Statement by Lee Ann Erickson Olmstead Subcabinet Listening Session Rochester, MN August 19, 2013

The cages are back, but they are gilded now. Providers are investing in lovely, high-end homes so residents have nice bedrooms where they spend most of their free time.

The identified list of barriers in the Olmsted Plan is all-important. The last barrier, the assumption that individuals with disabilities lack the capacity to make day-to-day decisions affecting the quality of their lives, deserves deep consideration.

At every annual meeting, a copy of the rights of the self-advocate is handed out. Each and every one of those rights can be and are taken away with no consideration for the wishes of the self-advocate. The right to associate is most often abused.

My two sons with disabilities own their own home. I am their guardian. Their inhome provider would not allow former staff to visit their home. I called licensing thinking they would address this issue. Staff made it clear licensing was not interested in rights of individuals. I could have called in a VA report, but when my son was struck by a staff some years ago, the result was a three-week suspension with pay for the staff. This staff member then came back to work with other people with disabilities. The Olmsted Plan needs to find a system that works.

A former housemate of my son continues to live in a four-bed waiver home. He develops close attachments to staff who care about him. It's very upsetting to him when staff leave. The people who control his life developed a program where this self-advocate has a chance to say his final goodbye. Then staff and he are instructed that no further contact can be made. This does not work well in a small community, where former staff work for other agencies and this self-advocate and former staff attend many of the same activities. In fact, this self-advocate makes every effort to say hello and even sit at the same table. He no longer is allowed to attend functions with his peers, so he sends greetings to former staff through his housemate.

These are two examples out of many. Too many providers are denying access to former staff. It has been my experience that when an organization provides good service, they welcome anyone because they are proud of their success. Currently,

many providers have their attorney on speed dial and their residents closeted in their rooms. The advice given by an attorney never seems to contribute to any kind of quality lifestyle.

Southeast Minnesota developed a quality assurance program that addressed these very issues. It focuses on the self-advocate, and good things resulted from a process called a VOICE Review. Funding to that program has been cut in the past few years. Person-centered quality assurance like this is a system that works; it needs to become a statewide program.

The Housing Access Services program also provides opportunities for self-advocates to have choices. When you are living in a home of your own, staff become more supportive and less controlling. Many of the barriers created by corporate adult foster care liability issues are eliminated. Transportation is a liability issue for many providers. As a result, ride sharing is not allowed. If your friend is not served by your agency, he or she cannot share a ride in your vehicle. Your neighbor cannot pick you up for church unless you have provided a background check and proof of insurance. A home of your own allows you to make your own transportation arrangements, just like others do who do not have disabilities. Quality of life improves in your own home.

The Arc Southwest Minnesota offers many opportunities for self-advocates to network together about what is important in their lives. Currently, we hear about people who want to come to activities or attend family events but they are short staffed. If family do not or cannot expend the extra effort to provide transportation, self-advocates miss graduations, family picnics, weddings, etc. A few days ago, I was talking with a family who is very upset that their son is very seldom allowed out in the community. He needs a one-on-one staff, and that position is being funded but it is not being filled. This family and their son want options. So do the rest of the families and self-advocates.

Minnesota knows how to provide a quality lifestyle for people with disabilities. It is our hope that the Olmstead Plan will eliminate unproductive paperwork and put efforts into productive support services for people with disabilities.

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