GOVERNMENT *In Brief*

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Government in Brief is published every two months as a vehicle to provide up-to-date coverage to NYSARC Chapters regarding current events in the field of developmental disabilities.

FROM WASHINGTON

TAX TREATMENT OF FOSTER CARE TARGET OF BILL

According to Senator James Jeffords (R-VT) current tax law restricts the use of foster care for persons with disabilities, denying them a valuable community placement option.

Under current law, foster care payments to families serving persons placed through a governmental agency are tax deductible. However, payments for foster care placements made through a private agency (excluding not-for-profit agencies and placement of individuals under 19) are not tax deductible.

According to Senator Jeffords: "my home state of Vermont, at the forefront of efforts to develop individualized alternatives to institutional care, authorizes local developmental services providers to act as placement agencies and to contract with families willing to provide foster care in their homes. The tax law's disparate tax treatment of foster care payments, however, impedes alternative arrangements. Persons providing foster care for individuals living in their homes (placed) by the government can exclude foster care payments from income."

However Jeffords noted that "for providers receiving payments from private (for profit) agencies, however, the exclusion is not available. These rules discourage families willing to provide foster care in their homes to persons placed by private placement agencies, thus reducing the availability of care alternatives."

Consequently, Jeffords and fellow Senator Christopher Dodd (D-Connecticut) have introduced legislation (S. 2568) to treat all payments for foster care equally. The bill would eliminate the current inequities and encourage greater use of foster care as an alternative to institutionalization in various states.

Echoing Jeffords, Senator Dodd stated: this "critically important piece of legislation ...will ensure fair treatment for individuals and families who provide invaluable foster care to children and adults" and encourage agencies who might otherwise avoid foster care because of tax implications, to use it.

"To ensure appropriate oversight," Dodd added, "this bill would require the placement agency to be licensed either by or under contract with a state or one of its political subdivisions."

The bill, introduced in 1998, is expected to be taken up when Congress reconvenes in 1999.

"This bill will advance the development of family - based foster care services, a highly valued alternative to institutionalization," Jeffords noted.

CLINTON BUDGET TO ALLOW RETENTION OF HEALTH BENEFITS
Employment of Persons with Disabilities Encouraged

The Clinton Administration announced that as part of its budget submission to Congress for the upcoming federal fiscal year, it would propose increasing the amount of earnings an individual could retain without losing Medicare and Medicaid benefits.

Under current law, individuals earning over a certain threshold - which varies from state to state - lose Medicaid and Medicare eligibility.

The Clinton Administration believes increasing the threshold will benefit tens of thousands of persons with disabilities who rely heavily on Medicare and especially Medicaid for health coverage. Under the proposal they could earn more and retain their Medicare or Medicaid coverage. They would not be forced into choosing between employment or health care coverage.

Medicaid funded prescription drugs and in-home care services were cited as especially vulnerable under the current earnings thresholds.

Under one version of the proposal outlined by Administration officials, people with disabilities could purchase Medicaid coverage even if they took jobs and earned income sufficient to lose SSI eligibility. SSI eligibility qualifies many persons for Medicaid funded health benefits. States would be given the authority to charge premiums for continued Medicaid coverage, allowing working persons with disabilities to continue to purchase services.

Initially Administration staff said the proposal was worth $1 billion over the next five years, but then backed away from obligating any funds. More recent reports indicate that the proposal will call for spending $1.2 billion over the next five years.

Some policy analysts believe that the proposal would save money over the long term by encouraging persons with disabilities to remain in the workforce, earn money and pay taxes. Currently 8 million persons with disabilities receive annual federal cash benefits of $50 billion, some of which could be saved if more were actively employed.

Clinton's proposal is similar to one proposed in legislation sponsored by Senators Kennedy (D-Mass.) and Jeffords (R-Vermont). The legislation did not reach the floor of either house.

STATE GOVERNMENT

NYS MEDICAID MANAGED CARE STILL STAGGERING

Medicaid managed care in New York State continues to stagger under the weight of inadequate reimbursement levels.

