

## Experiences of consumers with mental illness in the jails of North Carolina: Lessons for policy change.

By: Melissa R. Floyd, Anna Scheyett & Jennie Vaughn

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### **Abstract:**

This study aimed to explore the experiences of people with mental illnesses and their collaterals in the jails of North Carolina. Participants were interviewed by study personnel using semistructured interviews. Study recommendations that emerged for changes to increase the care that inmates with mental illnesses receive included: (1) conceptualizing care at all stages of incarceration process; (2) involving family when possible, reworking privacy procedures; and (3) increasing skills for working with treatment-resistant populations throughout the process. As part of a sister study, the authors were successful in stimulating policy change at the state level and describe this process.

**Keywords:** jails | mental health treatment | jail diversion | policy change | county jails | incarceration | mental illness

### **Article:**

#### BACKGROUND

In 2006, the North Carolina Governor's Advocacy Council for People with Disabilities (NCGACPD) contracted the researchers to provide a report about the state's county jail system as it relates to inmates who have serious mental illnesses. This article reports the results of the interview portion of the study, which focused on the experiences of consumers and families of people with mental illnesses, as well as the collateral reports of jailers and county/city mental health workers. In addition, the dissemination of this and a related study helped to stimulate positive policy change in the state. Several steps are seen by the authors as instrumental to this success and are described with the intention to aid other researchers in realizing long-term policy change as a result of their research.

People in jails have been found to have high rates of mental health symptoms or recent mental health problems, as high as 64% as compared to 21% to 26% of the general population (James & Glaze, 2006). People with mental illnesses are often arrested for nonviolent or “nuisance offenses” related to their mental illnesses (Ditton, 1999). Not surprisingly, jails can be dangerous

and unhealthy places for people with mental illnesses as they are more likely to be victimized by their fellow inmates (Lindsay, 2002). The isolation that many inmates, especially those who are acting out are subject to can also worsen symptoms of mental illnesses. Furthermore, it may be difficult for jailed inmates to receive their medications or appropriate mental health treatment (James & Glaze, 2006). People with mental illnesses may also spend more time in jail due to not being able to make bond, not being able to communicate, or not understanding their rights (Erikson & Perlman, 2001).

Because jail systems are county run and not state run, jails often have varying policies and procedures as well as differential resources with which to meet the needs of inmates who have mental illnesses. North Carolina has 100 counties, many of which, especially in the mountainous and coastal thirds of the state, are rural and lack the tax base found in more heavily populated areas.

## PROCEDURES

We conducted semistructured qualitative interviews with consumers and family members, jail personnel, and mental health workers. Study procedures and all study documents were approved by the UNCG Institutional Review Board for the Protection of Human Subjects prior to participant recruitment and data collection.

### Recruitment

#### Consumers and families

Recruitment e-mails and postcards were sent to advocacy groups throughout North Carolina. These groups included Traumatic Brain Injury Association, Autism Society of North Carolina, Association of Retarded Citizens (ARC) Chapters of North Carolina, North Carolina Alliance for the Mentally Ill (NAMI) Chapters of North Carolina, various mental health consumers' organizations in North Carolina; and finally, word of mouth through e-mail lists and social networks of study participants and advocates.

#### Local mental health workers and jail personnel recruitment

All local management entities (called “mental health centers” in other states) in North Carolina were contacted either by phone or e-mail to participate. Multiple attempts were made when there was a lack of response. About half of the centers responded with interest in participating. At that point, major jails in each of the mental health center catchment areas were recruited.

#### Respondent Numbers

This population, particularly family and consumers, proved difficult to access. It is unclear whether this was due to the difficult topic, the possibly painful memories associated with revisiting it, or a failure in recruitment strategies. So, while interview numbers were not as high

as expected, information shared was very rich and adds an invaluable, personal dimension to what we know about the experiences of people with mental illnesses in jails.

- Ten jail interviews were conducted by phone. A member of the research team spoke with jail personnel at various levels with different jail functions, (i.e., nurse, captain, guard, etc.).
- Five mental health worker interviews were conducted by phone. Although ten personnel agreed to talk initially, by the time the interview dates were set up, only five mental health centers participated. This may be attributable to the fact that a high level of turnover occurs in the current “mental health reform” context and some centers have gone out of business and/or have been consolidated.
- Nine family members/consumers were interviewed by phone, though they were all given the option of meeting face to face with the interviewer. Of these, one had a family member jailed in Pennsylvania and one interview was unusable. These interviews were extensive, often exceeding 15 pages transcribed. Three consumers participated but one was as a family member.

