



By MICHAEL D. KLEMENS

Ann Kiley of DMHDD: working with the shreds of a system

Ann M. Kiley took over the reins of the Department of Mental Health and Developmental Disabilities in February of 1986. Nine months later, the League of Women Voters of Illinois released a study of mental health care in Illinois that concluded: "People with serious mental illnesses have great difficulty in getting needed services because of the nature of their illnesses, the lack of resources and poor coordination of services."



Photos by Randy Squires

A month after that, Gov. James R. Thompson's Task Force on the Future of Mental Health in Illinois reported: "We do not have and desperately need a truly integrated system of comprehensive services for the mentally disabled." Cost of implementing their recommendations is put at \$300 million to \$600 million annually.

Things got no better. The federal government threatened to pull Medicaid funds because of lack of active treatment in state facilities. The American Civil Liberties Union sued over conditions at a facility for children. And the governor's inspector general found shortcomings with patient abuse reporting. At the same time local agencies that serve the mentally ill and retarded in community clinics, residential settings and day programs complain that Illinois spends too much on care for clients in state institutions. They are joined by advocates for the mentally ill who question the quality of care in state facilities that are overcrowded and understaffed.

All those problems rest on Ann Kiley's slight shoulders. Top Thompson

aide Paula Wolff calls it "one of a handful of incomprehensibly difficult jobs in state government." Kiley is responsible for a department that will spend \$625 million this year. Two-thirds of that will be used to run 21 state residential facilities for the mentally ill and the developmentally disabled, mostly the retarded. A third will be spent for services provided by 250 community based agencies. Kiley admits that there have been problems in large institutions. She acknowledges that community services are not uniformly available. "I think we have the shreds of a system," Kiley says.

'I give Ann pretty high marks for trying. . . I think she's been dealt a pretty miserable hand of cards'

To do her job she must deal with different constituencies. Kiley has to respond to inquiries from legislators; she must deal with groups that provide community services; and she has to handle demands from client advocates. And she must deal with them in two roles. She is spokesman for the governor and advocate and guardian for those under her care.

Lawmakers praise Kiley's efforts in a difficult position. "She has attempted very strongly to confront the issues. She's had to put out fires," says Rep. Tom Ryder (R-97, Jerseyville). Ryder follows mental health issues and offers an example. When the federal government began to crack down on lack of programming in state facilities, Kiley did not protest but moved ahead to boost programming and staff, he says.

There is almost no dispute that mental health is underfunded. Sen. Jack Schaffer (R-32, Cary) took that message to his colleagues on July 1, when lawmakers extended the spring General Assembly session a day, at least in part over the issue. (And in part in frustration by senators over the adjournment of the House.) He added \$8 million, an effort that was largely symbolic but put mental health in the spotlight. Schaffer says he could easily justify \$60 million to \$80 million in new spending. Underfunding has forced the department to emphasize its large institutions or face loss of Medicaid funding, Schaffer says. The neglect of community programs has in turn increased pressure on the institutions. "We have treated mental health very much like a stepchild in the last couple years, and those chickens have come home to roost," Schaffer says. He likes Kiley, however. "I give Ann pretty high marks for trying. . . . I think she's been dealt a pretty miserable hand of cards."

Mental health is not a partisan issue, and the comments from the other side of the aisle are not dissimilar. "I've got to hand

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it to her for working under almost impossible conditions," says Rep. Woody Bowman (D-4, Evanston). "Kiley gets good marks for empathy. She seems to feel for the people in her care and custody," Bowman adds. But he argues that the deck is stacked against Kiley because her boss, Gov. James R. Thompson, has provided no leadership. "We've been drifting for years and years and years," Bowman says.

Those who provide services to the disabled similarly damn the system, but not Kiley. Typical is Anthony Kopera, director of the Edgewater Uptown Mental Health Center in Chicago. He argues that Kiley is running the wrong system, the state institution-based operation, instead of an integrated system where local groups work hand-in-hand with the state institutions. "The state has not assumed responsibility for the mentally ill in Illinois. For those who are hospitalized, yes, but not for the mentally ill." Personally, Kopera has no dispute with Kiley. He says she has been one of the better directors since he arrived. She is direct, straightforward and honest, though not as sympathetic to community agencies as was her predecessor, Michael J. Belletire. But despite those qualities Kopera insists Kiley cannot do her job administering only the state system. Kopera offers a specific example. When Kiley first took office Kopera looked at the salary list for Kiley's central office. The lowest paid clerical staffer made more than his frontline clinicians. "She said that's not my problem," Kopera recalls. He insists it should be.

