

# Rules for care of retarded stalled

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For more than 10 years, the state Department of Human Services has failed in its attempts to establish a set of rules aimed at preventing abuse of the mentally retarded. A deadline set by state law passed two years ago.

The department has produced 33 separate drafts since 1982 and at least 39 before that, according to people who have participated in those attempts, but none have survived the heated objections of various interest groups.

The 1982 Legislature passed a law ordering the department to put the rules into effect by October 1983. Two years later it has not been done, and further delays are inevitable.

The recent death of a 38-year-old retarded man at Willmar State Hospital has prompted the Minnesota Association for Retarded Citizens (MinnARC) to renew its demand that the rules be drawn up and implemented.

The man died, apparently of a seizure, after being held down on the floor by three staff members. He reportedly had been violent.

Preliminary reports give no hint of malfeasance by staff members, and whether he might have survived if the employees had acted differently is uncertain.

But there has been evidence of maltreatment elsewhere. In 1983, the department reported 42 substantiated cases of maltreatment in the previous year by employees of state institutions. In one notorious case, seven employees at Cambridge State Hospital were fired in February 1983 for allegedly hitting mentally retarded patients. (An arbitrator ordered four of them reinstated.)

Even under the speediest of scenarios, it will be another year before new rules can be adopted, said Gerald Nord, a department consultant who began working on drafts and dealing with interest groups in 1982.

The rules are designed to control the use of "aversive and deprivation procedures" in residences and programs for the retarded. Earlier versions included programs serving other people, not just for the retarded, but the 1982 law narrowed the focus.

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Aversive and deprivation procedures could range from removing a person from group activities after a temper tantrum to the administration of mild shock in an attempt to break a person's compulsion to batter his face with his fist.

An aversive procedure is "the planned application of an unpleasant or painful stimulus resulting in the decrease or elimination of the target behavior" (such as self-injury), according to the latest draft.

Deprivation means "the denial, withdrawal, or delay in delivery of goods, services or activities to which the client is otherwise entitled" (such as removal from an activity.)

The set of proposed rules, which together are called Rule 40 (formerly Rule 39), place strict limits on use of the procedures. They set separate qualifications for people administering mild, moderate and intensive procedures; they require prior approval by a regional review committee before a treatment program using intensive procedures can be used.

At Willmar, patient John Dragoo repeatedly became agitated and struck two employees with his fist, said Lester Johnson, the hospital's chief executive officer. Dragoo was being held face-down with a "flat hand hold" when he apparently suffered a seizure, Johnson said. Dragoo's breathing stopped and staff members administered cardiopulmonary resuscitation. He died later in Rice Hospital in Willmar.

That prompted a letter to the department from the MinnARC demanding that Rule 40 be completed and implemented once and for all.

But the process had been revived two months ago because of similar urgings from the association in late summer, Nord said. Work had been "put on hold" in late 1983, he said, because of the press of other departmental business involving the retarded.

Francis Giberson, deputy human services commissioner, cited the department's heavy workload and limited resources, but he denied that Rule 40 had been put on the back burner since the legislative mandate.

Commissioner Leonard Levine said the department "continues to run into a brick wall" whenever it tries for a consensus on Rule 40. "But we're going to give it another try and see if we can't get a convergence of professional opinion."

John Clawson, a former legislator and cosponsor of the 1982 law that mandated a rule, said it is "an impossibility" to satisfy the conflicting

vice providers, advocates, parents of patients, county case managers, various professionals and others who met as a task force after the 1982 legislation.

Harold Tapper, executive director of the Association of Residences for the Retarded in Minnesota, said virtually all the group homes represented by his association must obey federal rules on similar issues. Rules against aversive and deprivation procedures are needed more in state hospitals than private group homes, he said in a telephone interview.

The department's delay, he said, "doesn't surprise me at all" because it "almost never meets its deadlines."

Dianna Krogstad, director of two Minneapolis area day activity centers for the retarded, had a different objection: the cost of paying the staff to carry out the rules. "We just don't have the bucks to implement it," she said. "It's absolutely frightening."

Under Rule 40, she said, a professional review team "would determine if my staff was competent to implement the (aversive and deprivation) procedures." She termed it "absolutely ridiculous" that an outside body would "oversee my hiring."

Some disagreements in task force meetings, Nord said, involved mundane tasks. If a retarded person needs help brushing his teeth, does a

staff person need a rule about guiding him with his hand?

"Some people felt that any time you place your hands on somebody this should be regulated closely," Nord said. "Others felt no, this is a normal part of training and assisting the client."

Any proposed rule must survive an arduous, time-consuming series of steps. They include giving notice to interested people, inviting and reviewing written comments from the public, holding a public hearing, publication in the State Register and review by the attorney general.

It will take another year, even if agreement comes quickly, Nord said.

State Sen. Allan Spear, DFL-Minneapolis, was Senate author of the 1982 law requiring a rule by October 1983. "I know it hasn't been done and we've been nagging them about it for a couple of years now," he said. "They keep coming back saying that they're working on it" in the face of "extraordinary difficulty..."

"I don't think it's an excuse for this kind of delay."