#### Question Formulation

Interview questions were formulated by the researchers in conjunction with the GACPD Advisory Team. Mental health workers and jail personnel were asked versions of the same questions which included:

- What do you see as special challenges for jails in your area related to inmates with mental illnesses?
- What special challenges exist for your mental health centers in providing services to jailed inmates? What do you attribute these to?
- What special needs do consumers in your area have?
- Are there any successes in your area related to providing services to consumers with mental illnesses who are jailed that you would like to share? What do you attribute these to?
- What would you like to see happen in your area when a person with a mental illness comes into contact with police for an infraction of the law?

Family members and consumers were asked the following questions:

- What are some challenges that you/your loved one faced in relation to their mental illnesses/DD during their jail experiences?

- What were some barriers to getting their/your needs met? What do you attribute those barriers to?
- In general, what should happen to consumers who come in contact with police officers for infractions of the law?
- What should not happen?
- What would you change about your experience if there were anything you could change?
- What were some successes, if any, during the process?
- Did you have any experiences with the local mental health center during the process?
- Do you think there are ways to pre-plan for this type of event, such as an advanced psychiatric directive? Have you tried this?
- Have you ever called the police to press charges against your loved one? What happened?

All interviews were audiotaped over the phone and then transcribed by the research teams. A graduate research assistant, trained by the principal investigator, interviewed jail personnel over the phone. The principal investigator interviewed all the families and consumers who participated. Families and consumers were given the option of being interviewed in person but tended to prefer the phone method. Interviews were semistructured around the questions listed; however, the family and consumer interviews were more “free form” and tended to last longer, with an emphasis on allowing the participants to “tell their story.” After transcribing, all responses were coded based on underlying themes under each question in order to organize the large amount of interview data. In addition, since all interviews were conducted and transcribed by the two main study personnel, data were inductively coded throughout the study (Maxwell, 1996). Checks were done throughout the study between the two researchers to ensure intercoder reliability and similarity in interviewing procedures.

## FINDINGS

### Jail Personnel Summary

Jail personnel in general voiced concerns about overcrowding and that they did not know what to do with the large numbers of people with mental illnesses who were being arrested. Many were concerned about the number of inmates with mental illnesses who were being jailed for minor infractions of the law and then were staying longer than average. Several voiced concerns about mixing people with mental illnesses in with the general population as they stated they felt this made the symptoms worse.

Jail personnel did not feel the local Mental Health Centers were able to help them, often due to closing or workload, but in some cases due to lack of interest and inability to bill for their time.

One jail worker stated real concern for what would happen to individuals with mental illnesses once the centers all closed and that they then “wouldn't be able to build jails fast enough to hold them all.” Jail personnel seemed very aware of the multiplicity of needs of this population, and were primarily concerned with lack of treatment. They were also aware that benefits are cut off when people are jailed and that people are often released with nowhere to go. There were very few successes to report. Several participants laughed when asked. These participants were an excellent source of recommendations for change, focusing mostly on increased training for officers, pre-booking jail diversion and on-site crisis workers. They were clear in stating that if jail could be avoided in lieu of the hospital, that this should happen. Some selected quotes follow:

I think we need someone here to evaluate these inmates when they come in. These officers are not trained to do that. They see them as just another crazy person that they have to deal with.

We put them in there with all the other inmates and it is like they are putting on a show...They are back there whooping and hollering and we can't keep them calmed down. It is like they want everyone in here to see them.

I do not think this is the best place for them and they need to go somewhere they can get some help. Help from people who are trained for this kind of thing. They do not need to be caged in here with these other animals.

I think they just need treatment. We are not doing anything with them at the jails besides babysitting them. Once they get back on the streets they are on their own. More than likely they will end back up in here too before too long.

#### Local Mental Health Center Summary

In general, the mental health center participants shared many of the jail personnel's concerns regarding overcrowding and petty crimes but focused more on lack of trained evaluators in jails, at intake, during incarceration, and at release. In discussing their own ability to meet the challenges of providing services to persons who are incarcerated and mentally ill, they cited the state's mental health reform and a lack of personnel as well as work overload as problems. Like the jails, the mental health center participants were clearly aware of consumer special needs. These participants tended to focus on housing and transitioning back into the community, as well as medication monitoring. They also had few successes to report. When asked what they would like to see happen they brainstormed partnerships, task force development and increased training of jail personnel and better communication among all concerned. Selected quotes follow:

In my opinion, the jails are just becoming an inpatient facility for people with mental illnesses. With the lack of mental health services in NC right now so many individuals are getting arrested for minor infractions of the law.

