



Summer 2003

# DELAWARE

A collaborative effort of the Center for Disabilities Studies & the Delaware Developmental Disabilities Council

## ABOUT THIS ISSUE

Our annual update issue gives us an opportunity to highlight the progress of current Delaware Developmental Disabilities Council (DD Council) and Center for Disabilities Studies' initiatives. As I reflect on the articles in this issue of *delAware*, I am struck by how such diverse articles can carry a common theme.

The DD Council advocates for change and educates the community about the preferences and needs of people with developmental disabilities. Our two major articles concentrate on the federal and state legislative process. By providing you with information about current state and federal legislation, we hope you will become more aware of the impact of these changes on Delaware constituents, as well as the need to advocate for legislation that will improve services for all Delawareans. Contact information for federal and state elected officials, as well as advocacy groups in Delaware, is provided for you to advocate for legislation or volunteer with an advocacy organization.

The Youth Involvement Initiative and the Fatherhood Initiative, two new projects of New Directions Early Head Start, train young adults and men to become role models and mentors for children and youth in their communities. Both programs rely on youth and adult volunteers to serve the needs of children in their communities.

The Early Learning Center (ELC) of the University of Delaware is scheduled to open in June to house a range of inclusive childcare services for approximately 225 children. Research and training opportunities for University of Delaware undergraduate and graduate students will also be offered through the ELC. University of Delaware students will have opportunities to learn how to serve the needs of children, families, and the community.

And, lastly, brief descriptions of research efforts funded by the Interagency Resource Management Committee (IRMC) highlight studies that focus on early childhood issues. These research projects can educate Delawareans on the needs of young children in the state.

While this issue of *delAware* does provide insights into DD Council and Center for Disabilities activities, the articles also express a more significant theme of education and advocacy. By educating ourselves on current federal and state legislation, as well as the needs of children, families, and our community, we are able to advocate for services and policies that will improve the lives of all people in Delaware.

Sincerely,

Tracy L. Mann  
Editor

*delAware* is sponsored by the Center for Disabilities Studies, University of Delaware and the Delaware Developmental Disabilities Council. If you would like to contact us, please call (302) 831-6974 or TDD at (302) 831-4689, fax (302) 831-4690, email to Tracy Mann, tlm@udel.edu, or write to *delAware*, University of Delaware, Center for Disabilities Studies, 166 Graham Hall, Newark DE 19716.

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## The State Legislative Process: Legislators and advocates discuss current legislative issues



You can advocate for the issues that are important to you, by participating in the legislative process.

In this article, four noted Delaware disabilities advocates discuss the role of advocacy in the state's legislative process. Discussants include the following:

- State Representative Pamela Maier (R- Drummond Hill);
- State Senator Patricia Blevins (D-Elsmere);
- Brian J. Hartman, Esq., Project Director, Delaware Disabilities Law Program (DLP); and
- Kyle Hodges, ADA Coordinator and Administrator for the Delaware State Council for Persons with Disabilities (SCPDP).

These advocates offer a step-by-step description of Delaware's legislative process and relate that process to five issues that are important to Delawareans with disabilities, including:

- victims and witnesses (H.B. 65),
- statute of limitations (H.B. 66),
- workforce issues (H.J.R. 3),
- accessible parking (H.B. 64 and H.B. 172), and
- Medicaid buy-in (an issue that is still garnering support and has not yet reached Delaware's General Assembly).

### Step-by-step legislative process

DLP Project Director, Brian Hartman, names the sequence of four steps of Delaware's legislative process as follows:

1. Develop the concept for a bill.
2. Obtain a prime sponsor.
3. Secure legislative counsel to draft the bill according to the prime sponsor's request.
4. Encourage other legislators to sign on as co-sponsors when the prime sponsor circulates the bill.

"Typically," explains Mr. Hartman, "individuals, who would like to change a state statute, first solicit the support of a prime sponsor or, preferably, a prime sponsor in both the House and Senate. The prime sponsor may then request legislative counsel to draft the bill. Once drafted, the bill is usually circulated among other legislators who may add their names as co-sponsors."

"For example, the DLP drafts legislation. Then, the prime sponsor will generally present the proposed bill to legislative counsel to review only for technical accuracy rather than independent drafting. A common variation on this sequence," continues Mr. Hartman, "occurs if the person or agency with the concept actually presents a proposed bill to a prospective prime sponsor drafted by the agency or independent counsel."

"Once the bill is written up by the attorneys," adds State Rep. Pamela Maier, "advocates try to get a co-sponsor in the House [as well as in the Senate]. This stage of the process gives weight to the legislation."

"It's especially good to get committee members as co-sponsors. Legislation like House Bill 65 [addressing the needs of victims and witnesses with cognitive disabilities] goes to my committee. [Legislators] choose to be on the committee, but the chair is appointed," notes Representative Maier, who has chaired Health and Human Development for six years.

"In committee, the process is mainly of education," continues Representative Maier. "The best time for witnesses and speakers to give testimony, to educate legislators on their needs, is while the bill is in committee. Once the bill gets to the floor, time becomes a factor. Not a lot of testimony goes on in the House, unless requested."

"If you belong to an organization like the DD Council [Delaware's Developmental Disabilities Council], the organization may approach the lead sponsor of the bill and ask to give testimony. The DD Council will be recognized on the floor."

