



ALBANY *Update*

CURRENT NEWS AND INFORMATION FROM
THE STATE'S CAPITAL

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FROM THE STATE LEGISLATURE

THE LEGISLATURE CONCLUDED ITS 2008 SESSION IN THE EARLY MORNING hours of Tuesday, June 25th. All totaled, the Legislature introduced 4,300 bills and passed 811 of them of which the Governor has, so far, signed 117.

A summary of bills of importance to NYSARC and services to persons with intellectual and other developmental disabilities is below. It should be noted that quite a few bills appear to result from the political aftershock of the Jonathan Carey incident in 2007.

NYSARC had three priority bills for the session. All three passed both houses.

While there were other bills of interest, these three were initiated, drafted and championed by NYSARC. They include:

NYSARC bond extender (NYSARC bill), A. 10592 by Weisenberg **PASSED BOTH HOUSES** and continues NYSARC's authority to provide tax exempt financing through the Dormitory Authority of the State of New York. The bill would extend NYSARC's authority to December 31, 2013.

Legislation requiring the development and demonstration of a simplified health care proxy (NYSARC bill) A. 11054 by Rivera **PASSED BOTH HOUSES**. The bill was broadly supported, particularly by providers and advocates. Unlike a standard health care proxy, it allows a health care agent to immediately begin to make decisions for the principal upon receiving approval by the principal.

NYSARC worked with the Self-Advocacy Association of New York on this measure which gives persons with intellectual and other developmental disabilities greater control over who helps them make health care decisions. The simplified format will also make what is otherwise a complex legal document accessible to many individuals.

NYSARC and legislative sponsors expect that, if the bill is signed into law, once it goes beyond the demonstration phase, it could have much wider application to other groups of individuals, including the elderly.

Legislation giving Surrogate Decision Making Committees the authority to withhold or withdraw life-sustaining treatment pursuant to the Health Care Decisions Act (NYSARC bill) S.7752 by Hannon, **PASSED BOTH HOUSES**. The bill would apply to persons without Article 17-A guardians or involved family members. Many of the individuals subject to the bill are served by NYSARC, have a history of institutionalization, are elderly, Medically frail and at heightened risk of catastrophic end of life situations.

The bill would authorize SDMCs to make a decision to withhold or withdraw life-sustaining treatment in accordance with the standards and procedures of the Health Care Decisions Act. It would be the first time a governmental entity has been given this authority in New York State.

If this bill is signed into law, it will be the fifth law enacted expanding the protections of the Health Care Decisions Act. Initially the Act only allowed court appointed guardians to make a decision to withhold or withdraw life-sustaining treatment. Last year the HCDA was expanded to give that authority to non-guardian family members.

S.7752, by giving the authority to SDMCs, would mean that the HCDA would, if signed, become fully comprehensive, covering all persons with intellectual developmental disabilities who do not have the capacity to make their own health care decisions.

Other bills of general interest:

There were other bills of interest to NYSARC and the field. NYSARC played an important role in a number of them. It should be noted that in the aftermath of the 2007 death of Jonathan Carey, high profile legislation emanating from the political shockwave of that incident continues to pour out.

Bills of interest include the following:

Legislation creating a statewide registry of employees found to have abused or neglected a consumer, S. 4474 by Morahan; A. 9609 by Zebrowski passed the Senate but **DIED IN ASSEMBLY CODES COMMITTEE**. The registry would have applied only to those employees terminated as a result of such finding and only to employees of voluntary programs, not state-operated programs. It is likely that the Codes Committee was concerned that the registry would be used to “blackball” individuals who were not convicted of a criminal offense and may have committed very minor infractions.

Legislation to expand the definition of a developmental disability, S.8043 by Morahan; A. 11020 by Weisenberg passed Senate and **DIED IN ASSEMBLY WAYS AND MEANS**. The bill would have included the inability to engage in “substantial gainful activity” in the term “developmental disability.”

Legislation establishing an Early Intervention Rate Restructuring Work Group and Early Intervention Demonstration projects, S.8050 by Morahan/A. 10901 by Jaffee passed the Assembly but **DIED IN THE SENATE RULES COMMITTEE**. The bill was aimed at addressing the longstanding underfunding of Early Intervention programs.

