

MEMO

To: Joint Finance Committee
From: Brian J. Hartman, on behalf of the following organizations:

Disabilities Law Program
Developmental Disabilities Council
State Council for Persons with Disabilities
Governor's Advisory Council for Exceptional Citizens

Subject: Division of Developmental Disabilities Services FY 11 Budget
Date: March 4, 2010

Please consider this memo a summary of the oral presentation of Brian J. Hartman, Esq. on behalf of the Disabilities Law Program ("DLP"), Developmental Disabilities Council ("DDC"), State Council for Persons with Disabilities ("SCPD"), and Governor's Advisory Council for Exceptional Citizens ("GACEC"). We are addressing three (3) components of the DDDS budget: 1) vocational programs for transitioning special education students, a/k/a "special school grads"; 2) emergency residential placements; and 3) ancillary services.

SPECIAL SCHOOL "GRADUATES"

Both the Federal and State governments invest considerable resources in the education of students with developmental disabilities. The Individuals with Disabilities Education Act ("IDEA") contemplates a smooth transition to the adult services system. This includes mandatory transition planning in which post-21 supports are identified and affirmatively linked to students leaving the special education system. See 34 C.F.R. §§300.320-321.

Historically, the State has provided funding for vocational and day habilitation services for students with moderate to severe cognitive disabilities "aging out" of the special education system. Services are subsidized by Medicaid funds for most, if not all students. These students are prepared to engage in productive vocational activities. They have a firm expectation of such work based on years of public school reinforcement. In FY 11, the Division projects that approximately seventy-seven (77) special education graduates will be eligible for such services. Unfortunately, the proposed budget omits funds for any new day habilitation/supported employment placements.

We have the following observations.

First, in recent memory, there has never been a Division waiting list for vocational programming for special education graduates.¹ Once initiated, waiting lists tend to grow into

¹On rare occasions (e.g. FY 03 and FY10), the Governor has omitted funding for special school graduates in the proposed budget. On such occasions, the funds have been incorporated into the final budget by the Joint Finance Committee.

systemic anomalies which become increasingly difficult to eliminate. For example, if a student leaves school “ready” for work, and then languishes at home for a year or two, extra retraining and motivational services will be required to recapture the same “readiness” level.

Second, alternative sources of vocational opportunities are no longer readily available. Historically, adults with disabilities seeking vocational training and job opportunities could turn to the Delaware Division of Vocational Rehabilitation (“DVR”). Unfortunately, DVR adopted a restrictive intake system (“Order of Selection”) effective November 17, 2008. Since adoption, DVR’s waiting list for new applicants with mild to moderate disability profiles has already grown to hundreds of individuals.

Third, there is some “tension” between the complete denial of habilitation/supported employment and State statutory guarantees:

§5502. Development of abilities.

Persons diagnosed with mental retardation or other specific developmental disabilities have the right to proper...education, training, habilitation and guidance as will enable them to develop their abilities and potential to the fullest possible extent, no matter how severe their disability may be.

§5503. Economic security and meaningful occupations.

Persons diagnosed with mental retardation or other specific developmental disabilities have a right to strive for productive work in meaningful occupations, economic security and a decent standard of living.

Title 16 Del.C. Ch. 55, Subchapter I, Declaration of General and Special Rights of Persons with Mental Retardation and Other Specific Developmental Disabilities. See also the DDDS enabling statute which imposes a “duty” to provide “vocational and supported employment opportunities and day habilitation services.” Title 29 Del.C. §7909A.

Recommendation

The Division estimates that \$565,950 would provide 9 month funding for all of the 77 graduates. The State would derive significant “bang for buck” from this investment which averages only \$7,350 per individual. We support inclusion of such funds in the budget.

EMERGENCY PLACEMENTS

The Division averages approximately 336 new applications for services annually. Historically, approximately 25-30 of such applicants are in crisis. They are victims of abuse or neglect, homeless, or individuals whose primary caregiver has died or become unable to continue care. DDDS has always received funds to cover the costs of residential and day services for such compelling clients. Unfortunately, the proposed budget omits such funding altogether. The Division estimates that it could cover 6-month funding of 25 emergency placements with \$775,015, i.e., \$31,000 per individual.

