

September 22, 2003

Michael Roanhouse
Office of Special Needs Assistance Programs
Office of the Assistant Secretary for
Community Planning and Development
Room 7262
Department of Housing and Urban Development
451 Seventh Street, S.W.
Washington, D.C. 20410-7000

RE: Homeless Management Information Systems (HMIS) Data and
Technical Standards Notice
Docket No. FR 4848-N-01

Dear Mr. Roanhouse:

On behalf of the Bazelon Center for Mental Health Law, I submit the enclosed comments on the HMIS Data and Technical Standards Notice published in the Federal Register of Tuesday, July 22, 2003.

If the ultimate goal is to mobilize resources to prevent or end homelessness of people with mental illnesses, it is essential that the proposed standards not further alienate this population by requiring them to divulge intimate personal information concerning mental health history as a condition for receiving services. Because of its grave implications for policy affecting homeless people with mental illnesses, we would strongly urge you to revise and reissue this notice in conformance with the specific recommendations included in our comments.

Sincerely,

Michael Allen
Senior Staff Attorney

Enclosure: as stated

Comments of the Bazelon Center for Mental Health Law

on

Homeless Management Information Systems (HMIS) Data and Technical Standards Notice **Docket No. FR 4848-N-01**

Introduction

For more than 30 years, the Bazelon Center for Mental Health Law (Bazelon Center) has focused on the development of community-based services and supports to keep people with severe mental illnesses from ending up homeless, incarcerated or institutionalized. For the past ten years, with increasing trepidation, we have watched the development of a national policy on homelessness, occasionally commenting on the way in which federal agencies have misconceived the problems facing our constituents and created programs that fail to serve their housing and mental health service needs.

With publication of the above-referenced notice, HUD has far exceeded the scope of the Congressional mandate to produce an unduplicated count of homeless people. By inserting program-level questions, the notice suggests that HMIS be used as a case management tool, an objective that will obliterate other laudable HMIS objectives by erecting barriers to effective support of homeless people on their individual paths to recovery and reintegration. If implemented as proposed, HUD's HMIS Data and Technical Standards will promote a regimented, Big Brother services system for which the price of admission is the disclosure of highly sensitive mental health and other personal information without adequate safeguards, the implicit waiver of federal prohibitions against such inquiries and, ultimately, submission to ever-broadening discretion of providers to exclude them on the basis of their mental health histories.

Not all of these unfortunate outcomes are apparent on the face of the notice. Rather, one has to dig deeper to understand how federal "data and technical standards" will drive the performance and internal mandates of state and local Continuum of Care (CoC) entities, how bureaucratic imperatives for uniformity will result in incentives for providers to make sure they ask each and every client the prescribed questions and to require answers of each, and how applicants and clients will perceive their obligation to answer these questions on pain of losing shelter and services.

With regret, we have concluded that full implementation of these standards would result in the self-exclusion of a sizable number of homeless people with mental illnesses, who will opt for low-demand providers rather than be forced to disclose their mental health histories and be compelled to engage with the kind of dysfunctional mental health services systems identified in the recent reports of the President's New Freedom Commission on Mental Health. At a time when Congress, HUD and CoCs ought to be focused on the success of innovative, trust-building, low-

demand homeless outreach programs like some operated by non-profits in Washington, D.C.,¹ Connecticut,² and California,³ the HMIS notice would erect new barriers to shelter and services and ensure a permanent class of homeless people outside the mainstream system.

The touchstone of the Bazelon Center's advocacy over three decades has been respect for the civil rights of people with mental illnesses. With other agencies, we helped to shape Section 504 of the Rehabilitation Act of 1973 and its implementing regulations. We had a major hand in the passage of the Fair Housing Amendments Act of 1988 (FHAA) and the Americans with Disabilities Act of 1990 (ADA), and worked with federal agencies which promulgated regulations under each.

In its own way, each of these statutes and regulatory schemes makes the following point: It is illegal, in the provision of shelter, housing and services, to discriminate on the basis of mental impairment, history of such impairment, or being regarded as having such an impairment. The FHAA's regulations are perhaps clearest on the point at issue in the HMIS notice: "It is unlawful to make an inquiry to determine whether an applicant for a dwelling...has a handicap or to make inquiry as to the nature or severity of a handicap of such a person." 24 C.F.R. §100.202(c).⁴

For our constituents, the central philosophical question implicit in the notice is this: Should homeless people be required to disclose intimate details of their mental health history as a condition of receiving shelter and supportive services? If not, shouldn't there be a very clear statement in these standards, and very clear advice to each applicant, that shelter and services cannot be withheld if they refuse to answer the questions? Unless the purpose of this notice is to

¹ The most notable of such programs is operated by the Community Council for the Homeless at Friendship Place, 4713 Wisconsin Avenue, N.W., Washington, D.C. 20016. Telephone: 202/364-1419. Website: <http://www.cchfp.org/>

² The pilot peer engagement specialist program was authorized by Conn. Gen. Stat. Ann. §17a-484b, and began funding programs in September 2000.

