MAKING PUBLIC MENTAL-HEALTH SERVICES ACCESSIBLE TO DEAF CONSUMERS: ILLINOIS DEAF SERVICES 2000

Bruce Munro-Ludders, Thomas Simpatico, and Daria Zvetina

Illinois Deaf Services 2000 (IDS2000), a public/private partnership, promotes the creation and implementation of strategies to develop and increase access to mental health services for deaf, hard of hearing, late-deafened, and deaf-blind consumers. IDS2000 has resulted in the establishment of service accessibility standards, a technical support and adherence monitoring system, and the beginnings of a statewide telepsychiatry service. These system modifications have resulted in increase by 60% from baseline survey data in the number of deaf, hard of hearing, late-deafened, and deaf-blind consumers identified in community mental-health agencies in Illinois. Depending on the situation of deaf services staff and infrastructure, much of IDS2000 could be replicated in other states in a mostly budget-neutral manner.

The availability of community-based treatment services in the United States has increased dramatically over the past 40 years through the development of the community mental-health center system. However, the evolution of this system of care has largely been haphazard and reactive, with little coordinated planning or consistent vision (Brooks, 1988).

People who are deaf and suffer from mental illness have not been spared the consequences of a fragmented mental-health service system. In a presentation in 1998 at the First World Conference on Mental Health and Deafness, Bernard Arons, then director of the Center for Mental Health Services at the U.S. Department of Health and Human Services, declared, "America is decades behind where it should be in providing public mental health services to Deaf people. Some states have no such services for them at all" (Brauer, Marcus, & Morton, 1999, panel discussion 1, para. 6).

The combined effect of a generally "user-unfriendly" system of mental-health service delivery coupled with the historical stigmatization of deaf people by society at large (Atcherson, 2002; Becker, 1981; DeVinney & Murphy, 2002; Hetu, 1996; Higgins, 1980) has created a generally disinterested, even hostile treatment environ-
ment when viewed from the perspective of individuals or stakeholder groups advocating for deaf services.

Historically in Illinois, as in most states, the mental health needs of people who are deaf have not been prioritized within the public mental-health system. A primary reason is that individuals with hearing loss who rely primarily on visual rather than auditory input to communicate with others and whose hearing loss occurred in childhood rather than later in life are a relatively small group, constituting less than 1% of the general population (National Health Interview Survey, 1994), and thus do not make up a significant portion of those individuals seeking access to public mental-health services. A second reason for the low priority given to the mental health needs of people who are deaf stems from the very nature of hearing disabilities and the accommodations they require for effective communication. In the absence of appropriate accommodations, people with hearing impairments are far more reticent about seeking access to services, particularly those that focus on mental health problems, which carry an added social stigma. As a result, deaf consumers have not placed great service demands on the system. A third reason for this low priority is that whereas consumer and family advocacy has become a driving force in much mental-health reform (Onken & Dumont, 2002), the Deaf community has taken longer than other groups to mobilize around this issue into a cohesive, politically powerful advocacy group (Crichtfield, 2002).

A Brief History of Mental Health Advocacy on Behalf of People Who Are Deaf or Hard of Hearing in Illinois

In Illinois, advocacy efforts began slowly more than 30 years ago with the formation of a citizens' committee aimed at obtaining "adequate mental health services for deaf people" (S. P. Quigley, personal communication, April 3, 1973). This led, in 1979, to the creation of the Deaf Mental Health Task Force, a group of concerned advocates, professionals, and a renowned Chicago-area Catholic priest competent in American Sign Language (ASL), Joseph Mulcrone, who had experience in working with deaf and hard of hearing people struggling with mental health concerns. The mission of the task force was to address barriers in the state's public mental-health system that were limiting access to care for people who were deaf or hard of hearing. In 1982, the task force developed the "Illinois Plan for Psychological Services for Deaf and Hearing Impaired Persons" and brought it before the Illinois Department of Human Services, Division of Mental Health and Developmental Disabilities, IDHS-DMHDD (Mental Illness Hearing Impaired Advisory Council, 1982). "The Plan" recommended hiring a state-level coordinator of mental health services for deaf and hearing impaired consumers, establishing an inpatient treatment program, expanding outpatient services, and creating targeted independent-living programs. In response to concerted advocacy by the task force, an inpatient unit and two group homes were eventually established. The Deaf Mental Health Task Force, however, continued to urge the hiring of a statewide coordinator, believing that the only way to effect systemwide progress was to embed a "boundary spanner" (Steadman, 1992) knowledgeable about both systems and cultures within the existing bureaucratic structure of the public mental-health system.

