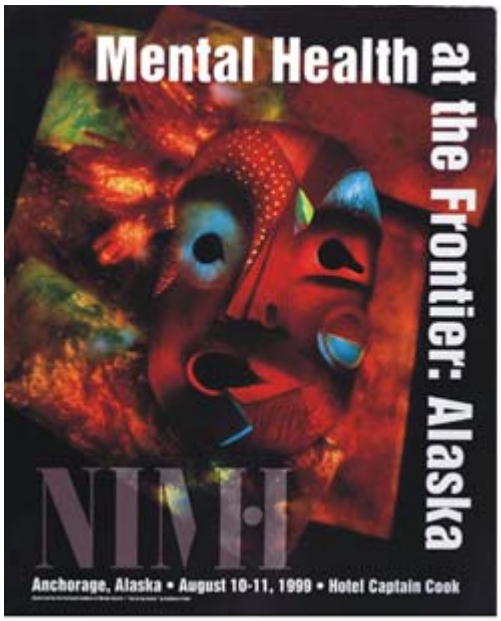
Mental Health at the Frontier: Alaska



The National Institute of Mental Health (NIMH) convened a meeting entitled "Mental Health at the Frontier: Alaska" on August 10-11, 1999 in Anchorage, Alaska. The meeting was preceded not only by planning meetings and consultations, but also by trips of researchers and program representatives to several towns and villages in Alaska. Among the towns and villages visited were Kotzebue and Selawik above the Arctic Circle, and Bethel and Kwethluk in the Yukon-Kuskokwim Peninsula. "We wanted our meeting to reflect the real lives of people who live in frontier Alaska," noted NIMH Director, Dr. Steven Hyman. The trips to these towns and villages provided a first hand look at the provision of mental health services in the Alaskan frontier and the conditions that affect people living in them. It also made clear that access to villages is not easy. Providers of health services are dependent on diverse modes of transportation such as boats and bush planes, to reach people who live in sparsely settled areas of Alaska.

This conference was the fourth in an NIMH series on rural mental health research and offered a grant-writing workshop, seminars on current mental health research, breakout discussion groups and a town meeting designed for Alaskans to give NIMH the benefit of their views as the Institute sets priorities for future research efforts. It also was an opportunity for Alaskans to learn about recent NIMH supported research findings and ways for Alaskans to access NIMH resources. Over 200 people from a variety of backgrounds including consumers, family members, providers, civic and state officials, and researchers attended the conference. The Mayor of the City of Anchorage, Rick Mystrom opened the meeting with supportive and encouraging welcoming remarks. In addition, Karen Perdue, Commissioner of the Alaska Department of Health and Social Services and Patricia Cochran, Director of the Alaska Native Science Commission made opening remarks to the attendees.

Staff of Senator Ted Stevens' office, who had actively encouraged NIMH to go to Alaska to get a better idea of its unique features, participated throughout the conference, as did staff of Governor Tony Knowles. Alaska's many ethnic and racial groups were also represented at the meeting.

It was often remarked that this was the first time so many of the people involved in the Alaska mental health field had gotten together in the same room and actively communicated with each other. As the meeting concluded, Dr. Grayson Norquist, Director of the NIMH Office of Rural Mental Health Research, expressed the hope that Alaskans would continue to build a research infrastructure and continue to meet so they could assess their needs and develop appropriate services. Participants were asked to identify what they thought were major mental health issues in Alaska, and how research might be directed to formulate solutions to these issues. This report presents findings and recommendations from that meeting.

Rural Mental Health

While Alaska has a number of cities, it qualifies not only as a rural area, but also due to its far-flung and often inaccessible villages, as a frontier state. The nearly 60 million Americans living in rural and frontier areas throughout the United States have the same mental and general health problems and needs for services as individuals who live in urban and suburban areas. Yet, rural areas have unique characteristics that present barriers to accessing mental health care. Access to, and availability of, mental health specialists (and often any kind of provider) have always been serious problems. Even regional hospitals and mental health care facilities are not always practical given the sometimes small numbers of people spread across vast areas. A common solution in Alaska has been the use of a traveling expert to provide care in different areas. However, this arrangement poses problems when acute crises occur or follow-up care is needed. Since medications are often filled on a monthly basis they can sometimes be difficult to obtain during the months when travel is very difficult.

Emergency mental health care at times takes place under less than ideal conditions or necessitates travel away from family and community. Poverty, geographic isolation and cultural differences further affect the amount and quality of mental health care available to people in rural and frontier communities. These issues and many others were among those discussed at this meeting. New, flexible approaches need to be developed that take the specific realities of a region into account.