³ Assembly Bill 34, enacted in 1999, authorized and funded a wide array of homeless outreach activities in California.

⁴ Inasmuch as several federal courts have found shelters, transitional housing units and other units funded by McKinney-Vento programs to be "dwellings" for purposes of the FHAA, this proscription would surely apply to the HMIS, which is merely an administrative adjunct of those programs.

create irreconcilable conflict between providers and homeless clients, there must also be a clear statement to providers that they will not be penalized, directly or indirectly, if a large percentage of their clients refuses to answer these questions.

The Scope of the Congressional Mandate on HMIS

Congress is certainly justified in ascertaining whether the current approach to serving homeless people has been effective. But the notice proposes and attempts to legitimize a degree of inquiry that goes far beyond the broad accountability data that Congress has required in the various pieces of legislation recited in the notice. Congress undoubtedly expected that HUD would balance the need for such data against the likely harms that would be worked by insistence on detailed disability questions posed to every homeless client. And Congress was also mindful of the FHAA regulations prohibiting disability inquiry, and could not have expected HUD or its grantees to ignore those provisions.

The very last paragraph of the notice raises an interesting question: In the face of all the concerns about client-specific questions, why did HUD insist upon collection and association of client-identifiable data, especially when the option of collecting anonymous data is available? That is, if the primary concern of Congress is to secure a valid count of homeless people and to determine whether the conditions of homelessness are improving as a result of federal expenditures, would not anonymous data have made it possible to achieve these ends without raising the concerns about disclosure and confidentiality? Even HUD itself seems to balance these concerns with respect to victims of domestic violence and people with HIV/AIDS in making clear that participation in HMIS by such providers is only “encouraged” rather than required.

Finally, inasmuch as Congress required federal agencies to report to the Interagency Council on the Homeless concerning “impediments to the use of the program by homeless individuals,” it is logical to assume that Congress would not have wanted HUD to adopt HMIS standards that created even greater impediments for people with mental illnesses to participate. Yet that is precisely what HUD has done in proposing national standards that encourage or require that every client be asked the following questions:

- “Have you ever been treated or hospitalized for a psychiatric problem?” and
- “Do you feel that you have any current psychiatric or emotional problem(s) such as serious depression, serious anxiety, hallucinations, violent behavior, thoughts of suicide?”

There is no greater impediment to the use of these programs than a requirement that each

applicant answer detailed questions about mental disability status.

The Proposed HMIS Standards

The Bazelon Center expresses specific concern about the following provisions of the proposed HMIS data and technical standards:

- Requiring personal identifying information (name, date of birth and Social Security Number) and disclosure of mental health history when a person is seeking services will result in a kind of national ID system and encourage the universal access to disability information associated with that ID to make decisions about admission to programs and eligibility for services. A better system would inquire about disability only when it is a statutory condition of eligibility. For reasons clear in the context of medical privacy, genetic discrimination and the ready access of many private actors to information traditionally considered private, we express the concern that this approach to homelessness will result in harmful disclosures and the potential for discriminatory decision making.
- Notwithstanding the strict guidelines applicable under the Health Insurance Portability and Accountability Act (HIPAA), it is unrealistic to believe that the thousands of small homeless services providers around the country could ever afford to become HIPAA compliant without diverting substantial resources away from direct client services.
- While the notice says that “[i]t is not HUD’s intention that clients be denied service if they refuse to supply identifying information,” 68 Fed. Reg. 43434, col. 3 (July 22, 2003), it is hard to understand how the mandatory participation of federally funded providers in HMIS reporting will result in any other outcome. When bureaucratic requirements force providers and local CoCs to document the services they have provided, for fear of losing their funding because of noncompliance with data-reporting requirements, providers will adopt practices that turn people away from services unless they provide personal identification and intimate personal information about their mental health status. HUD’s notice makes it clear that providing HMIS data will be a condition of funding for grantees of many HUD programs. *Id.* at 43435, col. 3.

- Nowhere does the notice specify the effect, on individual clients or on the providers serving them, of answering “99-Refused” to the mental health history and other such questions. Nowhere in the notice is any provision advising homeless clients that they can refuse to answer mental health (or other questions) without fear of losing shelter or services. When they are told by providers that information collection has been made mandatory by the federal government, clients will understandably believe that it is also mandatory to disclose this information if one wants services. The silence of the HUD notice in this respect reinforces the well-understood rule in many homeless programs: Noncompliance with rules is at your own peril.
- While only a handful of HUD programs (e.g., Supportive Housing Program and Shelter + Care) make disability diagnosis a condition for participation, HUD’s notice requires that mental health questions be asked of all clients. While the HUD programs mentioned in this paragraph enjoy an exception to the “no inquiry” rule, most other programs do not. Incorporating this requirement as a national standard will encourage other funders to make disability status an eligibility consideration, thus forcing clients to disclose in a much broader range of programs than Congress contemplated when it passed the FHAA.
- The very reason for the FHAA’s “no inquiry” rule is to make the issue of disability irrelevant to the eligibility for housing and shelter. By encouraging other HUD-funded providers to participate in HMIS, HUD is permitting those providers (such as Public Housing Authorities) to review sensitive information about disability. The notice does nothing to prevent them from using information about disability as grounds for discriminatory denial of mainstream housing opportunities.