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## Advocacy: Your Turn



While this issue highlights some notable disabilities advocates in Delaware, the voices of individual Delaware constituents contribute immensely to improving services in Delaware. If you, too, would like to advocate for any of the legislation mentioned in this issue or get involved, please contact the following organizations.

**Delaware Assistive Technology Initiative**

302.651.6790 or (800) 870-DATI • [www.asel.udel.edu/dati/](http://www.asel.udel.edu/dati/)

**Developmental Disabilities Council**

302.739.3333 • [www.state.de.us/ddc](http://www.state.de.us/ddc)

**Governor's Advisory Council for Exceptional Citizens**

302.739.4553 • <http://aosta.state.de.us/gov/gacecweb.nsf>

**Parent Information Center**

888.547.4412 • [www.picofdel.org](http://www.picofdel.org)

**The State Council for Persons with Disabilities**

302.739.3613 • [www2.state.de.us/scpd/](http://www2.state.de.us/scpd/)

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"We work hardest for our constituents," assures Representative Maier. "Contact your own personal representative or senator and ask him or her to vote for your bill. We usually decide (that's the majority caucus, which is currently Republican) if we agree with the bill's purpose. If we do, then, [the bill] usually has the votes to pass. Upon passage in the House of Representatives, the bill goes to the Senate which currently holds a Democratic majority."

"The process in the Senate," notes State Senator Patricia Blevins, "differs only slightly from that of the House. The bill is considered in committee, where the public and agency heads are encouraged to testify. These hearings are advertised one week in advance.

"Upon a majority vote of the committee," continues Senator Blevins, "the bill is released to the Senate for action. The bill is floor-managed by the sponsor, if it is a Senate bill, or by the committee chair if it is a House bill. The Senate gives the bill a full debate, including testimony from witnesses, if necessary.

"If the bill is a House bill and it is amended by the Senate," adds Senator Blevins, "it must again be considered by the House. If there are no amendments, [the bill] goes directly to the governor to be signed or vetoed. The governor cannot change the bill but can only accept it or reject it in the exact form in which she receives it."

### Two legislative success stories

Generally known as the "victims and witnesses" bill, House Bill 65 (H.B. 65) was introduced as an amendment to Title 11 of the Delaware

Code in the 142nd session of the General Assembly. Addressing the needs of victims and witnesses with cognitive disabilities, H.B. 65 added rights and protections for Delawareans who are unable to understand the legal process.

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**"A comprehensive workforce plan, which would strengthen partnership between the public and private sectors, is needed to address the complex service needs of all persons with many different disabilities."**

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Advocacy for legislation began a few years ago with a conference that was planned and sponsored by Partners in Justice with the DD Council's backing. "This issue came up," notes Rep. Maier, "that some people with disabilities needed their own version of the Miranda rights, that maybe they needed a friend present to make things understandable. People with cognitive impairments are victims many times over."

The legislation gained momentum with continued, vocal support from the Center for Disabilities Studies and the DD Council. Although some supporters struggled with components of H.B. 65, the advocates banded together to get the bill passed.

"Satisfied with the overall value of H.B. 65," explains the DLP's Brian Hartman, "they decided to endorse the con-

cept of the bill without proposing amendments. If you amend the bill after it has passed one legislative chamber, you will lose momentum. For now, the bill represents a significant improvement over the status quo." As a result, H.B. 65 was passed by both legislative chambers and signed into law by Governor Ruth Ann Minner in June 2003.

Generally known as the "statute of limitations" bill, House Bill 66 (H.B. 66) entered the debate regarding long-time sexual abusers. In recent years, the move toward legislation had gained public momentum, and H.B. 66, sponsored by Representative Maier, eliminated the statute of limitations for prosecuting sexual crimes against both children and adults. A report, given at a DD Council workshop in March 2000, cited a staggering statistic: 90 percent of individuals with developmental disabilities have experienced sexual abuse.

The Senate version, authored by Senator Blevins, focused on people who were under the age of 18 when the alleged crime occurred. "This is a different approach," notes Mr. Hartman. "The Senate bill only applied to crimes involving children. It also extended the time period for prosecution without eliminating the statute of limitations altogether."

In the bill's synopsis, Senator Blevins wrote, "This bill clarifies that the legislature intended its expanded statute of limitations for sexual offenses against children to apply to all persons who perpetrate such offenses, not just persons for whom the statute of limitations had not yet expired when the statute of limitations was originally expanded in 1992.

"Often," explains Senator Blevins, who has chaired the Senate's Health and Social Services Committee for nine years, "when children are sexually abused, they don't come forward until they are adults and have the faculty to realize what has happened to them. So, such crimes go unreported for a very long time. It's important to be able to go back and prosecute this type of crime, particularly, when one individual continues to commit the crime.

"The argument against this," continues Senator Blevins, "is 'Memories fade over time.' People are concerned about unjust prosecution or False Memory Syndrome. But a jury won't usually convict someone

of an old crime based on one person's testimony, one person's word against another. A jury has to convict 'beyond a reasonable doubt.' In many cases, the conviction comes about because of strong evidence or multiple victims."

Overall, Delaware's disabilities advocates supported the legislation. The SCPD endorsed the concept of H.B. 66 and worked successfully for its passage with outspoken supporters such as the DD Council.

