



State Health Watch

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The Newsletter on State Health Care Reform

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In This Issue

■ **Overcoming racial and ethnic disparities.** Studies indicate that there are inequalities in access to health care and quality of care delivered to racial and ethnic minorities. Here's the map to eliminate these disparities . . . cover

■ **Consumers help programs improve.** Want to know how to make a health care program better? Ask the people who use it. Programs with strong consumer involvement provide better care and save money cover

■ **Research identifies disparities.** New study identifies socioeconomic gaps in health care. 3

■ **Racial variations seen.** Parents report differences in health care for their children based on race, ethnicity, and insurance 4

■ **Olmstead compliance involves complex issues.** States working to comply with the Supreme Court's decision track cases that pinpoint complex legal issues 8

■ **Interpreters can improve care delivery.** Some people cannot follow medication instructions because they don't understand what they're being told. 10

■ **Funds for interpreters available.** Many states are not taking advantage of funds available to provide interpreter services in health care settings. 10

■ **Inserted in this issue:** State OMH descriptions on purchasing and regulatory strategies

States are learning to use leverage for social good and to save money

Increasingly, government agencies, health plans, consumer groups, and advocates are expressing concern about the disparities in health care services for racial and ethnic minorities. Some groups are finding ways to address these disparities, and finding that in the process, they are improving the quality of care and saving money. In this issue we look at the extent of the problem, its impact on people, and some of the solutions being pursued.

Despite progress made in the United States in ensuring access and delivery of health care services to those who need them, there still are points at which

the system may fail to meet the needs of racial and ethnic minorities, from insurance coverage to access to appropriate services.

The National Academy for State Health Policy (NASHP) in Portland, ME, says states, as major purchasers of health care services, have a number of tools to address disparities in care.

The most common — translation and interpreter services — are not sufficient, however, and states are starting to use their purchasing and regulatory authority to make more of a difference.

See Disparities on page 2

Listening to consumers means sharing power, a scary proposition that may save you money

It's been a long time coming, but public purchasers of health care services for low-income people are involving them in the operation of health plans.

Change comes none too soon for RoAnne Chaney, program officer leader of the Consumer Action agenda for Lawrenceville, NJ-based Center for Health Care Strategies (CHCS), which promotes the ability of

**Fiscal Fitness:
How States Cope**

consumers to navigate health care delivery systems, access needed services, and

participate in the design, implementation, and monitoring of publicly financed managed care.

"Consumers possess a lot of information that has been untapped," Ms. Chaney tells *State Health Watch*. "They often don't recognize that they even have important information. There is value in getting information that will improve health care."

A CHCS issue brief says that even with positive outcomes from consumer involvement, health care systems and public purchasers of care have been slow to incorporate con-

See Consumers on page 5

Disparities

Continued from page 1

On average, according to a NASHP report, Latinos and African-Americans have worse health status and access to effective health care than whites. On most measures, African-Americans are the most disadvantaged population, while on most measures of access to care, Latinos are worse off.

Health disparities increase costs and reduce quality of life. Diabetes, for example, which disproportionately affects racial and ethnic minorities, costs about \$100 billion annually in direct medical and treatment costs and indirect costs attributed to disability and mortality. Reducing disparities in diabetes health care prevention and treatment strategies would reduce unnecessary illness, disability, death, and expense.

Likewise, asthma detection, intervention, and treatment could reduce hospitalizations, disability, and deaths that disproportionately affect racial and ethnic minorities. Direct and indirect asthma costs are estimated to be more than \$6 billion a year.

Too early to assess effectiveness

NASHP project manager Jill Rosenthal tells *State Health Watch* that it's still too early to assess the effectiveness of many state efforts, although the assumption is that they will lead to change.

She says that in spite of the growing attention being paid to the problem, the issue of racial disparities can slip through the cracks if state officials fail to focus on it. Clear goals, benchmarks, and coordination of efforts are needed if results are to be seen, she adds.

NASHP's survey found that many state health care purchasers do not analyze service utilization, quality improvement, patient satisfaction, or

other data sets by race and ethnicity. Many purchasers noted the need for a common data set and more specific data about their racial and ethnic minority populations.

"Crude categories for capturing race and ethnicity make it difficult to identify the needs of specific populations," the report states. "Lack of data and performance measurement have left state purchasers without information to determine how to use resources most effectively to identify risk factors and develop interventions."

Agencies that purchase health care may address disparities through direct state activities and state contract requirements that address language and cultural barriers, outreach activities, collection and analysis of data for utilization and/or patterns of care, and quality improvement efforts that examine and improve the care provided to members of racial and ethnic minority groups or for conditions that disproportionately affect

members of minority groups.

Neva Kaye, NASHP's program director, tells *State Health Watch* that state efforts should not be totally limited to cultural competency.

Ms. Rosenthal notes that some state efforts, such as disease management programs, are seen as ways to improve care rather than efforts specifically intended to reduce disparities, making it hard to accurately assess how much really is being done.

