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VOR Weekly E-Mail Update
February 6, 2009

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Coming Up: Fernald Families seek help from the U.S. Supreme Court
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1. Seeking grown-up care: Doctors' unease found to leave many disabled adults with pediatricians

Note: Lack of access to health care is one major concern cited by families strongly opposed facility closures. This article is from Massachusetts, where the Governor has proposed closing 4 of the state's ICFs/MR.

Seeking grown-up care
Doctors' unease found to leave many disabled adults with pediatricians
By Patricia Wen
The Boston Globe
February 2, 2009

One day last week, Dr. Daniel Palant walked into his pediatric clinic, decorated with Mickey Mouse posters and antique baby bottles. He was prepared to see his next patient, whom he has known since birth: Shalom Lowell, who has Down syndrome. Palant loves meeting the same patients year after year, but he thinks that sometime soon this one should see a new doctor.

Lowell is now 26 years old and his body stretches well beyond the length of the examining table.

"It's best for him to see an internist," said Palant, after examining the young man, who has had recent bouts of fatigue. "He shouldn't be part of a pediatric practice."

The incidence of adult disabled patients staying with their pediatricians long after their 18th birthday is one of many issues raised in a report released today by The Arc of Massachusetts, an advocacy group for people with intellectual and developmental disabilities.

The study, "Left Out in the Cold: Health Care Experiences of Adults with Intellectual and Developmental Disabilities in Massachusetts," found that many disabled adults face longer waits than most people finding good internists, and that prevents them from getting the best care for common adult conditions such as hypertension, heart disease, or thyroid disorders.

The report found that, among other reasons, many internists avoid disabled patients because of uneasiness with them.

Also, many doctors feel that insurers do not pay enough to compensate them for the longer time it often takes to listen to - and care for - these patients. Leo Sarkissian, executive director of Arc, acknowledged that many disabled adults pose special challenges during routine visits.

Some talk slowly or unclearly about what ails them, and others panic at being touched, even needing to be restrained for a routine throat culture or ear exam. Some disabled adults may have physical limitations in simply getting up to the examining table.

"Doctors avoid them," Sarkissian said.

Della Jones, a Brockton mother, said her 18-year-old daughter, who has autism, will often "scream and push" during exams because of fears over the procedures, and Jones believes that is partly why she has yet to secure a good primary care doctor.

As a result, many pediatricians, who typically have more training involving disabilities, see their patients well into adulthood - some as old as 40, said Mandy Nichols, director of healthcare policy for Arc.

The report included interviews with more than 100 adults with disabilities, their parents or guardians, and community support professionals.

Two dozen physicians and other healthcare clinicians also took part in the study, funded by the Boston Foundation.

Nichols said there are no available statistics showing how many of the state's 180,000 disabled citizens see pediatricians as adults.

The report recommends that the state call for added training for doctors to become more sensitive to the needs of disabled adults.

Sarkissian said many doctors, if given the choice, talk directly to a parent or guardian about a disabled adult's medical problems, even when the disabled patient is in the examining room and able to understand. The report also calls for the state to increase insurance reimbursements to doctors who see adult patients with disabilities, accounting for the extra time and training.

Palant said he has long taken an interest in serving the disabled population because his older sister is developmentally disabled, and he has helped oversee her care for years. His pediatric practice has about a dozen adult patients with disabilities.

On Thursday, Palant listened as Lowell explained haltingly, but clearly, that he will often "fall asleep right after work," something that didn't happen before.

After Palant questioned Lowell about his sleeping and eating habits, the patient admitted that he sometimes has an erratic meal schedule and goes to bed late while living in his group home.

He vowed to get on a better schedule to boost his energy.

The session, which included a physical exam that prompted Lowell at times to break into fits of giggles, lasted about an hour.

Asked how much longer he plans to see Lowell, the pediatrician said he feels tremendous loyalty to the young man and his family.

"I play it by ear," he said.

