

NATIONAL PEDIATRIC & FAMILY HIV RESOURCE CENTER

Audioconference

Mothing & HIV: Providing Services for Women with HIV Infection and their Children

September 29, 1999
1:00 p.m. EDT

Coordinator

Good afternoon.

Dr. Sandra Lewis, you may begin.

S. Lewis

Good afternoon. Welcome to our audioconference, "Mothing & HIV: Providing Services for Women with HIV Infection and their Children." This conference is being sponsored by the National Pediatric & Family HIV Resource Center with funding support from the HIV/AIDS Bureau of HRSA, the Health Resources and Services Administration.

Special thanks to Carolyn Burr, Associate Director of the National Pediatric & Family HIV Resource Center and to Karen Hench and Pam Kowalski of HRSA.

I am Sandra Lewis, Psychologist with the National Resource Center. I will be your conference moderator this afternoon.

As many of you know, the HIV epidemic is continually changing, requiring that our service models also change to reflect the needs of women and children, as well as to be responsive to treatment advances. Within pediatric & family HIV, illness in the child has often been the reason families enter treatment. This highlights the multigenerational nature of HIV infection among women and children.

Since early in the epidemic, researchers like Carol Levine have informed us of the need to plan for the large number of children who are likely to be orphaned by the AIDS epidemic. In recent years, the uses of AZT therapy have helped to decrease perinatal transmission. This further emphasizes the need to delineate the care issues surrounding families where mothers are living with HIV and have both infected and unaffected children.

The aim of this conference call is to discuss some of these crucial issues as they arise in the form of children's psychosocial adjustment and women's health and psychosocial needs. In fact, the psychosocial interventions and permanency planning strategies will also be discussed.

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We have pulled together a panel of front-line, psychosocial service providers and researchers with expertise on today's topic. You will hear them respond to key questions, sharing their research, professional, and personal experience with you, our listeners. We are hopeful that this audioconference will enhance the services you provide to families affected by HIV.

Our panelists this afternoon are Barbara Draimin, from the Family Center in New York; Rex Forehand, from the University of Georgia in Athens, Georgia; Beth Kotchick, also from the University of Georgia in Athens, Georgia; Sandra Gossart-Walker, from the Family Support Center at Yale, New Haven, Connecticut; Linda Horton-St. Hubert, a woman living with HIV; and Jan Kriebs, a nurse practitioner from the University of Maryland, Department of Obstetrics, Gynecology, and Reproductive Medicine. I welcome you to our call.

After our conference, we will have a brief question and answer period where you, our participants (listeners), will be able to call in and ask questions of our specific panelists. I will let you know when that time has arrived.

We will begin with the discussion of psychosocial adjustment of children with a question directed to Rex Forehand.

Dr. Forehand, based on your research, how does maternal HIV infection influence children's adjustment?

R. Forehand

Thank you, Sandra.

Let me begin by noting that this is a question which has only recently begun to be addressed. There are only three studies examining the impact of maternal HIV infection on their non-infected children. All three of these have been conducted in the past three years. So, what we're really talking about is a new, but extremely important, field of study. All three studies, not surprisingly, found that children of infected mothers were negatively impacted.

Let me exemplify this by telling you briefly about the large-scale study we've completed. We worked with 250 non-infected children, some of whose mothers were infected and some of whose mothers were not infected. Children whose mothers were infected were doing less well than those children of the non-infected moms in four areas of child adjustment that are often examined whenever we study children. These four areas are externalizing problems, things like aggression; internalizing problems, things like anxiety and depression; social competence, which would be how kids get along with their peers; and cognitive confidence. The best example of this would be academic performance in school.

So, again, children were doing less well in all four areas if their mother was HIV infected. So, what we've concluded is that maternal HIV infection appears to have a rather global affect on multiple areas of children's adjustment. However, there are three, additional, very important things that we need to point out.

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The first is that the vast majority of children in our project had not been told that their mothers were HIV infected. What this suggests, since they were doing worse in terms of their adjustment, is that it's not really knowing that your mother is infected that causes difficulty for children, but rather other changes in the family, like parenting, that takes place with HIV infection.

Second, the magnitude of the effect of maternal HIV infection on children's adjustment is moderate. In other words, like most family difficulties for children, whether it's divorce or parental depression, maternal HIV infection does negatively influence the children's adjustment, but it by no means incapacitates them. They go on with their lives, but somewhat less effectively.