Legislation to create a uniform definition of abuse of children in residential settings, S.8534 by Morahan/A.11753 by Gordon, **PASSED BOTH HOUSES**. This was a major Governor’s program bill and appears to have originated with continuing concerns generated over the death of Jonathan Carey. The definition will apply to children’s residential programs licensed, operated or certified by OMRDD, OMH and OCFS (Office of Children and Family Services).

Legislation that expands the look-back period for information available under Jonathan’s Law, S.8389 by Morahan/A.10897 by Gordon, **PASSED BOTH HOUSES**. If signed by the Governor, this bill would allow eligible individuals until December 31, 2010 to request and receive information available under Jonathan’s Law which dates back to January 1, 2003.

Legislation requiring that residents of mental hygiene facilities have a right to a “balanced and nutritious diet.” S.8551 by Morahan/A.11482 by Gordon **PASSED BOTH HOUSES**. The legislation appears to have originated with continuing concerns generated over the death of Jonathan Carey. The bill also requires that meals be served to residents “at appropriate times and in as normal a manner as possible.” Exceptions may be made for “clinical” reasons.

Legislation limiting the number of consecutive hours that can be worked by direct care staff, S.11481 by Gorden/S.8547 by the RULES Committee, **DIED IN SENATE RULES AND ON THE ASSEMBLY FLOOR.** The bill originated with concerns generated by the Jonathan Carey incident. The bill would have limited the consecutive hours a direct care employee can work to 16. Given concerns raised by this bill another bill, S.8679/A.11756, described below was agreed to by the Governor and legislative leaders.

Legislation creating a workgroup to study hours worked by direct care employees in facilities licensed or operated by OMRDD, OMH and OASAS, S.8679 by the Committee on RULES and A. 11756 by Rivera, **PASSED BOTH HOUSES** on the last full day of the legislative session. The bill designates the Commissioner of OMRDD as the Chairperson and requires that the Workgroup report back to the Legislature by December 15, 2008. The Workgroup is to issue recommendations including what appropriate limitations should be placed on consecutive hours worked by direct care staff.

Again, the bill is an alternative to the outright limit on consecutive hours proposed by S. 8547/A. 11481 and seems to be in response to continuing concerns over the Jonathan Carey incident.

Legislation to authorize the release of the name, date of birth and date of death of an individual who was a resident of at a facility run operated by OMRDD, S.8057 by Morahan and A. 10933 by Zebrowski **PASSED BOTH HOUSES.** The bill is in response to efforts to memorialize those individuals who passed away while residing in institutions and who were buried in unmarked or numbered graves. NYSARC and other advocates had worked with former Commissioner Maul on the issue.

Legislation making “misappropriation” a cause for temporary suspension or limitation of an operating certificate, S.8049 by Morahan, **DIED AS A ONE HOUSE BILL.** The bill was a response to concerns generated by the investigation of the Evelyn Douglin Center.

Legislation requiring board member training, a procedure for determining executive compensation, disclosure of potential board member conflicts of interest and development of procedures to be used in the event of emergencies, S.8047 by Morahan and A. 11499 by Rivera, **PASSED BOTH HOUSES.** The legislation applies to voluntary agencies licensed by OMRDD and OMH. The legislation originated with concerns generated by an investigation conducted by the Commission on the Quality of Care into the Evelyn Douglin Center. The investigation found that the board failed in its fiduciary responsibility.

Legislation prohibiting nurses from working mandatory overtime, S.8637 by Morahan and A.11711 by Gunther, **AMENDED, PASSED BOTH HOUSES.** Originally the bill would have applied to voluntary community based programs licensed or certified by OMRDD. However, NYSARC and other provider organization staunchly opposed inclusion of such programs and the bill was amended to exempt voluntary programs from the new requirement. The legislation was initiated by the Public Employees Federation (PEF) which represents state employed professionals, including nurses. The amended bill applies to state run facilities under OMRDD and OMH as well as hospitals.