Then, one day after Governor Minner signed the legislation into law in June 2003, the U.S. Supreme Court issued a decision on Marion Reynolds Stogner v. California. Addressing the State of California's 1993 criminal statute of limitations for sex-related child abuse, the Court's decision undermined Delaware's successful passage of H.B. 66.

"This legislative success," explains Mr. Hartman, "was muted almost immediately by a Supreme Court decision holding that states cannot constitutionally revive a statute of limitations that has already expired to permit a sex crime prosecution."

### Efforts to change the system

Sometimes, after years of frustration with services, changing the system becomes the best strategy. Many disabilities advocates feel this way about Delaware's service-delivery system, because, according to these advocates, the current system cannot handle the demand. These advocates point to the growing number of people with disabilities who want to move into the community and the lack of available community-based services.

Additionally, agencies that currently deliver services to people with disabilities continue to struggle. Not only is the workforce too small to provide adequate services for Delawareans with disabilities, but the service-delivery agencies cannot provide incentives to attract new employees and keep them in the workforce. As a result, significant agency resources must be used to recruit and train new employees instead of providing services and improving delivery.

In March 2003, several disabilities-related advocacy groups endorsed a piece of legislation that addressed this service-delivery issue. Sponsored by State Rep. Pamela Maier and State Sen. Patricia Blevins, House Joint Resolution 3 (H.J.R. 3) was

supported by the following coordinating agencies: DD Council, SCPD, Governor's Advisory Council for Exceptional Citizens, Freedom Center for Independent Living, and Delaware Association of Rehabilitation Facilities (DeLARF).

These coordinating agencies contend that H.J.R. 3 is necessary because a workforce partnership between the state and community agencies is needed for quality, long-term service.

Commonly referred to as "workforce issues," H.J.R. 3 is actually more comprehensive. "This problem cannot be solved by focusing only on workforce issues," noted the report of the coordinating agencies to The Disability Legislative Event in April 2003, "but [it] also needs to address public policy, resource allocation, and the partnership between the public and private sectors... A comprehensive workforce plan, which would strengthen the partnership between the public and private sectors, is needed to address the complex service needs of all persons with many different disabilities" (p. 12).

To this end, H.J.R. 3 advocates system change, which begins with a study of the workforce issues that are critical to the delivery of services to Delawareans with disabilities and gives responsibility for the study to a newly created task force.

According to Mr. Hartman, the state raised concerns about yet-another task force and suggested revamping the resolution. No action has been taken on H.J.R. 3 since February 2003.

### Supporting the Medicaid buy-in

Many Delawareans with disabilities want the opportunity to work without fear of losing medical benefits. People with disabilities must either need an unrealistic wage to cover what an employer's health insurance denies, or they must find alternative help to meet their medical expenses. For many years, people with disabilities and disabilities advocates have advocated for a state Medicaid "buy-in" which would give consumers the opportunity to work while continuing to receive Medicaid benefits. Consumers who are eligible for Medicaid could purchase medical coverage at a reduced cost.

Last summer, 80 percent of the respondents to the Delaware Health Care Barriers to Employment Survey said

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(Continued from previous page) they would use the Medicaid buy-in program if it were offered. Seventy-three (73) percent of these individuals said they would work if they were assured of not losing their health benefits. In other words, Medicaid buy-in removes one of the major barriers to employment faced by Delawareans with disabilities.

"The state has indicated," states Mr. Hodges, "that it would try to implement the buy-in in Delaware in calendar year 2005, but doing the buy-in is fairly complicated. A change in the system is needed."

Now considered an option by the federal government, Medicaid buy-in has become a major task for each state. Delaware citizens with disabilities could enjoy expanded

employment opportunities, as well as a sliding-scale fee for their medical expenses: a scale which adjusts medical charges according to the patient's income.

In addition to SCPD support, several other advocacy groups support Medicaid buy-in, including Delaware's DD Council. These groups propose modernizing the employment-services system to make it accessible to Delawareans with disabilities, which includes securing health coverage with their employment.

"The role of advocacy here," adds Mr. Hodges, "has been to break down barriers to employment in the health-care context. The state is trying to do what it can, but groups and individuals are also needed to advocate. They could do this

with personal stories about people who would work if they didn't lose their health benefits."

### Accessible parking concerns

Advocacy efforts may start with an unmet need or an awareness of how everyday life can be improved, but those efforts must monitor the legislative process to ensure that the bills being introduced truly address the issues important to persons with disabilities. Accessible parking legislation began as House Bill 64, passed the House in March, but was "laid on the table" in the Senate in April.

According to Mr. Hartman, the new "parking bill," House Bill 172, essentially took the place of H.B. 64 and adopted a different approach.

For example, H.B. 64 required legal entities (businesses) to set aside parking spaces for people with disabilities and also erect and maintain the signs and markings indicating accessible parking, as defined by federal and state law. Penalties included \$50 for a first offense and \$100 for subsequent offenses.

In contrast, H.B. 172 requires a county government or municipality to adapt regulations for this signage. H.B. 172 includes provisions for penalties as well as for enforcement, an issue near and dear to the hearts of many disabilities advocates. In fact, this legislation was designed to address two concerns of drivers with disabilities:

- parking spaces that are clearly marked and reserved for people with disabilities; and

- a law that is written in such a way that it can be enforced.