"Just about every plan in New York City is running a deficit and it's either being subsidized by the commercial lines of business or where there are no commercial lines of business, by providers," said Steven Bory, Chairman of the New York State Coalition of Prepaid Health Service Plans.

In western New York matters may be somewhat better. According to John Anderson, chief executive officer of Blue Cross and Blue Shield of Western New York "we're still losing money on the State's Medicaid program. Over the last year we've made a substantial change in that position although were still not where we want to be."

In Erie County, over 48,000 recipients are enrolled in Medicaid managed care. Increased State reimbursement levels have eased the burden on that county's HMOs but Medicaid managed care continues to lose money. Ultimately the county expects to serve 68,000 individuals in Medicaid managed care. It's hoped that the increased volume will further ease financial pressures. However, if newer enrollees are more expensive to treat than existing enrollees, managed care losses could increase rather than decrease.

Overall in New York State, over 300,000 individuals are enrolled in Medicaid managed care plans. Exempt from mandatory enrollment are the elderly, persons with disabilities, persons with mental illness and mental retardation and persons with HIV/AIDS.

Typically plans complain that they must rely on commercial business lines to subsidize Medicaid managed care because State reimbursement rates are too low. Further, plans complain that the Medicaid population, often poor and unaccustomed to regimentation required by managed care, is an inherently difficult population to manage.

GOVERNOR SIGNS COLA BILL
2.5% To Lowest Paid Workers

More than half a year after not-for-profit workers began a massive series of rallies and intense lobbying aimed at improving wages to direct care and other low paid employees, Governor Pataki, on December 18, finally signed legislation providing a 2.5% pay boost.

The legislation appropriates $9.7 million for not-for-profit agencies serving persons with mental retardation and developmental disabilities. Separate bills funding the 2.5% increase were also signed for not-for-profit employees serving persons with other mental disabilities. All told, $30 million in additional funding will be made available for mental health, substance abuse, mental retardation, foster care and alcoholism agencies.

The pay increases are retroactively effective to the April 1 start of the State fiscal year and does not apply to programs already granted trend factors including ICFs/MR and programs funded through the Home and Community Based Services Waiver.

"These men and women perform critically important work that directly enhances the quality of life for thousands of mentally disabled individuals, children and their families," Governor Pataki said. "These are dedicated individuals who perform a vital service and I'm happy to sign this legislation."

The legislation was passed last June by the State Senate. However, the State Assembly did not act on the measure. Only when the Legislature reconvened for a special session in December to consider raising its own pay did the Assembly finally act, paving the way for the Governor's final approval.

Specific methodologies to disburse the COLA will be sent to all affected not-for-profit agencies.

<u>Coalition Wants More</u>

But not-for-profit agencies and their representatives in the State's Capital agree that an additional one time bump of 2.5% is not nearly enough. "We need more than that to recruit and retain employees," said NYSARC executive director Marc Brandt. Brandt added that "the problem has dragged on for years. In a labor intensive industry, advocates and family members know that care of vulnerable populations is no better than the employees doing the job."

Consequently, statewide mental retardation and developmental disabilities representatives have banded together to work with the Legislature promoting legislation to provide regular cost of living adjustments (COLAs) as well as additional salary increases, for low paid staff.

NYSARC, United Cerebral Palsy Associations of New York (UCP), the New York State Association of Rehabilitation Agencies (NYSRA), the Interagency Council of New York City Mental Retardation Agencies (IAC) and the New York State Association of Community Residential Agencies (NYSACRA) joined forces to survey existing wages and, in conjunction with the State Assembly, develop legislation to provide a permanent "fix" to the salary issue.

The legislation is sponsored by Assemblyman James Brennan, chairman of the Assembly Mental Hygiene Committee.

However, many experts believe that surmounting the issues necessary to pass the legislation in both houses and get the Governor's approval will be very substantial.