Later, grievances were brought against IDHS-DMHDD by advocacy organizations for reported cases of abuse involving deaf consumers, and, as a result, a subcommittee of the Appropriations Committee of the Illinois House of Representatives was formed to conduct hearings into these matters. As an outgrowth of the focused legislative and media attention that ensued, as well as the diligence of the advocacy conducted by members of the Deaf Mental Health Task Force, in 1988 a bill was introduced, HB3752, to formally create a statewide coordinator position (An Act Codifying, 1989). Although passed by both houses of the Illinois legislature, the bill was vetoed by the governor. In response, deaf advocates waged a vigorous campaign that resulted in an override that was one vote shy of unanimous in the House and unanimous in the Senate; thus, the bill became law.

During the period when HB3752 was pending, IDHS-DMHDD retained a consultant to assess the current state of public mental-health services in Illinois for deaf and hard of hearing people and make recommendations for enhancing the state's system on their behalf. As an outcome of this process, the then-director of IDHS-DMHDD met with the Deaf Mental Health Task Force and committed to hiring a statewide coordinator regardless of how the House bill fared. Also, in 1990, at the request of the director of the Department of Mental Health, the Deaf Mental Health Task Force was reconstituted as the Deaf and Hard of Hearing Services Advisory Council, whose purpose would be to "advise DMHDD on the planning, development, and coordination of programs and services which DMHDD provides either directly or indirectly to persons identi-
ified [as deaf, hard of hearing, or deaf-blind] and insure that such programs and services are accessible" (Deaf and Hard of Hearing Services Advisory Council, 1990, p. 1).

As a result of these advocacy efforts, by 1996 IDHS-DMHDDD (now known as the Illinois Department of Human Services, Office of Mental Health, IDHS-OMH) had three coordinators of deaf services, one whose focus was statewide, another whose focus was on metropolitan Chicago, and a third, hired as a result of an affiliate grant awarded to DMHDDD by the Helen Keller National Center for Deaf-Blind Youths and Adults, whose role it was "to make community mental health services accessible to individuals who are deaf-blind, and to assist in the transition of young people who are deaf-blind from educational services to adult services and supports" (Patala & Doyle, 1995, p. 1). At this time, Chicago's deaf stakeholders, advocates, and service providers were in the process of developing one of the most comprehensive and robust arrays of mental health services for deaf people in the nation, spanning specialized outpatient, inpatient, residential, case management, psychiatric, and social services, with programs that have been identified as national models or best practices for the mental health treatment of people who are deaf or hard of hearing (Critchfield, 2002). Moreover, Illinois was in the enviable position of having a budget of $2.5 million dedicated solely to the provision of fully accessible community mental-health services for this population.

