

**Focus Group
Parents and Family Members
October 7, 2008**

Interviewer: Jerry Solomon, PhD

Goal: To obtain feedback from family members of the mentally ill about their

- Experiences with the mental health system
- Reactions to the PEI workgroups recommendations
- Comments to the MHSA Steering Committee

Participants: The Santa Cruz chapter of NAMI was contacted and agreed to locate participants for the focus group. Six people participated. All were parents of children with serious mental illness. Most began noticing problems with their child's behavior in their teenage years.

Format: The interviewer introduced himself and explained the purpose of the two hour focus group. He gave a brief overview of the MHSA process and presented the PEI recommendations prepared by the various workgroups. The remainder of the group focused upon participants' reactions to the following questions:

- Did the PEI recommendations address what hasn't worked and strengthened what has worked in the mental health system?
- Might any of the recommended programs have helped you and your child as s/he entered the system?
- Does any recommendation seem more important to you to be funded than another?
- What do you want the Steering Committee to know that might help them with their decision?

Discussion: The participants began their discussion by exploring what hasn't worked for them and/or their child since they've encountered the mental health system.

- Many parents acknowledged multiple missed opportunities throughout the years. A few lamented about not having better knowledge of child behavior and development. "As a parent, I had nothing to compare my child's symptoms to...I assumed they were normal."

Others talked about working with mental health providers who did not have experience treating serious mental illness. "Many providers don't want to think a young child is seriously mentally ill."

Many agreed with one parent's statement, "No pediatrician will diagnose a young child with depression or mental illness."

One mother talked about not knowing where to get help for her child. It took her nearly two years to locate assistance.

- Ambivalence regarding labeling a child for funding reasons
- Too many treatment plans involving drugs
- A few parents shared experiences of being treated badly, or indifferently by mental health staff. Others talked about how frightened they were when their child was placed in isolation.

What did work

- Once a parent located services they were next faced with the challenge of paying for services. Many found effective services for their children within a few hour car ride from Santa Cruz if they had private insurance or had the means to pay out of pocket for services.
- One parent related that she had a positive experience with County Mental Health when her son entered the system.
- All agreed that meeting other parents and receiving peer education and support was invaluable in assisting them cope with their child's mental illness.

What would you recommend to the Steering Committee?

Most of those in attendance urged the Steering Committee to consider the following:

1. Provide better access to information regarding the services available locally. All liked the idea of an interactive website for local mental health needs and/or a funded systems navigator position.
2. Create a mental health system similar to the Regional Center, vrending services and collaborating with other systems (i.e., teleconferencing). This could be especially helpful when offering services to the 0-5 age group where trained providers are less available.
3. There is a need for trained/skilled professionals to work with infants and children. Until that is available a policy should be established that children are automatically referred to Langley Porter for assessment. Ideally, the mental health system would provide time for psychiatrists to be available to consult with primary care providers.
4. All pediatricians should be trained in assessing the signs and symptoms of serious mental illness in infants and youth and be familiar with local services.
5. Treat the families as allies in treatment planning. Offer family members respite.
6. Participants strongly supported the recommendations regarding the educating of parents about mental illness and “the system” by other parents and professionals. They felt a community-wide media campaign promoting mental wellness was an excellent idea.

Other comments:

1. Consider occupational therapy as another means of treatment
2. Services offered to youth on-site at the schools is crucial.
3. Research other service models that manage scarce resources. Fore example, might we want to collaborate with the Veterans Administration in working with people with severe trauma?
4. It's important to take into account the comments made during the CSS planning process.