

OBAMA ADMINISTRATION TRANSITION INFORMATION

The **Obama/Biden Administration transition** website is <http://change.gov/>: The site has many breakout subjects such issues as social security and disabilities; not too much is posted yet.

Government Accountability Office Transition Report: Following each presidential election, GAO serves as a resource to assist with the transition to a new Congress and administration. See, http://www.gao.gov/transition_2009/. Using its institutional knowledge and broad-based, nonpartisan work on matters across the government spectrum, GAO provides insight into, and recommendations for addressing, the nation's major issues, risks and challenges. Also located throughout the site are key reports for further research, as well as contact information for and video messages from GAO experts.

VOR Weekly E-Mail Update

November 7, 2008

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1. Virginia: California company to shadow DOJ investigators at CVTC

Summary: State-hired consultants will accompany DOJ investigators at its upcoming investigation at Central Virginia Training Center. The hiring of H&W Independent Solutions of La Quinta is consistent with a national standard of practice during such investigations. Tamie Hopp, Director of Government Relations & Advocacy for VOR agreed stating that many, but not all, states use consultants when preparing for Department of Justice Investigations. Hopp added that, "Our experience is that DOJ is not eager to file a lawsuit and will work with a state to address concerns." Families of CVTC residents have met with the state's consultants and have been in communication with DOJ representatives. "The family perspective is unique," said Hopp. "Not only are they another set of eyes and ears, they are intimately concerned with what's going on in a facility. They very much hold the position of 'fix it, don't close it.'" Families, she said, are not blind to the problems in facilities; "they're not willing to put up with anything but excellent care for loved ones." The degree to which families are satisfied, she said, "speaks volumes about the quality of care."

November 1, 2008

The Lynchburg (VA) News and Advance

By Cynthia Pegram

A team of three consultants from a California company will shadow investigators from the Department of Justice when they come to the Central Virginia Training Center in Madison Heights next month. The hiring of H&W Independent Solutions of La Quinta is consistent with a national standard of practice during such investigations, said Teja Stokes, commissioner of special projects for the Department of Mental Health, Mental Retardation and Substance Abuse Services.

"The consultant team is able to come in and help look at things that cause concern," said Stokes. The consultants know what kinds of questions may be asked, and what CVTC staff may want to look at, and what to expect.

"We have no clear idea of why the Department of Justice is coming -we have broad categories outlined in the letter," said Stokes.

The visit is set for Nov. 18-21.

The Department's Civil Rights Division notified Gov. Timothy M. Kaine by letter in August that an investigation would commence into the "care and treatment of residents at the Central Virginia Training Center."

The letter said, "We are obliged to determine whether there are systemic violations of the Constitution or laws of the United States in the conditions at CVTC. Our investigation will focus on protection of residents from harm and habilitation, and treatment programming."

This will be the first Department of Justice investigation of CVTC, a state residential program for people with intellectual disabilities. About 460 people live there. Many are also physically disabled and cannot walk.

Stokes said that Department of Justice findings are not reported for 12 to 18 months after a visit.

"Our consultant team will shadow the DOJ experts," said Stokes. The shadowing, she said, means that an action plan can be crafted and implementation begin "while waiting for final findings."

Making that effort, she said, shows that the state is proactive about issues that may be uncovered. Although the state doesn't know what triggered the Department of Justice investigation, Stokes said it represents "an opportunity for us to improve what we're doing and the services we provide for people."

Cost for H&W Independent Solutions will "not exceed more than \$2,000 per day per expert excluding travel time, or \$250 an hour for office-based work that does not equate to a full day's work," Meghan McGuire, state mental health department spokeswoman, said by e-mail after requests for the information by The News & Advance.

On its first request, The News & Advance was told the payment information was not available because it is protected as an "attorney work product." The News & Advance contended that since the investigation is of a state facility, and being conducted under federal civil rights law and by a federal agency, any payment to a private group should be public information.

Virginia is not the only state to have a state-owned mental retardation facility investigated or to seek help from private consultants.