Recommendation

We strongly recommend inclusion of the above funds in the DDDS budget. Parenthetically, to facilitate cost-sharing, we also recommend that the Department of Education be directed to accept referrals from DDDS to the ICT. Although the current statute indicates that the ICT "may" accept referrals from State agencies such as DDDS and DSCY&F, it categorically refuses to accept such applications. This prevents DDDS from presenting complex persons up to age 22 to the ICT for possible cost-sharing with school districts and other agencies.²

ANCILLARY SERVICES

The Division's budget has historically included funds for ancillary services such as client dental care and specialty care (e.g. podiatry; psychiatric services; therapies). The proposed budget includes a \$2.9 million reduction in funds which previously supported such services. Lack of funds for dental care is of particular concern. Delaware Medicaid does not cover adult dental services and recent studies have clearly linked dental disease with exacerbation of a host of physical ailments such as diabetes and cardiovascular disease.³

Recommendation

We recommend restoration of at least some of the funds for ancillary services.

Thank you for your consideration of our comments.

Attachments

F:pub/bjh/legis/ddbudjfc11

²Title 14 Del.C. §3124(b)(5) recites that the ICT "may accept and review cases initiated by other agencies". However, the DOE has adopted a practice of disallowing all such referrals. The GACEC forwarded a February 24, 2010 memo to the Senate Education Committee memorializing its recommendation that H.B. No. 254 be amended to require ICT processing of State agency referrals.

³Corroborative articles are included as Attachment "A".



October 24, 2008

Teeth cleaning is anything but routine for disabled

Fear, costs often stop those who are handicapped from going to the dentist -- but a nonprofit and proposed bill are trying to change that

By *HIRAN RATNAYAKE*
The News Journal

Roberta Heather was spooked by anyone who hovered over her, even if those people were trying to help her -- like dentists.

"She has always been very, very fearful of doctors and dentists and very uncooperative," said Pat Heather, her mother.

Fear is one of several reasons why adults with disabilities like Heather, who is mentally retarded, are less likely to get routine dental care than the general population. Routine dental procedures aren't covered under Medicare, the federal health insurance program for the disabled and elderly. The state contracts with dentists to pay for care for the disabled, but it only has a limited amount of money to do so. And Delaware is one of only seven states that does not extend dental coverage to the poor and disabled through Medicaid.

This year, a report put out by the National Association of State Directors of Developmental Disabilities Services found that about 35 percent of adults with disabilities did not get a routine dental exam in the past six months.

But the problems run deeper than economics. Dentists who face patients like Heather, 52, of Dover, generally don't have special training on how to work with them. In many cases, advocates say, the patients end up without routine care and end up in the emergency room.

Putting off routine dental care can lead to periodontitis, an oral disease that has been linked to a variety of problems that can affect the entire body, such as heart disease and diabetes. Rep. Bethany Hall-Long has introduced House Bill 359 to expand the Medicaid coverage as a way to address these problems up front.

"There's a lot of costs on the back end and this is something that can very much be prevented," she said.

But these adults won't get more help unless other issues are addressed.

Little incentive to help

Dr. Bruce Fay of New Concept Dental in Brandywine Hundred said his biggest deterrent to treating more disabled patients is the lack of punctuality.

"One of the consistent problems is that they are late to their appointments," he said. "And when you're providing a direct service, time is money."

Attachment "A"

Jamie Wolfe, a 42-year-old Dover resident who is wheelchair-bound, said punctuality is sometimes a problem outside of her control. She often relies on modes of transportation such as Paratransit and needs her caregivers to help her get ready in the morning.

"If one of my support workers runs late, it starts a domino effect," she said. "I've got two very dedicated people, but in the past I had people who wouldn't get me there on time."

Dr. Glen Goleburn of Bear-Glasgow Dental has had to cancel appointments since the patients were fed before an anesthetic procedure by their caregiver. And parents and guardians of people who cannot consent to anesthesia are not with the patient when Goleburn is about to treat them.

"I've had men in their 20s who are autistic or who have other developmental disabilities who are a lot bigger than me," Goleburn said. "If they don't want to have the procedure done and don't understand what's going on, they're going to try to stop you. We've been spit at, bitten, scratched ... sometimes the only way we can do an exam and even figure out what the patient's needs are is by sedating the patient."

Patients who are wheelchair-bound often must be hoisted by dentists and their co-workers into the dental chair.

"It's especially scary when there's two people who aren't trained in how to lift you," Wolfe said.