Brandt added that "a really meaningful fix will require substantially more money than the Legislature is accustomed to appropriating for mental health and mental retardation issues. And we can't argue that the solution is affordable if it is limited to mental retardation providers. We can't argue that only our employees should be the beneficiaries of a permanent salary fix. Legislators won't buy that."

According to NYSARC's executive director, Marc Brandt, "getting both houses to agree to the same bill will not be an easy task. Each house has a very different philosophy, especially concerning large issues like this one." Furthermore, by law, the Legislature is forbidden from obligating the State to spend money past the close of the fiscal year. Thus, any multi-year spending commitment must be approved annually even if it is contained in permanent statute.

Brandt added that "a really meaningful fix will require substantially more money than the Legislature is accustomed to appropriating for mental health and mental retardation issues. And we can't argue that the solution is affordable if it is limited to mental retardation providers. We can't argue that only our employees should be the beneficiaries of a permanent salary fix. Legislators won't buy that. They see problems of this kind everywhere."

A meaningful fix could call for huge salary increases. Survey data completed by the coalition of associations representing mental retardation and developmental disabilities providers shows an average starting salary range of approximately $14,500 to $16,500 for direct care workers. Some experts believe that it might take nearly double that amount to make a meaningful dent in recruitment and retention problems.

"It's tempting," said Brandt, "to throw up our hands and say what's the use. But if at the very least our efforts don't make matters substantially better, they are essential to keep them from getting substantially worse."

TOP STATE OFFICIALS GET RAISE
Approve Mental Health COLA, Dairy Agreement, Charter Schools

As expected, the Legislature took advantage of a window of opportunity and returned to Albany in December to give itself a pay raise. Under State law, a legislative pay increase cannot go into effect until the January 1 following an election, when the newly elected legislature formally takes office.

"The process in not a good one," admitted Senate Majority Leader Joe Bruno after a long night of ceaseless negotiating.

Since few legislators are willing to incur the wrath of the voters by approving a raise prior to elections, the usual practice is to vote a pay raise after elections but before January 1st, since raises enacted after that date would not take effect until the next January 1st following elections - a maximum of two years.

The pay raise, part of a broader deal including charter schools, milk price stabilization and pay for agency commissioners, was bitterly criticized for being negotiated in back rooms. "The process in not a good one," admitte Senate Majority Leader Joe Bruno after a long night of ceaseless negotiating.

New York's legislators have complained bitterly about going without a raise for the past ten years. The final pay increase raises their salaries by 38%, from $59,500 to $79,500.

In addition, lawmakers make stipends of $9,000 to $41,500 for leadership positions.

Additional legislation increased the Governor's salary from $130,000 to $179,000 and increased the salary of State agency commissioners to a maximum of $136,000, or by 33%. Prior to the raise, a cap of $103,000 on commissioner's salaries meant that many of their subordinates made more than they did.

"I had 12 employees in my department who made far more money than I did," said Michael Urbach, State Tax Commissioner. "In the beginning it didn't bother me, but after I made some significant accomplishments it began looming." Urbach's executive deputy made almos $15,000 more than he did.

Commissioners last received a raise in 1994.

A Commissioner's salary depends on the size of their agency. The largest agencies - the "A" list - include the departments of Health, Corrections, Mental Health, Mental Retardation, the State University, Environmental Conservation and the Office of General Services. Their commissioners will earn $133,000.

"B" list commissioners, heading agencies such as Tax and Finance, Labor, the State Police, Banking and Insurance will earn $127,100.

The smallest agencies, the "F" list, include the Employment Relations Board, State Liquor Authority and six others. Their heads will earn $90, 800.

Price of Pay Increase

The raise didn't come without a price. Governor Pataki demanded passage of a deferred pay clause. Thus, in the event that legislators don't pass a budget on time - April 1 - their salaries will not be paid until they do pass a budget. Legislators reluctantly accepted the measure.