"This legislation requires local governments to take the lead in prompting businesses to maintain proper signs," sums up Mr. Hartman. "After a warning, violators are subject to penalties defined in local ordinances."

Thanks to advocacy in the state legislative process, both chambers of the 142nd Delaware General Assembly passed a parking bill that meets the needs of people with disabilities. In July 2003, Governor Minner signed H.B. 172 into law.

To advocate for any of the aforementioned state legislative issues, please see:

Advocacy: Your Turn, page 2.

## The impact of current advocacy and federal legislative activity



While advocacy is often described as a challenging and exhausting activity, the benefits of advocating for the issues you support are immense. In the spring of 2003, advocacy for all people with disabilities at the national level remained crucial.

In order to effectively advocate for the issues you support, an understanding of current federal legislative activities is vital. For an overview of current advocacy happening on the national level, this article features six examples of disabilities issues debated in Congress this spring.

### The need for attendant services

Some disabilities advocates are finding success by educating elected officials and the public regarding the impact of proposed federal legislation on Delawareans. Both houses of the 108th U.S. Congress, for example, are expected to reintroduce the Medicaid Community Services and Supports Act (MiCASSA). With President George W. Bush's signature, MiCASSA would

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**"The best way to be involved," advises the DD Council's Patricia Maichle, "is to advocate on your own behalf. Educate yourself, and get involved."**

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become law, and consumers could expect hard-won community-based supports and services. Instead of being based on diagnosis or age, services would be provided in integrated settings according to each individual's choice and needs. People with disabilities can also expect a choice of service-delivery models and funding to help with the cost of transition into a community-based setting, as well as the availability of a consumer-authorized advocate to assist in the process. All in all, MiCASSA promotes consumer control and satisfaction.

Many Delawareans have been passionately advocating for community-based services for many years. Their successful advocacy in support of MiCASSA is demonstrated by the support of Delaware's Senator Joseph R. Biden. Senator Biden is a cosponsor of Senate Bill 971, introduced on May 1, 2003, the most recent MiCASSA legislation in the Senate.

"We asked Senator [Joseph R.] Biden for support on MiCASSA, and he gave it," says Patricia L. Maichle,

Senior Administrator of Delaware's Developmental Disabilities Council (DD Council). Ms. Maichle urges, "Contact your congressional leaders. They will respond to you. They may not always agree, but you'll know they're taking your opinion into account. Just because they don't agree, shouldn't stop you from giving your opinion. The best way to be involved," advises Ms. Maichle, "is to advocate on your own behalf. Educate yourself, and get involved." (See page 4, Your Federal and State Elected Officials.)

### Free Our People March on Congress

On September fourth, over one hundred members and supporters of Adapt, a disabilities rights advocacy group, met in Philadelphia to launch the Free Our People March. Traveling 144 miles to Washington, DC, activists and supporters hoped to raise awareness about providing choice and opportunity for people with disabilities to live in the community with the services and supports they need.

On September 17th the largest disabilities rights rally in history took place in Washington, DC, with an estimated 20,000 people attending. Activists gathered in Upper Senate Park to celebrate the 20th anniversary of Adapt and rally in support of MiCASSA.

Daniese McMullin-Powell, Adapt Delaware's organizer, discussed the purpose of the March and the rally in DC. "We need to free our people. We need choice and opportunities to live in the community. We need money to follow the individual into the community [as they transition from a nursing home]. We need MiCASSA to do that!"

For more information on Adapt or the Free Our People March, contact Ms. McMullin-Powell, 302-376-4399 or visit [www.freeourpeople.org](http://www.freeourpeople.org).

### Preventing child abuse

In 1974, Congress enacted the Child Abuse Prevention and Treatment Act (CAPTA) to acknowledge, treat, and, most importantly, prevent child abuse. Today, experts agree that legislation like CAPTA continues to be important, estimating that between 3 million and 5 million children are abused in the U.S. every year.

According to Ms. Maichle, children with disabilities are almost four times more likely to be victims of abuse and neglect than children without disabilities. Due to lack of funding, less than half of the children who are abused or neglected receive any services. The majority of public policies, instead of preventing the abuse from

ever happening in the first place, focus on treating children after they have been abused. CAPTA is essential because it is the only federal program that provides families with the primary tools for prevention.

This spring, Congress's agenda included the reauthorization of funding for CAPTA. To this end, the House of Representatives issued House Resolution 14 (H.R. 14), which authorized state and community-based grants. This funding would pay for family violence-prevention programs, stronger initiatives to combat child abuse, and measures to ensure that caseworkers inform parents of neglect complaints in a timely fashion.

S. 342, the Senate version of the CAPTA reauthorization, dropped H.R. 14's inclusion of referrals to Part C Early Intervention Program of the Individuals with Disabilities Education Act (IDEA) and did not elevate respite care to the list of core services as disabilities advocates had recommended.

"Interestingly enough," says Maichle, "the issue is not money but how to put more systems in place to keep kids safe when they are automatically referred to services under IDEA, Part C. This is an important issue for us," continues Maichle, "and like any important issue, you should still call Congress to make sure your legislators know where you stand because opposition could happen anywhere along the line. If Senator Biden hasn't heard from you in Delaware, then it could make a difference. Unless it's in their minds, the legislators might let it go. It's important to voice your opinion."

