Skibbie, Policy Director, Disabilities Rights Center

The 2010 session of the New Hampshire Legislature was dominated by the state's fiscal crisis. Cuts to services were threatened and implemented on what seemed like a constant basis. Any suggestion that a piece of progressive legislation would carry even a minimal cost was enough to jeopardize its passage. As the regular session drew to a close, substantial uncertainty remained about how many more cuts in services would be made during the budget revision process.

Despite the grim budget environment, the session did result in several victories for adults and children with disabilities:

#### INSURANCE COVERAGE FOR TREATMENT OF AUTISM AND PERVASIVE DEVELOPMENTAL DISORDER (HOUSE BILL 569)

Even though New Hampshire has a state law requiring parity in medical insurance coverage for the treatment of behavioral and other medical conditions, insurers have continued to deny coverage for therapies that have proven to be effective for autism spectrum disorders and pervasive developmental disorder. This session, the House and Senate passed legislation clarifying that those therapies must be covered under group medical insurance policies. While the coverage is subject to monetary limits and the new legislation will not affect all policies, many more children will now be able to access treatment that can provide lifelong benefits. During consideration of the bill, legislators heard testimony that as much as \$1.9 million per effectively treated child can be saved in adult developmental services and other expenses that are associated with the lack of early treatment.

(Continued on page 16)

## INSURANCE COVERAGE FOR HEARING AIDS (HOUSE BILL 561)

Legislation was also passed this session that would require group medical insurance policies to cover hearing aids and associated services; under the bill insurers are required to provide coverage for hearing aids every 5 years, subject to a \$1500 limit per hearing aid. The new law is the result of years of effort – this bill was carried over from last session to allow further legislative study and an analysis by the New Hampshire Insurance Department. This expansion of coverage has the potential to improve thousands of lives in New Hampshire, as some estimate that as many as one in ten of us experience hearing impairment.

#### REGULATION OF RESTRAINT OF CHILDREN IN SCHOOLS AND TREATMENT FACILITIES (SENATE BILL 396)

Beginning this fall, children in New Hampshire schools, treatment settings, and juvenile justice facilities will be protected against restraint techniques that are known to cause injury and death. In addition, even restraint techniques considered to be safe will no longer be permitted in such settings except to prevent serious injury. During its consideration of the child restraint bill, legislators heard about the dangers of inappropriate restraint from advocates, parents, and experts in medicine and child behavior. They also learned how restraint usage has been successfully reduced in many settings with fewer instances of injury and trauma to children and increases in the productivity and effectiveness of staff. The legislation requires regular reports by the Departments of Education and Health and Human Services on patterns of restraint usage in a variety of settings.

# FINANCIAL LIABILITY FOR PARENTALLY PLACED CHILDREN WITH DISABILITIES (SENATE BILL 520)

New Hampshire law has been silent on the question of how special education responsibilities are apportioned when children attend schools outside of their home districts through a tuition agreement. Although many in the educational field assumed that the district in which the child resides would be responsible for costs associated with special education, that belief was thrown into question by a ruling by the Department of Education. The Department's ruling jeopardized the practice of allowing students residing in one district to attend a school in another, either by paying tuition or through tuition agreements. Tuition agreements are often included in school districts' collective bargaining agreements with teachers; permitting teachers who live outside the district to have their children attend school in the district has been a factor in helping to attract and retain quality staff. Previous legislation addressing this issue has failed to move forward, but in this session, the legislature passed a bill to allow such tuition agreements and determined that the district of residence has financial responsibility (and decision-making authority) in special education matters. The change in law should be in effect by the start of the 2010-2011 school year.