However, significant issues and tensions remained. One of the greatest concerns centered on the fact that, while progress had been made in the establishment of specialty mental-health services for people who were deaf, these services had limited client capacity, were primarily located in Chicago and thus were not accessible to residents of other areas of the state, and, while highly valuable, did little to increase the capacity of the larger public system to provide accessible, appropriate care to potential consumers of deaf and hard of hearing mental-health services. In addition, as the statewide and regional coordinator positions were then structured, their occupants had little or no meaningful authority. They were not responsible for the management of contracted services, agency supervision, service or policy development, or direct supervision of program or resource development, and thus were ultimately unable to effect significant change or hold providers within the public mental-health system accountable for the accessibility of their services to deaf consumers. These role limitations, coupled with the fact that, to appease advocates, the statewide coordinator position was filled with an advocate for the deaf whose knowledge of the state's public mental-health system was limited, seriously hampered the capacity of the coordinators to function as boundary spanners to effect system-level change. Thus, despite the fact that an advocate was now functioning inside the state's system, tension and distrust between the advocacy community—as represented by the Deaf and Hard of Hearing Services Advisory Council—and the state's mental health authority continued, with advocates perceiving the state's efforts to be insufficient on the whole and more isolated and token than systemic in nature. This perception was due, in part, to the fact that, despite IDHS-DMHDDD's stated intent to establish the advisory council under its auspices and the attendance of the regional and statewide coordinators at advisory council meetings, the council continued, in reality, to function outside IDHS-OMH's formal service-planning process, and no real systematic planning with regard to deaf consumers was occurring within the state mental-health authority.

The situation was generally acknowledged to have reached a standstill when several events coalesced to propel matters forward, establishing the issue of services for deaf consumers as a part of the state's public mental-health system infrastructure-planning process, and engaging consumers and advocates in that planning process. First, the manager of the OMH Metro North Network proposed that because the Statewide Deaf and Hard of Hearing Inpatient Program was housed in the state hospital facility in his network, and because all but one of the five mental health services for the deaf were also within the Metro North Network, he should become the lead network manager for all deaf services in Illinois. The director of OMH supported this proposal, and the position was expanded to cover deaf services statewide. As a result, contract management for all community mental-health services for people who were deaf and hard of hearing was consolidated under his office. At the same time, Chicago-area IDHS-OMH staffs were in the process of establishing a metropolitan Chicago-level policy and planning body: the Greater Chicago Mental Health Services Planning Council. The OMH Metro North Network manager suggested that the Deaf and Hard of Hearing Services Advisory Council become part of the planning council's subcommittee structure. Then, he vested contract oversight and monitoring responsibilities in the Metro Chicago coordinator for deaf and hard of hearing services. Integrating
these new job responsibilities into this coordinator position was a first step
toward bridging the divide between consumer advocates and state officials.
Through this, the Metro Chicago co-
ordinator and the Deaf and Hard of
Hearing Services Advisory Council
(now a subcommittee of the Greater
Chicago Mental Health Services Plan-
ning Council) gained both consider-
able insight into the functioning and
constraints of the state's public men-
tal-health bureaucracy and increased
authority to effect change. Even
though the planning council was fo-
cused on the metropolitan Chicago
area, because all deaf services within
the state were consolidated under the
Metro North Network's contract um-
rella, the subcommittee functioned
as a statewide committee.
Establishing the Statewide Deaf
and Hard of Hearing Subcommittee
as a formal component of the state's
mental-health planning structure con-
ferred a number of advantages that
catalyzed and broadened the
committee's strategic planning capa-
city. First, although the original Deaf
Mental Health Task Force, and later
the Deaf and Hard of Hearing Ser-
vices Advisory Council, were intended
to have a statewide membership, the
fact that meetings were always held in
the same location (i.e., Chicago) meant
that members from other areas of the
state were not always able to attend.
This resulted in a functional attrition
in group membership over time that
occasionally was felt in a limiting of the
advisory council's focus to the
Chicago area. Once the council was
folded into the state's public/private
planning structure as a subcommittee,
it had access to state resources such as
teleconferencing capabilities, which
enabled its members to participate
from seven teleconferencing sites
across the state. This significantly
broadened the subcommittee's mem-
bership and increased the frequency
of participation. More important, as a
planning subcommittee, the group
now began to function, in reality, as an
authorized advisory group to the state
with regard to the prioritization of ser-
vice needs and the allocation of fund-
ing. In this capacity, in 1999 the sub-
committee determined the need to
identify the current standard of care
for deaf and hard of hearing mental-
health consumers seeking access to or
making use of community-based
mental-health centers throughout the
state, as a starting point for making
systemwide improvements in the avail-
ability of care.