"Once a bill is passed," adds Maichle, "make sure the state does what the bill says. It's your responsibility to make sure the government is doing as it promised."

### Meeting the need for respite care

Nationally, the number of adults requiring some type of help at home is predicted to rise to almost 40 million by 2020. Today, approximately 3,425 children from 1,500 families are denied access to respite care and crisis care programs weekly.<sup>1</sup>

This spring, acknowledging this overwhelming need, the U.S. Senate unanimously passed the Lifespan Respite Care Act (S. 538). Sponsored by Senators Hillary Clinton and John Warner, S. 538 provides grant money for community-based respite care services. This funding is targeted specifically for families with a child or adult with a disability living in the home. S. 538 opens the door for personal attendants to help family

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members, foster parents, or other adults who provide ongoing, unpaid care for anyone with a special need. "Without respite and other services and supports for caregivers," explains Ms. Maichle, "parents and other family members are forced to stay at home with the family member in need. These [caregivers] experience enormous stress, loss of employment, financial burdens, and marital difficulties. Some families have no choice but to place their loved ones in more costly institutional or foster care facilities.

"This bill is a godsend for families," adds Ms. Maichle, "because Medicaid does not cover respite care in Delaware. I heard a story about a family with a 40 year old. This family has taken care of the child for 40 years and has never been on a vacation! All they want is one week."

Opponents of the bill point to the financial cost of supporting a nation of caregivers in their homes. Advocates of the bill contend it is actually less expensive to keep an individual in the home or a community-based setting than an institutional facility. S. 538 also meets advocates' long-time call for criteria based on the individual and the family instead of the disability.

### Accessing the full range of Medicaid services

Including an option to "buy into" Medicaid, the U.S. Senate's Family Opportunity Act (S. 622) supports families who have children with severe disabilities but do not qualify for Medicaid. With this medical option, a family would have access to the full range of Medicaid services and, therefore, would be able to meet the medical needs of a child with disabilities. Importantly, S. 622 raises the family income limit so a family would not need to impoverish itself to receive medical benefits for the most vulnerable family member.

"The Family Opportunity Act keeps children out of institutions, helps families, saves money, and it's the right thing to do," sums up Ms. Maichle, who also chairs the Governor's Advisory Council for Exceptional Citizens.

Opponents of S. 622 note the current lack of medical services in the community and argue that children with severe disabilities are better off in institutions where the services are provided. Advocates have often expressed concerns about the inability of communities to provide services to people with disabilities.

### Riding to the rescue of Assistive Technology

The first assistive technology (AT) act was signed into law in 1988 and provided each state with a three-year grant. The intent of the grant was to build a structure to provide AT to the people who needed it. According to Beth Mineo Mollica, Director of the Delaware Assistive Technology Initiative (DATI), the original funding was "seed money" to provide a range of services from equipment, training, and technical assistance to funding guides and information.

With each successive reauthorization of the AT act, Congress acknowledged the need for AT support in the states. The last reauthorization, referred to as the AT Act of 1998, scheduled the winding down of federal grant money, known as the sunset provision, before the current economic downturn. This provision did not anticipate the growing need for AT.

"The status of AT needs in 2003," points out Ms. Mineo Mollica, "is very different than it was when we were first funded. There wasn't a demand for accountability. Some technology didn't exist, was unavailable, or wasn't needed by people yet. People age, technology introduces new possibilities, and new needs arise, such as the ALS-like symptoms that Desert Storm veterans are experiencing. [ALS is also known as Lou Gehrig's disease.] "The point is," emphasizes Ms. Mineo Mollica, "things are different."

This spring, although one year remained in the federal funding cycle, President Bush zeroed out the funding.

The Spring 2003 issue of the AT Messenger, DATI's newsletter, announced, "To the shock of AT advocates nationwide, the President's FY04 budget... eliminates all funding for state technology projects. This unexpected move effectively shuts down the state programs

a full year before the legislative authorization for the program ends."<sup>2</sup>

Ms. Mineo Mollica believes that some members of the 108th U.S. Congress supported the President's action, because they believe that the states can not only pick up the funding at this time but also that they have had sufficient time to establish a working infrastructure.

"Unfortunately, the states are broke," counters Mineo Mollica. "Budgets are in disarray. Plus, we got knocked off schedule when managed care and HMOs rewrote procedure in 1991. So, we had to start over. For DATI to have life in fiscal year 2004," Ms. Mineo Mollica continues, "we need a short-term fix. Congress needs to put the money back in the budget for 2004 and to waive the sunset provision so DATI has access to the funding. This is crucial because there's no other program that does for us what DATI does for us. Without DATI, there's no comprehensive one-stop resource for AT where people can try out equipment or get help locating funding."

Ms. Mineo Mollica concludes, "As advocates, we now have been put in opposition to the state. The entire legislative delegation in Delaware needs to hear from consumers. Disabilities advocates need to call their Senators and Congressman and say "This is useful, we benefited from it, and we want it to stick around."