## INTEGRATED RESIDENTIAL COMMUNITIES (HOUSE BILL 1572)

This bill was brought forward by several residential facilities in the southwestern part of the state. These providers operate residential services that house 15 or more individuals with developmental and/or emotional disabilities and use a congregate service model in which residential, day programs, and other activities are provided on site. The bill proposed a less rigorous licensing status for these facilities and made them part of New Hampshire's service delivery system, which could make these facilities eligible for funding under the Medicaid waiver. The bill passed the House virtually unnoticed after a unanimous recommendation by the House Health and Human Services Committee. In the Senate, the bill was opposed by ABLE-NH, the Developmental Disabilities Council, the Disabilities Rights Center, the Institute on Disabilities, the Community Support Network (the area agency association) and the Behavioral Health Association (the community mental health center association). Opponents brought attention to the problems associated with large congregate and segregated programs. The Senate did not agree with the House version of the bill and amended it to establish a committee to study the advisability of the substantive provisions of the original bill. The House concurred with the changes.

## Civic Involvement Resources

## The Disabilities Rights Center's Voting section

http://www.drcnh.org/Issue%20Areas/Voting.htm

#### NH Secretary of State, Election Division

http://www.sos.nh.gov/electionsnew.html

## US Department of Justice, Civil Rights Division, Voting

http://www.justice.gov/crt/voting/

# How to Turn Out Voters with Disabilities, a publication from the National Organization on Disability

http://www.nod.org/resources/PDFs/get\_out\_the\_vote.pdf

#### Voting Information, from the Bazelon Center for Mental Health Law

http://www.bazelon.org/issues/voting/index.htm

#### Impact, Feature Issue on Political Activism and Voter Participation by Persons with Intellectual and/or Developmental Disabilities

http://ici.umn.edu/products/impact/172/172.pdf

#### GoVoter.org - National Technical Assistance Center for Voting and Cognitive Access

http://www.govoter.org/

#### National Mental Health Voter Empowerment Program, from the National Consumer Supporter Technical Assistance Center

http://www.ncstac.org/index.php?option=com\_content&view=article&id=55&Itemid=58

## American Association of People with Disabilities (AAPD)

AAPD has a legislative advocacy section of their website. http://www.aapd.com/site/c.pvI1IkNWJqE/b.5606939/k.9319/AAPD\_Legislative\_Priorities.htm

#### New Hampshire Democratic Party

105 N. State Street, Concord, NH 03301

Phone: (603) 225-6899

Web site: http://www.nhdp.org/

## New Hampshire Republican State Committee

10 Water Street, Concord, NH 03301

Phone: (603) 225-9341

Web site: http://www.nhgop.org

#### State of New Hampshire

http://www.nh.gov/

## League of Women Voters of New Hampshire

http://www.lwvnh.org/index.html

#### The White House

http://www.whitehouse.gov/

#### **US** House of Representatives

http://www.house.gov/

#### **US** Senate

http://www.senate.gov/



# IOD TRAINING

## 12TH ANNUAL AUTISM SUMMER INSTITUTE

## A NEW View of Students with ASD: Implications for Inclusive Education

Participants will learn practical strategies to support individuals with ASD, their families, and their support systems. Six themebased break out sessions will provide participants the option of a concentrated learning experience in a specific area.

Dates: August 9-12, 2010

Time: MTW - 8:00 to 3:45,

Th - 8:00 to 12:00

Location: Crowne Plaza Hotel, Nashua, NH

Cost:

Full Conference: \* Professionals: \$499

\* Groups of three or more: \$450 each

\* Parents, Full-Time Students,

Self-Advocates: \$350

Single Day(s) (MTW only): \$150 each

Keynote(s) Only: \$50 each

Keynote Presenters: Ari Ne'eman, Cheryl M. Jorgensen,

Jeff Strully, Judy Endow, Larry Bissonnette, and Tracy Thresher

\*A limited number of rooms at a reduced rate of \$109 per night are available to ASI participants. To make reservations, call 603.886.1200. Please mention the ASI to guarantee reduced rate. Rate available through July 9, 2010.

## FIFTH ANNUAL APEX SUMMER LEADERSHIP INSTITUTE

Improving High School Culture and Climate through Teamwork, Leadership, and Data-based Decision-making

An opportunity for high school teams - comprised of school administrators, teachers, and other staff; community mental health providers; students; and parents - to build knowledge, skills, and resource connections that will improve school culture, student engagement, student achievement, and graduation rates.

