The author(s) shown below used Federal funds provided by the U.S. Department of Justice and prepared the following final report:

Document Title: Next Millennium Conference: Ending Domestic Violence; Essential Components of Collaborative Research

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Document No.:   184563

Date Received: September 27, 2000

Award Number: 1999-WT-VX-0002

MS. ROSEN: ...with domestic violence since 1981, and I've

worked in two different shelters, both in the Lansing area.

When I was at the Council Against Domestic Assaults in 1981

through 1985, there were a lot of people that would come to

us and request to do research, because we're so close to the

university. A lot of graduates would be wanting to do

research or to work on a dissertation or sometimes students

just working on a paper would want to interview people and

maybe meet with two or three survivors. So there was quite

a range with the type of research requests that we got.

I have a history with -- I got my bachelor's in social

work at the time that I started at CADA and I knew nothing

about research. I learned a little bit of methodology

courses and stuff, but nothing really, and then later I got

my masters, but when I first worked at CADA, I knew nothing

about research, and so I was in no position really, to

assess what type of research we should take on or not, and

really none of the staff were, and we didn't have any

protocol there in terms of how to handle it. The way it

worked is somebody would call on the crisis line or would

contact a volunteer or staff member at CADA and say hey, I

want to do research, can I come and do it at your shelter.

What we basically did very informally is whoever was asked

would bring it to the staff meeting and the staff would
usually delegate one or two staff to meet with the person
and then come back to the staff and decide whether to take
it on or not. We're really service providers. We don't
really know a lot about all the details about how one
conducts research and all the issues, so for us to review
that without really thinking about it, it was really quite
dangerous in the 80's and 90's, but we did it, and I'll give
you --

As I said, I'm not much of a researcher, but I'll give
you a couple examples of damaging research that some of you
might be familiar with. In the 80's, of course, there was
Gallison Stress that showed through the studies that women
battered as high a rate as men, if not higher, depending on
the study, and they used the conflict tactics scale, and
they didn't really look at the intent of the violence and
they didn't really look at how ones self reports or reports
one's partners violence. We don't really know -- I don't
know if there's a study that talks about -- if anybody knows
-- the difference in gender in how one reports violence for
yourself or your partner, but we certainly know that there's
a difference in when one is victimized with violence, how
much you report it versus if you're a perpetrator of
violence. When you're a perpetrator, the denial level and
the blaming other level is real high, and so when you're

dealing with interviewing perpetrators and victims, right

there that sets up real inaccurate information. So that's a

real damaging study for us service providers and for

battered women and for researchers, because people are

convinced that men are battered at as high a rate if not

more than women, so that's one example.

Another one that I remember that -- this was in the

90's, when the issues of domestic violence in the lesbian

and gay communities started to be discussed. There was an

article I read not too long ago, and I'm sorry I can't quote

who it was, that talked about a student who was just at a

university and she did a paper and she interviewed lesbians

who were battered, and she documented within her paper the

rate of battering that occurred within the population that

she interviewed. Another researcher took her study, somehow

got hands on her paper and quoted that and compared it to

rates of women who were battered by men and made the claim

and published it, that lesbians batter at a higher rate than

the battering that occurs in a heterosexual relationships.

Then somebody went and discussed that to the student who

wrote the paper and she was like no, that's not even where I

went with my research and that's not even accurate, so

that's another example of how those of us who aren't

researchers can take a fact and assume it's correct, and

there's some real damage to that when you're talking about

domestic violence, because as we know, people don't
understand the dynamics of domestic violence and there's
already enough victim blaming that occurs when you get
research to back up statements that demonstrate that women,
whatever, batter at a higher rate than men for instance.
That can be very damaging to service providers.

Just so I have a sense -- How many of you in this room
are domestic violence service providers? Okay. How many of
you think of yourself as researchers? Okay. That's
helpful. When I was at CADA, we got research requests a lot
and I'll give you three examples of how we handled it at
that time. With one example, we really didn't take part in
the research. In another example, we took part very
minimally, and in the other example, we took on a
collaborative relationship with Dr. Chris Sullivan, and I'll
briefly explain the different examples.

With the one research where we didn't really -- We
decided as a staff to not take it on. It was somebody that
was doing research and her premise when she was doing the
study, was that women who were battered are more depressed
and have a lower self esteem than women who were not
battered. I wasn't really clear if her premise was that
that's why they were battered, or if battered women are more
depressed and have a lower self esteem. She wasn't really
clear either, but the staff didn't feel like we could take

part in research like that, because she didn't have any real

understanding about what domestic violence was, and it felt

like the type of research she was going to do, could put the

survivors of people who came to our shelter in danger. Now,

at that time, we just said sorry, we can't help you.

Now, there are things we could have done, and we'll

talk about that after Dr. Sullivan talks a little bit about

the collaborative research we've done. I'll talk about

recommendations we have for you, for those who are domestic

violence providers, and researchers, in terms of looking at

how you can do research safely, but at that time we just

said sorry, we can't help you out. There were some other

options where we could have done the research.

Another example is somebody who wanted to do research

on dreams and she believed that all battered women have

flashbacks and bad dreams because of the domestic violence.

That wasn't my experience with working with survivors, but I

didn't know. I mean we didn't always talk about that.

Basically, what she wanted to do was interview women and she

did have a payment that she could pay them, $10 or $15 for

the interview. We didn't feel at the time that we wanted to

take part in allowing her to have access to all the files

and to call people up and have contact with our residents,

but we didn't want to discourage. There might have been

some interest there for people who are survivors to take

part in that kind of research, so we posted a flyer. I mean that was an option that we decided to do. It was in our shelter and in the counseling room. We just said if you are interested in taking part in this study, this is the person to contact.

Now, I don't know, because we never had follow up from that researcher, where that led. She may not have gotten any calls, she might have gotten tons of calls. We did not talk about come back to us in six months, come back to us in a year, share what you've found and we'll keep working on that, which is part of the recommendations we'll talk about after Dr. Sullivan talks. That's another example.

The third example is -- When did you approach CADA?

DR. SULLIVAN: In 1982.

MS. ROSEN: In 1982, and I started there in 1981, so it was soon after I had started with CADA. Chris Sullivan contacted CADA and was actually involved, and she'll talk a little bit about that. She was very involved in CADA. She decided she wanted to approach the staff and talk to us about doing an advocacy project, very in depth. I mean we're not talking about just interviewing a few people. We're talking about real in depth survey, and it has led to wonderful things and a wonderful, collaborative relationship over the years, which has continued since I've moved on to a different shelter within the same area, MSC Safe Place.

I've continued to be effected by the different research that

she's been involved in, in terms of having the clients at my

shelter now, have contact and be interviewed and stuff. So

with that, I'll turn it over to Chris Sullivan.

DR. SULLIVAN: I'd like to just talk a little bit about the

research that Holly was just mentioning. I have to come out

here and walk a little bit, because I am an academic and we

can't talk without walking back and forth. When I first

approached CADA, I was a graduate student at Michigan State

in community psychology, and some of the tenants of

community psychology are that we believe in doing social

action research. Not research just to gain information, but

to really try to make a difference, to create positive,

social change. We also believe that research should be

collaborative, that the people most effected by any social

problem are really the experts on that social problem, not

necessarily someone who simply received training in various

methodologies and how to do data analysis. We really do

believe that you get better research if you collaborate and

that you don't want to just care about the research process,

but that when you're done you want to know that you have

tried to make social change and hopefully have been

effective at that.