Some comments on Kiley are downright laudatory. "She is the best we've had so far, and I've been around for 25 years," says Don Moss, executive director of the Association for Retarded Citizens of Illinois (ARC). "She's fair. She's knowledgeable. She's a fighter for the department and for the people she's responsible for," Moss contends. Although his organization is preparing to take Kiley and the state into court to challenge the system (see "Going to federal court to force state funding," page 12), Moss says that is not Kiley's fault. And he says she has continued to cooperate in face of the pending legal action.

Others are not laudatory. David Stover, executive director of the Illinois Association of Rehabilitation Facilities, a group of not-for-profit agencies that is supporting the ARC lawsuit, notes that most new money last year went to state institutions and criticizes the reluctance to break away from the state institutional mode. "They're just not willing to wrestle that tiger," Stover says. And he claims the job is taking a toll on Kiley. "I think that the job of director of mental health has eaten her alive. It would eat anybody alive. She's not moving the system ahead."

Besides local mental health agencies that receive funding from the state, Kiley deals with advocates who stick up for the mentally ill and retarded. Their impressions, particularly their condemnation of the system, mirror the views of Kopera, Moss and Stover.

Among the most visible is the Mental Health Association in Illinois, which does advocacy for the mentally ill, oversight of programs, along with education and prevention programs. "I think much of the energy of the Department of Mental Health staff is spent putting out fires, because of our grossly inadequate system. Until there is a commitment from the top down that our system needs to be changed, it will be difficult for any director to be effective," says Jan Holcomb, past president of the organization. Kiley gets better marks. "I think she has attempted to listen and to correct some of the things that were within her purview," Holcomb says of Kiley.

Jerome L. Blakemore runs the association's site visitation program that takes volunteers on unannounced inspections of state institutions. Their visits have occasionally turned up intolerable conditions. For instance, on October 25 two members visited the D-North unit at Chicago-Read Mental Health Center and found it filthy. They found feces on the floor, foul odors, dust, dirt, cigarette butts, stopped toilets and an uncovered light switch next to a sink. The association described conditions as "inhumane, unsafe, intolerable and unnecessary." The conditions at Chicago-Read were the filthiest ever found. Visits more typically find the facilities understaffed and overcrowded. Blakemore says emphasis seems to be first on providing humane care. Effective treatment appears still to be a ways down the road, he says.

Blakemore suggests that his unannounced site visits provide a unique perspective on the operation of the system. They find conditions best when they inspect at the same time as the Joint Commission on Accreditation of Hospitals, the Department of Public Health or the Justice Department. "I just walk in and say, 'Who's been here?'" he jokes. For such inspections the bedspreads come out of hiding, Blakemore says. Holcomb has had reports of sprucing up a facility for an accreditation team. To promote a more homelike atmosphere, Holcomb says, the staff at one institution went out and picked up unclaimed photographs from Sears, bought frames at a discount store, and spread them about the patients rooms. The mysterious portraits may have impressed the inspectors, but did little for the patients, she suggests.

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Kiley herself has given support to the site visitations. After questions arose as to whether they could get in, Kiley gave Blakemore her home phone number if he ever had a problem.

Other advocates simply condemn the system. Eloine Plaut, director of of the Mental Health Association of Greater Chicago, expands on the role of the director: "One role of the director of the Department of Mental

Health is to provide a voice for the governor and reflect his views. The second role is to provide leadership, expertise, moral commitments, perspective and wisdom. . . . When those two tasks are in conflict, the role of the governor has to win. In this state mental health is simply not high on the governor's agenda of things to accomplish."

The third group that Kiley has to work with are her fellow members of the Thompson administration. They, too, praise Kiley, but predictably they do not condemn care for the mentally ill and developmentally disabled. "I think what makes Ann so valuable is her resilience," says Edward T. Duffy, director of the Department of Public Aid. "She's very easy to work with on problems. Ann Kiley does not say my way or not at all. She's really a team player," Duffy says.