- This last concern is reinforced by the section labeled “Elective Data Elements.” *Id.* at 43438, col. 2: “Particular programs (or the entire local CoC) may wish to collect assessment, service tracking, and outcome information in more detail than required by uniform HMIS standards. For example, with regard to behavioral health, a program may wish to capture significantly more information about a client’s psychiatric history or current status than is specified under the program-level data elements. Such elective data elements and response categories are developed at the discretion of each CoC.” By failing to inform providers and CoCs of the federal limitations on such inquiries, the HUD notice runs roughshod over the rights of clients and applicants; in fact, the notice seems to legitimize such clearly proscribed practices.
- It is not enough to say that sensitive information will be safeguarded by “firm policies and procedures to protect against unauthorized disclosure of personal information.....” *Id.* From the perspective of the homeless applicant, once mental health information is available within a provider agency, between provider agencies or within the CoC, there is no practical way to limit its availability to anyone who has access to HMIS and the ability to associate the personal identification information with the mental health history information. This is yet another reason that homeless people with mental illnesses will avoid contact with all parts of the system that require information to be provided. The end result is not better service to homeless people with mental illnesses; it is another service system entirely that does not participate in HMIS.
- The notice itself indicates that clients have little ability to control the dissemination of this information: “By providing data to HMIS user or developer for entry into HMIS, an individual provides oral assent to the uses described in the following section. Such assent should only be assumed if the individual has been advised how he or she could benefit by providing the requested information, how the data will be protected, and how the data will be used.” *Id.* at 43451, col. 1-2. Another provision, the second sentence of which makes no sense, says: “An HMIS user or developer may use or disclose protected personal information without the written consent of the individual in situations specified in this notice, subject to the notice’s applicable requirements. When the HMIS user or developer is required to inform the individual of, or when the individual may agree to a permitted use or disclosure, oral announcement is sufficient.”

- Program Level Data Elements: At least six “Program Level Data Elements,” which must be “completed as required by a locality or funder,” implicate very personal information concerning disability or health status: 3.2 (Non-Cash Benefits), 3.3 (Physical Disability), 3.4 (Developmental Disability), 3.5 (General Health Status), 3.7 (HIV/AIDS Status), and 3.8 (Behavioral Health Status). Again, by its refusal to articulate the federal limitations on such inquiries and hiding behind the “local option” language, HUD seems to endorse violation of its own FHAA and other federal regulations.
- The specific mental health inquiries themselves are not likely to yield useful information (particularly to someone not trained in mental health), are more likely to lead to discriminatory treatment than to insight about the services an applicant might need and, because of the reference to “violent behavior” (which may have its genesis in many causes other than mental illness), are unduly stigmatizing. Asking clients: “Have you ever been treated or hospitalized for a psychiatric problem?” and “Do you feel that you have any current psychiatric or emotional problem(s) such as serious depression, serious anxiety, hallucinations, violent behavior, thoughts of suicide?” is not likely, without much more invasive follow-up, to yield a better result for the provider or the client.
- Question 3.14 (Destination) implies that homeless services programs should be permitted to discharge clients to homelessness, jail/prison or other institution. That perspective should receive no endorsement from an agency which has proclaimed its interest in ending chronic homelessness.
- The provision permitting the CoC to suspend its obligation to provide an accounting of disclosures to a health oversight agency or law enforcement official when it would “impede the agency’s activities” is too broad and vague. A more definitive and compelling statement of such an impediment ought to be required in order to deny access to such disclosure of information to the person about whom the disclosure was made.

Conclusion

The most distressing aspect of the recent federal approach to homelessness is the paternalism embedded in the Continuum of Care (CoC) approach, which communicates to clients that they need structure and supervision to turn their lives around, and that continued access to services and a safe place to live depend upon adherence to a service or treatment plan devised by a provider. This approach has deviated from the usual rules applicable to subsidized and private market housing, and led to the development of a “secondary housing market,” where mainstream rules about tenancy and confidentiality do not apply. As a result, the public comes to see residents of such housing as “second class citizens,” whose personal histories and behavior become a legitimate subject of public discussion.

Homelessness, particularly for people with mental illnesses, is a national tragedy. We ask that HUD take a long, hard look at alternative approaches that have been successful in building trust and helping homeless people come inside and voluntarily engage in services and supports that can assist with their reentry into the societal mainstream.

Comments prepared by:

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