We also believe in what we call the competent

community, in that we look at people's strengths and we look

at community's strengths and we try to build on those

strengths, instead of the more traditional psychology which

is looking for deficits and trying to change those deficits.

That was the framework that I had, and I knew that I was

interested in trying to work in the area of ending violence

against women, so that's why I approached the Council

Against Domestic Assault and talked to the staff there about

can I volunteer and start talking with women and see where

this leads. I went through the training program, I

volunteered a lot, I ended up facilitating support groups,

and all the while I was talking with the women and the staff

and the volunteers to really educate myself about the issue,

because I knew I wanted to use research to create social

change, but that was all I knew at that time. At the same

time, I was reading the academic literature, which in the

early 80's, there wasn't that much of it. I probably read

the fifteen things that were out there, and of course, they

were all talking about these rather pathetic women with low

self esteem who simply needed to change their cognitive sets

to learn to leave this abusive relationship. Then I would

go and meet with women in the evening and realize that these

were some of the strongest, most courageous women I had ever

met in my life, and I couldn't figure out who these

researchers were doing their studies on, because it

certainly wasn't any of the women that I had had the

pleasure of talking with.

In talking with women over time, it became clear, as it became clear to all of you, that there were a lot of commonalities, and that what a lot of women were facing was that their communities were not supporting them. They were calling the police and the police weren't responding, prosecutors weren't responding, there was insufficient, affordable, low income housing, no child care, no transportation. You know. I don't have to tell you.

That's where we decided to focus. Women were telling me while I'm here at CADA, I have all these services and all this support, but when I leave, I feel like I'm sort of dropped in this void. Of course, this was the early 80's, and we didn't have a lot of the non-residential and ex-residential services that we now have. So that's also a historical change.

At that time, I was familiar with the project through Michigan State, where we were training under graduate students to go out in the communities and work with adolescents who had gotten in trouble with the court system. So I was familiar with a way that you can train under graduate students to be social change agents, and I talked to the women about that and said what would you think about when you leave the shelter if you worked with a student for a certain period of time helping you get all of those things

from the community that you might need. The women that I

was talking with -- I ended up with sort of a small group

that we would meet every week and try to iron out all these

details. They really liked that idea, but together we had

to iron out all the details. We had to decide together how

long would the intervention last, how many hours a week

would they meet with the student, what kind of training

would I have to give this student, because what the women

were really most afraid of was that I was going to send some

pip squeak in to tell them how to run their lives, or

someone who thought that they knew better than they did,

what they needed. We really talked about let's make sure

that's in the training and in the supervision, that the

woman would run the intervention.

My job was to train students, train under graduate

students at Michigan State University in learning about

domestic violence, replacing all the myths they had with

facts, learning about how they could be effective advocates

in the community to make the community more responsive to

women. We believed that the women didn't need to change.

It was my perception that the women were doing absolutely

everything under the sun that everybody could expect, so

there was nothing else they needed to do differently, but

they still needed someone to go with them, to be supportive,

to call different community members on their issues when

they weren't giving women what they needed and because all the women's situations were unique, I wanted to make sure that the training involved, being able to advocate in any number of ways for women, because I didn't want them to just be legal advocates, because not all women use the legal system. I didn't want them to just be medical advocates, because not all women need medical advocates.

The training had to involve transportation issues, child care, health care, employment, education, social support, legal issues, all of those kinds of things so that whatever came up, the advocate would be able to deal with. We decided together how long the intervention would last. We decided on ten weeks, because it seemed long enough to make change happen, but short enough to minimize the risk of dependency on either part, or people just thinking well, we don't have to do it this week because we have plenty of time. We came up with four to six hours a week that they would meet with an advocate, because that seemed a long enough period of time during the week to actually get some things done, but it was also a reasonable amount of hours to expect a student to be able to put in.

The point is we really worked out everything together because they knew what would be realistic, what they wanted, and I knew from working at Michigan State what kind of training I could provide students and what was realistic

from the student's prospective.

I'm not going to get into all of the results of this
research, but I did bring a report on it for those of you
who are interested in the results. The other thing is as
the researcher, I wanted to know if this intervention would
work. If women received advocates, I wanted to know was
that effective in helping them get the resources they
needed, in improving their overall quality of life, how they
felt about things, and hopefully that it would decrease
their risk of abuse because the thought was if women had the
resources they needed, meaning they had the personal
protection order if they wanted it, they had the divorce if
they wanted it, they had access to housing, that that might
protect them from the assailant's abuse.

The only way as a researcher that I could think of to
do that would be to have a control group, which means half
the women don't get the services. Now, this is often where
there's a conflict between researchers and service providers
because the service providers always go that's unethical, we
can't have half the population not getting something, and I
agree with that if the service is already available to
everybody. In this situation, we knew that we'd never have
as many advocates as there were women leaving the shelter
anyway, so we knew not all women would get the services and
it seemed to be the fairest way to decide who would get them

and who wouldn't, would be randomly instead of anybody saying you deserve it, you don't. It was kind of a nice set up to have a control group and that worked out well.

I also wanted to interview women over time. I wanted to talk to them every six months for two years, because no one had done that yet. No one had really asked women themselves what was going on in their lives. We were making a lot of assumptions, but we didn't know for sure, and the researchers at that time were saying you can't do that, this is -- because it was a shelter population, they're low income women, and it's like you're never going to be able to find them over time, because they're going to move a lot. They're low income, so they move a lot. They're escaping a batterer, so they'll move a lot and no one will help you in their family or friends find them because they're protecting them and they don't have phones, etc. Again, I sat down with the women and said how could I find you over time, because I think it's really important to hear from you over the next couple of years what's going on so that we can decide how to help the community become more responsive to your needs.

They helped me design the protocol to find women over time. They helped me realize that you've got to go out into the community, you can't sit in an office and use the phone. We talked about release of information forms, having an 800

number, all kinds of things that are very extensive

protocol. Paying women out of respect for their time and

finding them. Because of that protocol that they developed

-- They really gave me all of these insights. I ended up

getting the money to do the study and interviewed women

every six months for two years and we found and interviewed

94% of them or more at any given time period. That was

because they came up with that protocol.

Collaboration works for everybody. It works for the

researcher because the study is better. I wouldn't have

come up with this intervention on my own, especially if I

had just been paying attention to the professional

literature at the time. I wouldn't have come up with

something that worked. Let me back up and tell you that we

did find out that it worked. That's the good news too. We

interviewed women over time and found that even two years

after getting this very short term intervention, women who

had worked with advocates were experiencing less abuse,

higher quality of life, higher social support and had an

easier time getting what they needed from their communities.

It's very exciting partly because we know a lot of

shelter programs, a lot of domestic violence programs are

doing advocacy and everyone always wants to know is this

working. Now at least there's some evidence that this

particular program did work. That kind of collaboration was

helpful for me as a researcher, because I was able to have a
strong study. I was able to find women over time, to make
sure that I could trust the results I was getting. Of
course, if you can only find 60% of your sample, you can't
really trust what those data tell you, because the 60% you
found is going to look real different from the 40% of the
women you didn't find. That's why it's very important if
you do research over time that you talk to everybody.