"We threw the Governor a bone - he needed it to restore his credibility as a hard-line fiscal conservative," said Assemblyman Jack McEneny (D-Albany). "It's a meaningless thing really - it's a banana republic mentality that's supposed to pressure people to pass a budget when the Legislature is faced with a difficult decision."

Pataki also refused to sign off on the pay increase until the Legislature approved of his plan to funnel public funding to independently run charter schools. Supporters said the measure would better educate students with special needs by allowing each school to create its own educational policies, including the length of the school day and year. Critics blasted the bill as an attack on teacher unions and quality.

The Charter School measure left a bitter taste among education lobbyists. "The work that was done would never have been supported had it been held in the light of day with open hearings and public discussion," said Gregory Nash, president of the National Educational Association of New York, a teachers union. "Votes were sold last night at the expense of children in our classrooms and those responsible should be ashamed."

Mental Hygiene COLA Approved

Many observers believe that had the Legislature never sought a pay increase, the chances that the State Assembly would have passed the 2.5% Cost of Living Adjustment for low paid mental hygiene - including mental retardation - employees (See This Issue: Governor Signs COLA BILL) would have been diminished.

However, because lawmakers sought a 38% increase, many believe that it would have been awkward for them not to pass a 2.5% increase for some of the lowest paid, hardest working employees in the State. This became evident during the fall when talk of a special session to increase lawmaker's pay became widespread. Then many NYSARC chapters were told by their State legislators that the mental hygiene COLA was a top priority.

Indeed, the Legislature passed the COLA bill before approving the final version of their own pay bill.

FROM THE COURTS

DEATH PENALTY: MANIPULATED OR A WILLFUL PARTICIPANT?
The Debate Goes On

Texas viewers were shocked when 6 foot 6 inch, 190 pound Michael Hall bragged about the brutal kidnap-torture-murder of Amy Robinson, described as mentally challenged, in a field outside Fort Worth.

Along with Hall's friend Robert Neville, the self-styled white supremacists repeatedly shot Ms. Robinson with a pellet gun, crossbow and shotgun. According to reports, Hall laughed for the cameras while recounting the pain he put Ms. Robinson through before killing her.

But the monster on TV is not the same son that Karen Hall, Michael's mother, describes as a shy, insecure man who loves Nintendo, music and comic books. Mrs. Hall also describes her son as having mental retardation and therefore, she says, should not get the death penalty.

Mrs. Hall blames Michael's low intelligence and trusting nature for his involvement in the crime. With no arrest record, he became friendly with Robert Neville.

The two were co-workers at a local supermarket. They fished and played pool together. "He didn't kill her but was there," said Mrs. Hall. "He's not the thinker. It was Robert (Neville) who thought of the thing. I think if Robert told him to walk on water he would have."

But prosecutor Alan Levy isn't sympathetic. He intends to push hard for the death penalty. "There's no reason to support why we wouldn't," he said.

There are really two issues in the case. First, does Hall have mental retardation. His mother and past test results indicate that he has a borderline IQ. According to criminal justice professor Jim Quin "it's going to be a battle of experts whether he is or isn't mentally retarded and whether it affected his ability to tell right from wrong."

'That's really going to hurt the case," said Quinn. 'This crime shows enough foresight. These are more or less adult skills" and suggest he does not have retardation.

The State of Texas defines mental retardation as an IQ of 70 or below, but more than an IQ test is likely to determine whether or not Hall has mental retardation. According to local mental health expert Susan Garnett "there's not a clear line where you say.. Here is a person above the line who understands and below this is a person who doesn't."

Quin added that Hall's detailed description of the murder makes it appear that he helped plan the crime in advance. "That's really going to hurt the case," said Quinn. "This crime shows enough foresight. These are more or less adult skills" and suggest he does not have retardation.