Fed up with the hassles, Goleburn organized an August forum on the issue that was attended by State Treasurer Jack Markell, the Democrat for governor, and former candidate Mike Protack.

Funding was the dentists' biggest deterrent. Delaware's Division of Developmental Disabilities Services contracts with dentists to pay for dental care based on the need of each person.

The total amount spent by the division last year was \$417,300, which equated to an average of \$428 per person. Fay said dentists aren't adequately reimbursed by the state for their services and they also run into problems.

"Sometimes even in situations when we've had prior approval, we've had subsequent problems getting paid for the procedure, and that is the most frustrating of all," Fay said. "The perception to the average dentist in Delaware who is doing reasonably well is that there's not much incentive to go looking for a more difficult patient population to treat when you can easily find someone else."

Nonprofit eases woes

Dentists also say appointments with disabled patients often last longer than for those who aren't. Advocates say they often have trouble finding accommodating dentists.

"Several years would pass before I could find a dentist that would do anything for [Roberta]," said Pat Heather, who pays out of pocket for her daughter's procedures. Practice Without Pressure, a local nonprofit, is working to educate patients, caregivers and dental professionals and coordinate care. It brings disabled persons to Bear-Glasgow Dental so they can get used to the surroundings.

Heather has been able to have extensive dental work through the organization, which plans to someday open its own dental practice.

"Now she's willing to sit back and allow someone to examine her," Pat Heather said. "That's going to give us so much help down the road."

CEO Deb Jastrebski said she wants to reach patients before they've been through a harrowing

experience.

"You don't want them to get stuck in that negative cycle," she said.

Nothing To Smile About

Too few Americans get oral health care, spawning a silent epidemic of dental disease

By Carole Fleck



Marie Burton craves chilled watermelon and other cool fresh fruit, but she can't eat them. Carrot sticks are a favorite, and she adores a thick cut of steak, but she can't eat those, either.

Cold, chewy or crunchy cuisine is off-limits for Burton because her teeth hurt too much—at least the ones she has left. They're wiggly, broken and infected.

"I have teeth missing, and the teeth I do have ache," says Burton, 59, of Pawtucket, R.I. "I get this bad taste in my mouth all the time, and my stomach gets upset. I can't eat sometimes because I feel nauseous."

Burton has consulted with local dentists, but the dental plan provided by her \$22,000-a-year job as a quality assurance inspector is extremely limited. She says she can't afford the thousands it would cost "up front" to fix her decaying teeth. So she stays home and avoids socializing because, she says, she is embarrassed by her appearance.

"I don't like looking in the mirror or talking to people unless I have to," says Burton, a soft-spoken mother of three.

She doesn't like to smile or open her mouth. "It's awful," she says.

Like Marie Burton, millions of Americans have little or no dental care. An estimated 108 million have no dental insurance, more than twice the 46 million without health insurance. About three-quarters of people 65 and older are not in a dental plan.

The lack of access to affordable oral health care has long been ignored in the United States. But the problem is likely to get more attention as boomers retire in droves and lose their employer-provided dental benefits—and as evidence mounts that poor oral health may cause or worsen serious medical

Smoking may lead to more than half of all cases of gum disease among American adults.



SOURCE: CENTER FOR THE ADVANCEMENT OF HEALTH

problems such as diabetes and cardiovascular disease.

A growing number of studies indicate that bacteria from chronic gum infection can travel through the bloodstream to the heart and other organs. Researchers are also exploring the connection between gum disease and inflammation elsewhere in the body: If the lining of the arteries becomes inflamed, blood clots can form and cause a heart attack.

In one study, researchers from Columbia University's College of Dental Medicine and the Aetna insurance company tracked 145,000 Aetna subscribers with diabetes, coronary artery disease or stroke. They found that medical costs for those conditions were lower among subscribers who had sought early treatment for periodontal disease.

"The way the health care system functions, one might think the mouth isn't connected to the whole body," says William Maas, director of the division of oral health at the U.S. Centers for Disease Control and Prevention.

"Dental care is just as important as medical care, hospital care and pre-

scription drugs," Maas says. "It is inconsistent for society to recognize that oral health is important yet treat dental care as if it were discretionary."

