

MENTAL HEALTH RESEARCH WORK GROUP

Minutes of
September 15, 2000

Video Teleconference

ATTENDANCE

John Pugh, Trustee, Alaska Mental Health Trust Authority
Jeff Jessee, Executive Director, Alaska Mental Health Trust Authority
Mary Elizabeth Rider, Planner, Alaska Mental Health Trust Authority
Robyn Henry, NAMI Alaska
Katsumi Kenaston, Alaska Mental Health Consumers Web
Doug Veit, Rural Mental Health Directors Association
Jean Steele, Alaska Advocates for the Mentally Ill
Beth LaCrosse, NAMI Alaska & Alaska Mental Health Board
Dick Wilson, Alaska Young Family Network
Jan McGillivray, Mental Health Association in Alaska
Dr. Gary Hughes, Center for Human Development
Dr. Shelley Theno, Department of Psychology, UAS
Dr. Jerry Mohatt, Department of Psychology, UAF
Dr. Jim Allen, Department of Psychology, UAF
Dr. Mark Johnson, ACSES, UAA
Dr. Chris Brems, ACSES, UAA
Dr. Brian Saylor, Associate Vice-Provost, Health Affairs, UAA
Dr. Bernie Segal, UAA
Kim Shore, Chair, Psychology Department, APU
Ron Adler, President, Alaska Community Mental Health Services Assoc.
Commissioner Karen Perdue, Department of Health and Social Services
Millie Ryan, Governor's Council on Disabilities & Special Education
Pam Watts, Advisory Board on Alcoholism & Drug Abuse
Anne Schultz, Advisory Board on Alcoholism & Drug Abuse
Walter Majoros, Alaska Mental Health Board
Richard Rainery, Alaska Mental Health Board
Loren Jones, Division of Mental Health & Developmental Disabilities
Jim Herrell, Center for Substance Abuse Treatment, SAMHSA
Heather Ireland, Intern, Alaska Mental Health Trust Authority

CALL TO ORDER

JEFF JESSEE calls the meeting to order and welcomes participants at 8:30 a.m.. He explains that over a year ago, the National Institute of Mental Health (NIMH) visited Alaska and held a meeting, part of the purpose of which was to start people talking about research in Alaska and how Alaska might move forward. He says that despite the enthusiasm, nothing seemed to change following the meeting. He states that this past June, Grayson Norquist toured Alaska and talked about mental health research and part of the discussion concerned developing a mental health research agenda for Alaska as well as a plan for information exchange. Mr. Jessee explains that Grayson Norquist indicated that some small NIMH proposals could be funded out of discretionary funds.

JEFF JESSEE says that he got approval of Trustees to convene this steering committee with the goal of trying to bring together stakeholders to begin to develop a research agenda for Alaska.

JEFF JESSEE indicates the agenda can be modified if the group wishes, but suggests starting

with introductions.

(Individual introductions, those in attendance are listed on Page 1)

How do we increase the utility of research for Alaskans?

JEFF JESSEE states the thought behind this question is how to develop a sense of priority for applied research that could be of more practical use in the field.

DICK WILSON states that over a billion dollars worth of research from NIMH is going on, but there's more beyond that. He suggests a technology transfer such as an academy of sciences or a planning process brought together under the auspices of the Mental Health Trust Authority. He says under the planning process, a multidisciplinary team would be assembled to work with researchers on a particular issue in order to put the science to practice at the local level.

BETH LaCROSSE states that NAMI Alaska, with the help of the Mental Health Trust Authority, is conducting research on attitudes towards mental illness prior to and after a presentation on schizophrenia and other mental illnesses. She says they'd be happy to share that information.

WALTER MAJOROS states there are two discrete pieces, developing the agenda for the future and the process around that, which will take some time, but he says a plan is needed for dissemination of what already exists. PAM WATTS concurs, adding that a research bank is needed, a single place where data could be collected and made available.