The second issue is to what extent mental retardation should disqualify an individual from receiving the death penalty. In a 1989 case, the United States Supreme Court ruled that while a defendant's mental retardation must be taken into account as a potential factor in determining criminal culpability, execution of defendant's with mental retardation is not unconstitutional. According to Mrs. Hall "with (Michael) being mentally challenged, he didn't know what he was getting into."

In nearby Arlington, Texas, Leigh Ann Reynolds of the National Arc said that the death penalty should be prohibited for all people with mental retardation regardless of whether it's severe, moderate or mild. "With mental retardation, people have a hard time understanding the consequences of their actions. You want people punished, but you've got to ask `do they understand the punishment for the crime?'"

But the TV footage of the smirking men's graphic description of the crime and their claim that the trusting nature of their victim gave them an "adrenalin rush," hasn't exactly produced a public outcry for clemency, especially among the victims family. Said Ms. Robinson's father, Ben Grogan, the death penalty is "what he (Hall) deserves for what he did..I figure he's responsible for himself and he's got to pay for what he's done."

Commenting on Mrs Hall's defense that her son has mental retardation, Grogan stated that she is simply doing what any mother would do. "Wouldn't you if it was your child, right, wrong or indifferent?" he asked.

Since the death penalty was reinstated in 1976, 33 of 486 persons executed have had signs of mental retardation. Twelve of 38 states that allow the death penalty do not allow the sentence for persons with mental retardation.

Experts believe that the trial of Michael Hall is likely to be the focus of considerable attention, re-igniting the debate over executing persons with mental retardation.

MOST ADA SUITS LOSE

When the ADA was debated in Congress, opponents characterized the legislation as an open ended invitation for costly, destructive lawsuits against business, certain to drive their costs sky high at considerable detriment to the economy.

In fact recent statistics show that 94% of ADA suits have failed. Persons with disabilities have the dual burden of showing courts that they are sufficiently disabled to bring action but not too disabled to work. About half the cases are thrown out by judges before reaching the jury.

Carolyn Wheeler, an attorney with the Equal Employment Opportunity Commission, says that judges are dismissing cases largely because the ADA definition of disability is so complicated. The ADA defines a disability as a physical or mental impairment that limits a major life activity. But defining exactly when that happens is not always easy.

Since the ADA was enacted, 90,000 suits have been initiated. According to Steve Bokat, general counsel for the US Chamber of Commerce, while the vast majority of these suits have not been successful in court, they have given persons with disabilities leverage in reaching out of court settlements with firms seeking to avoid expensive litigation.

Some advocates believe that a recent Supreme Court ruling, which includes asymptomatic HIV within the ADA definition of disability, will broaden the scope of the law. However, events have yet to bear out that theory.

OLMSTEAD CASE TO SUPREME COURT Could Fundamentally Undermine Community Services

Is institutionalization illegal? Very often, according to the ADA.

Title II of the ADA states that "these provisions are intended to prohibit exclusion and segregation of individuals with disabilities and the denial of equal opportunities enjoyed by others, based on, among other things, presumptions, patronizing attitudes, fears and stereotypes of individuals with disabilities.... Integration is fundamental to the purposes of the Americans with Disabilities Act. Provision of segregated accommodations and services relegates people with disabilities to second class status."

In other words, "segregated accommodations" equals institutionalization.

That conclusion was substantially strengthened when the Eleventh Circuit Court of Appeals ruled that Title II of the ADA required the State of Georgia, in *L.C. v Olmstead*, to provide community based services to two women in a mental institution. According to the Arc of the United States *Olmstead v. L.C.* "has been relied upon in numerous lawsuits designed to influence state provision of services to people with severe disabilities."

The Arc adds ".....chapters of the Arc were beginning to look to (*Olmstead*) in determining litigation strategy to move states to community based rather than institutional services."

However the United States Supreme Court recently agreed to hear an appeal from the State of Georgia which claims that the Eleventh Circuit's ruling goes far beyond the requirements of the ADA. Twenty-two states have submitted a friend of the court brief in support of Georgia's attempt to overturn *Olmstead*. So far New York State is not among them.