A National Toothache

In May 2000, U.S. Surgeon General David Satcher, in the first-ever report on oral health by the nation's top doctor, called dental disease "a silent epidemic" among older people and children. The report cited a lack of insurance or the inability to pay as barriers to care.

Since then, not much has changed in the private or public sector to improve access to affordable dental care. Older Americans are still disproportionately affected because retirees no longer have dental insurance provided by employers and often live on fixed incomes.

Medicare, which primarily benefits people age 65 and up, does not provide dental coverage except in rare circumstances—such as surgery to treat oral injuries sustained in a car wreck. Medicaid, the federal-state health program for low-income people, provides a dental benefit for children. But only

about two dozen states offer Medicaid dental benefits for adults, and in most cases the coverage is severely limited.

Gradually more insurance companies are beginning to sell individual dental policies to consumers, although such policies account for only 2 percent of all dental plans, according to the National Association of Dental Plans.

On the bright side, more of today's older adults are retaining most of their teeth compared with previous generations, thanks to fluoridated toothpaste and water and other modern improvements in prevention and treatment. But "those teeth have been

Working adults lose more than 164 million hours of work yearly due to dental disease or dental visits.

SOURCE: CENTER FOR THE ADVANCEMENT OF HEALTH

through 60, 70, 80 years of use," says Ira Lamster, dean of the Columbia University College of Dental Medicine in New York, "so they'll need a lot of care to maintain."

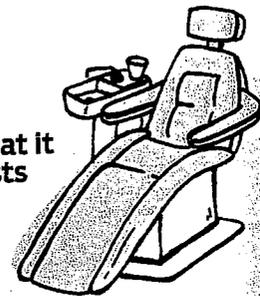
Little Help for the Needy

At Oral Health America, a nonprofit group based in Chicago, not a week

goes by without pleas for help from people around the country who desperately need dental care. The messages are heart-wrenching, says spokeswoman Elizabeth Rogers, and in many areas there are few, if any, low-cost options to suggest.

On Capitol Hill, a House bill (HR 4624), introduced last December but stalled in a subcommittee, would guarantee access to dental coverage under Medicaid for the most vulnerable citizens, defined as children or elderly, blind or disabled individuals. Advocates say the measure, sponsored by Reps. Charles Boustany Jr., R-La., and Robert Andrews, D-N.J.,

What it costs



Routine cleaning	\$56-81
Root canal	\$675-975
Upper denture	\$660-1,200
Lower denture	\$776-1,350
Crown	\$705-920
Bridge	\$2,093-2,741

SOURCE: DELTA DENTAL INSURANCE CO.

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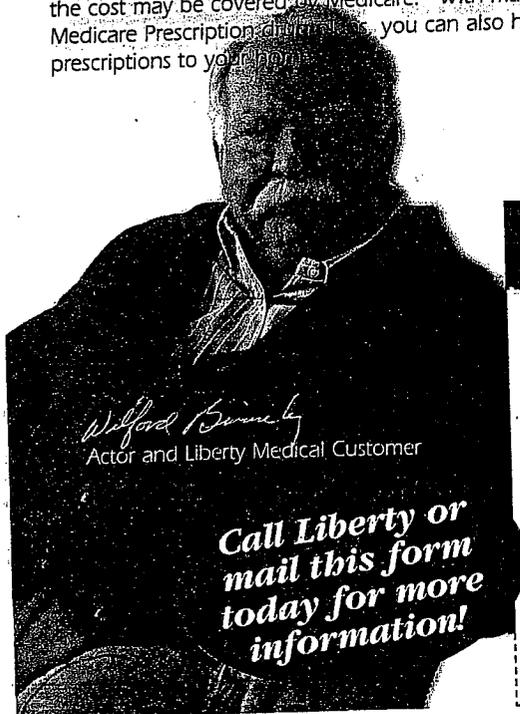
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- What is the universal antioxidant? (p. 4)
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- What herb can help improve memory and maintain circulation? (p. 25)
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- What herb promotes both prostate and urinary health in men? (p. 30)
- What herb provides antioxidant support and helps burn calories? (p. 32)
- What herb reduces occasional anxiety and everyday stress? (p. 33)
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In the 1950s, less than half of adults 65 and older kept their teeth, compared with 70 percent today.

SOURCE: U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

is a step in the right direction but doesn't go far enough.

