



Rochester-Daylight Conference Call

January 19, 2010: 9:15-10:30 AM

AGENDA

- Introductions
- Brief overview of Daylight Project - see attached list of components and update
- Overview of Rochester's areas of expertise and what may be available to the Daylight Project, and through what mechanism, e.g., charges
- Data Collection Methods specific for Consumers (i.e., individuals who are deaf or hard of hearing who use or have used Colorado's public mental health or substance abuse services) – including deaf or hard of hearing family members of consumers- useful for Program Evaluation and Assessment Components
- Other areas if we have time: lessons learned from Rochester work, rural experience
- Next Steps

Rochester Participants

Dr. (Steve) Barnett with the Department of Family Medicine and the Associate Director of the Rochester Prevention Research Center: National Center for Deaf Health Research (NCDHR)

Dr. (Bob) Pollard with the Department of Psychiatry and Director of the Deaf Wellness Center, University of Rochester

Daylight Project Participants

The meeting was conducted at MHCD with Ami, Mary, Lydia, and Anita on speaker phone (2 interpreters were also present); Jewlya, Mya, and Drs. Pollard (Bob) and Barnett (Steve) calling in.

Notes (I have not included information that we shared about Daylight)

- Introductions
- Brief overview of Daylight Project:
We reviewed the seven major components of the grant
- Overview of Rochester's areas of expertise and what may be available to the Daylight Project, and through what mechanism, e.g., charges

Bob - University of Rochester and Deaf Wellness Center (DWC)

http://www.urmc.rochester.edu/smd/psych/fac_staff/pollard_robert.html,

<http://www.urmc.rochester.edu/dwc/index.htm>, and Steve - Rochester Research Center - CDC-funded

http://www.urmc.rochester.edu/FamMed/about/fac_staff/barnett_steven.cfm,

represent multiple organizations and projects. Some highlights:

- Programs provide training and education at all levels, BA, MA, and PhD
- Focus is on academic and community (Rochester Deaf community) partnership that works to identify and improve the measurement of the health issues in Rochester's Deaf community
- Focus is on prevention and includes a Community Health Board
- Faculty is Deaf and hearing
- Major recent work has been on the adaptation of the [Behavioral Risk Factor Surveillance System](#) (BRFSS) – seen news article <http://www.news-medical.net/news/2008/07/29/40331.aspx>
- Specialized Interpreter Training, http://www.urmc.rochester.edu/dwc/scholarship/Interpreter_Training.htm
Robyn Dean, from the DWC. This training is now available on DVD and text book; 5 yr study concluded and results just accepted for publication. He will forward an advance copy to us (done).

Questions: (Anita) What is the most efficient way to collect info state wide from consumers and & family members? Where do they (Bob and Steve) see the potential overlap between their interests, what they might have to offer?

(Bob) First emphasized that it is important to know the degree to which DLP is/isn't connected to larger picture of MH issues enhancement Nat'l Coalition on MH & Deaf individuals (NCMHDI) - subsidiary of sorts of NASMHPD (National Association of State Mental Health Program Directors) founded (C Tate, CEO/ED) that group includes 5 of the US state directors of state MH programs. Important link to ensure that Daylight project is understood and informed by what a number of leaders in US have tried to do in their state MH improvement of Deaf MH services. The history is interesting and spotty. Some states do good job, some nothing, some fall apart when key people leave. He is optimistic about this program. These directors in various states have a wealth of experience that can be useful. Daylight needs to connect to other large

initiatives as well. Anita shared Candice's role with Daylight and support from DBH.
ACTION: Anita will touch base with Candice to talk specifically about NCMHDI

2) Bob/Steve-**Strong Connections** (tele med)

<http://www.urmc.rochester.edu/strongconnections/> it is a program with goal to provide certified MH interpreters to remote hospitals/other settings to place were no access to qualified interpreters. They page 24/7 and go though Video conf equip, our interpreter pops up on their video screen, we can control the camera to see all around the room, (**Fort Collins uses this**) and interpreters hear and see all. Provide direct services remotely.