2. GEORGIA: Changes ahead worry families

by Tom Corwin, Augusta Chronicle
Sunday, February 01, 2009

After church on Sunday, Theresa Senior likes to pick up her daughter from the Gracewood campus of East Central Regional Hospital and take her home to Hephzibah. But 50-year-old Terral is never out of her sight.

"She's going to get into something," Mrs. Senior said. "She's going to head right for the stove." Her developmentally disabled daughter loves to stir and mix but could also seriously injure herself. She has lived at Gracewood for the past 18 years when her family could no longer care for her. And her mother fears she will be turned out to fend for herself in the community.

"People who need to be watched 24/7 don't need to be in group homes because they can't handle them there," Mrs. Senior said.

Georgia's mental health system is poised to undergo a profound change of privatization that will see most of East Central and six other regional hospitals closed in coming years, to be replaced by two privately

built and operated psychiatric hospitals. The state will dramatically reduce the number of beds in institutions and instead double the number of community services for patients now being served in that setting, officials said.

According to a draft copy of the Behavioral Health Game Plan from December, the state will begin closing hospitals this fiscal year and close the remainder, including East Central, by 2012, going from 2,353 total beds available to 1,480. That would include 250 for the developmentally disabled at Gracewood, where the state's inpatient services for those patients would be consolidated, said Gwen Skinner, the director of Mental Health, Developmental Disabilities and Addictive Diseases.

"But the movement of people with developmental disabilities into the community will continue," she said. "If we are able to offer the same services in a community setting, then we would opt to move in that direction. But that's a cooperative relationship with the family and with the consumer as you look at what those services are because it really has to meet the needs of the family, not the agency."

Some families at Gracewood, however, feel as if they haven't been heard at all.

"They just completely ignored us," said Ann Knighton, whose daughter, Erica, has lived there since 1975. Her daughter, who doesn't talk and has a seizure disorder, needs constant supervision.

"I'm not going to sacrifice my child just to say she's in the community," said Ms. Knighton, who is planning to file a civil rights complaint on her daughter's behalf.

State officials said a thorough assessment process would take place first to assure the patient is going into the right setting.

"This plan is not designed to turn hospital patients out on the street," said David Noel, a spokesman for the Georgia Department of Human Resources, which oversees the mental health and developmental disabilities division. It is trying to turn around a system of hospital-first care to community-first, he said.

"You're going to be assessed," Mr. Noel said. "Every effort is going to be made to preserve your quality of life and your community life but obviously there are some cases where a state hospital is really the only solution."

And the state gets two new "state of the art" hospitals to replace aging facilities without having to fund them, he said.

The effort also allows parents and patients a chance to look at services they might not know are out there, Ms. Skinner said.

"We fully recognize that we have a number of people whose lives have pretty much been lived out in our hospitals," she said. "And so we are working very closely with their families on the transition. And most families, when they see that you can put together a good, solid package of supports and services, are willing to do that."

For instance, if someone needs 24-hour nursing care, the state can arrange for that through an expanded waiver program that allows the patient to receive those services in a home setting, Ms. Skinner said. And it is in keeping with the national trend away from institutionalizing those patients, she said.

"I think what you're seeing, the major change across the country, is that people will no longer go into hospital settings to live out their lives," Ms. Skinner said.

But for parents such as Gerald and Betty French, of Sylvania, whose daughter, Barbara, has been at Gracewood since 1974, the thought of having her outside its walls is frightening. Placing their daughter, who suffers from seizures and doesn't talk, in Gracewood was "the hardest decision we ever made," Mrs. French said.

"But it was the best thing for her," Dr. French said.

Even if the former patients find appropriate care in a group home, for instance, they would miss the outings Gracewood organized for them, to the fair or to shopping or a restaurant, Mrs. Senior said. There were dances and proms where the patients got to dress up and dance with soldiers from Fort Gordon, she said.

"Our kids live a really full life at Gracewood," Mrs. Senior said.

Now in their 70s, the Frenches worry more about their daughter's future than their own. If not in Gracewood, they ask, in what kind of home will she land?