Responses to NASHP from 28 state Offices of Minority Health indicated that 14 of the state purchasing agencies such as Medicaid, State Children's Health Insurance Program (SCHIP), and state employee benefits agencies, are using purchasing strategies to reduce racial and ethnic health disparities. (See **purchasing strategies chart, inserted in this issue.**)

Many reasons that states act

Factors that led states to use their purchasing power as a disparity

AHRQ wants your disparity data for report

Next year the Agency for Healthcare Research and Quality (AHRQ) in Rockville, MD, will submit to Congress its first report on prevailing disparities in health care relating to racial and socioeconomic factors in priority populations. The legislation mandating the annual reports identifies priority populations as low-income groups, minority groups, women, children, the elderly, and individuals with special health care needs.

AHRQ says its first report will focus on health care disparities for the identified groups compared to other Americans regarding access to and quality of care.

"The report will provide answers on a national basis to critical questions about disparities in health care and will permit development of a more complete picture of health care in America, including who has access to care and how good is the care received," AHRQ said in a *Federal Register* notice.

To facilitate preparation of its report, the agency has asked for nomination of measures and candidate data sets for inclusion in the report. Nominations should be sent to Sari Siegel, Center for Primary Care Research, AHRQ, 6010 Executive Blvd., Suite 201, Rockville, MD 20852.

(Access the *Federal Register* notice at http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=2002_register&docid=fr05jn02-50.) ■

reduction strategy included data that increased awareness of poor health outcomes for minorities, changing racial demographics, federal regulations related to availability of services for racial and ethnic minorities, availability of state funding to address disparities, community input, the cost of disparities, and state agency commitment to quality and public health.

Eleven of the 28 reporting states indicated they use regulatory strategies to reduce disparities, with the most commonly used regulatory

strategy aimed at increasing cultural and linguistic access to health services. (See **regulatory strategies chart, inserted in this issue.**)

The academy survey found that state strategies vary depending on population needs and evolving capacity. Despite the increasing attention being paid to the issue, state strategies still may not be strategic or focused, and states may not have the performance measures and data needed to assess the problem and develop solutions.

New York State Department of

Health Division of Family Health associate director Karen Kalajjian tells *State Health Watch* that the state's diverse population has led to significant efforts to overcome disparities in Medicaid managed care.

In the Medicaid managed care waiver project under way in 21 counties and most of New York City, she says, about 69% of enrollees are non-Caucasian. And in New York City, there are many ethnic minorities included within the overall Caucasian grouping.

A great divide exists between the insured and the uninsured

Even as the Agency for Healthcare Research and Quality prepares to develop its first report to Congress on disparities in health care, further research links other problems in health care to these disparities.

A survey by National Public Radio (NPR), the Kaiser Family Foundation, and the Kennedy School of Government at Harvard University in Cambridge, MA, points to a significant medical divide along socioeconomic lines in America. And a national tracking study issued by the Center for Studying Health System Change finds that ethnic and racial disparities in access to medical care among uninsured working-age Americans are much greater than disparities among insured people.

Based on a nationwide telephone survey of 1,205 respondents, the NPR/Kaiser/Kennedy School research found that the vast majority of people in the top income categories have very few problems getting health care or paying for it, while in the bottom income categories many people are burdened by such problems, and that the problems are likely to be serious.

While only 20% of those surveyed say they think our health care system works pretty well, there isn't a great push for sweeping change in the health care system.

People don't want significant change

The survey found that most people favor current methods of providing health insurance through guaranteed benefits from employers and public programs.

Four in 10 families reported at least one problem with access to health care, paying medical bills, or perceived quality of care in the past year. The uninsured, those who earn less than \$25,000 a year, and those

without high school diplomas are more likely to report having health care problems. And the number of people worried about impending health care cost and access is even higher than the number actually experiencing problems.

Meanwhile, the Center for Studying Health System Change survey finds that gaps in access to medical care between uninsured Latinos and African-Americans and uninsured whites generally are almost doubled those between insured minorities and insured whites. This survey involved about 60,000 people in 33,000 families.

"Health insurance is the key that opens the door of the health care system for most working-age Americans, but especially for Latinos and African-Americans," says study author J. Lee Hargraves. For example, 31% of uninsured Latinos and 36% of uninsured African-Americans reported having a regular health care provider in 2001, compared with 51.4% of uninsured whites — an access gap of more than 20 percentage points between uninsured Latinos and uninsured whites.

Among insured people, gaps between minorities and whites still were significant, but much smaller. Thus, 67% of Latinos and 71% of African-Americans had a regular health care provider, compared with 78% of whites. Almost one in three Latinos and one in five African-Americans lacked health insurance in 2001, compared with about one in 10 white Americans.

[Access the reports at www.kff.org and www.hschange.org.] ■

“We’re very cognizant of the need to make this program acceptable to persons with very limited proficiency in English,” she says.

“We go to a lot of effort to be sure we can find physicians who can meet their needs within our plans.”

Health plans wanting to contract with the state must go through a qualification process showing how they will meet beneficiary requirements, including cultural competencies and how they will meet the needs of diverse populations.

Plans must have sufficient providers in geographic areas in which ethnic or racial groups are found and must have staff with language capability for the populations they serve.

They must provide access to the physically disabled, have quality assurance plans, have written quality improvement protocols, and

have a member-services function to communicate with enrollees.