...with the closing of so many mental health centers there are simply not enough people to provide services. The few practitioners that are left have such high case loads they are not readily available to go visit consumers while incarcerated.

They need more treatment. They also need someone who can speak out on their behalf. I also do not believe they should be held in cells with all other inmates. I think they need to be handled with much more caution than other inmates due to the nature of their mental illnesses.

I would like to see a trained professional on staff at every jail in order to screen individuals for MI so these individuals can get some of the services they need put in place while they are incarcerated.

### Family and Consumer Results

These interviews tended to be much longer and less linear than the mental health center and jail interviews; many exceeded 15 single-spaced pages transcribed. Family members provided rich data in the form of personal stories and “expert” suggestions based on their own struggles. The majority of the family members interviewed were mothers of sons. There were also two significant others (both also female) who were interviewed. One met the criteria of being both consumer and family member. In addition, two male consumers participated in the interviews.

Families reported challenges throughout the process of arrest, incarceration and discharge, and transition back into the community. Particular pain was voiced about the trauma to themselves and their loved one of the arrest and jail experience in itself and the metamorphosis from being a mental health consumer with an “illness” to being a jail inmate and a “criminal.” They voiced much frustration with the barriers to getting their loved ones' needs met. Lack of communication and need for enhanced procedures for communicating with family members emerged as a strong theme across interviews. Proper, skilled assessment was also seen as a glaring need, especially at intake but also during the jail stay as some family members stated that their loved one would deny mental illnesses at first but would then deteriorate markedly while incarcerated. Finally, lack of adequate discharge planning and inability of consumers to meet even basic needs upon discharge (filling prescriptions, renewing benefits, having a place to live) were consistent areas of concern. Families largely described the local mental health centers as either underresponsive and/or overworked though there were some bright spots, especially those professionals who went out of their way, who stepped outside the rigid guidelines of blanket confidentiality for example, or who really listened to the family members.

The researchers were also interested in whether or not family members had experience with advanced directives but none did. All were fairly familiar with calling the police regarding their loved one and most felt the police did a great job of stabilizing the situations and calming their consumers while the situation remained domestic. The families were not as satisfied with law

enforcement's reactions when there were actual laws broken. Selected quotes from families and consumers follow:

They stuck him in a chair, they put him in confinement... that made his illnesses worse.

I called the hospital and I say, "My son's in jail and he needs to be in the hospital," and she says, "We don't take criminals."

I was never treated like I was believable, it was just like I was an inadequate parent.

He was missing for seven days and ended up being two miles away in the county jail.

I think, if you know that there is something wrong with this person and...even though they are adults I think that they need, at least their family members need to be notified.

"We were humiliated time and time again. And that shouldn't happen, the over reaction. I mean, it should be taken seriously, but at the same time, you shouldn't bring out the whole force...with lights blaring and embarrassing you in front of your neighbors and humiliating you in front of your friends."

## DISCUSSION

Much useful information was received from mental health centers and jails, in addition to that received from the families and consumers involved in this study of jail experiences of people with mental illnesses in North Carolina. It became clear that inherent in the responses were concerns about the treatment of people with mental illnesses at all phases of the jail experience.

### Initial Phases

The importance of proper intake and assessment of individuals with mental illnesses was reported again and again. Another issue that emerged from the family data was the concern that consumers who are reluctant to identify as mentally ill are being taken at "their word" during brief intakes and therefore are being allowed to seriously decompensate once they are processed. This concern underlines the importance of specialty training with treatment-resistant or reluctant mental health consumers. Increasing evaluation skills may also lead to the result that many participants hoped for, reducing incarcerations in favor of hospitalization and/or outpatient treatment whenever possible.

### Middle Phases

In addition to the importance of intake, participants voiced concerns about medical management while incarcerated in the form of proper medication being provided. They also underlined the importance of access to crisis management while in jails since some consumers came in appearing stable and then decompensated due to the stress of the jail environment, lack of medication, and/or emerging mental illnesses. Also emphasized was the need for specialized

services in jail such as isolation from the general population and flexibility of rules (allowing more activity, allowing books for reading, etc.).