Meanwhile, the Bazelon Center for Mental Health Law is developing a friend of the court brief in support of the Eleventh Circuit's decision. *Amicus* briefs in support are due in early March.

The Arc of the United States, whose opinion is shared by other major advocacy groups, believes that "the potential overturn of the Eleventh Circuit's decision would be a devastating blow in interpretation of the Americans with Disabilities Act and for people with disabilities seeking more integrated long term services through Medicaid."

Said NYSARC executive director Marc Brandt 'the Supreme Court's review of the case will provide the entire field of disabilities throughout the country with high drama it has not seen in a long time. A legal requirement that community placement must take precedence over institutional placement goes to the heart of everything we stand for and must be vigorously defended."

States fighting to overturn *L.C. v. Olmstead* argue in their brief that "if applied elsewhere, the Eleventh Circuit's interpretation of the ADA.... will necessarily affect the manner in which services are provided to individuals with disabilities in any group setting. It is self-evident that if a state spends enough money, virtually any person can safely and appropriately be served in his or her home (or more integrated community setting).

"However," the brief adds, "legitimate fiscal reality limits the ability of states to adequately fund community-based placements for all individuals with disabilities."

Central to the Eleventh Circuit's ruling was its ascertain that when experts agree that an individual is best served in the community, the ADA mandates community placement unless it results in a fundamental alteration of a state's provision of services.

Arguments against the *Olmstead* decision revolve around ADA provisions absolving states from providing community based services or "reasonable accommodations" if that would amount to a "fundamental alteration" to a state's service system or "undue burden" to the state or is not "reasonable."

Nevertheless, the Eleventh Circuit's decision is unambiguous. "By definition," it states, "where, as here, the State confines an individual with a disability to an institutional setting when a community placement is appropriate, the State has violated the core principle underlying the ADA's integration mandate."

Said NYSARC executive director Marc Brandt "the Supreme Court's review of the case will provide the entire field of disabilities throughout the country with high drama it has not seen in a long time. A legal requirement that community placement must take precedence over institutional placement goes to the heart of everything we stand for and must be vigorously defended."

NYSARC will follow this case and take all necessary action to support the Eleventh Circuit's decision in the United States Supreme Court.

AROUND THE NATION

NOD, HARRIS POLL RESULTS ANNOUNCED

The National Organization of Disabilities (NOD) issued findings based on a new poll done in conjunction with the Louis Harris organization. The poll, based on a sampling of 1,000 adults, compares the status of Americans with disabilities and Americans without disabilities. The NOD and Harris had completed two similar polls, the last in 1994.

As in 1994, the poll showed large gaps in key areas between persons with and without disabilities. Indicators or key life activities, were selected by persons with disabilities for comparison with the general population. Key findings include the following:

*Only 29% of persons with disabilities between ages 18 and 64 are employed full or part time compared to 79% of the general population. 72% of persons with disabilities who are not working, indicated that they would like to be working.

*34% of adults with disabilities live in households with total income of $15,000 or less, compared with 12% of Americans without disabilities.

*25% of people with disabilities have less than a high school education compared with 12% of the general population.

*54% of people with disabilities are registered to vote, compared to 74% of the general population.

*30% of adults with disabilities believe that existing transportation is inadequate for their needs compared to 17% of the general population.

*69% of adults with disabilities socialize with close friends, relatives or neighbors at least once a week, versus 84% of the general population.

These are just some of the survey results which included 125 questions and runs 175 pages. The survey however does not address gaps in obtaining housing. That will be the subject of future research between the Harris organization and the American Network of Community Options and Resources (ANCOR).

According to NOD Vice Chairman, actor Christopher Reeve, "this NOD/Harris survey will help all Americans better understand the lives and meet the challenges of those living with disabilities."

Individuals wishing to order a copy of the survey can call (202) 293-5960 or fax (202) 293-7999 or write to National Organization of Disability, 910 Sixteenth St., NW, Washington, DC 20006.