Third, all of the children in our study lived in an inner city environment where many, but certainly not all, women who were HIV infected live. Inner city children are faced with poverty and violence and many other adverse conditions. These conditions resulted in both groups of children in our study doing less well in terms of their adjustment than would be expected. Thus, for many children living in families with maternal HIV infection, the infection is just one of many difficulties many of these children face. In other words, it makes an already difficult situation even more difficult.

S. Lewis

Thank you, Dr. Forehand.

To Sandra Gossart-Walker, what psychosocial issues do you find in children affected by HIV?

S. Walker

Thank you, Sandy.

In my work with children affected by HIV, I definitely see a lot of the things that Dr. Forehand just mentioned. There's quite a variety of psychosocial issues that I've seen although the issues of loss and grief, as well as issues of portending loss and multiple loss, are quite significant for these children. Many of the psychosocial issues that I see are often related to factors associated with HIV disease, such as poverty and substance abuse, which, I think, is what Dr. Forehand was talking about before.

We need to remember that a lot of these children often experience numerous losses. Some are related to the disease itself, such as loss of a healthy parent, the deaths of more than one parent, or significant family members, and also other losses, such as multiple moves because of changes in caregivers. These losses also resulted in loss of a friend, support systems, and schools.

A lot of the kids that we see display their psychosocial struggles through acting out behavior or depression and, at times, even over-compliant behavior in their attempts to make things better. I think that's something that we often ignore is the very, very good kids. We think that they're coping fine, but in fact, they're really hiding a lot of the struggles.

The other kind of psychosocial issues that we see are kids that have to deal with their issues of secrecy and stigma. As I know as going to be discussed later in today's call that

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disclosure is a powerful topic when talking about HIV affected kids. Many of the kids are not told about the disease, yet many know that there's something very wrong in their families, but they're not allowed to talk about it. They're not allowed to know about it. Many are not allowed to ask about it.

Lastly, there's also concern about who's going to take care of these kids. Permanency planning can be quite complicated, leaving these kids feeling unsure about who will take care of them.

S. Lewis Linda Horton-St. Hubert, would you share with us how we can support families' efforts to normalize their lives? What specific support you feel children need?

L. St. Hubert I think, as Dr. Forehand and Sandra already said, I think a lot of it is based on social things that they deal with as well as providing families with the avenue where they can even begin to identify what is normal, what is our definition of normal, or what is normal with their family lives. If we can provide settings where families can get support counseling through social work, therapeutic sessions, or whatever, so that they can be able to begin to address because – and I believe it was Dr. Forehand said, HIV is only one of many abnormalities in most families that we're dealing with. To be able to address how we begin to work with families individually as unique entities that they may be is the first piece, I think as well as how to specifically support children. We need to be able to, again, in addressing with families and, as someone was talking earlier about earlier disclosures, we can work with families and supporting families around earlier disclosure. I know, for myself and other women that I have talked with about the issue of early disclosure, and I know there's no study around it, but most families who are able to disclose earlier to their children and be able to provide support services and to be able to get their children involved with other families that are diagnosed with HIV have experienced and expressed to me having better outcomes. Being able to bring them to social events where there are clinical, community settings is showing them – so children can see the positive sides of HIV versus maybe the rumors that go along the school and some of the things they may see in the media. So, I guess I push for earlier disclosure to be able to support families doing that.

S. Lewis Thank you.

Beth Kotchick, continue with the thought that Linda just shared with us. How can families that are affected by HIV infection facilitate the adjustment of children within those families?

B. Kotchick Well certainly, based on what the other presenters have already noted, many of these families are already facing a host of chronic and discreet stressors. As Linda just mentioned, trying to kind of normalize the family experience. One family's strength or resource that can serve as a buffer against those various stressors that they're facing, including maternal HIV infection, are parenting skills.

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We have found that parenting is one of the most important, protective resources for children in families faced with maternal HIV infection. By parenting, specifically, I mean, two aspects of parenting that are really important. One is that there's a consistent, warm and supportive, parent-child relationship. The second is parental monitoring of children's activities, knowing where your kids are when they're not at home and who they're with and what they're doing.

These parenting skills are important for all kids, no matter what the circumstances. We have found, in our study sample, that they are associated with better adjustment across the four domains that Dr. Forehand originally talked about. These findings were true regardless of whether or not mothers were HIV infected.