Conan Davis, chief dental officer for the federal Centers for Medicare & Medicaid Services, acknowledges that government could do more to provide widespread access to dental care and treatment. But it will take greater demand from the public to persuade Congress to consider a Medicare dental benefit.

And, Davis says, there are "the costs involved for care ... in a season where we're looking to reduce costs."

Don't expect states to help much either. "With the recession of 2001, states had to cut services," says Bernie Horn, senior director for the nonparti-

san Center for Policy Alternatives, a state policy organization in Washington. "It was a matter of which services can we save and who are we going to cut off from health care."

The Uninsured on Their Own

Richard Manski, director of health services research at the University of Maryland Dental School, hopes to learn

Options for Dental Coverage

The choices for coverage are limited but slowly growing.

Individual policies are generally more expensive than group policies provided by employers, says Evelyn Ireland, executive director of the National Association of Dental Plans (NADP) in Dallas. Annual premiums average from about \$206 to \$480 for one person; most deductibles are around \$50. Couples must buy two individual policies; family plans usually cover three or more people.

The two basic types of individual plans are:

DENTAL HMOs: Dental HMO plans are the most affordable, and consumers are required to go to dentists in the plan's network. The plans typically pay 100 percent for preventive care, 60 to 80 percent for fillings and 50 percent for extensive procedures like root canals. HMOs don't cap the cost of treatment they will pay in a year.

DENTAL PPOs: Preferred provider organizations typically pay the same rates as HMOs for preventive care and treatment. But most PPOs cap costs they will pay for in a year, typically from \$1,000 to \$1,500. Consumers who go to dentists in the PPO network will be reimbursed at a higher rate than those

who use out-of-network dentists. Dental indemnity plans similar to traditional health insurance exist but are not widely available. Dental discount plans, which cost about \$180 a year, are also becoming more popular. But they are not insurance policies and vary by state. "If a cleaning is \$40," says NADP's Ireland, "you may pay \$30 with a discount plan."

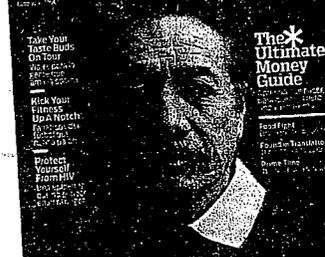
Membership associations, credit unions, professional associations and other groups sometimes offer members group coverage. Members pay the entire premium but usually get better coverage than individual plans provide.

Individual plans are offered by some companies, among them Aetna Dental Access, CompBenefits Dental, Delta Dental Insurance Co. (which administers the AARP Dental Insurance Plan), Dental Care Advantage, GE Wellness Plan, Patriot Plan and SafeGuard Dental and Vision. Not all of them cover periodontal services.

The NADP offers a free directory of dental plans at www.nadp.org.

Other sites with information on individual policies and plans: www.deltainsurance.com, www.dentalplans.com, www.ehealthinsurance.com, www.insuranceCo.com

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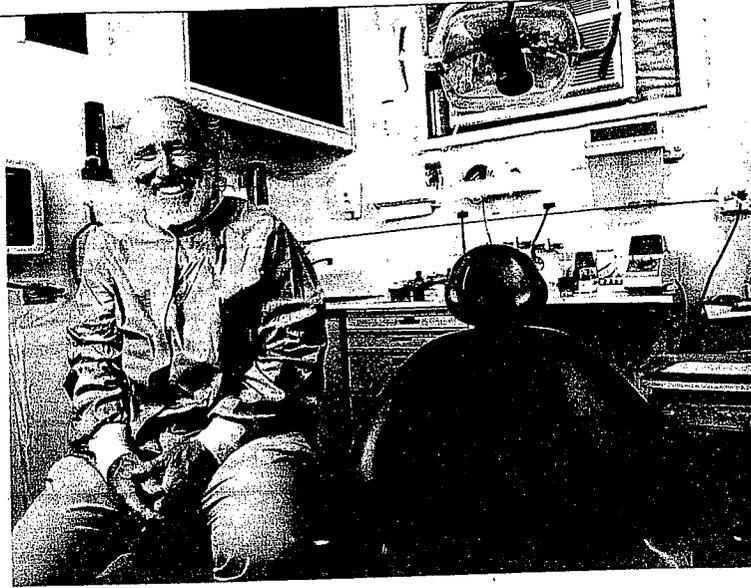
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if people will be able to maintain good oral health when they retire and lose their dental benefits. "We really don't know exactly what people are doing as they transition, if they're forgoing treatment," says Manski, who has applied to the National Institutes of Health for research grants.