Sign fluent staff of DWC offered to remote locations to client and fluent provider. Procedure and mechanism in place for doing it, providing video conferencing. Strong Connections tested a lot of equipment and connections to make sure video clear, quality needed for health evaluations using ASL is different than for standard telemedicine. Infrastructure requires adequate bandwidth for ASL assessment. Bandwidth, quality - are both ISDN lines rather than internet - also concerns about HIPAA, concerns about guaranteed bandwidth. Polycom equipment is used at all locations. Kathy Miraglia is the contact for this program.

ACTION: See specs at website. Is George's and hospital group familiar with this and is this the equipment that is being installed? Are we aware of Ft. Collins' use of Strong Connection?

Anita- For evaluation and assessment components. We have strong interest in learning how to collect best info from consumer & family members that is realistic, efficient, and give us diversity in our respondents. What have been their experiences in collecting information from consumers? What doesn't work, things you found particularly helpful?

Surveys that target providers, deaf consumers, family members (hearing & deaf), and data collection for groups from which we need data may be different. Online survey seems most appropriate.

For consumers who are deaf, survey (even using computer or kiosk) may not be best:

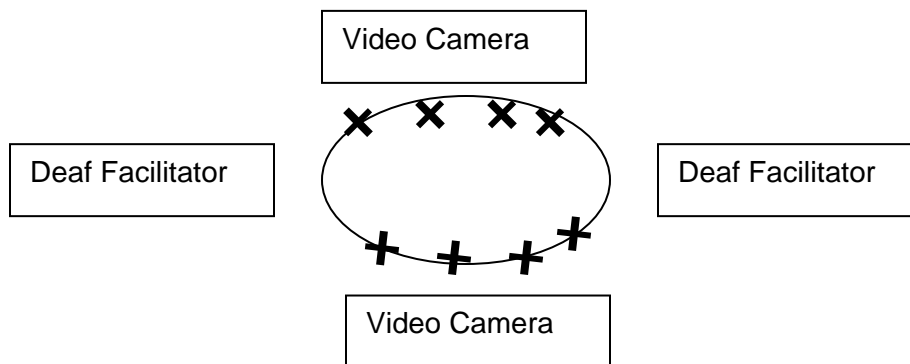
- Deaf communities/individuals don't have as much experience with written surveys as most hearing individuals - language and structure is unfamiliar/uncomfortable
- Deaf communities/individuals don't have the same relationship with surveyors - more likely to have trust issues, question the reason for and use of data/collection.
- The information we are looking for really doesn't really lend itself to quantitative data collection - You want minority experience, key informant interviews and focus groups best.
- Minority individuals who are grouped together feel safer than one on one. Will be more meaningful if they can interact w/ea other

- Recommend
 - Initial series of focus groups to gather info
 - Look at what we found, then go to town hall mgs to share findings, did we miss anything, overemphasis.
 - Use this to drive next step or participant verification, ask people to prioritize (participant verification)
 - Do not recommend an ASL survey for this.

Anita: -Focus group leadership. What are their thoughts about whether focus groups are best led by a deaf person with no hearing person in the room (as was described at the APHA meeting)?

Marjorie F. Goldstein, MPH, PhD with the National Development and Research Institutes, Inc. (NDRI) <http://www.ndri.org/ctr/deafresearch/staff.html> uses deaf research assistants and Beth Eckhardt (hearing), a medical anthropologist for conducting focus groups. Rochester researchers wondered how information collected during focus groups might be different w/o hearing person in the room, i.e., would quality or content of info be different - power differential is even greater than with other minorities? Focus groups were conducted as part of a CDC Prevention Study (perceptions of heart disease risk) in Rochester, NC, and CO (Denver).

Two researchers from Rochester lead the group, 2 cameras, oval table and facilitator on each side of oval.



Videos were translated and transcribed into English. The facilitators review and make any comments, notes. Rochester analysis team (deaf & hearing and not all hearing are fluent in sign language). Deaf staff mostly does analysis from the video. Careful to watch for biases of interpreters/translators.