MEDICAID MANAGED CARE HELPS PAY PROVIDERS LESS
Despite Problems, It's Here To Stay

A new collection of essays, "Remaking Medicaid: Managed Care for the Public Good" suggests that despite problems Medicaid Managed Care has faced, it is here to stay and gives states a distinct advantage in negotiations with providers.

According to the publication, research shows that state Medicaid managed care plans use HMOs to save "money by controlling payments to providers .." HMOs are characterized as "tough negotiators" who pay providers less than states otherwise would had they handled negotiations with providers directly.

According to one of the books contributors, Robert Hurley, two features of Medicaid managed care are particularly appealing to states. One the one hand, embracing prepaid managed care gives state governments a vehicle for shifting the financial risk of Medicaid cost inflation directly to HMOs acting as private contractors. On the other hand, the managed care strategy - and the waivers that facilitate it - "affords states opportunities to extricate themselves from the commitments and entitlements that have been extended to beneficiaries and providers over the life of the Medicaid program."

"Remaking Medicaid" insists that despite problems with Medicaid managed care it presents an opportunity for states which is "too valuable to squander." Further, Medicaid managed care is "here and likely to stay."

Other contributors to "Remaking Medicaid" emphasize the advantages which Medicaid managed care programs offer to persons who are either underserved for have unique needs. Said Sara Rosenbaum: "there are at least as many problems in making the fee-for-service system work for Medicaid beneficiaries - the most important is that, unlike managed care, fee-for-service medicine does not promise access to covered services. It is the promise of service, not just the coverage, that makes managed care such a potentially important advance for Medicaid beneficiaries."

Because of state budget cutbacks, many HMOs have either gotten out of the Medicaid managed care business or sharply curtailed operations, leading some experts to conclude that Medicaid managed care will ultimately fail.

However, "Remaking Medicaid: Managed Care" suggests that with profits harder to come by in commercial managed care lines, Medicaid managed care may be coming relatively more attractive and more viable over the long range.

Remaking Medicaid: Managed Care For The Public Good, edited by Stephan M. Davidson and Stephan A. Somers is available for $45.95 from Jossey-Bass Publishers at 888/878-2537 or via the Internet www.joseybass.com.

ANNIVERSARY CELEBRATION MIXED
150 Year Old Institution Lauded, Panned

Recently the Walter E. Fernald State School in Waltham, Massachusetts celebrated its 150th anniversary, making it one of the oldest institutions for persons with mental retardation and developmental disabilities in the country. However, the event triggered more policy debate than celebration.

"There are two kinds of people in this world, institution and community people and I'm a community person," said Chansky who chairs a governmental affairs committee for the Massachusetts Chapter of the Association of Retarded Citizens and whose 35 year old son with mental retardation lives in the community.

"I would argue that Fernald operates more efficiently and provides better services" for persons with mental retardation than a community setting said George Mavridis, president of the Fernald League for Retarded Children, an advocacy group which sees the school as "a last hope."

Mavridis, whose cousin resides at the institution, believes that persons with the most severe disabilities "are never going to live in a four-bedroom community residence because they need more intensive nursing care..." and "for them Fernald is the least restrictive and proper environment."

Opposing Mavridis' point of view are people like Lucie Chansky. "There are two kinds of people in this world, institution and community people and I'm a community person," said Chansky who chairs a governmental affairs committee for the Massachusetts Chapter of the Association of Retarded Citizens and whose 35 year old son with mental retardation lives in the community.

Chansky added that "I believe that all people who (currently) live at Fernald would be served in the community and have more productive, integrated, normal lives than they do in an institution."

The controversy swirling around Fernald is not new. A class action lawsuit was filed against Massachusetts for conditions at the institution in 1974. While conditions have improved since then, incidents have left a lingering stain. In 1988, a 64 year old resident was found strangled after her head became stuck in the rails of her bed. In 1996 a 49 year old resident who could neither walk or speak was raped at the facility.