More than 800 rural counties in the United States have high poverty rates, but only 25% of people living in rural areas qualify for Medicaid - compared to 43% in urban areas. Women head 46% of rural households, and of these families, 27% are living below the poverty level. The elderly are also disproportionately represented in rural areas. Most rural counties have no practicing psychiatrists, psychologists, or social workers, and less than 20% of psychotropic medications are prescribed by providers with formal mental health training.

Recognizing the magnitude of mental health problems throughout rural areas of the United States, Congress has taken several actions to address these issues. One such action was the establishment of an Office of Rural Mental Health Research (ORMHR) in the NIMH. In an attempt to learn about mental health problems in different rural and frontier regions of the country and to stimulate research to address these problems, the ORMHR has held annual meetings in rural locations around the United States (e.g., Mississippi and New Mexico) including the recent Alaska meeting.

Overview of Alaska

Alaska is the largest State in size but ranks 49th of 50 states in population with approximately 600,000 residents. Alaska's frontier status is reflected in its population density of 1.1 persons per square mile, the lowest rate nationwide. If this same population density were to exist in Manhattan, there would be two people living there. Alaska Natives comprise 17% of the state's population with the majority living in rural and frontier communities. Over 95% of all rural villages in Alaska cannot be accessed by road and are several hours flying distance from the more populated cities of Alaska. The costs of flights are very high due to lack of competition, and it is often impossible to reach these communities due to weather conditions.

Accurate estimates of the number of people in Alaska with mental illness and those with co-morbid substance abuse are not available, but co-morbid mental illness and substance abuse disorders (e.g., alcohol abuse and inhalant abuse) are considered major problems. In addition, existing data indicate that Alaska has the second highest rate of suicide in the nation and Alaskan women have twice the rate of substance abuse compared to the national average. Alaska Community Mental Health Centers have seen an increase in people with severe mental illness served at their clinics. In 1984, 945 individuals were identified as having a severe mental disorder; this number rose to 2,799 in 1995. There are no data on the actual number of individuals with mental illnesses who have not received care. Thus, current figures are a conservative estimate of the number of people with such illnesses. There are many reasons why individuals in this population might not receive mental health services, but a major barrier is the lack of availability and access to any kind of provider. In addition, lack of insurance and inability to pay for care, stigma associated with mental illness, distrust of providers from another culture, and opposition to taking psychotropic medications may account for why individuals living in rural and frontier areas may not receive any care. The majority of providers in frontier areas of Alaska are nurses, social workers, and primary care physicians, with few psychologists and no full-time psychiatrists. Most specialty care is provided by clinicians who live in cities and travel great distances periodically. In addition, Alaska ranks 50th in proportion of community hospitals.

NIMH staff, including the Director of NIMH, and researchers heard first hand from people living in villages about the problems facing their communities and children. High rates of unemployment, low education, and poverty render many villages in rural and frontier Alaska vulnerable to family and community violence, suicide and other health and mental health problems. Though local resources struggle to address these problems, the overall service structure often is underdeveloped, and thus, cannot adequately treat those in need. There are high rates of co-occurring alcoholism and substance abuse disorders with mental illness. Preventive mental health interventions are considered insufficient throughout the State.

Although Alaska Natives account for 17% of the population, they comprise 33% of Alaska mental health consumers. Unfortunately, few treatment programs in Alaska Native communities reflect attention to cultural values. Program planners need to partner with such communities to develop systems of care that work with people in these communities. The need for mental health services is particularly acute among Alaska Native

adolescents. They commit suicide at a rate several times that of youth in the lower 48 States. This is a particular problem among boys. In 1992, it was estimated that only 1/3 of Alaskan youth with a mental health problem were getting the help they needed.

Many attendees at the meeting viewed the absence of a comprehensive state mental health plan and service system as a major barrier to providing much needed mental health services. This is seen as particularly detrimental for children and adolescents. Coordination between mental health providers and school districts is suggested as one way to identify and track children who need care. Many attendees believe that providing services for depression could prevent many child and adolescent mental health problems. Also, attendees pointed out that more training is needed for local paraprofessionals (e.g., village counselors), so they can provide mental health services, especially to children and the elderly who are often isolated. The Rural Human Service Delivery Program was cited as an example of current efforts that promise future advances.