BERNIE SEGAL agrees a repository is needed, but says the next step is a concentration on the transition of research to practice. He says the knowledge base needs to be identified, but that assistance on using information and translating it to practice for improved service will further drive research. He says that on the federal level, this is called Research To Practice, which involves improving the level of care or services in the field.

RON ADLER agrees, explaining that the only value for research is to improve the best practice standard approach for delivery of service. This involves, he says, direct services to consumers and families, as well as re-engineering system designs. He comments that re-engineering is important for Alaska, given the geographic complexity. He states that upon creation of an Alaskan think tank, the question is how does it get to providers and practitioners and how to begin to incorporate training on the models. WALTER MAJOROS agrees, but adds that that cannot be done without good data.

JERRY MOHATT comments that what is being discussed has been referred to as a technical assistance center, a clearing house for information and research, as well as a technical assistance center. He suggests that as the group discusses building infrastructure that a focus should be on shared resources between the state and grants applied for to build the kind of infrastructure that will help disseminate the information. BRIAN SAYLOR relates that Grayson Norquist indicated that NIMH's infrastructure funding is limited and that he discussed a risk. He states that Mr. Norquist also encouraged the researcher-initiated research, the RO-1, which is project focused rather than infrastructure focused. He says it was his impression that NIMH typically works on researcher initiated project centered funding over a few years. He explains that the relevance of the research to the community is more on Alaskan's side than on NIMH funding side.

LOREN JONES says that a lot of the research that Mr. Saylor talked about is project specific and that what Mr. Majoros is referring to is more population based or epidemiological based. He says that having a database that only looks at who shows up for treatment doesn't provide good planning data. He says there are two sides, the research that's specific to various programs or research based and that that is population based or epidemiological. He comments that if NIMH

doesn't fund the epidemiological type research, then part of the agenda needs to focus on where other funds may be available to do that kind of study. WALTER MAJOROS states that he was referring to more performance, making data, defining methodology for gathering data. In order to have successful applied research, he says the infrastructure must allow an evaluation of the effectiveness of current services as a baseline.

KAREN PERDUE says she is unsure if the technical assistance center and the epidemiological approach have any confluence, but that in other kinds of public health approaches there is usually some group or individual tasked with a population based function. She explains that typically there is a registry established, and that a core vital events function and a core epidemiological function is critical and is an important function that is missing in Alaska. WALTER MAJOROS says he is unsure a registry for people suffering mental illness is appropriate. KAREN PERDUE agrees, explaining that she was suggesting something comparable. JEFF JESSEE asks if the idea is something that takes some measures of mental health status and develops some kind of broad population based data about how Alaska's doing. KAREN PERDUE concurs and states that at least a collection of those things that are available is missing in Alaska.

JIM ALLEN comments that regarding epidemiological research, prevalence data on the extent of problems is not available. He adds that he believes NIMH would not fund the infrastructure for a technical center or for the dissemination of information. He says it is important for this group to look at partnerships with the state, private agencies, organizations or foundations to establish such a center.

JEFF JESSEE comments that although NIMH has served as a catalyst to get this moving, it will be necessary to go beyond NIMH to meet the agenda. BERNIE SEGAL suggests that what could come from this effort is an approach of people working collaboratively to identify needs and resources. He says that NIMH is concerned that Alaska doesn't have the infrastructure to do NIMH funded RO-1 projects. RON ADLER suggests also starting at the other end, coordinating grants at a strategic level through research arms within the state to supply the bricks and mortar for larger strategic thinking for research to move forward. BERNIE SEGAL agrees, stating that short-term objectives should be established with the overall goal of improving the services and lessening the adversarial condition in the state. He adds that this must be done in a multicultural setting.

JERRY MOHATT agrees, stating that work should start with small projects while looking at the long-term planning process for getting larger RO-1s or other funding mechanisms, and that it must be done collaboratively. WALTER MAJOROS agrees with the short- and long-term agenda, but adds that groups in Alaska have done a poor job of sharing successes and disseminating information about the state, about projects that are successful.