Illinois Deaf Services 2000
In order to identify barriers to deaf
people’s access to mental health ser-
VICES in Illinois, and thereafter to track
progress in improving access, the
Statewide Deaf and Hard of Hearing
Subcommittee developed the Illinois
Deaf Services 2000 (IDS2000) ini-
tiative. To date, this initiative has resulted
in the establishment of service acces-
sibility standards, a technical support
and adherence monitoring system,
and the beginnings of a statewide
telepsychiatry service. The overarching
goal of the initiative has been to pro-
mote long-term sustainable improve-
ments in the accessibility and appro-
priateness of mental health services
for deaf, hard of hearing, late-deaf-
ened, and deaf-blind consumers.
The initiative has several compo-
nents. The first to be developed was a
statewide "front-door" service acces-
sibility standard—the Illinois Standards
of Care for Deaf, Hard of Hearing, Late-
Deafened, and Deafblind People, or ISOC
(Munro-Ludders & Hedding, 2000).
Development of the ISOC began with
the premise that the provision of ap-
propriate services to deaf consumers
is the responsibility of the mental
health system at large, meaning that
mental health services for deaf con-
sumers must be “mainstreamed” and
accessible through the “front door” of
all state-funded mental-health service
providers. The final ISOC standards
were created and refined in a 2-year
process that included task groups fo-
cused on standards development,
feedback from deaf consumers in nine
town hall meetings, and discussions
with deaf-blind and late-deafened
advocacy groups. Presented in a doc-
ument and videotape format, the ISOC
carefully instructs service providers
about basic guidelines for accessible
mental-health services for deaf con-
sumers.
Once the ISOC was developed, a
survey based on ISOC standards was
created to begin assessing the accessi-
bility of community mental-health ser-
vices across Illinois. The aim of the
survey was to help community mental-
health agencies to identify areas where
attention would significantly improve
access to mental health services for
deaf people without necessarily re-
quiring the intervention of “mental
health deafness experts,” who tend to
be a rare and potentially costly com-
modity. The survey instrument was
structured to focus on eight key areas:

1. telephone accessibility
2. whether there was routine training
   of agency staff on the ISOC
3. whether there was posting and
distribution of information to
   staff and deaf consumers inform-
   ing them of the existence of the
   statewide coordinator for deaf
   and hard of hearing services, as
   well as providing information on
   how to obtain access to that per-
   son
4. whether there was routine training
   of agency staff on how to hire
and work with sign language interpreters
5. whether the agency had clear and relevant sign language interpreter policies
6. whether the agency had routine staff training on Deaf culture, clinical implications of mental health and deafness, TTYs, and ASL
7. whether the agency had a resource list for assistive listening devices for nonsigning deaf consumers
8. whether the agency had the name and telephone number of a “deaf expert” for consultation purposes (regarding Deaf culture and for general technical assistance)

The survey instrument was also designed to be simple so as to facilitate an agency assessment process that was not too onerous or time consuming, and that might spark some measure of change as a result of the assessment and feedback process alone.

Findings From the Baseline and Follow-up Survey Data
Following its development, the survey was administered to staff at 131 community mental-health centers across the state. The OMH statewide coordinator and Metro Chicago coordinator of deaf services conducted all site visits using an “Accessibility Survey Form.” It typically required approximately 1 hour to complete the 10-question instrument. During survey visits, agency staff raised numerous questions about the accessibility needs of deaf consumers, and frequently requested training regarding mental health and deafness. Baseline data from the agency surveys revealed that a majority of mental-health service providers were unable at that point to provide either accessible or appropriate care for consumers who were deaf.

While 50% reported having TTY equipment, only 8% reported that staff knew how to use it. Similarly, only 9% were familiar with resources and procedures for securing interpreter services.