A major issue raised by Alaskans - one that was discussed several times during the conference - is that far too many children with serious problems are sent away from their villages to cities or even out of Alaska for care, away from family and friends. This is very costly and places additional stress on families. Follow-up services are inadequate when the child is discharged and returned to the community. If the child relapses, the problem could become a vicious cycle that leads to removing her/him from the community once again, obtaining expensive inpatient treatment away from home, and eventually returning to the same community and family conditions that contributed to the initial problem. There is a need for residential and day-hospital programs so children can be closer to their families during treatment. Treatment needs to include both medication and psychosocial rehabilitation in order to achieve successful, long-term outcomes. In addition, it is essential to involve family members in planning local community services. Many family members and consumers at the conference recommended a significant expansion of community-based services for all populations.

Financing of care is a major problem since a large proportion of those in rural and frontier locations do not have any health insurance. Individuals who must rely on Medicaid cannot be treated for depression or other mental disorders while they are being treated for alcoholism. Also, a policy limiting medication refills to a 30-day cycle is viewed as a major barrier to compliance. The lack of parity in reimbursement for mental health care is just one more significant barrier that individuals face in obtaining care.

Providing care through videoconferencing or telemedicine is seen as another promising way to reach rural and frontier families, but there are unanswered questions regarding its effectiveness and whether providers will be reimbursed. Providers and insurers are hesitant to do much with telemedicine until standards of care are defined. In the absence of adequate community-based services or receipt of care through long distance modes, many individuals are ending up in a law enforcement system that does not provide mental health services. Yet, Alaska is not unique in this problem among the rest of the U.S. It was suggested that special training be made available to law enforcement officials to allow them to respond in an appropriate and culturally sensitive way to individuals with mental health problems.

Research Needs and Recommendations

Participants identified potential ways in which research could be used to address approaches and solutions for the existing mental health problems in Alaska.

Enhancing the Ability to Conduct Research: A persistent theme heard at the conference was the difficulty in conducting research in Alaska. It is often not feasible to assemble an interdisciplinary research team in remote areas. Research in rural and frontier areas of Alaska is very expensive to conduct, and must be designed to measure provision and outcomes of care in culturally diverse rural communities. There are few resources in Alaska for conducting studies in the mental health area. Investigators who come from outside Alaska are rarely knowledgeable about Alaskan life, culture or general environmental influences. Participants frequently mentioned that there is a big difference between "academic" researchers simply conducting a study on a population versus those who might conduct research and then help develop subsequent services through a partnership with the community. Some participants cited the Hudson Light Project as an example of a culturally relevant model of care that needs to be assessed to determine its potential transportability to other rural areas. The model was developed "from the ground up" in a remote community.

Recommendations:

1. There is a need within Alaska to form partnerships among those who are able to conduct research and members of the community. It was suggested that the Universities and the Alaska Mental Health Trust Authority could facilitate such partnerships with the community.
2. Many suggested that Alaska should formulate a coordinated research program agenda and encourage the development of joint research projects across the State.
3. The State and/or NIMH should provide funds to develop a pool of research experts who could consult when research projects are identified.
4. The Universities should investigate the possibility of applying for support to build their own research infrastructure through the Minority Research Infrastructure Support Program (M-RISP) at NIMH.
5. Supplements to existing grants should be used to train people from Alaska who have an interest in learning how to do research.
6. Small supplements to existing grants could be used to develop pilot projects on issues of importance to people in Alaska. The current NIMH Center on Native Americans and Alaska Natives was suggested as a good opportunity for both training and grant supplements.
7. The NIMH should ensure that peer reviewers on the groups that score grant proposals (i.e., its initial review groups - IRGs) have expertise on Alaska when proposals are submitted for Alaskan research.

Understanding the Extent of the Problem: Although it is clear that mental illness and co-morbid substance abuse disorders are significant problems in Alaska, the extent of the problem is not well defined. It is not known exactly what problems are most prevalent in various age populations and in what localities. Although many participants thought it was crucial to understand the factors that lead to the development of these illnesses in rural and frontier communities, they also thought it was imperative to look at factors that protect people from such illnesses (e.g., strong family and community support systems). The Community Based Suicide Prevention program was cited as an example of a successful prevention program.

Recommendations:

1. There is a need for studies to delineate the extent of mental illnesses and co-morbid substance abuse in Alaska. It is particularly important to understand the types of illnesses and problems found in various segments of the population and geographic areas of the State.
2. Studies should focus on resiliency factors and what improves health status. Work is needed on the best prevention programs for the kinds of problems found in Alaska.