Legislation to overhaul state requirements for self-insured workers’ compensation groups, S.8708 by the Committee on RULES and A. 11756 at the request of John, **PASSED BOTH HOUSES.** The bill was the product of a closed door deal between the Governor and legislative leaders. NYSARC was concerned that the bill could devastate the NYSARC Workers’ Compensation Trust. However, draft legislation appears to have been modified to at least partly to assuage the concerns of various self-insured trusts. Still, the full impact of the legislation must be analyzed. Preliminary information suggests that if there is a negative impact on the NYSARC Workers’ Compensation Trust, it may take a couple of years to materialize. In the interim, if deemed necessary, further legislative or court action is possible.

In a press release on the legislative session, Governor Paterson's office said of the workers' compensation bill: "In the aftermath of the default of several self-insured workers compensation groups, the Governor took steps to protect employees by strengthening regulations for workers compensation self-insurance."

Legislation to require posting of non-profit executive compensation on OMH and OMRDD websites, A11430, passed the Assembly and DIED AS A ONE HOUSE BILL. The bill would have also required the posting of information relating to members of non-profit board members.

THE LEGISLATURE DID NOT REAUTHORIZE THE AUTHORITY OF NON-PROFITS TO utilize financing through local Industrial Development Authorities. There were protracted negotiations all year that reached a frenzy during the closing moments of the legislative session. Most observers thought that some deal would materialize. But it didn't.

At issue were union demands that non-profit agencies pay union-level wages for IDA financed projects. Reports called the unsuccessful attempt to reauthorize this source of non-profit financing a "union victory."

It is unclear what's next for IDA non-profit financing. There have been reports that the legislature is likely to return possibly in July or after elections and that IDA financing will be on the agenda. But those reports are rumors which are utterly unconfirmed.

SENATE MAJORITY LEADER JOE BRUNO QUIT AND WAS REPLACED BY SENATOR DEAN SKELOS of Long Island. Skelos represents portions of Nassau County.

The most prominent rival to Skelos was Binghamton Senator Tom Libous. After being appointed Deputy Majority Leader, Libous said of Skelos "in my mind and heart he has earned this awesome responsibility."

Bruno's announcement came as a surprise. However, the Senate Majority Leader has a grueling job and at age 79 many wondered how Bruno could do it though he seemed to fare well during the legislative session.

Speculation on the reasons for Bruno's retirement go beyond age. He has been the subject of an FBI probe and the Republican Majority Conference is facing an extremely tough election. Nationally, Democrats are expected to surge in the fall elections and pick-up of substantial additional seats in Congress. They are also expected to do well at the State level. This has many wondering if New York State's Senate Republicans can hold onto their slim 32-30 majority in the State Senate.

A number of Republican Senators are elderly and their districts are increasingly Democratic. Some wonder if the Republican Senate Conference felt that Skelos, who is both younger than Bruno and not the subject of any probe, would be a greater asset in the upcoming struggle to hold onto the Senate Majority.

Bruno: a friend of the field. Skelos: long sympathetic to persons with disabilities

Joe Bruno will be remembered fondly by advocates for persons with intellectual and other developmental disabilities. During his tenure, the field enjoyed record budget increases and managed to pass key pieces of legislation including the Health Care Decisions Act for Persons with Mental Retardation. He was close and always accessible to both NYSARC's Saratoga and Rensselaer Chapters. His staff worked closely with NYSARC State Office staff.

He will be missed.

Senator Skelos has a fine reputation with advocates. He was intimately involved in legislation creating the Early Intervention and Preschool programs. He is well known to NYSARC's Nassau Chapter. In 2004 NYSARC

worked with Skelos to pass legislation mandating child safety seat use until age 7. In 2006 NYSARC also worked with Skelos' office on legislation to nullify the US Supreme Court's *Schaffer v Weast* decision. In the absence of a state law to the contrary that decision moved the burden of proof in impartial due process special education hearings to parents, rather than school districts. In 2007 New York passed its state law to the contrary.

Big issue will be Senate Majority after November elections

The big issue for Skelos however will be whether or not he can help the Senate Republican Conference retain their Majority in the fall elections.

The jury is still out on what a possible switch in the Senate majority party will mean for NYSARC and services to persons with intellectual and other developmental disabilities.