And just last year, notorious experiments conducted at Fernald came to light when it was revealed that residents of the institution were used as guinea pigs by the US government and fed radioactive breakfast cereal in the 40s and 50s to test the effects. The revelations brought a public apology from President Clinton and $1.85 million in damage payments to former residents from MIT and the Quaker Oats Company.

Even the original name of the institution - the Massachusetts School for Idiotic and Feeble Minded Youth - sends chills through today's advocates.

And today the School's appearance is marred by dilapidated buildings and a deteriorating physical plant due to lack of State funding.

Once home to 2,500 persons, today 393 adults reside at Fernald. Some advocates maintain that these persons are best cared for in the institution. Others maintain that Fernald is an ill conceived anachronism and that existing residents should be moved into the community.

According to the State's Assistant Commissioner of the Department of Mental Retardation, Larry Tummino, existing residents "present a lot of challenges" and "we're not going to create a position of our own and move forward without having everyone at the table to discuss future plans. For now, he said, "our goal is to provide the best quality of life" for Fernald's residents.

TENNESSEE SUED OVER MEDICAID MANAGED CARE PRACTICES
Persons With Developmental Disabilities Forced Into Nursing Homes

"TennCare routinely refuses to provide medically necessary care in the home even though such are is mandated by law and ostensibly covered by the program," said a 41 page lawsuit filed against the State of Tennessee which alleges that the State's Medicaid managed care program's failure to provide in-home, community based care is forcing persons with developmental disabilities into nursing homes.

The suit was filed in federal court on behalf of six individuals with disabilities by the Tennessee Justice Center (TJC). It claims that TennCare's practices are a violation of the ADA's requirements that publically funded services be provided in a least restrictive setting and a violation of federal Medicaid requirements. The suit asks the State to provide home and community based care

to eligible TennCare recipients rather than nursing home care.

The executive director of the TJC, Gordon Bonnyman, asserts that the State's current policy is a consequence of the influence of the HMO industry on the one hand and nursing homes on the other. Persons with disabilities are trapped between the two, he says. HMOs - acting as contractors to TennCare - save money by forcing persons with disabilities into nursing homes since they don't cover nursing home services.

However, the State of Tennessee is obstinate. Tennessee Health Commissioner Nancy Menke told lawmakers that TennCare was never intended to pay for long-term care services. She added that TennCare will change its regulations to reflect that policy.

Meanwhile, it appears that TennCare reimbursement policies for long-term care will continue to force persons into nursing homes. For example, one of the plaintiffs represented in the case, Stephan Newberry, is eligible for in-home care of up to $1,080 annually from TennCare while the actual cost is $6,000. Blue Cross, the HMO responsible for him, must make up the difference. The obvious economic incentive for Blue Cross is to place Newberry into a nursing home.

"The big question," says Bonnyman, "is how you pay for long-term care services if the HMOs have to deliver them."

Save these dates to celebrate NYSARC's 50th Anniversary!

Laurel Run 1999

A statewide run recognizing the aspirations and accomplishments of people with mental retardation and other developmental disabilities.

May 1, 1999

Laurel Run begins in the eight (8) start counties with representation from every chapter in the State.

June 11, 1999

Laurel Run concludes with a ceremony run to the steps of the Capitol with representatives, consumers, families, dignitaries, and friends from every county in New York State.

Black Tie Gala

June 11, 1999

NYSARC's 50th Anniversary celebrates with "Our Golden Past . . . Our Shining Future" black tie Gala to be held at the Terrace Gallery of the New York State Museum.

Annual Convention

October 21 - October 24, 1999

NYSARC, Inc. Annual Convention
Kutsher's Country Club
Monticello, New York

"Our Golden Past . . . Our Shining Future"

Convention Highlights:

* Recognition of founding members, chapter staff, consumers, legislators, families and friends of NYSARC.
* Convention exhibits and trade show.
* Multi-tracked convention program for family, staff and consumers!