Anita- what is the cost per focus group for that?

8 hours per hour of group. Not to think of the above as the gold standard, but rather to think about the sophistication of research. Do you need that level of data integrity for this kind of data collection project? Will you be analyzing for themes/analysis or more for general ideas suggestions. Want people to interact, what add to each other and foster a safe environment for exposure. It is expensive,

Anita. If we don't need that level of data or don't have resources, what is next level?

Steve - Matching resources and needs. Sit down with representative group, discuss the kind of information we want to gather, and ask them what is best way to get honest responses, how to make the environment.

Need to assess how comfortable consumers who are deaf with mental health and substance abuse problems are with hearing mental health providers. This will help determine who facilitators should be so as to not inhibit feedback. Video record is fine, note taking in room, flip charts, or on white board to do ongoing participant verification step. You can have video or skip it, depends if you need.

Steve - you can also have interpreters quietly translating into voice tape recorder that can be transcribed. Transcription time 4 hrs for audio tape hr.

Bob agrees that focus groups are the way to go.

Sign Language Dysfluency - summary.

- 1:1 interviews with individuals who are dysfluent - will share much more if not intimidated and uncomfortable with those who are more fluent [critical within larger deaf diversity]. Also need to be aware of the extent to which sign language dysfluency may be a function of the mental illness - may be very difficult to tease apart. Anita wondered if this issue will turn out to be related to geography, i.e., will we find more dysfluency in rural regions where individuals who are deaf may not have as much opportunity to be around other people who are deaf and acquisition of sign language is impeded [question for key informants perhaps].

Consumers may not know sign language well for various reasons; language disfluency proportion of MH pop is even larger in this area and difficult; service providers can work with this, this is a very big deal in mental health services to deaf, substantial need, ability to be engaged in non specialized services questionable.

Anita asked about cultural competence/focus groups beyond deafness with regard to ethnicity - issues related to recruitment and openness vs. intimidation in the group (as found in previous work).

Bob - with regard to language, see more Spanish speaking parent/family of a deaf child, can happen with other languages as well. Encounter foreign sign language much less frequently.

Anita asked for their ideas on how to get Ethnic representation? Seen any special needs in recruiting or managing data collection.

Bob - Important to see the focus group as learning *from* deaf people @ core topics to do research and identify the deal breakers to participating. They have done several focus groups where participants were selected based on demographics, e.g. Deaf elders in Rochester, African American, Asian graduate students. The report is completed and they are working on a manuscript. He will send us the report.

Lydia asked Steve to speak to the differences they found between the focus groups that were led by deaf individuals without hearing people in the room vs. the way they usually do it. Having an Anthropologist [facilitator] from outside of community helpful. Have mixed deaf & hearing group analyze. There were differences, but what they are exactly has not been determined yet. Has not been analyzed yet but there are indicators of differences in what was disclosed. "Difficult subject"

Anita asked about their specific availability for consultation and possible mechanisms.

Bob provided a number of mechanisms.

- 1) NCDHR, DWC - where a percent of faculty time can be purchased - such as on grants
- 2) Consulting fees
- 3) Phone calls like this one because they are nice guys
- 4) Contractual arrangement for x,y z services, e.g., NCDHR paid for CDC

Steve emphasized the need to get broad input and identified other resources.

- 1) Melanie Navajo, UC San Diego. (Anita was aware of a paper she did thru Co Rehab) Cancer Ctr, and Sadler, Georgia runs it, does a lot of cross cultural work and Melanie has some experience, qualitative in co. May be worth chatting with her
- 2) Elaine Jones- Ph.D. Nurse hearing U Arizona Tuc, cardio vascular disease/reduction in deaf community. Has sign language. Some qualitative data collection. May be resource as well.

They also referred to NCDHR's cross-cultural competencies/ethics curriculum <http://www.urmc.rochester.edu/ncdhr/training/cross-cultural.cfm>.

Anita - we will review all of this within the context of our objectives, resources - time and budget and determine what is the best work we can do?