"If she was capable of being in a home," Dr. French said, "she would be in our home."

GEORGIA'S PLANS

Georgia's "game plan" for transforming mental health and developmental disabilities services envisions transforming from institutional care to community care by 2012.

The state has released two Requests for Proposals to privatize forensic mental health services and to build two new psychiatric hospitals, one in Atlanta and one in south central Georgia. The state would then close all but a few pieces of the seven regional mental health hospitals.

The plan envisions consolidating its 250 developmental disability beds at the Gracewood campus of East Central Regional Hospital, which has the highest level of expertise with those patients. Other patients would transition to the community with a package of support services tailored to individual needs.

The "game plan" envisions funneling the money into expanded community services that would essentially double the capacity of community programs in addition to adding some new services.

3. CALIFORNIA: Fund cuts the major issue

Note: As in many states, this article contains the myth believed by so many politicians that closing centers will save money: "One way out of the deficit would be shutting down or consolidating three of four state developmental centers, Hansen said." It is up to VOR advocates dispel this myth. See the

[January 23, 2009 edition of The VOR Weekly Update](#) for advocacy tools, including an 2009 Cost Comparison Study Update.

Mediha Fejzagic DiMartino
The Daily Bulletin
01/30/2009

Something was not right.

Yet, no one said a word.

While a majority of guests on Friday at the Inland Empire Caucus' fifth annual legislative breakfast worked on their eggs and potatoes - others wondered why they were not being served.

A few minutes later, Karen Jones, executive director of Pomona Valley Workshop, addressed the big elephant in the room - the empty plates representing an expected cut in state funding to agencies serving disabled people.

"Did it cross your mind that there may have not been enough resources for those breakfasts," Jones asked.

The plea to lawmakers to not cut funding amid state budget concerns was the theme of the breakfast.

While everyone in the ballroom eventually received breakfast, officials from IEC - an advocacy network of local agencies serving more than 5,000 people with disabilities - are not sure they will see the same thing happen for their clients.

"People we serve didn't choose to have a disability and they need the state of California to uphold its commitment of the Lanterman Act," Jones said. "They have rights, as we all do."

The act gives people with developmental disabilities the right to receive services in their community in the least restrictive way.

The expected cuts will be severe.

In the next 17 months, the state Department of Developmental Services is looking at \$500 million in cuts, or 12 percent of the DDS' overall budget.

Governor Arnold Schwarzenegger's proposed three percent mid-year cut to the department's \$4.2 billion annual budget, or \$40 million, is awaiting action by the Legislature, said Dwight Hansen, the breakfast's keynote speaker and a lobbyist.

The adjustment will be followed by \$117 million in cuts for fiscal 2009-10.

An additional \$334 million reduction that surfaced in the Schwarzenegger's January budget, may also be implemented next fiscal year, Hansen said.

And that's just the start of the avalanche.

"If we don't have those original dollars, we are at risk of losing our federal matches as well," Jones said.

The budget cuts threaten various adult programs such as vocational training, job coaching services and adult day care.

Production at workshops may also be halted, Jones said.

"It's not just job loss for our disabled population, it's a ripple effect in larger community," she said.

"They will no longer pay taxes, and companies will lose a cost-effective way to run their business."

To continue providing services for clients, Hansen said he is prepared to tighten his belt.

"The enemy is not the governor or the regional center," Hansen said. "The enemy is the economy."

One way out of the deficit would be shutting down or consolidating three of four state developmental centers, Hansen said.

At \$300,000 a year per bed, the 24/7 care facilities housing 1.6 percent of the state's disabled population absorb 20 percent of the department's budget.

"For every person living in one of these institutions, there are literally 100 others with the same condition living in the community," Hansen said. "We would be saving two-thirds of their \$700 million budget in the long run."

More than 7,000 state employees running the facilities oppose the change.

"Remember these individuals," Jones said. "We don't want to balance the budget on the backs of the most fragile Californians."

Tamie Hopp

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