It was good for the women because we were able to come
up with a program that women found effective. Now we're in
the process of trying to disseminate that program in various
areas. It was also helpful for CADA, because one, they
wanted to expand services for women, so they were excited to
support something that was giving women more services, but
also a couple years into the research, I was able to sit
down with CADA staff and write a grant proposal for a new
position at CADA for a full-time advocacy coordinator,
because we had reason to believe that this was helpful to
women and they did get money for that position, which is now
an institutionalized position at the program.

Collaboration works for everybody when it works. It
just makes sense. It's not just the ethical and right thing
to do, but it really does pay off for everybody. I want to
give you one example. When we talk about collaboration,
there's two different things that can occur. One is when a

researcher approaches the domestic violence program and
wants to do their own thing. The other thing is when the
program is looking for an evaluator. There's a little bit
more out there on that and we're not going to talk as much
about that today, but our belief is you still have to really
check out that person.

Just to give you an example of some collaboration I did
a couple of years ago, where I was approached to be an
evaluator was the Pennsylvania Coalition Against Domestic
Violence. They were looking for someone to help their
programs figure out how to look at outcome, outcome
evaluation. That's the big thing now. Everybody's freaking
out about outcomes. Somebody at PCADV had heard about my
work, so they brought me in and they kind of checked me out,
read some of my work, talked to people and then decided that
yes, they wanted to collaborate with me, for me to help them
develop outcomes for programs throughout the state. What
that meant -- It took us about nine months to do this,
because we went across the state and met with all the
domestic violence service providers, got their input. Then
I would go away and come up with a draft and share it with
everybody again, get their input, keep sharing it. It had
to go back and forth to come up with some outcomes and an
outcome manual that we knew people would like, that they
would use. Part of that collaboration is now they want me

to shamelessly hock this manual that they have for sale,

that people have found helpful doing outcomes. One of the

chapters in here is on when do you need an external

evaluator and how do you find that person, how do you get

that.

We're going to talk more today about the other

situation, which is when researchers approach you, because

that's one of the downfalls, I think, of all this money

being available. We do have some researchers who never were

interested in this area before, never did anything in this

before because there wasn't money in it and now there is,

and they're coming out of the woodwork. At least with some

of the granting agencies, Violence Against Women Office, and

National Institute of Justice, those folks are saying it's

got to be collaborative research, you've got to get out

there and collaborate, as opposed to when they used to at

the last minute say could you sign this support letter.

It's happening more and more and a lot of people are having

negative experiences.

As Holly was saying, a lot of service providers don't

know how to recognize really bad research. Holly and I and

the Michigan Coalition Against Domestic and Sexual Violence,

have been working to create a protocol that some programs

might be able to use when they're approached by researchers

to really have their own internal review process to decide

whether they want to work with this researcher or not.
We're basing that in part on a wonderful theme that Susan
McGee wrote that we made copies of for everybody, that also
talks about she has some guidelines of what she makes
researchers go through who want to work with her at her
program at Ann Arbor.

I'm going to turn it back to Holly, who is going to
talk a little bit about where we're at with this current
protocol.

MS. ROSEN: There are two documents that we're going to hand
out related to that. One is this green flyer from Susan
McGee and also this packet here that is our draft protocol.
It's in draft, because we've just been working on it for the
last few months.

I just want to say that we were very lucky with Chris
Sullivan. She went through our training and we trusted her.
We said go ahead, do this support group. We felt that she
understood the dynamics of domestic violence and was not
victim blaming and was very aware of the community in terms
of it having an important role, of whether they're
supportive or not for battered women.

Those of us who are advocates, or who are domestic
violence providers, I know that if you've done it for more
than two years probably, you kind of look at people as
either getting it or not getting it. Like if you're

involved in -- I mean when you start out with volunteers at

the beginning of your training, maybe this many of them kind

of understand the dynamics in domestic violence and the

victim blaming. A lot of people just don't understand. I

didn't before I started this work. By the end of the

training, hopefully everybody gets it and if they don't,

they'll get it before long.

When you are involved in community work, in terms of

collaborative community coalitions or responses -- whatever

you are doing with your prosecutors and police and all the

people that you're working with, there are people who get it

and people who don't, and then there's people who get it

sometimes and then they say these victim blaming or whatever

responses and you're like they don't get it, I thought they

did. Your trust in them drops a little bit. That's the way

we are when we work with domestic violence survivors,

because all it takes is a few victim blaming comments or

responses from the community to shut a door for that women,

and the same thing is true for researchers.

It's really important for those of you who are

researchers to try to get it. Some of you may already get

it and that would be because maybe you grew up with it or

you knew somebody, but even that doesn't guarantee you get

it. Maybe you've worked with it or been trained in it or

volunteered in it at a shelter or whatever. It's real

important for researchers if you're going to approach

domestic violence programs, to show and demonstrate that you

understand it. We probably trusted Chris Sullivan more than

we should have, now that I know more about it than I did.

Chris would, while she was doing research with us, she'd

sometimes hear about the graduate student who was

approaching us and she'd say let's look at the implications

of that one, and she'd help us process as a researcher, kind

of how to respond to other researchers that came to us with

a request and it was very fortunate, because it really -- we

took a big risk and it could have backfired big time on us.

I think it's important as those who are working with

victimless prosecution, they look at safety first before

prosecution. I think for the research, we need to look at

safety first and then research outcomes. I think it's

really important for us to look at that. This handout here

kind of has some step by steps to think about if you're the

researcher or the provider, to consider. In some

communities, it will be easier to implement this than

others. This is just a draft and things to think about.

One thing to think about is if you are aware of any

researchers within your region, and that could be like Chris

Sullivan in Lansing, Michigan, that could be part of this

region -- If you know people who have done research or you

trust people because of the papers they've written and they

know about research, that's somebody to contact and talk
about whether they would be willing to be on our review
panel. If there's any way that you could have a review
panel in place, especially if you're in a shelter or program
near a university that approaches you a lot, it's probably
in your best interest to come up with a plan before you're
approached and think about how would we handle it.
Sometimes when you have a research request, they really
pressure you and it's hard to pull together something.
DR. SULLIVAN: You must collaborate quickly.
MS. ROSEN: To think back, how many researchers would do
what Chris did, in terms of going through our 40 hour
training, working in the shelter, going to support groups,
talking to women, taking back some ideas and then talking to
women again. I mean that's really, really good excellent
collaborative work, and not all researchers are not able to
do that. A recommendation in Susan McGee's and it might be
in ours is that any researchers go through your training, if
not all of it, some of it. The domestic violence 101
pieces, they should at least go through that at a minimum.
Then if they're able to volunteer a few times, it makes a
difference. To do that or to do ride alongs. Those are the
kind of experiences that really change your prospective, so
that you get closer to getting it and maybe you get it right
away.

Getting back to the review panel. While we were talking, Chris Sullivan and myself and the representative from the Michigan Coalition Against Domestic and Sexual Violence, we were trying to think who would be on this review panel, what's a good idea, and having a researcher is probably a good idea, because those of us who are service providers just don't always get it in terms of the research part. It doesn't have to be someone in your community. With the type of communication we have now, with teleconferencing, e-mail, whatever, you can communicate and have some kind of review panel that doesn't have to meet face to face. A researcher on there is a good idea.