*Financial problems and the
brushfires they provoke
come with the territory*

When the General Assembly is in session, says Paula Wolff, Thompson's director of programs and policy, she is sometimes mistaken by legislators and community agency officials for Kiley. But Wolff says she has not cut any deals. And she is a Kiley fan. Department heads, in Wolff's view, have to do internal management, policy development and deal with outside groups. Many have strengths in one or two of those areas and hire someone to do the others. Wolff insists Kiley is strong in all three. Wolff maintains that the appointment of Kiley reflects well on the governor, who overcame the fact that she was a woman and married to a Thompson insider (James W. Kiley, a former Thompson aide and the director of the Illinois Housing Development Authority until his resignation in January). Wolff sees in Kiley acceptance of her role as caretaker. She cites the willingness on Kiley's part to accept 3 a.m. phone calls on problem issues. Wolff does not dispute shortcomings found in the system, but contends that it is more integrated than it has ever been. Dissension, Wolff suggests, emanates from the shortage of money that forces groups to fight for their piece of the pie. "I think it's going to take working with the interest groups and the General Assembly to decide what it means to have an integrated system," says Wolff.

Kiley predecessor Belletire sees other reasons for Kiley's and mental health's woes. Interest from legislators tends to come from those who have large institutions in their districts and want the jobs, he says. The media has not become enamoured of mental health issues since the push to move patients who were warehoused in large institutions into community settings. Belletire says the issue of mental illness among the homeless almost grabbed that attention, but fell short. Because there is no easy solution, short of a scientific breakthrough, support is harder to generate. And unlike education where every lawmaker has a school district back home that also raises money for education, mental health is viewed as a state problem. As such it must compete, directly, with other state human service programs.

The problems existed when Kiley took the helm. She does not dispute the findings of either the League of Women Voters or the governor's task force. She notes that there has been little new money to implement new programs since the release of either report. "We have had to prioritize within our existant resources," she says. That means they have cut administrative staff and boosted numbers of direct care employees: "I think we clear and away operate the lowest administrative budget of any state agency." And Kiley says she and the Department of Public Aid have increased by 15 percent the number of days of psychiatric treatment the state will pay for in general hospitals. That has somewhat reduced the pressure on state institutions, she says.

Many of the problems are financial, Kiley insists. "The pie gets smaller. Protecting your percentage is not a victory. If you don't move forward you move back." The critical moment, she says, was July 1, 1984, when the temporary income tax of 1983 lapsed. She jokes about the enormous sense of relief felt by all citizens when the tax passed. (She does not mention the enormous sense of fear that pervaded lawmakers about retaining the tax.) "I mean you went out and celebrated. Right? Very few people even recall when that occurred, and yet that half-a-percent was critical to human service agencies." And in the competition with other human service programs Kiley says her department has not fared well.

Kiley sees long-term neglect for her particular agency, which lost in the competition with other human services. "In past years I'm not sure mental health has captured the imagination of either the assembly or the administration in terms of a hot issue. We have had other human services certainly at the forefront in past years," she says, citing the example of child abuse. But Kiley senses that the neglect of her department may be coming to an end. "I think that same kind of very strong consciousness is about in the field of mental health, in the field of developmental disabilities," she says. She attributes that to an increasing demand for services, an increasing expectation that they will be available.

Her vision for the future should gladden the hearts of the community service advocates. "I am a very strong supporter of geographically accessible community services. . . . We need to rethink how we've looked at state hospitals. What state hospitals can provide are some highly specialized services. . . . They can provide the kind of crisis backup available in a geographic area." But before that can be done, Kiley says, there is a need for stable housing arrangements in the community, for both the mentally ill and the developmentally disabled. That is her first priority.

Along with the critics of the current system, Kiley favors

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a move away from direct care in institutions. She is an administrator, however, and worries more about accountability than do advocates and local providers. "This agency historically has provided direct care service. In the future as we truly grow out of a predominantly institutional mode how do we assure service in the community? How do we provide *for* it as opposed to provide it? And how in fact do we regulate it? These are big questions." Kiley the administrator worries about controls and public confidence. "Community programs that the public does not trust will fail," she contends.