Tamie Hopp is director of governmental relations and advocacy for the Voice of the Retarded, a 25-year-old national advocacy organization that supports living options that include appropriate placement in large state facilities.

Hopp, based in South Dakota, said many, but not all, states use consultants when preparing for Department of Justice Investigations.

"We've recommended that to families in the past . not so much to prepare, but to have another set of eyes alongside of DOJ while it's happening."

Hopp said, "Our experience is that DOJ is not eager to file a lawsuit and will work with a state to address concerns."

At CVTC, consultants met last month with officers of Friends and Families of CVTC as well as selected CVTC staff and state representatives.

"The family perspective is unique," said Hopp. "Not only are they another set of eyes and ears, they are intimately concerned with what's going on in a facility. They very much hold the position of 'fix it, don't close it.'"

Families, she said, are not blind to the problems in facilities, but "they're not willing to put up with anything but excellent care for loved ones."

The degree to which families are satisfied, she said, "speaks volumes about the quality of care."

Mark Wiesel, co-owner of H & W Independent Solutions, referred a request for an interview to Jane Hickey of the Virginia Attorney General's office. Hickey did not respond to a telephone request for an interview, but a spokesman from the Attorney General's office referred the call back to the state mental health department.

2. Illinois: Grassroots effort brewing to save health care facilities

Summary: This article details the courageous efforts of Howe Facility families and others to save the facility, which is facing closure in July 2009. Supporters of Howe, which sits on very valuable land, are fighting to have the facility recertified. Many blame certification problems on top management and state officials who he says haven't held anyone accountable for the center's decline. One by one, new directors came and went. Note: This article came about after the President of the Howe Family Association encouraged reporter and author Kristen Schorsch to tour the facility.

The Southtown Star

October 19, 2008

By Kristen Schorsch, Staff writer

Everywhere Barbara Foster goes, she's talking.

At church, at the beauty salon, in her neighbor's yard - she's chatting up a storm trying to save decades-old health care services and hundreds of jobs in the Southland, including her own.

"Oh my God," Foster said with a laugh. "When I get to talking, people listen."

That's the point, said Foster, who has spent her 34-year career tending to residents and patients at a pair of state-run health care facilities in Tinley Park slated to close.

She's part of a growing grassroots effort to prevent the state from shuttering the Howe Developmental Center and the Tinley Park Mental Health Center, which lost millions in federal Medicaid funding last year after providing substandard care and lax recordkeeping.

Fliers are being posted.

Calls are being made.

Keep a lookout for a few pickets, too.

"We're trying to get everybody on board for this battle that's coming," said Louis Volpi, president of American Federation of State, County and Municipal Employees Council 1591 and a 23-year Howe worker.

Everybody includes families, advocates, small-town mayors and state legislators - everyone who has a stake in the future of Howe and the mental health center, which share a sprawling 295-acre campus along 183rd Street at Harlem Avenue.

Public hearings on the closures are set to begin next month. Organizers say they're slowly building an army to once again prevail.

Four years ago, dozens of lawmakers decried Gov. Rod Blagojevich's plan to close the Tinley Park Mental Health Center, which he said would help ease a \$1.7 billion state deficit.

The state was going to sell the land to the highest bidder, and Tinley Park officials had big plans for the prime site near bustling Interstate 80.

But several local lawmakers wanted no part of it.

Cook and Will county boards, 10 Southland mayors and even then-state Sen. Barack Obama cried out against the closure. Patients would become homeless, they said.

Crime would spike, overcrowding state prisons even more. No other community health center or hospital was prepared to absorb patients from southern Cook, Will, Grundy and Kankakee counties, they said.

During the next year, the state took a beating for its plan. Blagojevich pumped millions into the mental health center to keep it alive as state officials formed a task force to dive more in-depth into the center's fate. Nurses at the Tinley Park center said staff levels were dangerously low, and a new law required the state to get the nod from a bipartisan commission before it could close any state-owned or -leased facility.

The task force decided a psychiatric hospital should stay in the Tinley Park area before the mental health center was closed and sold. The state Department of Human Services said the hospital would close, but officials didn't have a timeline, a target date for when the state would transfer services or put the mental health center up for sale.