Having someone from the service providers in the area or region is a good idea. If you have an active state wide coalition, domestic violence and sexual assault coalition, having a representative perhaps who would be willing to be on a review panel would be wise, and then having people from your program and having women who are formerly battered or who are going through your program, if any of them are interested in being on a review panel when it's needed, so that when research comes to you, you can sit down, get the information from the researcher, go to the review panel, get some ideas, get back to the researcher and go from there.

We also included a sample application that the researcher could fill out. Now, I didn't know what human

subject approval was before all this, but any researcher
knows that you have to get human subject approval when
you're doing this type of research. Any university or
research institute or place that would oversee the research
would have a human subject's approval board or group and you
as the advocates or domestic violence providers should see
the written documentation that there has been human subject
approval. I mean I certainly wouldn't have thought of that.
That's in there too. Having them go through things that
they would agree on. For instance, Chris Sullivan has
always been very open with our staff when I was at CADA to
say this is what we have found in our research and in
practicing with us on the conclusions before publication and
then as it goes to publication making sure that we get
copies and that we get that feedback. I think that's really
important to have researchers agree that if you are going to
do research at our program, you're going to have access to
our files, you're going to have access to our clients, that
when you get the results, that we can have input as to how
we're going to conclude those results.

If you know about research, you know that you can draw
thousands of different conclusions from it. It really
depends on your prospective and how you analyze the data.
For instance, the study that showed that women batter at a
higher rate than men. If you really look at the dynamics of

the behavior within the violence, you could draw a totally

different conclusion. It's really important to have

providers be involved in the conclusion drawing and to have

the researcher agree that if you disagree with the

conclusions that the researcher comes up with, that they

would put that in writing within the research outcome. That

this is the conclusions that we came up with, those who are

involved, we acknowledge that MSC Safe Place and the Council

Against Domestic Assault provided us with access to clients

and they disagree with our findings. At least then when

people are reading it they can see that okay, not everybody

agrees with it and it gives a different prospective on it.

That's another thing.

Safety is really important. This is what you get in

the training. When you first start volunteering at a

shelter and you have to return a call to somebody who has

been coming to the services, you're just going to pick up

the phone and dial them and ask if Chris there, even if some

guy answers the phone. Who is this. Okay. You might have

just put Chris in danger, because the assailant might have

answered the phone. When you're in training you understand

that there are certain safety issues to consider when you're

calling a woman who is being battered at her home or at her

place of employment. For me, I learned 15, 18 years ago if

I call a woman and a man answers or even a woman that I know

isn't her voice, I'll say is Holly there and they'll

immediately, no suspicion, they'll say sorry you have the

wrong number and they'll hang up, and I don't have to think

of the name because it's my name, and that way I don't even

-- It's not even hi, is Chris there, no, who is this, I'll

call back later. Then he's like who just called you, some

woman called you, and then there's suspicions and

accusations and stuff. That's a dynamic that those who do

advocacy for women who are battered know. It's a given.

If you're a researcher and you aren't trained in that,

how are you going to know that. That's just one example.

Caller ID puts a whole other technical -- When caller ID

came out, we had to have a lot of staff training, some say

what's the implications of this, blocking if you're calling

from home, because you don't want people to know what your

home number is, that kind of thing. So there's a lot of

implications that you have to look at.

I think that's it since I'm running out of time. After

your presentation, we'll open it up for questions.

MS. CHINO: I'm going to talk a little about collaborative

research, but I'm going to come from my experience in Indian

country. We have done a lot of research with tribes. I am

a tribal member. I'm also a researcher, I'm also on the

IRB, so I've seen research from many different prospectives.

I wanted to share some of the things that we've learned

along the way, because right now there's a big push among tribes to really limit research and restrict research and to develop tribal research protocols, which is a really good thing because a lot of damage has been done. Because we're at this end of the continuum now working on restricting research and developing research relationships, I think we can really share some of what we've learned along the way with people who are still kind of on that journey. I call this lessons from Indian country.

I thought I'd start with a couple definitions of collaboration. This one is a really good one. Collaboration is a mutually beneficial and well defined relationship entered into by two or more entities to achieve results they are more likely to achieve together than alone. I liked it because they talked about mutually beneficial and relationships and achieving things more than they could achieve individually.

I also found this definition which I like a lot and I think is probably a lot more descriptive. Collaboration is an unnatural act among unconsenting adults. No matter how we choose to define collaboration, I think everybody will agree that it's not easy, it's very difficult as one very astute focus group person said.

If collaboration is so difficult, why do we need to do it? Why are we bothering? Other than the fact that federal

funding agencies are now saying let's collaborate, there are

other really important reasons to collaborate. For one

reason with domestic violence, there are multiple

manifestations of domestic violence. It's not a simple

cause and effect relationship like it is with some other

research issues and research questions. It's very complex

where there are causes of domestic violence we don't even

understand yet, and the manifestations go beyond physical

causes and injury to emotional issues, social implications,

political implications. Not only are we talking about an

issue that results in injury and death, but it's also a

criminal issue. So as researchers, we really need to keep

all this in mind.

It's also a sensitive issue as everybody in this room

knows. I mean it effects us emotionally and it effects us

physically and it effects us in many other ways and we have

to acknowledge and understand the fear, the guilt and the

confusion that may surround this issue for both participants

and for researchers.

Domestic violence is also a multi disciplinary issue.

Again, I'm probably preaching to the choir here, but every

time you begin to address the issue, you have to include

health and justice and social services and education and

employment. It effects every facet of our community and

almost every facet of our lives. The impact goes far beyond

just the individual. It effects the individuals, couples,
families and entire communities. There are really important
reasons to get everybody to work together on it.

A couple of reasons why it's so difficult is for one
thing we're bringing a whole group of people together who
have very different prospectives and very different
perceptions. We all may have that same common goal to build
healthier communities, but we have different ideas about how
to get there and different ways of understanding situations,
no matter how much we know about the issue. We also have
opposing self interests. Many of us do this work for very
personal reasons. I mean I'm one of those people who does
this work for very personal reasons, and my reasons lead me
to look at maybe this piece of the issue and somebody else
wants to look at that piece of the issue. Participants have
their own reasons for participating in research and we have
to honor and acknowledge those differences.

Researchers and researching collaboration is also about
power and control, which is interesting, because domestic
violence is also about power and control. Any time you get
human beings together there's going to be some struggle over
power and control issues and we have to acknowledge that
within the research setting and within the collaborative.

What have we learned about collaborative research in
Indian country, and we're still learning. We're still on

our journey, believe me. Many tribes have come together
now, because we've had to. We've seen the devastation of
domestic violence in our community and we don't have always
the expertise within our communities to address this issue
effectively. We also have a history of turfism between
agencies that are funded from several different sources that
don't want to give up scarce resources to work together.
There's a fear of coming together. There's a history of
disagreement that have gone on for generations. It really
forced us to kind of rethink the issue. We also, as Indian
people, had to call in researchers from the outside and
believe me that's really scary, because these people have
done so much damage to us in the past, how do we rebuild
those relationships.