Her regulatory scheme would license a local agency like Edgewater Uptown to provide core services for clients. The agency would find the client a place to live and provide — or contract with other agencies to provide — emergency and support services. Without licensing every site where the mentally ill or developmentally disabled reside, the licensing program would leave responsibility at a local level, Kiley says. She views it as a step short of, but a step toward, guaranteeing services in the community: "I think it is the step we can now put in place." Mandates, be their requirements for community services or for schools to teach parenting, are hard to pass. And it is hard to sell the governor and budget director on new programs that guarantee services, she says.

Going to federal court to force state funding

An organization representing agencies that serve the developmentally disabled has decided it stands a better chance getting funding for its clients in the federal courts than through the Illinois political process. The Association for Retarded Citizens of Illinois (ARC) is preparing a legal action against as many as six state agencies, including the Department of Mental Health and Developmental Disabilities and the Department of Public Aid. They have hired a coordinator and are assembling the class of clients on whose behalf the lawsuit will be brought.

The action will allege that the state and private institutions are not providing the active programming required under federal regulations to receive Medicaid funds. There will actually be three suits. Two will be against nursing homes where the ARC contends that 3,000 patients are residing and not getting the programming required by federal law. One will be against Chicago nursing homes and a second against those downstate. The third suit will charge that public and private institutions, from the Jacksonville Developmental Center to the ARC's own facility in Springfield, are not providing treatment. Part of that suit will also allege that services are lacking for the young adults aging out of public school special education programs and for the retarded who have aging parents.

Pat Wear II is coordinating the litigation. He says the

Financial problems and the brushfires they provoke come with the territory, Kiley says. She can handle them and she does. But what she insists is important is not to be consumed with the daily crises and to keep a long-range view. She does that by spending a day a week outside of her office, she says. And she tries to speak to persons outside the mental health community about the issues. "One thing I think I will be very critical of in the field of mental health and developmental disabilities is that we have a habit of talking to one another and not to a broader constituency." She thinks her efforts have paid off in acceptance of community facilities and even some support for more money.

Kiley moved to her post from a position as assistant to the director of the Department of Public Aid. She had worked previous stints for the Governor's Planning Council on Developmental Disabilities, for the Department of Mental Health and Developmental Disabilities and for the Illinois Developmental Disabilities Advocacy Authority. She is 40 years old. She received a bachelor's degree from Northern Illinois University in 1971 and a master's degree in anthropology from Governor's State University in 1978.

Kiley says she enjoys her job. She praises her staff. She says employees who can get excited about new ideas after receiving four layoff notices in 18 months keep her up. "This is what government should do, so if you want to work in government this is the best place to be." She admits that the constant financial woes are draining. "It would be terrific to unleash this staff and arm them with some new resources to generate those programs," she says.

Kiley acknowledges only that she works long hours and could put in no more. Her associates say she is aware of the physical toll the job takes. "There are moments when you say this is one tough job, but I'm not tired yet," she says. "I have a lot to do." She will get no argument there.□

problem is in the reimbursement rates provided by the state to private agencies. A small intermediate care facility would be paid as little as \$38 per day (half from Medicaid) for housing and serving a retarded individual, while the state charges \$127 per day (again half from Medicaid) for individuals in its institutions. "You can't do active treatment for \$38 to \$50 per day," Wear insists. "The state probably can't provide active treatment in institutions for \$127 per day," he adds.

"It's clear to me that the Department of Mental Health and Developmental Disabilities' priority is preservation of the federal money in institutions. They basically have done nothing to develop a community system." Wear says. As a specific example Wear cites the fact that the state is in its third year of offering no public support of new group homes, a trend not found in other states.

As a result. Wear contends, Illinois is seeing increases in its institutional population. One of their clients is a woman with a seven-year-old who could not find 20 hours of respite care a month. For lack of the \$3,000 it would cost to provide that, Wear says, the youngster was institutionalized, at a cost of \$10,000.

The lawsuits will be filed by summer and Wear is confident of victory. With it, he says, will come oversight by the federal courts that transcends department heads, governors and General Assemblies: "I think it's the only alternative left to us here in Illinois." He acknowledges that an ARC court victory will cost money initially, as the state builds up community programs. Over a longer period, he says, less expensive community programs will allow depopulation of the institutions.

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