JEFF JESSEE states that along that line, he has heard that just putting everything out on a web site isn't of utility to people because of the time it takes to sort through that type information. PAM WATTS disagrees, stating that if information is organized categorically, it would be enormously helpful. WALTER MAJOROS states that placing information on a web site has to be part of a more complete strategy, such as placing items on the agendas of various boards and commissions. BERNIE SEGAL adds that that is a relatively easy task and helps to build linkages, but also has advantages and disadvantages. JERRY MOHATT agrees with the sharing of information through a multiple set of means, web and newsletters, but that that is not an appropriate area of funding for NIMH.

JEFF JESSEE asks what amount of funding would accomplish that short-term goal. JIM ALLEN comments that it would require a full-time person. JERRY MOHATT suggests it would cost a minimum of \$100,000 a year, as a ballpark.

DICK WILSON states federally there have been technical assistance centers set up on a variety of subjects, and that the national library of medicine has a database that gets down to translating available information into standards and guidelines. RON ADLER states that NIMH is interested in wraparound services and how they apply to a variety of ethnic groups. He says the issue is how to coordinate four or five area grant applications over the next year that will get coordinated at the state level to begin to get data on best practice approaches to Alaska.

JERRY MOHATT says they've been doing some children's work in the interior that relates to the dissemination center. He says the Circles of Care project is applying a wraparound model and that once that's in place, it could be a great thing to collaborate on and develop a research project that NIMH might be interested in.

BETH LaCROSSE indicates that members of NAMI and NAMI Alaska are working on a program that offers wraparound services for the clinically mentally ill and that it may be something NIMH would be interested in funding. She adds that if a PACT program could be developed for Alaska that does not result in forced treatment, the wraparound services might be able to be funded by NIMH, if consumer services and other data were included.

MILLIE RYAN comments that the group might want to look at identifying a particular research project and set up a model protocol for getting it out to practice so that what works well can be evaluated in terms of getting it to the field.

ROBYN HENRY states the discussion involves introducing innovation and then implementing innovation at the practice level. She suggests looking at the way Alaska encourages and discourages innovation. She says service reimbursement is one way the State discourages innovation and suggests taking a look at the way Medicaid regulations decide what is reimbursed and what's not. DICK WILSON concurs, stating that the research agenda demonstration projects need to take into account things such as Medicaid funding and blending funds.

JIM ALLEN comments that providers and consumers are suggesting expansion of the research agenda to include research on state level policy. He says there is not a statewide plan in place. WALTER MAJOROS takes exception, stating that the Alaska Mental Health Board (AMHB) does a strategic plan for mental health services and suggests he mail one to Mr. Allen.

BRIAN SAYLOR states that the notion of demonstration projects that have adequate controls that say one intervention is superior to another in generating expected outcomes requires a level of sophistication and consistency in record keeping and a level of participation that would be a stretch for Alaska. He adds that comparing one intervention across a number of sites, looking at program efficiencies, utilization, cost, and outcome effectiveness assumes bringing together community mental health system participants. He says it also requires significant commitment at the state level and the associated policy boards to ensure continued funding until the project is completed. He adds that in some ways, RFP processes get in the way of that. DOUG VEIT comments that with respect to consistency, it won't happen among rural providers unless there is adequate funding. BETH LaCROSSE suggests that developing the database will require piecing together data from the various agencies on those receiving services.

WALTER MAJOROS states there has been phenomenal change in the last four years in terms of the level of collaboration between the providers, the state, the AMHB and consumers and that he feels Alaska is ready to move forward on some of the basic information pieces. DICK WILSON says SAMHSA grants and other grants are available to do the baseline studies, set up a good program and outcome studies to make sure the programs are working. He comments that blended use of Medicaid funding is working in other states, but that it will require putting five years into developing a program with adequate controls.

SHELLEY THENO states that when talking about database dissemination, infrastructure, or even research protocols, it is important to consider regional differences and regional controls over the kind of research done in each community.