The issue quietly fell off the radar - until last month.

On Sept. 5, state officials once again announced they plan to close the state-run mental health center. But this time, officials said they

aim to build a new psychiatric hospital, which contracted doctors would manage and state workers would staff. They also threw in the closure of the Howe Developmental Center, another state-operated facility, where residents have lived in a cluster of homes since the early 1970s.

The announcement was a joy for advocates who for years have called on the state to close Howe and the mental health center, both of which were stripped of their federal dollars last year; Howe for providing substandard care and the mental health center for lax recordkeeping. The mental health center has since been recertified.

But the announcement was brutally jarring for many whose children have lived in or used the facilities for decades.

"I don't know what we're going to do now," said Dorothy Mikrut, whose son has lived at Howe on and off since 1985.

The gloves are off

Louis Volpi, of AFSCME, blames the problems at Howe on top management and state officials who he says haven't held anyone accountable for the center's decline. One by one, new directors came and went, Volpi said.

"I still say it's about this land," he said. "(The state) just wants to close us down and get us out of Tinley Park. We're going to say 'no,' and we're going to fight and I mean to the last."

Realtors don't know exactly how much the land is worth, but the property is in a region experiencing explosive growth. The state first has to offer the land to another state agency, then local government

gets dibs, according to Central Management Services, which handles the state's real estate.

Tinley Park has asked a consulting firm that drew up redevelopment plans two years ago for the mental health center site to dust them off for an update, Trustee Patrick Rea said.

Plans then called for a variety of homes, parks, commercial space and maybe a school. Tinley Park might have a hard time convincing businesses to move in thanks to the 9 percent Cook County sales tax rate that took effect July 1, Rea said. Will County, which has a 7 percent sales tax rate, is just across 183rd Street.

Since Lilia Teninty became director of the state division of developmental disabilities about a year ago, she said several people have been removed from their positions, from managers to supervisors, to help fix problems at Howe. Equip for Equality, a federally-mandated watchdog group for people with disabilities statewide that has called for Howe to close, has investigated the deaths of 25 people at the facility in the last three years.

Closing Howe is not about money, Teninty said.

"It's unfortunate to think that's what people are tying it to," Teninty said. "We are concerned about the quality of care of everyone we serve. Clearly the center was run for a full year without Medicaid match and today runs without Medicaid match. We took resources from other state-operated facilities to run (Howe). ... It's just gotten to a point where we recognize we need to move on."

Howe residents will follow the nationwide trend of moving into community-based homes, or they can move into other state institutions. It's up to residents and their guardians. Mental health patients - the center provides acute care to patients for a week or two - can stay in fewer beds at the Tinley Park center or move into new units at Madden

Mental Health Center in Maywood or Chicago-Read Mental Health Center on the city's Northwest Side.

State officials intend to close Howe and consolidate the mental health center into one building by July 1, 2009.

A long road ahead

State Rep. Al Riley, (D-Olympia Fields), an urban planner by trade, said the state should have shovels in the ground now if its wants to open a psychiatric hospital in 2011.

The state would have needed to pick a site, which it hasn't done yet, make sure the land is zoned for a hospital and hosted public meetings to let residents know a psychiatric hospital was going to be built in their back yard, Riley said.

"The people just want you to deal the cards up straight," said Riley, whose district includes parts of Matteson, Tinley Park and Oak Forest, among other communities.

The state's hasty decision to close the Tinley Park health campus only will breed mistrust, Riley said.

"I think there should have been hearings about the feasibility of doing this beforehand instead of the Draconian, 'We're going to cut it,' Riley said. "How you manage what you do determines whether or not people are going to think the fix is in."

Tanya Anderson, chief of clinical services for the state division of mental health, said the state is looking everywhere for buildable

property and is consulting construction and finance experts to make sure the project is done right. Officials are concentrating on land in Will and Grundy counties because the areas are booming, Anderson said.

"We're really concerned about being able to provide the best care that we can for our patients," Anderson said. "We know we can't provide the best care in our current facility."

