

Tighter rules sought for medication

Group targets doses for elderly

By Sam Roe
TRIBUNE REPORTER
and Christina Jewett
PROPUBLICA

Health advocates are calling for tough new rules on the use of anti-psychotic drugs in Illinois nursing homes, including tighter controls on doctors who prescribe the powerful medications.

"Medical care should help you get better, not get worse," said Wendy Meltzer of Illinois Citizens for Better Care, an advocacy group for nursing home residents.

A Tribune investigation recently showed how many frail and vulnerable Illinois nursing home residents have been unnecessarily dosed with anti-psychotics, leading to harm and an increased risk of death. One psychiatrist, the Tribune found in a joint investigation with ProPublica, provided assembly-line care to thousands of mentally ill patients.

The advocates want Gov. Pat Quinn's Nursing Home Safety Task Force to address these problems. While the task force has focused on violent felons housed in nursing facilities, chairman Michael Gelder said the group will also target the misuse of psychotropic drugs.

"We want people to be safe and cared for in nursing homes, not threatened or unwillingly sedated," he said.

Reforming the system likely will be challenging. The FDA has approved anti-psychotic drugs to treat serious mental illnesses, such as schizophrenia, but doctors may also prescribe them to geriatric patients with other conditions, such as dementia, in a common but controversial practice called "off-label" use.

Meltzer said one way to stop nursing home doctors from using the drugs to "chemically restrain" residents is for the state to refuse to pay for certain medications.

For example, if a nursing home doctor wrote a prescription for an anti-psychotic that can be injected—suggesting the medication is being used to sedate a resident—the pharmacist would not fill the order unless the physician received permission from the Illinois Department of Healthcare and Family Services. Meltzer also said the state should not pay for multiple antipsychotics for the same resident or for psychotropics at dosages over recommended limits without prior approval.

In addition, Meltzer called for Illinois to require nursing homes to use standardized consent forms for each psychotropic drug. Documents show that hundreds of nursing residents have been given psychotropics without their permission since 2001. In other cases, facilities downplayed the dangers.

Nursing homes, Meltzer said, should have a formal process of explaining the benefits and risks of taking psychotropics. Right now, she said, the goal of many nursing homes is to simply get residents to sign the forms as opposed to explain the options.

Other possible reforms address problems raised by the ProPublica-Tribune investigation of Chicago psychiatrist Dr. Michael Reinstein.

Illinois law requires psychiatric hospitals to report patient deaths, but three deaths of people under Reinstein's care were never reported, said Illinois Department of Public Health spokeswoman Melaney Arnold. The agency grants and revokes the licenses of psychiatric hospitals, but it cannot levy penalties for lax death reporting because that law is on another agency's books.

Advocates said this inconsistency should be fixed, but Arnold characterized the problem as beyond the scope of her agency. "If (legislators) want to make a change to the law, they are welcome," she said.

Mark Heyrman, a University of Chicago law professor and mental health advocate, called on Medicaid to consider a doctor's cumulative disciplinary record when weighing sanctions. The agency records show, has taken repeated action against Reinstein but has not punished him as a repeat offender. Either, it has looked at him one audit at a time.

Heyrman said he wondered if it was wise for Medi-

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caid to give tax dollars to doctors who have had repeated run-ins with the agency. "It seems to me there should be a higher standard for that," he said.

But overall, he said, Medicaid pays psychiatrists too little. "If we want decent care we have to raise the payments," Heyrman said.

Advocates also said Illinois should require drugmakers to publicly disclose payments to doctors so that their patients can be aware of possible conflicts of interest. One pharmaceutical company gave Reinstein nearly \$500,000 to promote a drug that Medicaid records suggest he prescribed 41,000 times. Reinstein has disputed Medicaid's prescribing figures.

State Rep. Jack Franks,

D-Marengo, has pushed a bill since 2005 requiring drugmakers to report the amount of money and gifts they give to doctors, nursing homes and hospitals. The bill has not passed, but he said he plans to re-introduce it next session.

He called Reinstein "the poster child for why we need this law."

Reinstein, through his attorney, said he agrees that drugmakers should disclose payments. He said he no

longer accepts payments from pharmaceutical manufacturers, and if any are sent to him, he donates them to charity.

He also said he would cooperate and assist the task force if asked.

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Nursing home reforms

Legislation introduced in the General Assembly on Tuesday would provide disabled children in Illinois nursing homes with a variety of new safeguards, including stiffer penalties for poor care and tougher rules on when families must be notified of violations.

The reform package, sparked by a Tribune series, also calls for stricter rules on the use of psychotropic medications, bans on new admissions at troubled facilities and more oversight when deaths occur.

In October, the Tribune reported how 13 children and young adults have died since 2000 at a North Side facility now called Alden Village North. Gov. Pat Quinn instructed his senior health policy adviser, Michael Gelder, to draft legislation to protect residents at the roughly 300 facilities in Illinois caring for the developmentally disabled.