During new member screenings, plan physicians are expected to identify special health needs and cultural needs. Informational and marketing materials must be published in languages other than English if at least 5% of the enrollees speak another language.

To improve access to health care services, the state agency contracts with community-based organizations to assist in outreach and enrollment activities.

Ms. Kalajjian says the organizations are encouraged to hire staff that are culturally and linguistically appropriate, that must be able to work in more than 38 languages across the state.

While people can opt out of managed care if they can demonstrate language barriers, she says only seven of more than 300 such requests in New

York City had to be granted. In all other cases, enrollees were directed to providers who spoke their language.

Special issues with women

Under leadership of former U.S. Surgeon General Antonia Novello, Kalajjian says, New York state is trying to recognize cultural differences in approaches to health care. For instance, in the Hispanic culture, women put their families first and would be the last to go to the doctor. The agency is working to help Hispanic women to accept that if they care for themselves first, they will be better able to care for their families.

In Massachusetts, Group Insurance Commission executive director Dolores Mitchell tells *State Health Watch* that her general approach is to be sensitive to cultural differences and needs wherever there is an opportunity. Often, she says, there

Age, race, ethnicity, and insurance coverage add up to trouble

Agency for Healthcare Research and Quality survey data indicate that while a majority of parents say they have had good experiences in obtaining health care for their children, there are significant variations reported by age, race/ethnicity, and type of insurance coverage.

The agency says that parents of publicly insured (such as Medicaid and State Childrens Health Insurance Program) and uninsured children (20.4% and 15.8%) were more likely to say they had experienced a problem receiving necessary care during a doctor’s office or clinic visit than were parents of privately insured children (7.9%). They also were more likely to say that the health provider never or only sometimes explained things carefully.

The findings include:

- Parents of black children were more likely than parents of white or Hispanic children to report that health care providers always showed respect for what they had to say.
- Black and white children were more likely than Hispanic children to have their parents report that providers always explained things in a way

they could understand.

- Hispanic children were less likely than white or black children always to get appointments for routine care as soon as their parents wanted.
- Uninsured children were less likely than those with private coverage to have their parents report that health care providers always spent enough time with them.
- Uninsured children ages 6-17 were much less likely than children that age with public or private coverage to receive care for an illness or injury as soon as their parents wanted.

Data were collected in 2000 and early 2001 through a new questionnaire added to the agency’s Medical Expenditure Panel Survey. Parents of a nationally representative sample of 6,500 children under age 18 were asked about the timeliness in which their children received needed and routine medical care and their experiences during their children’s care.

[More information is available at www.meps.ahrq.gov/papers/st3/stat03.htm.] ■

are basic issues to be resolved.

“For instance, access may not mean whether a person has insurance coverage but whether he or she has transportation to be able to get to a health fair. You have to bring programs to poor neighborhoods and not just hold them downtown.”

Ms. Mitchell’s commission maintains contracts with smaller neighborhood health center-based plans that otherwise might not meet contracting criteria and makes sure they offer materials in multiple languages. And her staff use yearly HMO site visits to ask providers what steps they take taking to demonstrate cultural sensitivity and competence and to leave a message about concerns that Mitchell wants to see pursued.

Beth Waldman, MassHealth’s director of program implementation, says the agency is concerned with overcoming disparities in getting people to apply for Medicaid and then getting them quality care once they are enrolled.

Of the one million MassHealth members, about one-third are racial or ethnic minorities and 15% are self-identified as speaking a primary language other than English.

Ms. Waldman says they try to enhance the patient-doctor relationship to enhance the clinical care process. Providers are encouraged to use trained medical interpreters and to employ appropriately bilingual staff.

Translated materials available

On the member side, MassHealth has expanded availability of translated materials. Staff make efforts, she says, to communicate information correctly in appropriate dialects. Materials are targeted to groups in specific geographic areas, and mini-grants have been given to community-based organizations to facilitate outreach in targeted communities.

State efforts to eliminate disparities

can be helped by more collaboration among state agencies, NASHP says.

Often, Ms. Rosenthal says, agencies may not be aware of each other’s roles and mutual interests. For instance, state Offices of Minority Health may not be actively involved in state purchasing or regulation of health care as a strategy to reduce disparities. Strong leadership can overcome these shortcomings and force action.

Ms. Mitchell says she feels strongly that overcoming racial and ethnic disparities is the right thing to do and should not be subjected to a cost-benefit analysis.

“For instance, access may not mean whether a person has insurance coverage but whether he or she has transportation to be able to get to a health fair.”

**Dolores Mitchell
Executive Director
Group Insurance
Commission
Boston**

“I can be hard-headed about what things cost and what we can expect to get from them,” she says.

“But I don’t think cost benefit matters when it comes to this issue. As a major purchaser of health care services, if we decide certain things need to be done, we tell the plans, ‘Do it because I’m the purchaser and I say so.’ Whatever leverage you have as a large purchaser, you should use it for social good as well as cost savings,” Ms. Mitchell points out.