The 50-year-old mental health center has shared bathrooms, lacks wireless Internet capabilities and has terrible line of sight, meaning staff members can't always see patients at risk of hurting themselves if they hide in a corner, Anderson said.

Country Club Hills Mayor Dwight Welch said his position hasn't changed in four years. In 2004, he was one of 10 Southland mayors who accused Blagojevich of putting a "quick fix" sale ahead of long-term health care services in the southwest suburbs. He said he's still worried the impact of the shuttered health facilities will ripple throughout Cook County through job loss and a further strained economy.

"Unless we find alternative means of taking care of the needs for the mentally indigent and handicapped, you just can't say 'We're going to close,'" Welch said. "All that does is there will be more people on the street."

Homewood Mayor Rich Hofeld, who joined Welch four years ago to fight the mental health center closure, said his concerns about location haven't changed.

"Four years ago, I thought there should be services for residents as well as the families of the residents so they wouldn't have to travel to (Chicago) Read or others so far out of the area," Hofeld said. "To me, that is just wrong."

The state plans to redraw the boundaries for Tinley Park, Madden and Chicago-Read mental health centers so patients still could seek care at a facility near their homes, Anderson said. DHS also plans to buy bed days from hospitals in case the health centers don't have enough space, Anderson said.

Before her stint in the state Senate, Maggie Crotty spent years working in the classroom, in storefronts and on fundraising for people with disabilities. She's fought to increase their rights and strongly believes services for people with disabilities and mental illnesses need to remain in the Southland.

So when the public hearings begin, Crotty (D-Oak Forest) will be there.

"The thing I always relate to is how would I want to be treated," Crotty said.

3. Montana: Supporting Individuals with Developmental Disabilities to Live in Their Communities with Their Families (From the Director's Desk)

Summary: As this article indicates, the focus of Montana's "system change" efforts has been to encourage family caregiving: "In the early days of de-institutionalization, state staff went out to the counties across Montana and developed provider organizations to help develop community services. It took months to develop a network of community providers that support individuals living with their families" (emphasis added). This emphasis continues to this day, probably due to Montana's challenging geography: "It was difficult to imagine community-based services in the fourth largest state in the country. Montana encompasses over 147,000 square miles

and covers mountain terrain, river valley, and prairie. It takes about 10 hours to drive from the western border of Montana to the North Dakota border. Montana is considered a frontier state because it has small isolated pockets of population, with almost one million people residing in the entire state." Montana became the first state in the United States to gain approval for a 1915(c) Home and Community-Based Services Waiver in 1981. Included in the Montana "vision" for services to people with disabilities is this: "People should be provided supports in the communities and settings of their choice, whether traditional, congregate, individual, or an untried alternate." Montana does have one large state ICFs/MR with about 90 residents.

Jeff Strum, State Director, Montana Developmental Disabilities Program.

Community Services Reporter

NASDDDS October 2008

See www.nasddds.org for subscription information.

Since the mid-1970s when the State of Montana began to de-institutionalize, the Montana Developmental Disabilities Program has focused on and supported individuals living with their families in community settings. In the early days of de-institutionalization, state staff went out to the counties across Montana and developed provider organizations to help develop community services. It took months to develop a network of community providers that support individuals living with their families. The staff were dedicated and families were passionate about services being provided for their family members so they could live at home.

It was difficult to imagine community-based services in the fourth largest state in the country. Montana encompasses over 147,000 square miles and covers mountain terrain, river valley, and prairie. It takes about 10 hours to drive from the western border of Montana to the North Dakota border. Montana is considered a frontier state because it has small isolated pockets of population, with almost one million people residing in the entire state. Small towns dot the vast landscape and many have less than a few hundred people. Farming and ranching is the main source of income for many Montana families. To overcome obstacles as vast as these, state staff worked diligently to

put together the resources needed to support Montana's goal of community living and family supports for individuals with developmental disabilities. Without the tenacity and willingness of the people of Montana to realize their dream of family-supported services, Montana's home and community services network would have never been established.