I'm going to talk about three of the main lessons that
we've learned. One is that we need to recognize the
different needs that exist between the community, the
research community, the providers and the participants. We
need to learn from our past experiences and we need to build
collaborative relationships between communities and
researchers. We've learned that yes, we have to do this.
We cannot do it ourselves. We cannot allow researchers to
come in and do it without us. We have to have that
collaborative relationship.

When we're talking about different needs -- I just

really took a leap here and tried to sum up what researchers
want and what communities really want. I think maybe this
is okay, because on one hand researchers, we really want to
understand the big picture. We have feelings, we have
ideas, we have things we want to test and we want to be able
to generalize to other populations. Communities want to
know what's happening within their communities. Providers
want to know what's happening with the women in my
community, what's going on here. They really don't care
about things as much that are going on in other parts of the
country, so there's a difference right there. Researchers
want participation. We need that sample size. The more the
merrier. I mean it's really important. We really want that
powerful end. Communities, they want respect for the people
who are going to participate in the research and I'll talk a
little bit more about what respect really means, and
researchers want publications. I'm not trying to be flip
here, but we really want to share what we've learned and we
want feedback from the academic and the scientific community
and we want to know -- this is what we've learned, let's ask
the next question. Communities want solutions. They want
to know how to solve problems and they want strategies for
solving them. Right up front, we have very different needs,
and if we can acknowledge them and understand them, then we
can maybe begin to address some of the issues together.

Briefly, the history of research in Indian country has been, like I said, devastating, but it's helped us to define kind of where we've been to where we want to go, and I think this probably holds true for a lot of communities where research has come in. At the very bottom is what we call safari helicopter run research, where the researcher comes in without asking, takes what they want, goes off, publishes and nobody ever hears from them again. I think fortunately, we're getting past that a lot. The next level up in acceptability is the research reports back results. Unfortunately, this doesn't always happen and we still have to remind them can we please hear back what you found. The next level is the community and the researcher negotiate what we call quick pro quos. It's like well, I as the researcher, will come in and do this for you and in turn, can you help me increase participation, can you help me understand some of the issues, define the context, things like that.

This is kind of where we're at right now, but we really want to progress even further. We really want to get to these next three steps if possible. One where the community and the researcher both build capacity. We don't just do things for each other, we learn from each other. The community gains skills, research skills and information, and the researcher gains skills about the people that they're

working with, and they gain skills about the issue. Like
Chris and Holly said, make the researcher attend the
training. They should learn as much as they learn from the
community. Even going beyond that, ideally, the community
and the researcher should be partners. They should come
together and develop the ideas together, but ultimately what
we're trying to reach for in the Indian country is where the
community determines and initiates the research and then
solicits the researcher. Ideally, for tribes that will work
best, but this is -- we're working in that direction and
that's not always true, but if we could at least try to get
to this point, then we could probably get a lot more
effective research done.

When we collaborate on research, who benefits? I think
everybody benefits. The participants benefit, because they
have a chance to learn something about themselves, their
communities. They have a chance to be altruistic
ultralistic and participate in something. Researchers
benefit. The quality of all our research when we
collaborate with a community goes up enormously. I mean
what we learn, it may be more difficult, it may cost more,
but we learn more, and the communities ultimately benefit,
because the participants have learned something, the
researchers have learned something and the community should
hopefully benefit from our results.

Basically, collaborative relationships should promote
mutual achievement. We all gain from it. It should
minimize harms. Here, I'm talking about risks from
research, and I'll talk about that in just a second. It
should also maximize the benefits. I mean it shouldn't just
benefit the researcher, it should benefit everybody, and it
should increase scientific validity, acceptability and
feasibility. When we put out a publication as a researcher,
it should -- we should know the context in which we
conducted the research. We should know our community. The
community should have had involvement in interpreting the
results and in helping us write the paper.

Collaborative relationships should educate the
communities about the value of research. This is really
important to me as a native person and as a researcher, I
really get hurt when my other Indian people say to me no
more research, we've been researched to death, and it's like
but wait, give me a chance. Also too, this is a chance to
educate researchers about communities and about the value of
community participation and what people can add other than
just being another number.

What are the essential components of collaborative
research? I think these are the basic building blocks.
First you've got to trust each other, and this isn't easy.
You can't just walk in and say I trust you. This is a

process and I'll talk about that in a minute. We also have

to define the common framework. Chances are --

(END SIDE A, TAPE ONE)

MS. CHINO: ...and asking the community to participate and

respond. I think the researcher really has to be as up

front as possible and share as much information as possible

to make sure the community knows they are being responsible

and they are being accountable. Participants in communities

can also take responsibility in making sure that everybody

is included, that everybody's differences are honored, that

the community has input. The communities can be a lot more

proactive in making sure that the research is useful, not

only to the researcher and to the community as well. There

really needs to be a balance between the self interests and

the health interests.

We have our personal reasons for doing what we do, but

there are also the larger health issues, and we really need

to honor both. I can't just go and do a piece of research

and feel good about it unless I address some personal issues

maybe along the way, and we have to realize that a lot of

people may have that. People who participate may

participate because they're personally touched by the issue

and we have to honor that as well as the fact that they want

a healthier community as well.

I could go on for days about research ethics and

sometimes I do, but I won't here. Holly and Chris mentioned

the IRB process and human subjects protection. The key

element of that is informed consent. Informed consent too

often, you hear researchers say well, I'm going to consent

them and then we'll do the research stuff. Informed consent

must be a relationship. This is such a wonderful

opportunity to get to know your participant. This is not

just the participant saying okay, I agree to participate in

the research. This is where you explain what you're doing,

why and how it will benefit them, potential risks, potential

-- things that could go wrong, things that they should be

aware of. This is your chance to hear from the participants

as well to see do they really feel comfortable doing this

and honor them if they say no, and if people say no, maybe

you need to rethink your research design. This is a chance

for dialogue. I really push an effective and informed

consent process. Yes, we have federal requirements, but

let's think of it in terms of a relationship. It's not just

a negotiation. We're really building a relationship here,

whether you're going to be together for five minutes or it's

a long term study and you'll be together for years.

Another ethical issue is that as researchers

particularly with domestic laws, we're going to have access

to very sensitive information, and no matter how many

waivers of confidentiality we find, no matter how many

promises we make, there's always that risk to participants

and especially to communities that there will be some

negative results back from the research, that something will

harm somebody along the way, because the information is so

sensitive. That also links to confidentiality and

anonymity. How do we protect the people that we're working

with. An issue is protecting the community as well, because

we've had incidents where researchers go and public some

horrific data about name the tribe and so everybody in the

world gets this misinformed opinion about what this tribe is

all about, and what these people are all about, and it does

not honor the people who live there and it is not helpful.

We really have to understand how do we get the information

we need and give it back in a good way and not harm people

along the way.

Another key ethical issue is the perception of risks

and benefits. As a researcher I may think this is harmless,

I'm just going to ask you a few questions about your

relationships, but to a participant, this could be

devastating. It could bring on flashbacks. It's more

obvious, I think, with medical research. A blood draw may

not be anything to the researcher, but when you line up a

bunch of six month old babies and want to do a blood draw on

them, you're going to have a lot of screaming and crying and

upset parents and maybe they don't see the risks and the

benefits the same way you do. This is a matter certainly
for negotiation and something that really needs to be spent
a lot of time on. This is also the piece that will build
trust. If you want to build trust between the researcher
and the community, take a lot of time working on these
ethical issues. Really sit down and pay attention to them.