[Contact Ms. Rosenthal and Ms. Kaye at (207) 874-6524, Ms. Kalaijian at (518) 473-1134, Ms. Mitchell at (617) 727-2310, and Ms. Waldman at (617) 210-5371.] ■

Consumers

Continued from page 1

sumer involvement in service design and monitoring.

To help convince states, health plans, and providers to make more of an effort to involve consumers, they are being asked to show how consumer input can help save money, improve outcomes and quality of life, and reduce hospitalizations.

Ms. Chaney cites several examples of ways in which consumer involvement has helped save money and improve health outcomes. In Michigan, for example, The Wellness Plan has worked to better identify immunized children and decrease the administrative costs associated with collection of Health Plan Employer Data and Information Set (HEDIS) immunization statistics. The plan implemented a cross-referencing system intended to increase the number of complete immunization records captured by its administrative data and increase the immunization rate for 2-year-olds from 43% in 2000 to 80% in 2004.

Through better data collection and outreach to parents and providers of children missing immunizations, The Wellness Plan increased the number of 2-year-olds with complete immunization records captured by its administrative data from .44% to 17% and boosted HEDIS immunization rates from 43% to 52% from 2000 to 2001.

In Rhode Island, the state worked with consumers, health plans, and other organizations to design a health indicator system to evaluate health outcomes for RIteCare managed care beneficiaries. One result has been that 80% of all children in RIteCare are screened annually for lead poisoning, markedly higher than the 20% of children on Medicaid nationally. And since many of those screened have lead poisoning, the state has

implemented an environmental abatement program.

In Portland, OR, Outside IN is a consumer organization that is focusing on the state's increasing numbers of homeless youth. It wants to raise the number of homeless youth who appropriately access health care and involve them in restructuring the Oregon Health Plan. In the group's first two months, it brought 107 homeless youths to see physicians.

Use of consumers to help re-do enrollment materials in Massachusetts is credited with increasing the percentage of enrollees who chose a health plan on their own from 30% to 70%. Other research has shown that people who are actively involved in the health care system are more likely to take steps to maintain their health, saving money overall.

CHCS says consumers and their advocacy organizations have resisted the transition to Medicaid managed care, thinking the flawed fee-for-service system that they understand is better than a new system that they don't.

"The fear and distrust arising when there is limited contact between consumer representatives and state and health plan officials exacerbates" the tension between consumers and managed care, the issue brief says, and that tension "undermines efforts by states or health plans to engage consumers and limits the opportunities for consumers and consumer groups to help improve managed care programs."

Officials don't understand

State agency and health plan officials often may not understand what it's like for a family where parents and children have different health care providers and managed care programs.

"States and health plans need to understand the complexity of this experience," CHCS says, "and they need consumer input on what health

care access and delivery system problems exist and how to fix them. Families need education on preventive care and tools for navigating managed care and gaining access to services. While many states and health plans have some type of educational materials for beneficiaries, states generally have not asked consumers what information they need before the materials are developed."

CHCS has provided seed grants of up to \$25,000 each to 18 consumer organizations to support development of innovative projects to strengthen consumer and family involvement in publicly financed managed care.

One grant went to Rhode Island's RItCare program, which has had great success with consumer advisory boards, according to Rhode Island Center for Child and Family Health director Tricia Leddy, who runs the RItCare program in the state's Department of Human Services.

Ms. Leddy tells *State Health Watch* that RItCare has used a consumer advisory committee with the Medicaid program since its inception in 1993. The committee meets monthly. "We get very good attendance, mostly advocates and consumers with just a few providers. It has been a fabulous opportunity for consumers to bring up issues to people who can take the ball and run with it."

State officials must want input

She says the key to success is for attending state agency officials to have the ability and accountability to make change.

"Relevant issues are raised at these meetings," Ms. Leddy says. "There is training provided before the sessions to help consumers learn how to be effective advocates."

The consumer group assisted the state in developing a member-satisfaction survey, making sure that questions on the survey cover items of

importance to consumers, such as transportation issues and language interpreter services.

"They have been very vocal not just about service delivery issues but also about eligibility issues," she says. "They insisted that we shorten the application form and make it a mail-in process. They do a great job in reviewing written materials to be distributed by the state or health plans to be sure they can be understood."

Ms. Leddy says consumers prepared the guidelines for the state agency and health plans in developing handout materials. The result is "drafts that already are pretty good." It has reached the point, she says, that staff wouldn't think about sending out a member-services packet without first obtaining consumer review and input.

Consumers raise other issues

The consumer advisory group also has raised issues — such as access to telephone service — that probably would not have been thought of by state officials, according to Ms. Leddy.

"People can lose their phone service because they don't pay the bill," she says, "but if they have to use the phone to get prior approval or do other things for their health care, it can be a problem. The state and health plans teamed up with advocates to approach the phone company and get a change in the policy on access to the lifeline telephone service."

Another issue resolved with the advisory group's involved distribution of bus passes to beneficiaries. Under a welfare-like system, recipients had to report to a local office monthly and stand in line for a bus pass. After advocates questioned the process, the state streamlined the system so that RItCare beneficiaries can obtain passes at any supermarket selling them to the general public.

“They showed us how we can provide a benefit to people with dignity and respect,” Ms. Leddy says.