Once this network of community providers was established, the last remaining obstacle was funding. This barrier was removed when Montana became the first state in the United States to gain approval for a 1915(c) Home and Community-Based Services Waiver in 1981. Since that time, Montana has continued to nurture the concept of living in the community with family. In 2001, Montana's unique, limited funding Community Supports Waiver was approved. The waiver was created based on the premise that family and natural supports form the foundation for community living. Given those supports, many individuals did not need high-cost plans to live and work successfully within the community. This specialized waiver offered services such as education, social/leisure recreation, health and safety, companionship, personal care, homemaker services, respite care, pre-vocational rehabilitation, supported employment, environmental modifications, adaptive equipment, private duty nursing, residential habilitation, and transportation needs that assured continued support for community access.

In August of 2008, Montana submitted a request for approval of its newly created Children's Autism Waiver. This waiver provides intensive supports for children from age 18 months to eight years and their families. Montana chose to focus the waiver on this age because research has shown that intensive intervention at an early age has proven most successful for children with autism and other related disabilities that fall within the autism disorder spectrum. A dedicated workgroup of stakeholders, comprised of providers, family members, state staff, and educational staff met for many months to craft the components of this waiver. The basic premise of the Children's Autism Waiver is that children can and should be served in their homes with intensive supports; children with autism can be helped to live successfully in the community with their families. This waiver provides, at a minimum, 20 hours per week of services to children with autism and their families who are requested to commit to this intensive schedule in order to assure that the child and the family's needs are met. The Children's Autism Waiver has a time limit of three years, which is why the number of hours per week must be no fewer than 20. Support services include respite care, transportation, environmental modifications, adaptive equipment, and goods and

services. A funding restriction applies to these services where no more than \$4,000 of the child's cost plan can be spent. The bulk of the cost plan must be spent on behavior-related training techniques.

Montana providers, state staff, individuals, and family members have shared the same vision for services:

. People should be safe, healthy, and free from abuse.

People should be provided supports in the communities and settings of their choice, whether traditional, congregate, individual, or an untried alternate.

People should have a choice of providers and individual caregivers, and control of how supports are provided.

People should have caregivers who are qualified, trained, and respectful of their individual differences and values.

People should be provided essential supports in as cost-effective ways as possible without sacrificing quality.

People's natural supports should be utilized and enhanced whenever possible.

People's resource allocations should be determined in a rational and defensible way and primarily be used for direct services, keeping administrative costs as low as possible.

People should have more options for meaningful work, opportunities for personal growth, expression of talent, and a share in responsible community living.

People should learn about their rights and responsibilities and be encouraged to exercise self-advocacy skills.

People should be encouraged to exercise an increasing amount of control and choice in their lives while being provided with reasonable protection when there is imminent risk of serious harm.

People should learn skills and appropriate behaviors that will enhance their acceptance and participation in their communities.

Montana faces many challenges when providing services to many of its residents. Most communities in Eastern Montana are losing population, leading to a lack of professional and other support staff for those that continue to reside there. As a result of the changing demographics, many of those communities will have difficulty continuing to offer congregate living services. Other smaller individually based services may have to replace those currently found in many small Montana communities. More innovative approaches that meet the problems associated with the shrinking population, lack of resources, and the cost of getting services to those individuals will have to be found.

Montana's mission, in the past and present, states: "The Developmental Disabilities Program supports choices and opportunities for people with Developmental Disabilities in their communities." It is the fostering of this mission and values that is the cornerstone of the Montana Developmental Disabilities Program.

Supporting people living with their families, working and sharing their lives, empowered by choice in services, is the outcome Montana Developmental Disabilities Services works each day to achieve. These services provide a growing sense of self-esteem and a belief that individuals with DD are members of the community, supported and nurtured by their families and friends.

Tamie Hopp

**REFERRAL/MEMBERSHIP/CONTRIBUTION
FORM**

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Voice of the Retarded

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Elk Grove Village, IL 60007

847-253-0675 fax (for referrals or credit card payments)

Tamie327@hotmail.com (for referrals or credit card payments)

FOR REFERRALS: ___ The contact information provided is for someone I think would consider membership with VOR.

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