### The reauthorization of IDEA

Those involved in reauthorizing the Individuals with Disabilities Education Act (IDEA) of 1990 have experienced struggle and success. Marie-Anne Aghazadian, Executive Director of the Parent Information Center (PIC) of Delaware, believes that a good working relationship with Delaware's elected officials has helped make her advocacy work a success. "Although Congressman [Michael N.] Castle tends to support the Republican line," explains Ms. Aghazadian, "he listens. When we work with him, we go as a consortium to make sure we're all saying the same thing."

The consortium of advocates for IDEA includes the following groups:

- DD Council
- Governor's Advisory Council for Exceptional Citizens
- State Council for Persons with Disabilities
- Arc of Delaware
- Autism Society of Delaware
- Disabilities Law Program
- Down Syndrome Association of Delaware
- PIC of Delaware

"We were concerned about some of the language in the IDEA revisions," continues Ms. Aghazadian, "that, among other things, the language proposed a ban on using nonfederal funds for lobbying purposes. After listening to us, Congressman Castle (who wrote this legislation) removed this 'gag order' language."

The consortium also expressed concerns about the short-term objectives of a child's education plan. Disabilities advocates believe these objectives provide parents with essential information about a child's progress. The parents rely on timely updates in the same way that parents with children without disabilities rely on report cards. Historically, IDEA's short-term objectives gauged progress with the use of a communication device and other similar categories, but Castle's revisions deleted these objectives.

After hearing the consortium's concerns, Congressman Castle changed the revised short-term objectives, retaining them for students with severe disabilities. "I think we've done a really good job of educating Congressman Castle's staff," states Ms. Aghazadian. "They'd never seen an individualized education plan [IEP] before, but now they're making informed decisions about IEPs and short-term assessments. When the House and Senate bills go to conference, we hope our recommendations will be considered."

1. [www.archrespite.org/NRC2.htm](http://www.archrespite.org/NRC2.htm)  
 2. [www.asel.udel.edu/dati/Atmessenger/index.html](http://www.asel.udel.edu/dati/Atmessenger/index.html)

## YOUR FEDERAL AND STATE ELECTED OFFICIALS

### Federal

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 202-224-5042 (D.C.)  
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<http://biden.senate.gov/>  
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**U.S. Senator Thomas R. Carper**  
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 302-674-3308 (Kent Co.)  
 302-856-7690 (Sussex Co.)  
 202-224-2441 (D.C.)  
 Fax: 302-674-5464 (Kent Co.)  
<http://carper.senate.gov/>  
 E-mail: Click the "e-mail me" link on the webpage

**U.S. Representative Michael N. Castle**  
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 302-736-1666 (Kent Co.)  
 302-856-3334 (Sussex Co.)  
 202-225-4165 (D.C.)  
 Fax: 302-428-1950 (New Castle Co.)  
 202-225-2291 (D.C.)  
<http://www.house.gov/castle/>  
 E-mail: Click the "e-mail me" link on the webpage

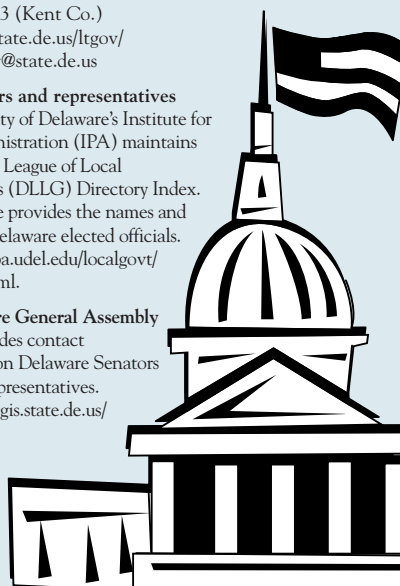
### State

**Governor Ruth Ann Minner**  
 Phone: 302-577-3210 (New Castle Co.)  
 302-744-4101 (Kent Co.)  
 800-292-9570 (Statewide)  
<http://www.state.de.us/governor/>  
 E-mail: click the "e-mail Governor Minner" link on the webpage

**Lt. Gov. John C. Carney, Jr.**  
 Phone: 302-577-8787 (New Castle Co.)  
 302-744-4333 (Kent Co.)  
<http://www.state.de.us/ltgov/>  
 E-mail: [ltgov@state.de.us](mailto:ltgov@state.de.us)

**State senators and representatives**  
 The University of Delaware's Institute for Public Administration (IPA) maintains the Delaware League of Local Governments (DLLG) Directory Index. This Web site provides the names and contacts of Delaware elected officials.  
<http://www.ipa.udel.edu/localgovt/dllg/index.html>

The Delaware General Assembly website provides contact information on Delaware Senators and State Representatives.  
<http://www.legis.state.de.us/>



## New Childcare Research Reports from the Center for Disabilities Studies



The Interagency Resource Management Committee (IRMC), a

Delaware state-level government committee, funds several exciting projects at the Center for Disabilities Studies. IRMC members include the Secretaries of Education; Health and Social Services; and Services for Children, Youth and Their Families; as well as the state Budget Director and Controller General. The results of the studies described below identify the outcomes of programs funded by IRMC and support policy recommendations and resource allocation.

The **Delaware Early Care and Education Baseline Quality Study** will produce a final report based on observations and interviews with program directors and over 576 early care and education teachers in 201 early childcare programs. The study includes family childcare settings, center-based programs, Head Start and Early Childhood Assistance Programs (ECAP), part-day programs for 3 to 5-year-olds, and programs for school-age children. Data analysis has provided information on early care and education in Delaware.