Plans also make changes

Health plans also are acting on issues raised by the consumers. Leddy says that when a consumer-satisfaction survey found a problem with language translation services and that provider staffs were confused about protocols for requesting services, the plans jointly developed a uniform request form. “There was a round of applause when that development was reported at the next meeting,” she says.

Now the process is being used to find ways in which to better provide services to children with special needs. Advisory committees are identifying needs in the delivery system and ways in which these children can be brought into RteCare.

Another group working with a consumer advocacy grant is AXIS Healthcare, which helps those with physical disabilities find the care they need when they need it, according to executive director Chris Duff.

“In the traditional world, we would be called a care management organization,” he tells *State Health Watch*. “But our clients are clear that they don’t want to be managed. Rather than becoming a health plan, we want to partner with providers to help them deliver services to this particular population.”

AXIS Healthcare’s partner in this venture is UCare Minnesota.

The plan has delegated all utilization review and most provider relations activities to AXIS for its clients. As they put together a pilot model, they started a consumer working group that now has been meeting for more than three years. They also have used consumer forums and focus groups to listen to what disabled people say they need in health care access and delivery.

“Our clients really believe that our

approach is different,” Mr. Duff says. “They believe that we care what they say. They talk about ‘our program’ rather than ‘that program.’ We no longer will speak in any public setting without having a consumer participating with us. It’s pretty arrogant for us to say what they need.

Listening is the key

“Health care is one of the last areas in which the customer is truly not listened to. Retail has it down, and banking is getting it. To truly listen, you have to be willing to share power, and that’s a scary concept for health plans and regulators.”

Mr. Duff says AXIS hasn’t found a downside. He says members have challenged the company on meeting times and about providing information in alternative formats. “They’ve

told us when we’re missing something,” he says. “We don’t always change, but we sometimes make modifications.”

Mr. Duff says the AXIS clients can accept that not all its staff members are disabled. “Hire people to get the work done, is what they tell us, but don’t pretend to speak for us.”

AXIS now has 100 members, with a goal of getting to 300 to 500. “We’re now in the process of tweaking our stages of growth,” he says. They also are evaluating the program in hopes that other states will be able to apply the lessons they’ve learned to improve coordination of care for the physically disabled.

[Contact Ms. Chaney at (609) 895-8101, Ms. Leddy at (401) 462-1300, and Mr. Duff at (651) 556-0863.] ■

TV time: ‘Is your child one of the 5 million?’

The Kaiser Family Foundation has joined with Viacom Outdoor Group and CBS Television in a campaign to tell parents about public health coverage options for uninsured children. The campaign will use TV public service announcements, bus posters, and bus cards to ask “Is your child one of the 5 million?” — referring to the estimated 5 million uninsured children eligible for public health insurance coverage.

The yearlong effort urges parents to call a toll-free telephone number, (877) KIDS-NOW, for more information on getting coverage for their children.

There are more than 9 million children uninsured in the United States, with more than half of them eligible for Medicaid or State Children’s Health Insurance Program but not enrolled.

“Lack of insurance leads to delayed or foregone care,” says Diane Rowland, Kaiser Foundation executive vice president.

States have had some success enrolling more children in recent years, but outreach to low-income families is always a challenge. Studies have shown that one of the primary barriers to enrollment of eligible children remains a lack of awareness or confusion among parents about existing programs.

Those who call the toll-free number maintained by the U.S. Department of Health and Human Services are connected with enrollment workers in their home states. National TV spots will air on CBS for a year, with a new version of the ad aired every four months. Transit print ads are localized for New York City, Philadelphia, and San Francisco. They are in English and Spanish.

[View some of the ad materials at www.kff.org/cbs.] ■

Implementing *Olmstead* decision involves analyzing complex legal concepts, states discover

States implementing community integration under the Americans with Disabilities Act (ADA) and the landmark U.S. Supreme Court decision in *Olmstead v. L.C.* are closely monitoring cases that interpret complex legal concepts such as “fundamental alteration” of programs and “reasonable pace” of change.

Analysis of recent cases testing these two principles by the Center for Health Services Research and Policy at George Washington University in Washington, DC, indicates that states are faced with trying to understand and comply with a series of balancing tests built into the ADA and *Olmstead* decision.

Center executive director Sara Rosenbaum tells *State Health Watch* that the ADA “balances the rights of individuals with disabilities against other institutional interests. And *Olmstead* does the same kind of balancing.”

Olmstead was the high court’s first attempt to deal with the ADA as it applies to qualified persons with disabilities who have been determined to be in medically unnecessary institutional placements.

No definition in the decision

According to Ms. Rosenbaum, court cases to date indicate that there is no fixed definition of the level of effort needed to achieve a “reasonable pace” in implementing community integration. Rather, the concept is seen as related strongly to the context of each case and varying with the circumstances under consideration, the facts of each case, and the courts’ efforts to balance the law’s goal of community integration against the level of public resources available to provide the full range of

services necessary to the support of people with disabilities.

Although it didn’t define reasonable pace, the Supreme Court in *Olmstead* said that a public agency could successfully defend against a claim of discrimination if it could demonstrate that it was making reasonable modifications in its programs and services to achieve community integration. “By implication,” Ms. Rosenbaum says, “the very establishment of a reasonable pace standard for measuring when the state is acting in a lawful manner even though all needs are not met immediately amounts to a validation of the concept of waiting periods.”