John Thomas, a dentist at the VA Medical Center in Gainesville, Fla., has a good idea of what Manski will find. "I see patients over 65 in all areas of the community who have untreated oral problems because they can't afford treatment," he says.

Some of his patients take matters into their own hands, like the man who fixed a broken denture by gluing it together with epoxy and a white T-shirt. "The T-shirt was still bonded on the denture by the time he came to me," says Thomas, who points out that only a small percentage of veterans get free dentistry. Patients who can't afford treatment come to the center as a last resort, he says, when they have pain, infection or swelling.



Edward Schaaf of Chicago's Free People's Clinic is "an angel," a client says.

"What we often find is that people who've not had access to dental care walk around with a mouthful of abscesses or bad teeth," says Schaaf, 74, who started the clinic's all-volunteer dental program more than 20 years ago. "For every call we get for medical care, we get 10 calls for dental care."

Has Compassion, Will Drill

In the decade that Shirley Boykin went without dental care, she lost more teeth than she cares to admit.

Then she found the Free People's Clinic in Chicago, one of the few community clinics nationwide that offer free medical and dental care to working-poor, unemployed and older clients, the "people who fall through the cracks," says clinic director Edward Schaaf.

When Boykin, 64, went to the clinic, Schaaf told her he wanted to help. "I told him I didn't have any money, and he said, 'I didn't ask you for anything.' He wanted to help the needy," she says. "He's an angel."

Many patients at Schaaf's clinic get by with a small pension or Social Security. "They're barely eking out an existence," he says. "Where are they going to come up with \$1,200 for new dentures?"



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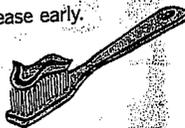
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M0506

Tips for good oral health

- Brush with a fluoride toothpaste and floss regularly.
- Seek professional dental care regularly, even if you have artificial teeth, to maintain a healthy mouth and to detect disease early.
- Stop smoking and limit alcohol consumption.



The question is whether public pressure will force Congress to add a comprehensive dental benefit to Medicare now that the lawmakers have dealt with

the program's prescription drug benefit. Marie Burton isn't optimistic. She's just about given up on finding a dentist who will fix her teeth and restore her smile—and her self-esteem—at a price she can afford.

"I've hit a very big brick wall," says Burton, who takes medication for diabetes, high blood pressure and cholesterol.

"I guess I'll never know what it would be like to have fresh breath again," she says, "and to not feel ugly." ■

TO LEARN MORE about dental care and overall health, go to www.aarp.org/bulletin. For black-and-white reprints of this article, call (866) 888-3723.

Where to Go for Help

- Call your local or state dental association to find dentists in your area who provide reduced-fee services to low-income families and older adults.
- Call your county or state health department to find health centers near

you with dental clinics that charge for services on a sliding scale. ■ Dental schools often have student clinics where care is provided at a reduced cost, but it can take months to get an appointment.

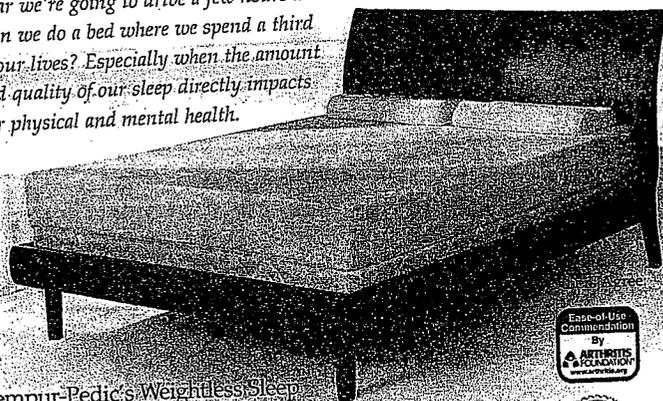
Online Resources

- ToothWoman Network: Go to www.toothwoman.net to see if low-cost or free dental services are available in your state.
- U.S. Bureau of Primary Health Care: Go to bphc.hrsa.gov and

click on "Find a Health Center." ■ American Dental Association: For links to state dental societies, go to www.ada.org and click on "Dental Organizations" and then on "Constituent (State) Directory."

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