Involving the Community: Another major issue expressed by participants is that researchers should involve the community, consumers and family members in designing, developing, and assisting in the research project. However, it was also noted that it is often difficult to get researchers, providers, and consumers to agree on what outcomes are important to measure. Nonetheless, it was reiterated that one must take an approach to research in rural and frontier areas that includes consumers to ensure that the results are consonant with the community's cultural values regarding mental health care. Further, Alaska Natives do not want to cooperate with researchers who will not include community representatives since they believe that their prior participation in studies often did not lead to meaningful research results or change in their communities.

Recommendations:

1. Research proposals should incorporate the perspectives of consumers, family members and the community.
2. Once research results are finalized, it is imperative that researchers work with the community in the dissemination of the findings.

Considering Cultural Issues: Attention to cultural issues is particularly important in Alaska. Many of the existing healthcare programs do not incorporate the concerns of the Alaska Native populations they serve. Alaska Natives are interested in developing programs that reflect their native values and lifestyle. In addition, they want to know what makes a community resilient and keeps people healthy. They want to use traditional health practices in their healthcare services.

Recommendations:

1. Research projects that focus on Alaska Native populations must partner with those communities in the design and implementation of the project and in the dissemination of the results.
2. The Native Corporations, Village Councils, Alaska Native Health Board and Alaska Native Science Commission should be consulted about the research needs and design of studies in their communities.
3. The Native radio system and press should be used when research projects are started in Alaska Native communities to get the word to the community.
4. Studies should be designed to investigate the effectiveness of Alaska Native health practices in the prevention and treatment of mental illnesses and co-morbid substance abuse.

Focusing on Mental Illness and Substance Abuse: Co-morbid substance abuse and mental illnesses are particular problems in Alaska, especially alcohol and inhalant abuse. Participants at the conference were interested in sharing information on programs that have worked for others. They were also interested in measuring outcomes of treatment that were most relevant to their communities.

Recommendations:

1. Studies are needed to determine the extent of co-morbid substance abuse and mental illnesses.
2. Research is needed to determine which programs are most helpful in both preventing and treating these illnesses.

Helping Alaskan Youth: A major concern at the conference was the extent of mental disorders in children and adolescents. One of the biggest problems in treatment is the fragmentation of services and the lack of continuity (see discussion above). It was also noted at the conference that the elderly population has very similar problems with access and continuity of services.

Recommendations:

1. Special emphasis should be placed on developing studies in children and adolescents.
2. Research is needed on developing the best community level services for children and adolescents. This was also noted to be a research need in the aging population.

Developing the Best Ways to Deliver Services: Research is needed on the best ways to organize and finance mental health treatment services in Alaska. It is important to understand how to make services "seamless". Participants were interested in research on the use of paraprofessionals to deliver treatments in frontier areas. In addition, many were interested in the effectiveness of peer counseling. Due to the great distances from specialty services for most of the rural and frontier areas, there is an urgent need to determine whether diagnosing mental illnesses and managing care over time can be done as effectively through telecommunications as it is in a clinic-based practice. Some specific questions about using telecommunications to deliver care to isolated populations arose during the conference. These included questions about the effectiveness of this technology for diagnosis and treatment, especially for severe illnesses, concerns about whether third parties would reimburse these types of services and how licensing regulations would apply when care is delivered across State lines. There are several models of long distance care that could be studied, including a noted model of child psychiatry and neuropsychiatry in Kentucky. Also, further exploration of the types of systems and bandwidths, and protocols need to be studied. Research regarding ethical issues in use of telecommunications must also be investigated since patient confidentiality and security is paramount. In addition, without access to services in many areas, people with mental illnesses are ending up in the legal system where there are often inadequate mental health services.

Recommendations:

1. Research is needed on the best ways of organizing and financing mental health services in Alaska. Particular attention is needed on services that are seamless, easy to access and based in the community.
2. Research is needed on the effectiveness of peer counseling and paraprofessionals to provide mental health services.
3. Research proposals on delivering specialty mental health services through telehealth are of particular importance in Alaska.

4. Studies are needed on the best ways to deliver mental health services to those in the legal system.

Summary

This meeting underscored the urgent need to formulate a research agenda to address the mental health problems facing Alaskans. Most important was the recognition that Alaskans need to develop a research infrastructure in the State to investigate these problems. The meeting was the first time that many of the key players in Alaska mental health had met in the same room. Thus, an immediate benefit was to strengthen a dialogue among Alaskans about how to proceed in addressing mental health issues in their State. Many of the problems identified in Alaska are similar to those found in the lower 48 States. Some solutions may be unique to Alaska but it is also likely that what is accomplished in Alaska will be relevant to what should be done in the lower 48 States, especially in rural and frontier areas.

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