As each segment of the report is completed, representatives from the three state agencies will meet to review the analysis and begin to make policy recommendations based on the information. The final report will be available in the

fall of 2003.

The **Child Find Study** will report on interviews with families who have had children receiving special services from their school district for 24 months or less. Currently, interviews with the parents of 75 children, kindergarten through grade 4, are proceeding. Children who were identified for special services since they started school or within the last 2 years are included in the study. Parents will be interviewed about the family, the life of the family before the child entered school, and the child's early experiences. Each child's school records, health records, and program records, including any programs that have also served the family, will also be reviewed. The anticipated completion date for the Child Find Study is spring 2004.

The **Delaware Early Childhood Longitudinal Study** has followed the progress of 500 children who have now taken the fifth grade Delaware Student Testing Program (DSTP) in school. All fifth grade students in Delaware are required to take the DSTP. The study focuses on a group of students that includes children who attended Head Start and ECAP programs, children who received special services as 3 and 4-year-olds, and a sample of students who did not receive services as preschoolers. The DSTP test scores and classroom grades will be collected and analyzed this fall. The findings of this study will be

reported in late spring 2004.

The **Delaware Early Childhood Longitudinal Study II** will use the same structure as the first Delaware Early Childhood Longitudinal Study to identify a new group of children who will start kindergarten in the fall. This cohort will be followed for the next 10 years.

The Center has done several studies with participating families and reported on family satisfaction regarding their involvement in the Birth to Three Early Intervention System's Child Development Watch (CDW). In the spring of 2002, a sample of families who had children active in the CDW program were surveyed about their experience and expectations of the program. This survey, which has been conducted since 1996, can now provide the Birth to Three Early Intervention System with trends in the perception of families of the services that they have been offered. This year, the survey added questions regarding the plans parents are making and the expectations they have as their children transition from CDW.

These evaluation studies are directed under the leadership of Dr. Michael Gamel-McCormick, Dr. Martha Buell, Debbie Amsden, and a research team of graduate and undergraduate students. For more information contact Debbie Amsden, Research Coordinator, (302) 831-3633, or [irmc@udel.edu](mailto:irmc@udel.edu).

## Coming Soon: UD's Early Learning Center

In August 2002, the University of Delaware purchased the former Girls, Inc. building on Wyoming Road to house the Early Learning Center (ELC). The ELC will provide year-round, full-day childcare for approximately 150 children from birth to five years old, as well as approximately 75 school-age children.

The ELC will be an integrated childcare center that will offer the following:

1. high quality child care for children from birth to 12 years old and family support services;
2. pre-service training for undergraduate and graduate students in many disciplines, including early childhood education, physical therapy, nursing, psychology, nutrition, and individual and family studies;
3. research on children and families; and
4. training and technical assistance for early care and education programs throughout the region.

The children enrolled in the ELC will be from a wide variety of backgrounds, and at least 20% of the children served will be children with disabilities.

The building will have four distinct areas serving infants, toddlers, preschool-age children, and school-age children. In addition to these four areas, the building will include space for observation and teaching, two therapy assessment rooms, a family meeting room, a parent resource room, two family-child research rooms, a breast feeding room, a kitchen for providing meals to children, and a half-size gymnasium.

The ELC will be a University-wide program administered through the Center for Disabilities Studies. With strong emphasis on pre-service

training, research, and serving the community, this site will be unique in the state. ELC Director, Karen L. Rucker, brings more than twenty years of experience working with young children and their families. Ms. Rucker has overseen the renovation of both large and small child care facilities and has extensive experience working with large childcare centers. She emphasizes the importance of having a center that is inclusive of children of all abilities that can be a model for other programs. The Director stated, "The need for inclusive child care, and especially for inclusive school-age care, is so great that we must be able to show how these services can be provided throughout the community for as many children with disabilities as possible."

From February to June of 2003 the ELC building was used by the Christiana School District to house a number of its early childhood special education programs. The need for emergency quarters for these programs arose when Leasure Elementary School's roof collapsed after a snowstorm in February. The University was eager to assist one of its community partners with a facility specifically designed for early childhood programs. In the meantime, design plans for the new ELC have been proceeding.

Construction drawings were delivered in late June. Demolition of the building began in mid-September and renovations will take place throughout the fall of 2003 and winter of 2004. The ELC is scheduled to be open to children and families by June 2004.

For more information on the Early Learning Center please contact Karen Rucker at [krucker@udel.edu](mailto:krucker@udel.edu).

### THE 3RD ANNUAL

## Disability Awareness Day Picnic



Friday, Oct. 3, 2003 • 10 a.m. - 3 p.m.

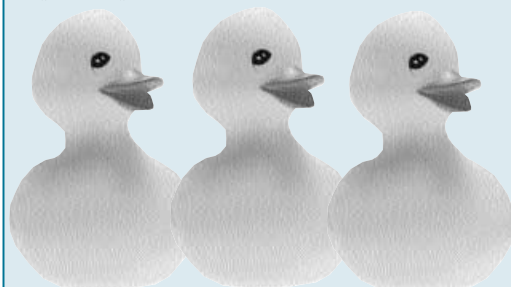
Smyrna Municipal Park  
504 N. Main Street, Smyrna, DE

DJ • Free food • Fountain drinks  
Special Events



Sponsors: Developmental Disabilities Council, State Council for Persons with Disabilities, State Independent Living Council, Governors Advisory Council for Exceptional Citizens, DELARF, Division of Vocational Rehabilitation, ARC, United Cerebral Palsy, Easter Seals, National MS Society LogistiCare, Freedom Center for Independent Living, Independent Resources, Inc.