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 TRIBUNE WATCHDOG UPDATE

Nursing home rules passed

Deaths of disabled patients will need to be reported to state

By Sam Roe and Jared S. Hopkins

TRIBUNE REPORTERS

For years, deaths of disabled children at Illinois nursing homes faced little scrutiny. Regulators weren't always informed, coroners weren't notified — even some family members weren't told whether neglect was involved.

But that could soon change as the Illinois Senate on Tuesday joined the state House in passing sweeping reforms to safeguard thousands of children and adults with severe developmental disabilities.

The proposed new laws, sparked by a Tribune investigation, require nursing facilities caring for the developmentally disabled to report all deaths to state regulators as well as to local coroners or medical examiners.

Other reforms include stiffer fines for poor care, stricter rules on the use of psychotropic medications and fewer roadblocks to closing facilities.

State officials and some advocates described the measures as the most significant effort in a generation to help disabled people living in Illinois nursing facilities.

ties.

"This is a major victory for people with developmental disabilities and their families," said Michael Gelder, senior health policy adviser to Gov. Pat Quinn.

But some said the legislation doesn't go far enough. For instance, Wendy Meltzer, a leading advocate for nursing home residents, said the state will need more inspectors to enforce additional laws. "Otherwise, this whole exercise becomes pointless," she said.

Teresa Garate, assistant director of the Illinois Department of Public Health, disagreed, saying new powers will make inspectors more effective. Under the legislation, she said, "our department is better armed."

In October, a Tribune series documented a 10-year pattern of death and neglect at a North Side nursing facility now called Alden Village North. The newspaper found that 13 children and young adults had died in cases that resulted in state citations for neglect or failure to investigate.

State officials announced they would close the home, and Quinn asked his staff to draft legislation to protect residents at the roughly 300 other facilities in Illinois caring for the developmentally disabled.

The legislation, which is expected to be signed into law by the governor, applies only to facilities for people with developmental disabilities, such as cognitive impairment. Similar reforms were adopted last year for nursing

homes for the elderly and people with mental disabilities.

In addition to reporting all deaths, facilities for the disabled would be required to disclose any medication errors or unusual incidents that occurred within 30 days of the deaths.

But neither the state nor coroners would be required to investigate.

"That's a problem," said Deborah Kennedy, head of abuse investigations at the watchdog group Equip for Equality. "The state is missing an opportunity to be very proactive."

Dr. Thomas Kupferer, president of the Illinois Coroners and Medical Examiners Association, said the legislation could help identify deaths that need investigating, and if neglect or wrongdoing were involved, "hopefully, it will be uncovered."

The proposed reforms also require facilities to notify a resident's guardian when inspectors find violations directly affecting that person, regardless of the severity of the infractions. The Tribune reported that some parents did not know that the state had cited Alden in the deaths of their children until told by the newspaper.

"That's a terrific step in the right direction," Kennedy said.

The legislation increases some fines, but advocates said the penalties remain low. The maximum fine would be \$50,000 for large facilities and \$25,000 for those with 16 and fewer residents, according to state officials.

"For for-profit places, you need something much stronger than that," said Zena Naiditch, president and CEO of Equip for Equality.

The plan also calls for stricter rules on the use of psychotropic medications, including new protocols to prevent drugs from being administered to residents without their understanding and consent.

Meltzer said some facilities have used psychotropic drugs "not only to treat the symptoms of diagnosed illnesses but also to control behavior so as to make life easier for the staff. We need legal controls that make it more likely that these dangerous drugs will only be given when it is appropriate and necessary."

Although the legislation does not boost minimum staffing levels, it mandates that children receive one-on-one time with licensed nurses.

Currently, kids are required to get at least four hours of one-on-one direct care each day. Low-paid nursing aides provide the bulk of this care. The proposal calls for the state to establish a rule requiring that nurses provide at least some of the care.

Amber Smock of Access Living, a nonprofit advocacy group, said the change was inadequate and more one-on-one time was needed.

David Noe, whose 14-year-old stepson lived at Alden and died in 2010 in a case that resulted in a citation, said the legislation was "too little, too late for my son's

benefit. But overall, it's going to help. Any kind of help is better than no help at all."

Responding to the legislation, Alden officials said in a statement: "We, along with others in our industry, have long advocated for this important reform. ... We are pleased that it recognizes the unique needs of the developmentally disabled population and that they are a different population from other nursing home residents. We support this bill and we look forward to its implementation."

The facility remains open while appealing the state's effort to shut it.

Industry leader Michael Bibo of the Center for Developmental Disabilities Advocacy and Community Supports, which represents facilities for people with disabilities, did not return messages seeking comment.

Over the past several months, state officials, industry leaders and advocates met to discuss what reforms should be included in the legislation. Smock, who was involved in the talks, said the process was difficult at times because the needs of people with disabilities were weighed against what was cost-effective for the state and profitable for nursing home owners.

"What should be a debate about moral justice ends up twisted by budgetary demands and profit margins," she said.

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