Eight federal courts have addressed reasonable pace issues arising under *Olmstead* and many of the cases also have involved Medicaid “reasonable promptness” requirements. When confronted with defining what is a reasonable pace, courts have looked for guidance to *Olmstead* itself and its interpretation of the law, Medicaid law and regulations, and other court decisions that have looked at similar issues.

States should prepare to act

So far, Ms. Rosenbaum says, no particular set of facts is a predictor of how a court will resolve a reasonable pace claim. In half the cases, courts issued preliminary or final decisions in favor of those who were challenging states. It appears that once a state includes a waiver service in its state plan, courts are likely to determine that it must be administered in line with federal law and regulations, including Medicaid’s “reasonable promptness” requirement. Courts generally have rejected defense based on alleged inadequate funding as the

cause of delayed community services once a state has instituted a waiver program, especially if the waiver meets Medicaid’s cost neutrality requirement. A cost argument may be successful, however, if a state can show that the needed support would result in a “fundamental alteration” of the program.

It also has been found that if a court employs only a Medicaid analysis in looking at a program design, states are relatively likely to be found in full compliance with the law and courts are more likely to permit long waiting lists. That isn’t as true, however, if a court looks at both Medicaid and the ADA.

Courts have been willing to permit states to maintain long waiting lists for waiver services once state programs have reached the federally approved maximum population limit. And they have been willing to permit long waiting lists when a state can show that requested changes would result in a fundamental alteration of the program.

Be sure funding is available

Ms. Rosenbaum says that as part of their *Olmstead* planning process, states should carefully look at existing programs to remove any possible discriminatory administration and identify resources for development of new services. If a state outlines a program in its health services plan, it should make every attempt to ensure that the program receives sufficient funding to support the number of individuals described.

As uncertain as “reasonable pace” may be, the concept of “fundamental alteration” is even more difficult because it is intertwined with the legal principle of community integration at

the heart of the ADA. Public entities are required to make reasonable modifications to their programs and activities, but not to the extent that the changes represent a fundamental alteration to their program.

Ms. Rosenbaum says that a fundamental alteration changes the basic character of something, and cites the debate over PGA golf pro Casey Martin's desire to use a cart in tournaments as an example of something that is not a fundamental alteration because use of a cart does not change the basic nature of the game of golf.

She says the point at which a proposed modification becomes a fundamental alteration is critical in understanding the scope and reach of the ADA.

"As state community integration planning efforts proceed in the wake of *Olmstead*, stakeholders could determine that proposed changes that are fundamental alterations will be candidates for long-term reform and prioritization. Those changes that have the characteristics of reasonable modifications may be more readily accomplished within a relatively short time frame through either formal or informal agency action, depending on the scope of administrative powers granted an agency by a state legislature," Ms. Rosenbaum explains.

Fundamental alteration defense

The Supreme Court's analysis in *Olmstead* identified certain parameters to state obligations, according to Ms. Rosenbaum.

The court clarified that a decision to furnish public service at all is a matter of state discretion. It rejected a framework articulated by lower courts and found that in determining the magnitude of a state's remedial obligation toward any particular member of a protected group, a state can weigh the welfare of the entire group. And the court made clear that

despite existence of the fundamental alteration affirmative defense, that defense is not boundless.

Ms. Rosenbaum says the high court "intimated that a state cannot simply raise the defense each time a claimant requests a modification to a program or service, and it appeared to assume that state officials would develop a method to continually identify persons who were capable of living in integrated settings with reasonable modifications, and for whom institutional care is medically unnecessary."

As a result of cases considered to date, Ms. Rosenbaum offers some emerging principles on fundamental alteration:

- Courts are likely to defer to a state's professional judgment on whether individuals satisfy criteria for community services.
- Courts will scrutinize eligibility criteria for evidence of discrimination in cases in which a state claims that modification of the criteria would amount to a fundamental alteration, or where there has been an actual finding that institutionalization is medically unnecessary.
- Courts generally will not require a state to change essential programmatic features, but will require changes that affect more peripheral aspects of a program.
- Courts generally will not order a state to change a program's eligibility requirements once the requirements are determined to be indispensable to the character of the program.
- Courts are likely to require a requested change when a state has made previous exceptions to program requirements.

"Taken together," Ms. Rosenbaum says, "the reviewed cases suggest that courts will defer to state discretion, if reasonable and reasonably exercised, regarding the appropriateness of community services for a patient. When

the service is not considered appropriate, this effectively ends the reasonable modification/fundamental alteration test, unless a plaintiff can successfully challenge the fairness of a state's review process.

"Once community placement is found to be appropriate, a court will exercise considerable power in scrutinizing a state's fundamental alteration defense. A state may be able to claim that a proposed change would affect the integrity or essential features of a program, but its past conduct in administering the program comes into play at this point, as would the reasonableness of criteria that appear to be discriminatory in their exclusion of persons who already have been found to be able to live in the community," she continues.