There are also contextual issues that researchers need.
Again, I think the burden is on the researcher, but the
community here can be very helpful, and the participants can
be very helpful in defining what the social, political and
cultural context of the community is, because otherwise you
remove the research from the context in which it occurs.
You're looking at behaviors and things that happen, but
you're taking away half of what's going on if you don't
acknowledge the social context and if you don't respect the
social context, and certainly, particularly with tribes, if
you don't acknowledge the political context of what's going
on and don't respect it.

Another contextual issue is definitions
interpretations. Even if everybody speaks the same
language, we are all going to interpret things differently.
We are all going to have different ways of defining things.
So take some time. Sit down and talk about what the
definitions are. Talk about what the interpretations of the
data and the results mean. As researchers, you will learn

more from your communities than you probably will from your
colleagues about how things can be interpreted and the
community will also learn from you as researchers different
ways to interpret things.

Another contextual issue is support for the researcher.
Here, I mean who's funding the research, who's driving,
because this can impact your research. If the Department of
Justice is driving your research, then you're going to have
a justice focus. If the CDC is funding it, you're going to
have maybe more of a health focus. The community needs to
understand this and together make sure you honor your
funding agency, honor the community and honor the research.

Another contextual issue is what are the risks for
stigmatization. I mean how sensitive an issue are you
dealing with, how much depth are you going to get into and
what is the potential. Not just researchers to participant.
Even if I take no identifying information from this person,
will my results stigmatize this family. Will my results
stigmatize this community. These are really challenging
questions for researchers and sometimes we have to give up a
piece of the research to protect those who have contributed
to it.

There are also participatory issues, and again this is
another -- This will address that common framework, that
second building block. If you sit down and work together on

these, you will have a common framework for --

Another key piece is the participatory issue and here's where the actual collaboration comes in. If you've built the trust, you have a common framework, how do you work together. This means talking about who is going to be included, not just the participants, but what other agencies are going to be included, who from the community, who from the local government, how are people going to be included and at what point in the research. Does everybody just come in for the data collection or is everybody part of the process from day one through the publication and beyond. Who is responsible for clarifying those roles and responsibilities. That's what a collaboration is all about, everybody has something to do, everybody knows their role, everybody contributes and everybody benefits. Who makes the decisions? If the researcher is making all the decisions it's not a collaboration. If the community is making all the decisions, it may not be a collaboration either. How do you work together to decide that.

Just for you non-researchers, data management really matters. Information sharing is really important. How do we communicate as researchers and as community people what we need, how we need it and how can we get it in a respectful way. How can we do this? It sounds really good. It sounds like well, we just sit down and talk. How can we

do it? I don't have an easy answer, but what I thought I'd

share with you is a process that we've been using that I

personally learned about a few years ago and I've

incorporated it into almost everything I do because it's

just so darn youthful and I thought I'd share it as a

framework for beginning to think about building

collaborative relationships.

There are four basic steps and they have to go in this

order or it probably won't work. The first thing you need

to do is you need to build relationships. If you go in and

say we're going to do research now, you're not going to get

anywhere. You have to go in thinking I'm going to build a

relationship with this community. Communities reach out to

researchers. We want to build a relationship with this

research community. After that you have to build skills.

We all know a lot, but we all don't know everything we need

to work together effectively. We may need to work on things

as basic as communication skills. How are we going to share

information, how are we going to talk to each other, how can

we better understand what we need.

We can also build practical skills. We can build

skills in the communities. If you need people to help with

data collection, teach community people how to do it. I

know graduate students are nice and cheap. Let's teach

community people some skills. Let's help them become good

researchers.

The third step is to promote interdependence. This is the actual working together piece. How do we maintain effective working together? We come in and everybody contributes, everybody benefits. We honor and respect the individual things that each of us bring to the process. We all bring different skills and we have to recognize and acknowledge that. The fourth step is to promote a commitment to it, and that comes from paying attention to the first three steps. If we have a commitment to the research, to the process, to the issue, we encourage that and we promote that, and that will then lead around to building new relationships as we grow as researchers in communities.

Building relationships is about inclusion. It's about trust, it's about open communication and a respectful environment. We don't even talk about the research right away. We talk about who we are as human beings, how do we want to come together, how do we want to be together, how do we want to respect each other, do we respect each other, why are we there. That's what building relationships is about. It's creating a safe place to do effective research. It's creating a place where everybody feels comfortable, community, participant and researcher.

Building skills is about interpersonal communication

skills. It's about how we talk together, how we share
information, everything from data management to talking to
participants and making sure our informed consent process is
-- I'll talk about that -- is working the way we need it to.
Building skills is also honoring the differences and
maximizing the abilities and contributions of everybody.

Interdependence is recognizing the mutual reliance we
have on each other, valuing all the contributions, solving
problems and making decisions together and promoting
responsibility and accountability. The commitment piece
means reciprocity, that back and forth. We all have to give
and we all get to receive. It means even after the research
is over, continued advocacy and support, and it means
focusing on both short term and long term results.

A successful collaboration builds on self interest and
health interests, it bridges research communities and
regular communities. It honors the differences from both
sides. It focuses on the process and it insures adequate
long term support to the community. That way we don't do
that dropping in, helicoptering out.

I brought a couple of slides about some of the research
we've been doing, mostly to show why research is really
important. This is just one slide from one study that we've
done at the university that looked at the domestic violence
homicide rate. One thing we found out that we didn't know

before this study was that the legality of domestic violence

is horrific for native women. We are really at high risk

for dying. Our injury rates are higher and our death rates

are much higher. This really raises the red flags for why

isn't there a more concerted effort from the state and from

other agencies to address this. So there is a value to

research. I'll skip the other slides that are basically the

same kind of thing.

What I wanted to do in the last seconds is one of the

most effective collaborations that the School of Medicine

has done in the past couple of years is the intimate partner

violence death review team. What we did was we used the

child fatality review model and we brought in -- We brought

in participants on the fatality review from all aspects of

the community. This was a true collaboration. We had the

police, we had the Indian health service, we had Pueblo

legal services, district attorneys, Morning Star House which

was the native American advocacy and shelter service for

Indian women, we had Coalition Against Domestic Violence &

Sexual Assault, their local shelters, the Department of

Health. We had many people coming together to do these

death reviews.

What we did was we had case scenarios and everybody

would bring their information about the case, because these

were deaths, we had public information. We had the social

worker who may have worked with the women bring her
information. The police officer who worked with the woman
brought in his information. What we did was we learned one,
about all the different things that went on before the
death, at the time of the death and the results of what
happened to the perpetrator. We also identified the gaps in
the system and could make recommendations specifically. In
this case, law enforcement, if they had done this, we may
have prevented that. If social services had been able to do
this, we may have prevented it. If the health care
community had done this, we might have been able to prevent
this.

It was very helpful to us not only in identifying the
risk factors, but also in identifying the gaps and figuring
out what can we do better next time to prevent this. This
was our famous collaboration. I brought only about 25 of
these, but if somebody wants one and there isn't one left,
I'll mail you one. This talks about the collaborative
effort and the results of the death review committee, and
I'll stop there. (applause)

MS. ROSEN: We have a lot to talk about. If you have
questions or discussion, if you have case examples that
you've been dealing with, or if you have potential
strategies that you might have used to solve them or perhaps
not solved them.

