Minnesota Governor's Planning Council on Developmental Disabilities

DEVELOPMENTAL DISABILITIES PROGRAM, STATE PLANNING AGENCY
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June 3, 1987

The Honorable Harry H. McLaughlin
United States District Judge
Clerk of the United States District Court
514 United States Courthouse
110 South Fourth Street
Minneapolis, Minnesota 55401

Dear Judge McLaughlin:

The Governor's Planning Council on Developmental Disabilities has existed since 1970 and is a federally funded program responsible for planning, coordinating, and evaluating services to persons with developmental disabilities. The Council, appointed by the Governor, consists of 27 members, half of whom are family members or individuals with disabilities.

Since the Welsch Consent Decree was signed in 1980, there have been dramatic changes in how people think about individuals with developmental disabilities. The change in philosophy is reflected in our publication, A New Way of Thinking (Appendix 1):

1. People with disabilities want to be seen first of all as people, not the retarded, or the disabled.

2. People with disabilities want to experience love and friendship, not paid caregiving.

3. People with disabilities want to experience continuity in their lives especially with people who are important to them rather than hundreds of hands touching them because of shift patterns or staff turnover.

4. People with disabilities want to be treated with dignity and respect rather than as objects of abuse, objects of charity, or

objects of pity. Everyday we have the opportunity to negotiate. We negotiate with those around us--what we do at work and at home. In contrast, people with disabilities are regulated. We make rules for people with disabilities rather than negotiate with them.

5. People with disabilities want to have access to opportunities and information, to make choices and exercise rights no matter how severely disabled. We need to teach people with disabilities to respond to four questions in order to make choices--"I need, I want, I like, I dislike."

6. People with disabilities want to have an opportunity to contribute and be productive rather than keeping busy doing inactive treatment like stacking blocks, stringing beads, and assembling puzzles.

People with developmental disabilities have special needs, but their basic needs are the same as ours.

Funding, policies, and services have often focused on special needs and fostered dependence, segregation, and isolation. As a result, basic needs have gone unmet. The basic needs are the same as yours:

1. Having a home--not a roof over our heads, not a service setting or not a specially constructed piece of real estate that government pays forever to maintain.

2. Learning skills which are useful to our lives and careers, not just going to school in a separate building or a separate wing or a separate class from nondisabled peers. We do not endorse 20 years of public education to teach someone to print his/her name, count to 10, and read a few words. Education must be geared to what the student must do as an adult--to live and to work in the community.

3. Developing and sustaining relationships with people who are not disabled to assure a connection with the community. Friendships start

> at an early age, and so children with disabilities should be integrated at an early age in regular settings with children who are not disabled. Security and stability doesn't come with bricks and mortar. It comes with mandates, advocacy, and making sure people are connected with other people.

This letter is intended to provide our Council's opinions about the Welsch negotiated settlement. During the past seven years, our Council has prepared policy analysis papers on topics related to the Welsch Consent Decree. Because these papers would be too lengthy to submit to you, I am enclosing a very concise summary of each paper which was published in our Three-Year State Plan (Appendix 2: Summary of Policy Analysis Papers).

We strongly support all parts of the negotiated settlement. We are very pleased that there is a special initiative to place individuals with the most severe disabilities. Today, children with the most severe medical disabilities are living at home or in small, normalized settings. There are as many or more children and adults with severe disabilities who live outside the regional treatment centers as in those settings.

We are very pleased to see the reaffirmation that children should not live in regional treatment centers. We support an external monitoring office that provides a full range of response from volunteer advocacy to legal advocacy.

We are concerned that the negotiated settlement does not provide enough attention to building capacity and providing training for staff in community and regional treatment centers. At this point, the knowledge exists to do state-of-the-art programming; however, there is no systematic mechanism to provide training, technical assistance, and consultation to providers statewide. Training requirements should be mandatory for staff.

Case management is also a major concern because there are not enough case managers employed by counties to do a good job. There is lack of funding to hire enough case managers which will require legislative action. Additional training, technical assistance, and consultation is necessary for case managers particularly in state-of-the-art practices.

Again, let me reiterate our support for services in the community for all people with disabilities.

Cordially,

Colleen Wieck, Ph.D.
Executive Director

CW/amc

Enclosures