To reserve a space, please call the Developmental Disabilities Council, (302) 739-7192/3333.



## Training and supporting the role models in each child's life



This year, two New Directions Early Head Start (NDEHS)

projects, the Youth Involvement Initiative and the Fatherhood Initiative were created in response to the continuing needs of children. The two programs provide opportunities for young adults and fathers to develop, share, and hone skills that support them as positive role models in their communities.

Under NDEHS's direction, both projects are improving life for Delaware's youngest children by training and supporting responsible and aware role models.

### Youth Involvement Initiative

The Youth Involvement Initiative trains both high school and middle school students in mentoring skills and teaches them the value of becoming a mentor. This spring's first training session attracted twelve young adults to the Hilltop Lutheran Neighborhood Center in Wilmington.

These student-mentors gain many valuable strengths including an understanding of the benefits of challenging the young minds of children through age appropriate activities. Each mentor learns, for example, how to read to young children and to help children build their thinking skills. The program's on-the-job training builds the mentors' self-confidence, and their experience in

a leadership position sharpens the mentors' interpersonal skills.

"To be a mentor," explains Heidi Beck, NDEHS's project leader, "you have to be mentor material. Attending class and being on time are the types of behavior we want to teach our children. As a mentor in the Youth Involvement Initiative, you need to show a positive attitude about school and learning."

According to Ms. Beck, the student-mentor is guided toward healthy, positive life choices and models positive behaviors for the child.

Team building is an important component of the program. These young adults learn to rely on a team model to be effective mentors and advocates for children. They master skills by working on community group projects, such as park cleanups. This experience teaches leadership, how to successfully work in a group setting, and the mastery of the interpersonal dynamics necessary for working together in a group.

### Fatherhood Initiative

The second NDEHS project highlights father figures as positive role models in children's lives. Beginning with the first session in January 2003, six Delaware men received leadership training aimed at supporting the children and families in their community.

Fathers, grandfathers, and



Above: Scottkana Waters (right), Youth Initiative Mentor

men, who are interested in supporting their own families and becoming role models in their community, meet once a week to participate in this program. Active participation in the four-month program focuses on a wide range of early childhood needs, including education, health, nutrition, and family dynamics. Participants receive training on child development and parenting skills and have the opportunity to practice the skills and activities that support not only the child but also the child's mother.

As a modified Parents as Advocates, Counselors, and Teachers (PACT) program, the Fatherhood Initiative also presents opportunities for participants to network with previous graduates of the PACT program. In a retreat setting, the men practice their counseling skills in one-on-one and group situations and are encouraged to play an active, thoughtful role in supporting other men involved in the training.

"The retreat offers support for the fathers," notes NDEHS's Ms. Beck, "and helps them

## Announcements

### Call for posters!

The poster sessions at the Life Conference typically highlight projects or research, which is considered to be instructive, innovative and representative of best practices in the field. Proposals are due by November 1, 2003.



The annual LIFE Conference is the largest gathering of people working with and for individuals with disabilities in Delaware. The conference will be held at the Dover Sheraton Hotel and Conference Center on January 22, 2004 from 8:00 a.m. to 3:45 p.m.

For more information contact Mark Bernstein, Center for Disabilities Studies, 302-831-3458 or mjbarns@udel.edu.

### Inclusion Conference

Mark your calendars for the 10th Annual Inclusion Conference to be held on November 6, 2003, from 8:00 a.m. to 3:15 p.m. The keynote address will be given by Marti Snell, Coordinator of the Special Education Program at the University of Virginia. Her research and writing focuses

on inclusion and severe disabilities. Registration materials will be available in September.

If you would like more information, please contact Marsha Mills at the Developmental Disabilities Council by phone at (302) 739-7193 or e-mail [mmills@state.de.us](mailto:mmills@state.de.us).

### Employment Opportunity

Freedom Center, a consumer-driven organization providing a variety of services and supports that enable persons with disabilities to live independently, is seeking a creative, positive, self starter to join their staff as an Independent Living Specialist.

For more information call Debbie Bain at (302) 376-4399 or 1-866-our-rights or email her at [FreedomCIL@yahoo.com](mailto:FreedomCIL@yahoo.com).

Freedom Center is an equal opportunity employer. People with disabilities are strongly urged to apply.

*Would you like your organization's employment opportunities announced through our newsletter or website? Email [tm@udel.edu](mailto:tm@udel.edu) for more information.*

build confidence in their parenting, child care, and daily management skills. It's also a great opportunity for sharing and problem solving."

Since September 2002, funding has been provided for these two initiatives by the Department of Health and Human Services Administration for Children

and Families through the Head Start Bureau. NDEHS supports the continuation of both projects and hopes to expand the Youth Involvement Initiative into more community settings.

### For more information

Contact Heidi Beck at (302) 831-0478 or [hbeck@udel.edu](mailto:hbeck@udel.edu) for more information.