...: I have a question for Chris. Are you finding at all that your research is attacked or subjected to criticism because of the collaborative nature that you've used to develop it. I'm thinking specifically of the fact that when one departs from the status quo, people begin to accuse of bias, etc., forgetting that working actively to maintain the status quo is bias as well.

DR. SULLIVAN: Yes. That's a really good question. If you collaborate as a researcher, do you end up being basically denigrated by your peers and does your research get trashed. I've been fortunate with my research, because I have an experimental design and it's longitudinal and it's a large end. Researchers can't say anything about it. They have to like it. That's a really good point, because that's true and that's something to think about as far as why some researchers don't want to do this. It doesn't enhance their career for the most part. There's still a lot of fields where the belief is research needs to be objective, value free, and I certainly just believe that that's not true, that there's never value free research. My perception is that if anybody comes to you and says I'd like to look at this, but I need to be objective and value free, I wouldn't work with that person personally, but that's certainly something that does come up, yes.

...: _____ at the university where I obtained a Ph.D.

and I'm finding that they're not actually, in my opinion,

tough enough in criticizing research _____ I actually

think it has implications for anybody to go in _____

that they're not thinking about the payment issue, when we

talk about doing _____ they're not thinking enough

about the kinds of risk losses that we should be providing

to women and not thinking about _____ follow up. I'm

wondering if you know of any IRB's that are working to

educate themselves on the issue or anybody _____ the

goal.

MS. CHINO: The Indian health service IRB is -- At the

national level, we have really worked very hard and we've

managed to really annoy a lot of researchers along the way,

but we think ultimately it's for the benefit of everybody.

We make sure that we have community members on our IRB at

all meetings. We don't have a quorum unless we have a

community member. We have non-medical people. We have a

full array of people and we take all perspectives into

account. We still have a long way to go, but I like our

IRB, because we're over cautious and too many IRB's are not

cautious enough. I would be unhappy if I was in another

IRB, but I know we're kind of one of the few that are really

working hard on protecting people.

...: I was thinking of that and I think it's important that

it be in your protocol or community's programs. I know my

experience is they _____ in my research.

MS. CHINO: The university IRB isn't as concerned as the

Indian health service IRB, so what do we do.

DR. SULLIVAN: We think that you should see the person's

human subjects approval, but you shouldn't assume that that

means much. I think that's an excellent point, because

universities don't understand. A lot of universities will

say you're just going to call women, great. Even some

funders, I've seen that with National Student of Mental

Health, National Student of Justice, some researchers there

reviewers there don't get it either. It's something, but

it's not enough, and the IRB is an institutional review

board for those of you who don't know what an IRB is.

...: _____ but the National Crime Victimization

Survey is _____ right. _____ talk about a way

to gather data and this is the way _____ I'm a

researcher and we've been part of doing focus groups around

the country with practitioners about their relationship with

researchers. Practitioners with domestic violence and

sexual assault, criminal justice, public health. One of the

-- We're also trying to find out when has the collaboration

been good, whether it's been negative and how the

practitioners use research in their work and we found that

there's plenty of examples of these drive by researchers. A

lot of people will call up, particularly graduate students

and _____ and want access to your clients or let me do

this and people have been _____ out. What we found

from the practitioners side, and we've done 15 focus groups

around the country, is that a lot of practitioners for

example, wanted help from researchers about how to evaluate

the fact sheets that you have to send out when the state

legislature calls you or the _____ have to respond to

legislation. I wondered if you all had found the positive

dimension other than what you said working with Chris, where

you have interacted with researchers where it's been

valuable or where you would want _____ where you think

research could enhance some of the work that you do.

MS. ROSEN: Yeah, the fact sheets you have to update every

year or every few years and use outdated research dates and

try to figure out where it came from and all that stuff. It

gets complicated. Personally, the shelters I've worked with

have not utilized a lot of local research to gather those

kind of statistics, but there is a value to having access to

good research to support the work that we do. It's just

hard to find the research even that does that. I mean it's

really hard to find. I don't know if that's what you were

getting at. If more of us had relationships with

researchers, we could probably have access to more -- Like,

you know more of the research that's out there than I do,

and create more research that's more valuable. There is a

potential to have more value, valuable relationships. The
reality is -- I don't know with those 15 focus groups if you
did DV focus groups, sexual assault, health or if you just
did 15 mixed, but I would be interested -- I would think the
domestic violence and sexual assault programs trusted
researchers a lot less than medical for instance, because
you're dealing with a lot of history of mistrust and
reinforcement of a lot of myths that we're trying to combat
just on our daily jobs. So researchers have to do a lot
more to get our trust than if you were a doctor where you're
doing research constantly with new drugs and -- I mean
that's part of what you do in the medical field. Research
is a part of your daily reporting to patients and you have
to stay up to date with it. Domestic violence workers
don't, and we don't trust you guys, researchers. You have
to prove to us that we can trust you. There is a value in
that relationship definitely.

...: There was nobody medical on the research. Just
personally some of the ones that I did, the ones in
Massachusetts where I live, there's a saturation of
universities. Those folks are like bombarded by requests to
open up their files, their meetings and everything else. In
Florida, it was like being in a different country, because
they would clamor for participation with researchers,
because most of the sexual assault programs had never had a

relationship with researchers except University of Miami

Medical School. It was really like being in two different

countries talking to the same folks who work in sexual

assault programs. I think we have to take into account what

it's like to be in a university town where the state is

saturated with academic institutions versus places where

there's not.

MS. ROSEN: That's a good point.

...: I have a question about when you're doing your

research -- I feel really uncomfortable with _____ to

go to the files. I think that's really _____ that's

probably my most _____ about women and the

confidentiality _____ that they allow that to happen.

I think that one of the things that happened the last couple

of years is that _____ critical analysis of advocates

to _____ never allowing people to go to a woman's

file. I really feel uncomfortable with that and find that

to _____ That's what happens when you go to a program

and it's very _____ was she raped, did she call in

time, did she call the police, what were her injuries like,

how many times was she in the shelter _____ That is so

intrusive in her life and we're here as advocates trying to

restore that dignity back to that woman and then on the side

you've got somebody doing research and he says let's look up

her file and let's figure out what's going on in that

woman's life, and I think there's something wrong with that

picture.

MS. ROSEN: I agree, and I think that's why we're doing

this, so that we can say providers beware, be careful. We

opened up files to this advocacy research program because

there was guaranteed confidentiality procedures that we

trusted that her folks were going through and looking and

getting information and a lot of the file stuff actually was

follow up. I mean you had already made contact with people

and that was just trying to locate the woman. I don't know

of many programs that do open up their files to researchers.

I'm hoping that isn't happening. I agree.

...: I think that's happening and one of the trends that I

see that _____ because of the money involved

_____ clear and simple. One of the things I see

because of the money is _____ is that there is just a

rampant of therapists who are going to communities and

praying on _____ because there's so much money

floating around. That's the _____ issue. One of the

issues is the impact, not money. It's what it's like. I

think that's one of the key ones. I think that's happening.