However, over the years many upstate NYSARC chapters have developed close relationships in rural and small town areas with their Republican Senator who, because of the nature of their districts, are easily accessible. That accessibility has been critical to NYSARC since the majority party status of those Senators made them very influential.

FROM WASHINGTON

FINALLY, THE US HOUSE, SENATE AND PRESIDENT AGREED TO A BILL which extends moratoriums holding off implementation of six of seven CMS Medicaid regulations. The regulations, if implemented, would have devastated services to persons with intellectual and other developmental disabilities, particularly in New York State.

The President signed the final bill on June 30th concluding the battle over the regulations which went on for well over a year.

HR 2642 continues the moratoriums until April 2009. It holds off regulations curbing Medicaid for 1) rehabilitation services 2) school based transportation and administration 3) graduate medical education 4) provider taxes 5) targeted case managements and, most importantly for services in New York State, 6) reimbursement of public facilities.

The only regulation that will go into effect curbs Medicaid for outpatient services. While that is of enormous concern to New York City's Health and Hospital Corporation (HHC) it does not appear to impact services to persons with intellectual and other developmental disabilities.

The moratorium extension was passed as part of a massive Iraq War Supplemental funding bill which contained a variety of items, including domestic initiatives.

The House approved the measure on June 19 by a vote of 416 to 12. On June 27 the Senate approved by a vote of 92 to 6. All of New York's House members and the state's two US Senators voted for the measure. Also included in the bill as spending on Medicaid for Katrina survivors, military construction, education aid for GIs, funding for the Iraq War, the moratorium and more.

Thanks to all those chapters, advocates, professionals and families who advocated with their congressperson and New York State's US Senators for a final moratorium.

New York's entire congressional delegation should be thanked for their efforts and support on behalf of our programs and services. We urge you to write or call them and express your thanks.

FROM THE US SUPREME COURT

THE US SUPREME COURT ISSUED ITS LONG AWAITED DECISION ON JUNE 19TH IN CHAMBER OF COMMERCE OF THE US V. BROWN, ATTORNEY GENERAL OF CALIFORNIA.

The High Court, in a 7-2 decision, ruled against California Assembly Bill 1889 which, among other things, prohibits employers that receive state grants of more than \$10,000 from using such funds “to assist, promote, or deter union organizing.”

The California law is very similar to New York State’s Labor Neutrality Act, enacted by the State Legislature in 2002. NYSARC and various other State associations, including UCP, have a longstanding suit against the New York law. The suit was suspended in lieu of the Supreme Court decision.

The Supreme Court decision appears to be a very significant victory for litigants against the New York law. The extent of that victory and whether it will completely pre-empt action by NYSARC and other plaintiffs will soon be determined by parties to the New York State case.

The Supreme Court decision overturns a decision by the 9th Circuit which upheld the California law. The High Court declared that the National Labor Relations Act “preempts” the California law because it regulates employer speech in circumstances where Congress intended free debate. The Court cited prior US Supreme Court decisions as well as the Taft Hartley Act. The 1947 Taft Hartley Act (Congress overrode President Truman’s veto) amended the National Labor Relations Act to protect non-coercive speech by employers and unions from state regulation. Based on the NLRA, as amended by Taft Hartley, the Supreme Court concluded that the California law amounted to an “unfair labor practice.” The Taft Hartley Act recognized that an “unfair labor practice” could be applied to acts by unions and employees, not just employers.

In its summary of its decision, written by Justice John Paul Stevens, the High Court stated: “California’s policy judgment that partisan employer speech necessarily interferes with an employer’s choice about union representation is the same policy judgment that Congress renounced when it amended the NLRA (National Labor Relations Act) to preclude regulation of non-coercive speech as an unfair labor practice.”

The High Court dismissed arguments by California that Assembly bill 1889 was modeled after federal statutes. Also, the High Court rejected the argument that the California law is valid since it merely replicates lawful practice by the NLRB regulating employer speech on the eve of elections.

NYSARC and other plaintiffs expect further guidance from counsel on the case against New York State’s Labor Neutrality Act.

In anticipation of the Supreme Court hearing this case, NYSARC and other co-plaintiffs submitted an amicus brief.