



NAMI Florida



August 10, 2011

Ms. Susan Kaempfer
AHCA
2727 Mahan Drive
Bldg. 3, Room 1229
Tallahassee, 32308

Dear Ms. Kaempfer,

Thank you for allowing me to speak on behalf of NAMI Florida to the Assisted Living Workgroup. The following are excerpts from my presentation:

- In 2005-2008 NAMI participated in a pilot program, Personal Outcome Measures, funded by the Department of Children and Families. The goal of the program was to interview persons receiving mental health services through various programs and agencies, including ALFs. As I was trained and certified to interview I personally visited several ALFs in Circuit 20, talking to individuals about their quality of life. Questions were asked such as:
 1. What are your goals
 2. Where do you want to live
 3. What do you feel you need for supports
 4. Do you have access to your environment
 5. Are you happy or sad most of the time
 6. Do you feel safe

There were approximately 25 questions, all to gather information about a person's quality of life and self-direction.

- Ironically many residents were not opposed to living in an assisted living facility but objected to not having choices in their life.
- Residents stated that they perceived staff and other residents as their family.
- Responses to questions were similar regardless of where the person lived or from whom they were receiving services from.
- As we look at housing for individuals with disabilities I believe it is important that we consider how "the person" perceives their living situation whether it be in a group home, ALF, community housing or a homeless shelter.

I respectfully ask the Workgroup to speak to the individuals who live in these facilities and ask what is important to them. Look at their quality of life and ask what can be done to improve what is important to "the person".

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Abuse and neglect was found to be an issue at one specific facility. Their license was revoked but within 30 days they had reopened with a license under another name. I would like the workgroup to address the following:

- How will these facilities be evaluated and by whom?
- What are the expectations and how will outcomes be measured? What will be the criteria?

In conclusion our findings were that persons who had direct contact with persons who had a mental illness were not educated on the illness. They lacked empathy, communication skills, and no understanding of the biology of the illness. There was a lack of understanding that persons with a diagnosis were not in control of their behavior. This often resulted in frustration and anger.

One of the comments that was often repeated by several persons at the meeting was that residents were afraid to report abuse for fear of losing their services. I would like to say that the majority of persons that were interviewed had the fear of losing benefits regardless of where they lived or who they were receiving services from. Persons with mental illness are often dependent on the State for food and shelter and have historically had the fear of disclosing information.

Materials were distributed to the Workgroup outlining NAMI Florida's education and support programs. We have a course called Provider Education which would specifically address the needs of Mental Health Education to Providers.

Thank you,

Judith Evans

Judith Evans, Executive Director
NAMI Florida, Inc.