I think that part of that is that we're not -- because of

this money _____ don't benefit women. One of the

things in the program is -- I was so frustrated because

_____ $300 for a woman to get _____ one day. I

was so frustrated, because all these millions and millions

of dollars are floating around, but we can't even get $300

for a woman to get _____ There's something wrong with

this picture, you know. _____ have all this research

just happening ____._____ where do you go and it's like

these things are more _____ in women's lives. For

some reason, we have other ideas about what needs to be

researched. I'm so disturbed by that.

DR. SULLIVAN: I agree with that and I think that's

something we should really be disturbed about, because I

think you're right. I never used to hear so much about

researchers wanting access to women's files until Stop

Grants and all this other Violence Against Women Act money.

Personally, I think it's unethical ever to give researchers

permission, because the program doesn't have permission to

do that. As Holly was saying, I looked in women's files

after they already agreed to be participants and said yes,

you can look in my file for information to find me, but

that's real different from just going through a shelter and

going let's look at how many women were sexually abused as

children and let's look at how many had drug problems. That

kind of thing I think is completely unethical.

MS. CHINO: It violates the consent process. I mean that's

what informed consent is all about to try to make sure that

doesn't happen.

...: _____ to have a woman call me and say I don't

understand what's happening to me _____ interview the

researchers and they were like _____ The thing is the

women didn't even understand what was going on. There's

such a need for _____ to do that and the need for

_____ what this means to their lives and the

information about their lives _____

MS. ROSEN: The hard thing is while they're receiving

services, there's often confusion of is this part of my

service provision, is this required and if I don't take part

in that, will I be able to stay here. You have to make sure

that if you involve researchers while people are currently

receiving services, that they are very clear that they have

the option to say no and that this is not going to effect

their stay at the shelter or their involvement in the

program. I think that a lot of people don't think of that.

...: I had a couple of questions. One was how many people

here are coalition people? Are there any coalition people?

That second _____ at least in South Carolina, we don't

-- I mean we're starting to do collaborations with research,

but we're not doing a whole lot and I think because we're

not into that _____ our membership, that we are in

position to actually do this kind of research real

effectively. That was just an observation. The other thing

is -- My observation and the ability of funds and the number

of people that are coming out of the woodwork, there was an

observation made that we're professionalizing in a way that

_____ this mental health template on our services and

how we do things that doesn't really fit, and when we're

starting to talk about research, another concern that I have

is that we're putting a template on that doesn't address all

of the nuances of the community that you're servicing. I

have a concern that there aren't enough African American

researchers. I mean because you ask different questions.

We know that when a man asks questions -- We see the

literature coming out, the whole Cobra and -- Anyway --

(laughter) It pisses me off. When you have literature like

that and there's more and more money available for people to

really kind of exploit it, which is what she was talking

about, exploit a community, and we don't have enough people,

I guess my question is how do we get more _____ I mean

obviously you're not talking about recruitment, but it is a

research issue. Who is doing the asking. I mean I've never

been real _____ about research. It makes me want --

It's a different way of looking at it, because I don't want

somebody interpreting me. It's like they're going to talk

to me -- There was two white women that did a study on black

women and why some black women were _____ and were

they happy, were they not and it's like --

MS. ROSEN: That gets into involving -- If you're going to

be interviewing a large number or even some African American

women, hopefully there will be some of them involved in the

questions. Again, that gets back to the collaborative part

of going to those who you're going to interview and if there

aren't African American researchers, perhaps if the

participants are, definitely have that representation

involved, because I'm sure there aren't many researchers

that are.

...: I have a response to that question. There is a group

called ARAG and I always forget what the other A is, but

it's Applied Research something. It's a group of people who

developed _____ domestic violence, who are trying to

pull together appropriate _____ and they're not all

published and _____ but I'll try to find it for

anybody who is interested. That is a _____ This is

stuff that we as domestic violence providers and coalitions

can trust this research, because it's coming from those of

us who know the fields, but also know research. The other

comment I would like to make is for Dr. Chino. Your

presentation, I think, is one of the finest presentations

I've seen on collaboration in general. We need to think

about research as just another piece of collaboration in the

big puzzle, informed as always by advocates. It was

brilliant.

...: Two questions. _____ talking about community

based research in a typical field. Is it a recognized field

at this point and if so, _____ the larger symptom, for

example, domestic violence _____ people funders to

help _____ to establish a _____ this kind of

research and _____ the population.

DR. SULLIVAN: There is social action research that is a

type of research that's out there. It's not really a field

like sociology or psychology, because within either of those

fields and others, you can do social action research or not,

but it is a type of research that I agree, I think should be

what you use when you're trying to create change in

communities. It doesn't make sense to pull people into labs

and do little things to them to learn much about them in my

opinion.

MS. CHINO: I think also there's been a push from the

funding agencies, because they're heard the participants and

particularly CBC comes to mind. Every RFP they've put out

lately requires community based research, and how people

define it is still kind of fuzzy, but there is a push now

and I think it's a good direction.

...: _____ that you did Dr. Chino, did you --

MS. CHINO: I didn't do it, it was my colleagues.

...: _____ stakeholders with the survivors and the

victims --

MS. CHINO: Yes. Everybody was included. In fact, they

were very helpful in helping fill in some of the gaps along the way and it limited the number of reviews we could do and the number of cases we could bring to the team, but it also enhanced the quality of the information we obtained from the ones we were able to do.

...: Who shared in that _____

MS. CHINO: This was a joint effort between the U & M School of Medicine Department and Emergency Medicine and the Office of the Medical Examiner, and from there it just kind of grew to become this multi collaboration.

...: _____ something else about the concern you raised about the _____ Harvard Medical School, which is not a bachelor's degree, but they are interested in the _____ in trying to find out what would make _____ what are their interests, what do they want to know and _____ people that I respect a lot _____ I think that _____ we don't know clearly what it's going to hold and _____.

...: _____ the federal control of human subjects protection _____ and since that happened there's been a couple of interesting developments. I think that the service providers rely much more in the future on the _____ come from an IRB or an institution or university. Duke has _____

MS. ROSEN: Yeah, it was Duke.

MS. CHINO: It was Duke.

...: _____ the Chicago Tribune either Friday or
Saturday and the headline was the University of Illinois
Chicago _____ stopped every piece of their research.
Their IRB had to go back and review every piece of research
that they're doing, so there's been a giant crack down on
human subjects, and the university _____ I just put a
proposal through this year too, and it ended up -- I called
it Researcher _____ but they at least, had a jump on
it. I don't know how at my institution they managed to
_____ but I think that there's big things happening in
that, in that there's more and more realization _____
ethics area.

MS. ROSEN: I think everybody who works with a researcher
should have a copy of 45CFR46, which is a code of federal
regulations. Go on to the OPRR web site, the Office of
Protection for Research Risks and find out what researchers
should be doing and then you set the standards, you set that
bar how high you want it set so that the researcher is
respectful of what your agency is doing and the people
they're going to work with.

...: _____ controlled by federal law and you can go
on that web site and find out what it is that researcher is
supposed to do. That's an excellent _____

MS. ROSEN: It's out of NIH. It's OPRR, but it's probably

NIH/OPRR, I don't know.

...: _____ human subjects _____ or some

question and that will get you there.

MS. ROSEN: I'm pretty sure it's part of the NIH main web

site.