"Cost alone is not a defense, particularly where the spending is via an entitlement program or where the legislature has shown a tendency to fund institutional care while underfunding community services. A state may be able to defend against a claim that eligibility criteria are discriminatory by presenting evidence that supports the conclusion that the criteria are an essential feature of the program or are there to protect beneficiaries, public safety, or program viability.

"An open question is what this means for state Medicaid programs insofar as they cover services but make distinctions in availability of coverage based on a disability. If the logic of *Olmstead* is applied to this practice, it may well be that even though such a practice may not be a violation of the Medicaid statute's comparability or anti-discrimination rules, the distinction may be a violation of the ADA as articulated by the *Olmstead* majority because it would amount to discrimination based on the type of disability."

[Contact Ms. Rosenbaum at (202) 530-2343.] ■

Interpreter services improve care and payment

New research shows that when hospitals increase interpreter services for uninsured patients who have limited English proficiency, quality of care improves and there's a better chance the hospital will receive at least some payment for services provided. Although federal funding for interpreter services is available from the Centers for

Medicare & Medicaid Services (see story, below), only five states use it.

A national survey of uninsured people, conducted by The Access Project, a Brandeis University-affiliated national resource center for local groups wanting to improve access to health care, found that a significant portion of respondents who need an interpreter but did not get one left

the hospital without understanding how to take prescribed medications.

Report author Dennis Andrulis, a research professor at the State University of New York Downstate Medical Center in Brooklyn, says the patients "are sending a strong message that failure to communicate effectively may cost patients their health and be bad business for doctors and hospitals."

Federal funds are available for interpreters

While cost is a primary concern of health care organizations in providing language services for patients, providers may not be aware of available funding or do not take full advantage of it, according to a Commonwealth Fund survey conducted by the National Health Law Program (NHeLP).

Federal matching funds are available to states for Medicaid and State Children's Health Insurance Program (SCHIP) enrollees, and the Department of Health and Human Services also provides funding or technical assistance for language interpretation. State and county health departments are other potential sources.

Report author Mara Youdelman, a staff attorney with NHeLP in the Washington, DC, office, says that providing interpreters "not only increases the quality of health care for those with limited English proficiency but reduces burdens on providers and could ultimately save health care costs. Without using interpreters, doctors cannot effectively communicate with their patients or accurately diagnose and treat their ailments. . . . We look forward to working with the administration and Congress to ensure the availability of the support, education, and technical assistance necessary to implement these policies, and to identify effective programs and put them into practice."

Some points from the survey:

- States using federal matching funds for translation services for Medicaid and

SCHIP enrollees are Hawaii, Maine, Minnesota, Utah, and Washington. NHeLP says that more states could develop mechanisms to obtain federal reimbursement for interpreter services and the Centers for Medicare & Medicaid Services could enhance mechanisms for reimbursing interpreters who help Medicare beneficiaries. States can receive a 50% administrative match, and even more if they adopt language assistance as a covered service.

The report profiles Washington state's system of direct payments to language-service agencies and Minnesota's system of requiring providers to purchase interpreter services and then be reimbursed by the Medicaid agency, and lays out pros and cons for each model.

- Other funding sources are state and local government initiatives. In Massachusetts, for example, since 1989, most hospitals have submitted plans for providing interpreter services as part of the state's determination of need process, which requires that providers reassess health care needs in the community and respond accordingly whenever a provider seeks to add or expand services or when ownership is transferred.

Through this process, the report says, more than 50 of the state's 80 hospitals have addressed providing interpreter services, training staff, and tracking services. Also, in 2000, the Massachusetts legislature passed a law requiring that every acute-care hospital provide competent interpreter services in connection with all emergency department services provided to every non-English speaker who is a patient or

who seeks appropriate emergency care.

In Hennepin County, MN, the Office of Multi-Cultural Services was created in 2000 to help deliver services to its diverse refugee and other new American populations in an efficient, effective, and culturally sensitive manner. The county's 44 staff members speak 28 languages and act as a bridge between county departmental staff, those with limited English skills, and the rest of the community. Community outreach liaisons assist with forms completion; connection to resources, social services, health and child care issues; and home visits. Liaisons can accompany clients to medical appointments and have helped many understand the complexities of health care and managed care, the report says.

- Managed care organizations that enroll Medicaid, SCHIP, or Medicare patients or otherwise receive federal financial assistance have to comply with federal law and regulations that require that patients have access to language services. The report profiles The Alameda Alliance for Health in California and its Cultural and Linguistics Program that oversees policies on translation of materials and interpreter services. If a staff member who speaks a patient's language is not available, the organization will provide an interpreter at no cost to the patient. The provider directory specifies the languages that providers and their staff speak, and patients can obtain additional information and assistance from member services.

[Contact Youdelman at (202) 289-7661.] ■

Access Project director Mark Rukavina tells of a Hispanic man from Virginia who was prescribed three medications and mistakenly assumed he should take all three at once. He ended up in a hospital emergency department with a severe reaction. Only then was an interpreter found to instruct the man how to take the medications as prescribed.