DOUG VEIT asks if there is any research on the research as to why information does not get into the lower levels where it is supposed to be performed. LOREN JONES states his opinion that it has to do with the way the funding comes down. He states that often research reports are submitted from the researchers to the agency and from the agency back to the federal government, and that the federal government won't release information until a project is completed. He adds that another reason is that coordinators for projects often have falling outs, and that the research is owned by the funding agency or the service agency. Mr. Jones comments that some rural communities have in the past been burned by researchers and are hesitant to allow information to be disseminated, which also serves as a barrier. He suggests a technical center may assist in communities buying in and agreeing to participate in research and allowing results to be disseminated. He adds that sometimes researchers don't want information to be disseminated before it has gotten into a juried journal. BERNIE SEGAL agrees, but adds that things are changing slowly and that unless research is meaningful to the community, it should not be done. He comments that the issue of ownership of the research is always a factor. MILLIE RYAN suggests that another barrier to dissemination of research is that it is not always written in language people can understand.

BERNIE SEGAL mentions that Senator Stevens' efforts and infusion of dollars to different state agencies has had a major positive impact. He suggests the professional staff workers to staff the agencies must be well trained adding that this is a severe need in Alaska, particularly in Native communities. JEFF JESSEE states that although the mental health research agenda is being discussed, the participation of people at this meeting involved in substance abuse and alcohol issues is a testimony to the fact that there is a growing understanding that these are issues that need to be dealt with together.

LOREN JONES says that over the last eight or nine years, a lot of good data relating to the alcohol field has been generated, but that it has not been pulled together and analyzed such that it can begin to be translated down to the practice level and the training level.

WALTER MAJOROS states that through the Trust Authority, there is an effort to take a leadership role in funding innovation in the mental health system, as well as substance abuse, developmental disabilities, and seniors. He comments that because the states is not the provider of document development, the centralized information that is taking place begins to be lost and that the information should be collaboratively analyzed before doing more creative research.

MARY ELIZABETH RIDER comments that most program evaluators are not providing instruction on how to apply the research in particular communities. She suggests when solutions are found in one community, there should be a way to share that with similar communities. She adds that there are very few rural providers writing up the groundbreaking work that is taking place in the field.

BRIAN SAYLOR indicates that sometimes the CSAT requirements for project evaluation bypass the state level and the community next door. He says it is a relationship between the program and the federal government. He suggests giving Alaska's people guidance and giving direction to researchers so that they choose something that is considered a real need by the affected groups. He adds that someone needs to be the keeper and updater of the research agenda and that that agenda should be widely circulated to researchers. He suggests the Trust Authority could fill that role. He adds that if there is a final arbiter that could lend support to the credibility of a research project, it is the Trust Authority and its associated beneficiary boards.

JERRY MOHATT suggests looking at a model of what is being discussed in terms of dissemination called the Rural Systemic Project, a UAF project funded by NSF. He says it's been in existence for five years and provides the things being discussed but associated with rural education and transfer of knowledge to schools. JEAN STEELE says that from the standpoint of a consumer, she can see where training is lacking in the smaller communities and suggests setting a target date to upgrade standards. She concurs that the Rural Systemic Project would be a good guide because it includes everybody.

JOHN PUGH suggests regional laboratory models may be another example to look at, such as Northwest Educational Laboratory, which is working well in the region. He says they provide dissemination of knowledge, do technical assistance, innovation, and demonstration projects to inform practice and education. He says these laboratory models have worked out a framework and that the group should not have to reinvent the wheel regard to that.

What do we do now?

JIM HERRELL suggests the group spend time defining terms so that it is clear what evaluating services means as compared to conducting research, the primary purpose of which is to develop knowledge that would be valuable to other programs. Speaking for CSAT and SAMHSA, he says there are grant programs that would support technology transfer studies. He says if the interest is on integrating systems or doing things more efficiently or obtaining more collaboration, they're interested in studying services and getting more wraparound services. He adds there is almost no knowledge in the field of how to do culturally targeted treatment. He says all these things are fundable through his agency.

