

The Consumer and Family Perspective on Mental Health System Reform

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THROUGH ITS WELL-REGARDED public policy program, NAMI North Carolina (National Alliance for the Mentally Ill of North Carolina) has been at the forefront in advocating mental health reform over the past several years. It is clear North Carolina's mental health system needs to change and we all need to change with it. The people of NAMI North Carolina are proud to live in a state that is so progressive in looking squarely at its treatment of people living with the circumstances of severe and persistent mental illness.

At this time, however, as we are looking both forward and back, it is good to take stock, to keep certain guideposts in mind. For NAMI North Carolina, the most critical guidepost is the daily welfare of consumers and their family members. Consumers and the family members who care for them—these are the brave and extraordinary people who make up NAMI North Carolina.

What is NAMI North Carolina?

NAMI North Carolina has been advocating on behalf of consumers and family members since its very beginnings in the early 1980s. It does this through its public policy program; the NAMI North Carolina Helpline (1-800-451-9682), which provides information, referral, and support to callers from across the state; the NAMI North Carolina Young Families Program, which educates school officials about mental illness in children and adolescents; and its thirty local affiliates offering support groups, the Family-to-Family Education Program (described below), educational materials, and other community support services. NAMI North Carolina has carved out a niche for itself as the only organization working to improve the lives of people living with the effects of severe and persistent mental illness, and it works closely with other statewide advocacy organizations based in Raleigh, notably other member organizations of Coalition 2001, a consortium of advocacy organizations working to improve the lives of people living with mental illness, developmental disabilities, and substance abuse problems.

The Need for Respite Care

From the standpoint of consumers and family members, it is instructive to look at the settings where patients with severe and persistent mental illness are currently discharged from hospitals. According to the North Carolina Department of Health and Human Services, out of a total of 17,534 discharges in 2002, the overwhelming majority of discharges—10,118 or 58 percent—were to private residences. The second highest number of discharges—1,193—were to correctional facilities, followed by 917 to homeless shelters.

Tragically, these numbers tell us about the terrifying decision many of our family members are forced to make regularly and sometimes even several times a year. In a desperate bid to keep their adult children with severe and persistent mental illness out of correctional facilities and homeless shelters, family members send them to psychiatric hospitals instead where they are treated for a few days and then sent home. This happens again and again to families who receive no respite of any kind in return for their unending provision of care. Not only do they not receive respite, but they are rarely included in decision-making when the state actually does provide help in the form of severely limited hospital stays.

Is the number of discharges to private residences only bound to increase as more hospital beds are closed across the state and the already extremely limited acute care currently being provided through our psychiatric hospitals is no longer available? Will the revolving door of discharges begin to spin faster? For the sake of consumers and their family members, the answer to this question needs to be “no.” We need to build capacity for provision of humane acute care in our local communities so that the family members currently providing it will finally be able to get some relief. The North Carolina Mental Health Trust Fund, created to help us build community capacity as we downsize our psychiatric hospitals, can be a source of funding for startup of acute care programs.

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Family Psychoeducation

Other family members, those who have not yet moved beyond their grief, will benefit from family psychoeducation. In partnership with the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS), NAMI North Carolina is already taking steps to expand its acclaimed Family-to-Family Education Program as a statewide best practice in family psychoeducation. Through this program, family members attend twelve intensive classes over twelve weeks to learn how to manage the effects of severe and persistent mental illness in their lives. Our hope is to add consumer psychoeducation in the future, with the help of a newly formed consumer council to our board of directors.

Quality of Life Issues

We also need to take a hard look at the quality of life for our consumers. Living at home with your parents when you are an adult is not the answer, but then neither are correctional facilities or homeless shelters or rest homes. Without question, adequate housing is a critical need for our consumers, as is transportation, and we applaud the North Carolina Department of Health and Human Services for looking at these issues across the spectrum of our consumers' needs. NAMI North Carolina stands ready along with other advocacy organizations to help our state find the money that will pay for the viable options in housing and transportation our consumers so desperately need.

We also enthusiastically support the establishment of a strong network of psychosocial clubhouses across the state. We have only a handful compared to other states. This situation needs to be remedied sooner rather than later.

As mental health reform moves forward, our hope is to work in partnership with other organizations to foster the implementation of statewide best practices that will help improve the quality of life for our consumers. There is already considerable information about best practices in assertive community treatment, illness self-management, integrated dual disorder treatment, jail diversion, recovery and peer support, social skills training, supported employment, and supported housing. We will look to the leaders of our Local Management Entities (LMEs) and the new advocacy office within the MH/DD/SAS to ensure that an adequate menu of best practices for consumers is found across the state. We are already encouraged by the strong interest expressed in recovery programs by local Consumer and Family Advisory Committees (CFACs) across the state, and we look forward to having a *state* CFAC that will bring this interest into clearer focus.

Key Points for System Reform

Beyond quality of life, we continue to be concerned about more basic issues surrounding mental health reform. Through our public policy committee's extensive comments on important mental health reform documents developed by the state over the past year and a half, we have reiterated key points we believe

will remain important if not meaningfully addressed. (NAMI North Carolina's public policy documents are posted on our website located at www.naminc.org.)

Chief among these key points is that there continues to be a lack of consensus around the critical areas of qualified provider network development and quality management. There is also far too much variability around how these are defined and how they should be operationalized. It is clear that the state should facilitate the development of this consensus.

We continue to believe there should also be a real investment in meaningful technical assistance and training in all areas. The state needs to provide leadership in technical assistance and training so that we will have uniformity across LMEs and particularly in the area of best practices. We are concerned that the massive changes created by reform efforts are being undertaken without the resources and expertise that will make them positive and successful.

As an organization that exists to serve consumers and family members, we have a particular concern about client rights. We believe it is critical to address the establishment of a statewide appeals and grievance process for all clients. Establishment of such a system and integration of client rights activities into quality management processes is essential. We will be looking to the state to address this issue in a meaningful fashion over the next year or so.

Finally, we need to ensure that the North Carolina Mental Health Trust Fund is not taken away from us to solve state budget woes. This money is available to help us build community capacity and there can be no excuses for any future reductions to it.

Separate Systems for Mental Health, Homelessness, and Criminal Justice

We want to close by expressing our concern about the separation among and between the systems for mental health, homelessness, and criminal justice. There is considerable interest in how homeless shelters are facing the onslaught of clients with mental illness, for example, but no true collaboration as of yet between the mental health and homelessness systems. There is strong interest in criminal justice issues, but police across the state still do not have all the tools to respond when a family calls on behalf of a very sick consumer. The tools are available, but North Carolina police departments have not come together to make dealing with mental illness a priority issue. Advocacy organizations need to come together to make sure they do.

The downsizing of our psychiatric hospitals continues to move forward even as concerns about community capacity and money are growing. It is the job of NAMI North Carolina and all advocates and other advocacy organizations who are passionately concerned about the future well-being of consumers and their families to keep our eyes on the prize—to make sure that the community capacity we have been promised becomes a reality. If it does not, we will have not only the state, but also ourselves, to blame.