### Exit Phases

The exit phase of the jail experience for persons with mental illnesses was emphasized again and again as a crucial step in maximizing (or, more likely, undermining) consumer stability. The lack of transition planning seemed to be a common experience. One family member described her consumer walking all the way from jail (in another county) to her house when released, with prescriptions and no way to get them filled. Another stated that she is not mentally ill but had difficulty navigating all the social systems to get benefits reinstated when her loved one was released. Commonly voiced was the dilemma of consumers having nowhere to go upon discharge and no linkage to follow up with mental health services. All participants worried that the overworked mental health centers were not able to devote the time needed to work with these consumers and that, for this reason, many consumers would be back in jails again in the near future.

### LIMITATIONS OF THE STUDY AND FUTURE DIRECTIONS

This study, in many ways, represents a “first look” at people with mental illnesses in North Carolina's jails. There were limitations to the study and the study methodology that should be considered when weighing the results. Furthermore, future studies would benefit from less reliance on self-report and broader recruitment strategies, especially in the area of developmental disability.

#### Difficulty accessing consumers and family members and relatively small sample size

As stated earlier, efforts by the research team to contact consumers and family members for recruitment failed to net a substantial sample size. In the case of local mental health workers, the small sample size is likely due to the chaotic state of many county centers due to privatization issues in North Carolina's recent mental health reform. The study recruitment method of going through advocacy organizations needs revision, because a substantial number of persons with the jail experience were not accessed. Future studies may also consider the use of a toll-free number so that consumers and their families can call in for free. One consumer advocate stated that this may have been a barrier to more consumer participation, since prospective participants had to call the researcher to indicate their interest.

#### Reliance on self-report and recollection

In the future it will be important to actually observe people with mental illnesses in the county jails of North Carolina. The reliance on self-report and recollection could be mitigated with first-hand observation. In addition, self-serving bias on the part of jails and local mental health center personnel would be decreased with direct observation of procedures.



Inability to factor out the turbulent mental health reform context

The current mental health context in North Carolina, fraught as it is with privatization hurdles and confusion regarding new procedures, as well as a decrease in available mental health beds, makes it difficult to understand how well the jails would be functioning if this were not the case.

## CONCLUSION

A need exists to conceptualize care of inmates with mental illnesses at all stages of the incarceration process and to make sure that there is uniformity to the process across counties. Particular attention should be given to jails in rural areas as the possible lack of resources and adequately trained personnel may lead to difficulties with meeting the multiplicity of needs presented by the inmate with mental illnesses. Final recommendations include:

- Improve assessments of incoming inmates (evidenced based screening tool) by increasing access to trained evaluators. This could lead to increased incidents of jail diversion.
- Increase access to treatment/crisis intervention while incarcerated.
- Increase discharge/transition planning and followup, linkage to local mental health center, access to discharge medications.
- Involve family when possible; rework privacy procedures to enable this to happen.
- Increase skills for working with treatment resistant population throughout all phases.

## THE ALLIMPORTANT “SO WHAT” QUESTION

As stated earlier, this study was a part of a sister study also funded to look at systems in place for inmates with mental illness. As part of the dissemination phase, the researchers presented the findings to the NC State County Commissioners Association. Also present was a state representative with a keen interest in this area. As a result of this meeting, new legislation was introduced in that same session into the State legislature, which now requires all NC jail inmates to have a mental health screening as part of the intake process. Rarely have the researchers been able to have the satisfaction of having the “so what” question behind most research results answered with action steps. It was extremely gratifying and, in retrospect probably occurred through the following:

- Involving researchers who had extensive professional networks
- Study commissioning done by a state agency with experience in disseminating results (the funder issued press releases, sent to counties and generated press around the study results).
- Involving state agencies (in this case the NC Division of Mental Health) from early days.

- Forming an Advisory Committee for the studies, which assisted with question formation from the beginning of the study, and therefore felt invested in the process and the results.
- Inviting key stakeholders to be part of the Advisory Committee and having it be heterogeneous, made up of families and consumer advocates, policy makers, state officials, and academics.
- Disseminating results in public meetings, with political invited guests.
- Facilitating additional exposure such as public television “Mental Health” program appearances and newspaper interviews.

The researchers hope this information is helpful to others who are tackling public health issues such as mental illness and jails, and hope it will aid them in realizing long-term policy change as a result of the dissemination of their research results.

#### Acknowledgments

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