Following implementation of the baseline survey, ongoing ISOC dissemination and training was instituted for agencies within each of Illinois’s nine regional mental-health networks. In addition, the statewide and Metro Chicago coordinators, the Statewide Deaf and Hard of Hearing Subcommittee, and other OMH staff met to review the baseline data and develop a strategy for improving service accessibility. It was determined that, in addition to wide-scale dissemination of the ISOC, a monitoring and technical assistance process would be instituted whereby community mental-health centers would be surveyed every 2 years to assess progress toward service accessibility. Thus, in 2002, using the ISOC as a benchmark, local “deafness experts” began conducting biannual technical support and monitoring site visits and follow-up surveys of community mental-health care providers. The original group of 131 agencies was divided into two groups in a manner ensuring an even distribution of scores across both groups. Site visitors

<table>
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<tr>
<th>Survey Focus Area</th>
<th>Agencies Reporting Provision of Service (%)</th>
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<tr>
<td></td>
<td>2000 (baseline year)</td>
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<tr>
<td>TTY/telephone accessibility</td>
<td>19</td>
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<tr>
<td>Use of the ISOC videotape and document in routine staff training and performance reviews</td>
<td>56</td>
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<tr>
<td>Availability of information on the statewide coordinator of deaf and hard of hearing services</td>
<td>38</td>
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<tr>
<td>Routine staff training on hiring and working with sign language interpreters</td>
<td>9</td>
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<tr>
<td>Effective policies on sign language interpreters</td>
<td>42</td>
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<tr>
<td>Routine provision of staff training on Deaf culture, TTYs, American Sign Language, and clinical interventions with deaf consumers</td>
<td>11</td>
</tr>
<tr>
<td>Resource list for assistive listening devices for nonsigning deaf consumers</td>
<td>55</td>
</tr>
<tr>
<td>Contact information for a “deaf expert”</td>
<td>41</td>
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did a return survey of the first 64 agencies in 2002, with plans to survey the rest in 2004. Each of these monitoring and technical support visits is designed to impart an overall understanding of the quality of agencies' efforts to adhere to the standards, and underscores the validity and importance of abiding by the standards. Site "deafness experts," many of whom are deaf themselves, are employees of other IDHS offices or of IDHS grantees. This collaboration provides an opportunity for the state to track progress toward service accessibility for deaf consumers and for site monitors to educate mental-health service providers about their "home organizations," local resources, and opportunities for future consultation to improve services for consumers of mental health services who are deaf.

Results from the 2002 site visit survey process were encouraging. Specifically, when survey data from the 64 agencies were compared to these agencies' baseline survey data, increases in service access were shown in every area on which the survey focused (see Table 1). Moreover, the total number of deaf, hard of hearing, late-deafened, and deaf-blind consumers identified in community mental-health agencies increased 60% from the baseline data collected in fiscal year 2000. In addition, in 2002 the associate director of OMH requested that the results of the survey process be reported biannually to the IDHS-OMH Department Strategic Planning Sessions, which are held annually.

Conclusion
The progress being made in Illinois through IDS2000 demonstrates that with motivated and accountable leadership and a single set of guiding principles governing the process, important system change can begin for previously alienated stakeholder groups. Depending on the status of a state's existing deaf services staff and infrastructure, much of IDS2000 could be initiated elsewhere in a mostly budget-neutral manner, building on the existing ISOC document. In Illinois, IDS2000 minimized additional funding needs by reallocating staff and resources, and by identifying state and local partners with shared interests.

Among others, four challenges were faced by Illinois OMH that would likely also be faced by other states:

1. Because deaf consumers are not a very sizable segment of the population served through states' mental health systems, these systems often do not place a high priority on initiatives to address deaf consumers' needs.
2. A general ignorance exists in regard to deafness.
3. There is a lack of legal or legislative mandates to compel action.
4. There is a local and national dearth of staff qualified to work with deaf consumers of mental health services.

For deaf consumers, distrust of the system, stigma, and a general ignorance about what constitutes mental illness hamper efforts to generate community and consumer support and participation in mental-health service development. However, if state officials, consumers, deaf and mental-health service providers, and advocates promote change, innovations such as the creation of "boundary spanner" roles and active consumer engagement strategies can begin to address such barriers, and thus make IDS2000 a feasible and effective model.

References
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