Dates: August 18-19, 2010

Time: W - 8:00 to 4:15, 6:00 dinner;

Th - 7:30 breakfast, 8:30 to 1:15

Location: Attitash Grand Summit Hotel and

Conference Center, Bartlett, NH

Cost: \$275

\*Dinner on 8/18: \$35 (additional)

\*Includes breakfast and lunch on 8/18 and 8/19.

\*Does not include accommodations. Please contact the Attitash Grand Summit Hotel at 603.374.1900 to make reservations.

Keynote Speaker: Dr. George Sugai

Featured Presenters: Hank Bohanon, Ph.D.; Dan Habib;

LeDerick Horne; Howard Muscott, Ed.D.; William Preble, Ph.D.; Scott Ross, Ph.D.; and Jessica Swain-

Bradway, Ph.D.

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mail a completed registration form INSTITUTE ON DISABILITY
56 OLD SUNCOOK ROAD, SUITE 2
CONCORD, NH 03301



fax a completed registration form **603.228.3270** 

# SUPPORTING FRIENDSHIPS! FACILITATING SOCIAL NETWORKS FOR YOUNG ADULTS WITH DISABILITIES

Learn about social networking and the role that a facilitator can play in supporting friendships and developing a network. We will also discuss potential funding sources for facilitation and make plans for ongoing training, support, and mentoring for families and facilitators who are interested in forming a social network for someone.

Date: September 13, 2010

Time: 9:00-3:00

Location: UNH Institute on Disability

Professional Development Center

Cost: \$85

Presenter: Lisa Hasler

# & EVENTS

### 2010 REAL CHOICE CONFERENCE

The Real Deal: Yesterday's Successes Shaping Tomorrow's Choices

Sharing lessons learned, sustaining momentum, and exploring future opportunities

Date: September 21, 2010

Time: 8:00-3:30

Location: Center of NH Radisson,

Manchester, NH

Keynote Presenter: Bill Hall, MD

## PICTURE THIS! THE ART OF GRAPHIC FACILITATION

An accelerated learning experience in graphic recording and facilitation where participants will develop basic skills in using visual language to record meetings. Provides examples of visual strategic planning and problem solving tools that can be used to organize information "in the moment".

Date: September 24, 2010

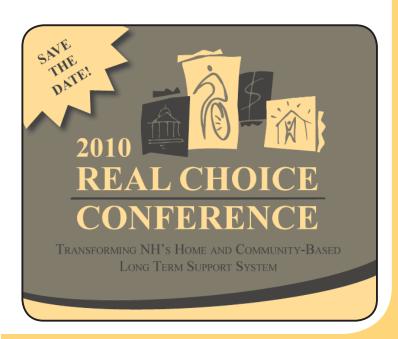
Time: 9:00-3:00

Location: UNH Institute on Disability

Professional Development Center

**Cost**: \$99

Presenter: Patty Cotton, M.Ed.



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- ♦ Help America Vote Act
- ♦ Legal Rights for Medicaid Services
- ♦ New Hampsbire Leadersbip Series
- Personal Stories

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18 Low Avenue, Concord, NH 03301-4971

Voice and TDD: (603) 228-0432 ◆ 1-800-834-1721 ◆ FAX: (603) 225-2077 TDD access also through NH Relay Service: 1-800-735-2964 (Voice and TDD)

"Protection and Advocacy System for New Hampshire"

The Disabilities Rights Center is dedicated to eliminating barriers to the full and equal enjoyment of civil and other legal rights for people with disabilities.

#### INSTITUTE ON DISABILITY/UCED - UNIVERSITY OF NH

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

Phone (Tel/TTY): (603) 862-4320 ♦ Fax: (603) 862-0555 ♦ Website: www.iod.unh.edu

#### Institute on Disability/UNH - Concord

56 Old Suncook Road, Suite 2

Concord, NH 03301

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

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

#### NH COUNCIL ON DEVELOPMENTAL DISABILITIES

21 South Fruit Street, Suite 22, Room 290

Concord, NH 03301-2451

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

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

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