Mr. Andrulis says the survey results strongly suggest that having an interpreter may help non-English speaking

patients find financial assistance to pay for medical care. More than half the survey respondents who needed but did not receive interpreters said they were never asked if they needed help in paying for medical care; compare that with slightly more than a third who needed and got an interpreter.

The report says the finding on medications has serious implications for a U.S. health system that is struggling to improve the quality of care for an increasingly diverse population. For

patients not fluent in English, the lack of an interpreter could lead to misdiagnosis and negative health outcomes.

“This is a wake-up call for hospitals that are worried about malpractice suits,” Mr. Rukavina said. “If they care about preventing medical errors, they’ll pay close attention to our finding that there is a strong association between interpreters and understanding medical instructions.”

The issue is becoming increasingly important in light of census data showing the doubling of Hispanic populations in 22 states during the past 10 years. More than 30 million people, or 11% of the U.S. population, are foreign-born and many have limited English proficiency.

Mr. Rukavina says the survey concludes that interpreters should be more widely available. “Hospitals and doctors must work together to ensure interpreter services are there for patients who don’t speak English well,” he says. “Patients should be offered interpreter services at no cost. This is required by the Civil Rights Act of 1964, and these services should be funded. The federal government provides funding to states for interpreters through Medicaid and [State Childrens Health Insurance Program], but only five states have used this funding source.”

Mr. Rukavina also says that standards for medical interpreters are needed and family members should not be called on to serve as interpreters for their relatives. He recommends that states follow the lead of California and Massachusetts in requiring health care institutions to provide qualified interpreters for people who don’t speak English well.

The third thing the report recommends is more research into the relationship between language barriers and medical errors.

[Contact Mr. Rukavina at (617) 654-9911, ext. 229 and Mr. Andrulis at (718) 270-7726.] ■

Many organizations seek HIPAA delay

Although the Centers for Medicare & Medicaid Services has urged health care organizations to move expeditiously to comply with Health Insurance Portability and Accountability Act of 1996 (HIPAA) rules on electronic transactions and code sets and not seek a delay, more than 13,000 organizations already have asked for an additional year to come into compliance.

The Administrative Simplification Act signed by President Bush last December moves compliance deadlines from October 2002 to October 2003 for most covered entities. To qualify for that delay, organizations have to file by Oct. 15, 2002, explaining how they will achieve compliance.

CMS has posted a model compliance plan at <http://cms.hhs.gov/hipaa/hipaa2/ASCAForm.asp> and encourages electronic filing of compliance documents. ■

This issue of *State Health Watch* brings you news from these states:

Alabama	insert	Minnesota	p. 10
California	pp. 7, 10, 11, insert	Nebraska	insert
Connecticut	insert	New Hampshire	insert
Delaware	insert	New Jersey	insert
Georgia	insert	New York	pp. 3, 7, insert
Hawaii	p. 10	Oregon	p. 5, insert
Maine	p. 10	Pennsylvania	p. 7
Maryland	insert	Rhode Island	p. 5, insert
Massachusetts	pp. 4, 10, 11, insert	Texas	insert
Michigan	p. 5	Utah	p. 10
		Washington	p. 10
		Wisconsin	insert



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Clip files / Local news from the states

This column features selected short items about state health care policy.

Few Medicaid kids screened for lead

WASHINGTON, DC—Only about 20% of the children in Medicaid are getting screened for elevated blood levels of lead, which can retard growth and lower intelligence, a federal official said June 5. The federal-state insurance program for the poor requires that all Medicaid-eligible children receive a blood screening test for lead at 12 months and 2 years, as recommended by the Centers for Disease Control and Prevention. Any child age 2 to 6 for whom no record of a test exists also must be screened, program rules say. Medicaid pays for the screenings and any diagnostic or treatment services required for children found to have elevated blood lead levels. It also will pay for a one-time investigation to find the source of the lead.

But Medicaid has run into problems collecting data on screening tests and ensuring the tests are performed, said Ruben King-Shaw, deputy administrator for the Centers for Medicare & Medicaid Services. "We have very few powers to enforce this kind of provision," Mr. King-Shaw told a Senate Banking, Housing and Urban Affairs subcommittee. He estimated that about 20% of Medicaid-enrolled children under 6 are screened — about 1.3 million children.

—Associated Press, June 5

Correction

In the May 2002 issue of *State Health Watch*, a Clip File story discussed questions raised by state auditors about the Washington state's Medicaid program. The story indicated that auditors questioned whether eligibility was adequately verified for the Medicaid program's enrollment of more than 900,000 people. In fact, the questions related only to the state's Basic Health Program, which has about 58,000 subscribers. ■

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State OMH Descriptions of Health Care Purchasing Strategies

OHM — Office of Minority Health

Source: National Academy for State Health Policy, Portland, ME.

State OMH Descriptions of Regulatory Strategies

²⁵ As reported by the New Jersey Department of Health and Senior Services, New Jersey regulations aimed at increasing cultural and/or linguistic access to services include hospital and ambulatory facility licensure rules.

²⁶ Massachusetts described Determination of Need requirements regarding interpreter services (see section on oral interpreter services) but did not categorize these requirements as a regulatory strategy.

OHM — Office of Minority Health

Source: National Academy for State Health Policy, Portland, ME.