



State of Minnesota

Office of the Ombudsman for Mental Health and Mental Retardation

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Editorial Department
StarTribune
425 Portland Av. S
Minneapolis, MN 55488

RE: Guest Commentary-Voiceless and
Vulnerable

Dear Editor,

I appreciate the StarTribune raising the issue of treatment of Minnesota's citizens who have Developmental Disabilities. These citizens are the most vulnerable of our citizens. The deaths profiled in this series are truly tragedies. No death that is preventable should be considered acceptable. The ultimate purpose of the Ombudsman's Medical Review Process is to improve care for the living. If this series results in an honest and comprehensive public debate of the serious gaps in this system, your newspaper will have provided a public service.

Minnesota is known for passing laws and complex rules on how the system should work. However if those systems are not appropriately funded to accomplish the goals, then people will continue to blame each other. The transition from institution to home based community living is not complete. Many things need to happen to complete the infrastructure needed for this transition. Funding is key but some of the systems are flawed. In some cases funding is not in the right place and others there is not enough. We should not use this as an excuse to return to the days of the institutions. We all need to be working together to surround these vulnerable citizens with the assistance they need to fully realize their rightful place in the community to the highest level they can attain by directing resources closest to the client. More bureaucracy is the least effective method.

Unfortunately your series was not comprehensive enough in covering the full spectrum of problems in this system and some of the first lines of defense for these voiceless and vulnerable citizens. From the calls for assistance received at the Office of Ombudsman for Mental Health and Mental Retardation we get a glimpse of what clients and families face in obtaining appropriate services. The first line of defense is always an active and involved family. In addition to that or in some cases in place of that is the role of the county social service system through its case management and foster care licensing systems. County case managers make many of the decisions about the appropriate level of services and living arrangements for each client. Many of the deaths reported in the series happened in foster care settings. Licensing of foster care homes is delegated to the counties. There was no mention of the role of the public guardianship system in Minnesota or of the federal funding or rules governing these services.

As the Ombudsman, I have monitored the types of cases that cause citizens to call the Office of Ombudsman for assistance. After considering the cases, the following are some of the areas that the Ombudsman hopes will be discussed. The needs and roles of:

- **Families.** No amount of government resources will ever replace the love, care and concern of actively involved family, friends and community. Yet in the past families were encouraged to turn their loved one over to the government. While government no longer encourages families to give up their children to institutions, the systems in place push families away by more subtle methods. The system of accessing services can be a very impersonal bureaucracy that is complex and difficult for a family to navigate. Professionals and providers can make them feel inadequate for not being as knowledgeable about the systems. This often-adversarial system causes families to compete for insufficient services and then the families are often looked at suspiciously as though they are trying to cheat the system. Families and friends need more respect and need to be viewed as a partner in the care of their loved one. They need help, not bureaucracy and cynicism. Families are truly the first and best lines of protection.

- **County Case Managers.** The case manager is supposed to help their clients and families access the appropriate services based on the individual needs of the person with a disability. However the case managers often feel pressure to protect county resources. The counties receive state and federal funds to provide case management and are required to provide the Department of Human Services with a Social Service Plan. However there is no adequate mechanism in place to hold counties accountable to following the plans or to provide case management in accordance with state rules. Minnesota has a case management system that is overloaded putting a burden on the case managers trying hard to meet the needs of their clients.
- **Public Guardianship.** When a disabled citizen is a ward of the state, the duties of the Commissioner of Human Services are delegated to the county. Often this duty is assigned to the case manager who is then in a conflict of interest situation. They must balance their duty to spend county resources in a reasonable manner while having the legal obligation of the guardian to aggressively pursue all services that the ward is entitled to as well as what is in their best interest. At the state level, one person coordinates the guardianship services supplied by the counties and does so on a part time basis. That person must review and decide whether or not to grant requests for instructions as to treatment decisions at the end of life for these vulnerable citizens. Only the state guardianship office can order the approval of a "Do Not Resuscitate" order. These types of services and decisions should not be done on a part time basis.
- **Providers and caregivers.** There is little incentive to go into this work, there are few professional training courses and there is little or no respect given to those who do this work. Every system has its "bad actors" and they must be removed from the system but the vast majority of caregivers are not given the tools they need to perform these services. There are also many good caregivers in the system that try and do deliver quality care despite the limitations.
- **Doctors, nurses and other medical professionals.** More training must be given to these community providers in how to work with persons with cognitive disabilities. They need to better understand how to interpret pain and other symptoms of illness especially when dealing with those who can not speak for themselves or who do not understand what is happening to them.
- **State agencies.** All of us who work in this field must be open to looking at new ways of doing our work in better, more effective ways that are cost effective so that most of the resources can go into direct services and not just more bureaucracy. The ombudsman has a goal to establish a program of "Community Visitors", volunteers in the local areas that go into facilities and programs and visit with clients and staff. They could then provide information back to the Ombudsman on what is happening in this new dispersed system of community care. We need to authorize more programs like the Region 10 Quality of Care program in Southeastern Minnesota where local groups provide the licensing function using multi-disciplinary teams with knowledge of their region.

Minnesota should be judged as a society by how we treat our most vulnerable citizens. Adequate funding and resources are critical. But money is not the only answer to all of the problems. Until we, government and public alike, value these disabled citizens, their families and care givers, we will spend millions of dollars and continue to fail. Always remember that adding **Dignity and Respect** to the services provided to persons with Developmental Disabilities does not cost a dime.

Sincerely,



Roberta C. Opheim
Ombudsman