JIM HERRELL indicates that Alaska has more grants per capita than any other state, which proves Alaska knows how to get grant money. He adds that providers submit grant applications but lack research staff and that researchers provide elegant proposals to do trivial things because they have no connection with the communities. He suggests getting providers, policy makers and researchers together for grant applications.

GARY HUGHES explains that the role and function for basic or experimental research is the research element and that there is concern for outcome or performance based research, epidemiology, and systems change. He says technology transfer and dissemination and training aspects of research have been discussed. He provides the following what-if scenarios:

What if the Trust was used to establish research or prioritize the research needs for mental health?

What if that was done around the context of research as he's laid out?

What if that research agenda or priority list was distributed to all agencies, institutions, communities and providers?

What if a research-planning group dropped out of the Trust that would help identify or refine the research questions, identify skills and functional requirements to do the research and identify the resources that exist in Alaska?

What if that research team includes not only researchers but people from rural communities and consumers?

What if that team is responsible for the development of the proposal and the grant?

What if this cross-functional team developed a report based on the information and provided it to the Trust so that the Trust would be informed on the status?

GARY HUGHES suggests that process would involve technology transfer, dissemination and training on information gained through research that is based on relevant priorities. BRIAN SAYLOR says that knits things together nicely, but adds he would add a commitment to train the Alaskan research community rather than people from out of state.

DOUG VEIT comments that the suggestion was made that terms be defined. He says he'd like to

expand that to defining the problem the group is attempting to address. He asks the following rhetorical questions:

Are we envious that somebody else is doing research and Alaska is not doing much?

Are we looking for a cheaper way to provide services?

Are we looking for best practice in terms of getting services to identifiable clients?

DOUG VEIT indicates providers have all had site surveys and suggests those surveys would be a good place to go for basic information as to what people on the lower level see as the problem.

BETH LaCROSSE asks who will be the population to be studied and included in the research. She asks if it will focus only on people receiving mental health services, unserved populations, Trust beneficiaries.

WALTER MAJOROS states that the AMHB has initiated a number of different planning processes and that the development of a framing document has been very helpful in the initiation process. He suggests a subcommittee of the group develop a framing document to deal with issues such as definition of the problem, common language, and short- and long-term strategies that have been discussed. LOREN JONES agrees that that is a good place to start. He adds that the what-if questions deal with what is the desired outcome. He comments that most of today's problems were somebody's solutions yesterday and he urges that the group be cautious and know what it is that is wanted of a final product.

JEFF JESSEE states that the Trust is the facilitator of gathering people who need to form the framing documents and that to that end, the Trust will be looking at the planning boards and commission and the administrative agencies to play a major role. BERNIE SEGAL suggests there are no solutions for any issues that will be developed unless everyone is in this together. He adds that maybe the Trust has taken the first step by convening the group.

JEFF JESSEE announces that minutes will be provided of today's meeting and will be disseminated to participants. He suggests getting together with stakeholders to identify a group to develop the framing document and answer some of the questions that have been raised in this meeting. JERRY MOHATT agrees that would be the next step. He adds that the group did not discuss the existing ongoing efforts and that it would be good to indicate what those are in the framing document. WALTER MAJOROS says it may not be necessary to itemize those things but rather to inventory current research. JERRY MOHATT comments that centralization should not stymie innovation at the local level.

BETH LaCROSSE reiterates that without a definition of the population, the questions cannot be answered. She adds that the population that is determined will have a significant effect on the results. JEFF JESSEE suggests that's another issue for the framing document subcommittee.

BERNIE SEGAL comments that there has been little research within the Center for American Indians and Alaska Natives with respect to what is happening in Alaska and that there has been concern over the Alaska Native section becoming part of that. He suggests an umbrella to have NIMH begin to invest those funds in Alaska. JERRY MOHATT disagrees, stating that the Center was involved in the research that led to the development of the IHS program. He states that would be a good source of information and collaboration.

JEFF JESSEE reiterates that the minutes will be distributed and networking will begin to identify the group to take the next step. He thanks everyone for their participation and concludes the meeting.

----- Mental Health Research Work Group Meeting Concluded at 10:20 a.m. -----