However, we did find that HIV, like other stressors, served to disrupt parenting. The HIV infected mothers, in terms of the parenting aspects that we were measuring, were demonstrating lower levels of parenting in those two important areas. They reported poor relationships with their children and less awareness of their children's activities outside the home. So, one area to address, in terms of providing services to families dealing with HIV, is to strengthen parenting skills, and to provide a supportive network and social support network that will allow parents to tap other resources to enhance their relationship with their children and to have them be more effective monitors of their kids' activities.

S. Lewis

Thank you, Beth.

Sandra Gossart-Walker, could you add any other type of mental help interventions that you've personally utilized to support children and the outcome of those?

S. Walker

Well, I think the children, as Beth was just saying, need a variety of services. Some kids need things that just normalize their lives, like recreational opportunities or mentoring opportunities. Other kids need things that are much more HIV specific, especially for those kids who know about HIV in their family. So, that might be a support group. Other kids in families may need some more formal, psychotherapeutic services.

In our program, we provide home-based and community-based, mental health and support services for children and families affected by HIV. Overall, the intervention is aimed to support families in staying together. Our child and family therapists go out to the children and their families rather than waiting for them to show up in a traditional mental health or child guidance clinic. This means that the therapists meet with the children in their homes, in their community centers, or in the schools.

Sometimes, the home isn't conducive to therapy. So, other options are used. Flexibility is, basically, the rule. We try to meet the families where they're at. So, families and kids may be met in a park, in a McDonald's or Burger King, or even in the office with the therapist providing transportation if that's a problem.

Obviously, here, therapeutic boundaries does become an issue. This arrangement needs to be explored in supervision – and with the child's family.

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Our program, specifically – we provide a range of mental health services, including individual therapy for the children, family therapy, psychological testing, psychiatric consultation, and parent guidance. Permanency planning is also an essential piece of our work. We provide community-based support groups for HIV-affected kids and for their alternative caregivers, meaning aunts and grandparents and older siblings.

S. Lewis Sandy, what would you say has been the outcome of at least one of these interventions, particularly, let's say, doing therapy in the home or a McDonald's?

S. Walker Well, we don't have any formal outcome measures, but what I do know anecdotally, and personally from working here, most of the families that we get referred to us are often labeled non-compliant or treatment resistant, two terms that I don't like. But, I find that if the therapist goes out to their home that I don't think I'd be over-exaggerating if I said that there's a 90% compliance rate. For the most part, the caregivers (the moms, the grandparents) do want their children to receive services, but they have such overwhelming other needs that getting to therapy is too difficult. So, if the therapist comes to them, most of the time they are available.

S. Lewis Thank you.

Barbara Draimin, continuing along those lines, what ways can providers and agencies actually help to facilitate children's adjustment?

B. Draimin Well, I can certainly take off on Sandy's, "We do it at McDonald's;" but, I would start by, "The Family Center treats the family as a whole although not necessarily together at the same time." What that means is that we're very committed to the parent or caregiver and all the kids in the family. If it's a caregiver who's taken two of her sister's children after her sister died of AIDS, and the caregiver has two other children, we wouldn't think of only treating the two children who were orphaned from AIDS. We would only think of treating all four children and the caregiver. That makes a very big difference to the caregiver because they are trying to recreate a new family as a whole.

In the same way that Sandra mentioned, we think that any clinician needs to visit the home and the community at least once. Actually, we do 90% of our work in the home because it's so hard for a parent who's ill and has three children to come see us.

We find it very important to address the needs of the parent, particularly because so many of the parents have never seen or experienced good parenting themselves. So, as an example, we had a Christmas party with 500 people. When the parents showed up with their children - we had about 15 art tables for the children, the parents said, "Where are the art tables for us?" Or, when a buddy goes to pick up a child in a mentoring program and takes them to a movie or a library, and the parent says, "Can't I go, too?" So, the parents have a lot of needs, which is very important for us to address as well.

The kids also need their own programming. Of course, the traditional and obvious kind would be support groups and individual counseling. But, the less traditional that we're finding possibly more effective in at least the outreach and recruitment phases, are activity-based groups, like summer camp and adventure groups - high and low ropes; skill-based

programs, like a video group, where a group is making a video, or computer classes where they come after school here to the family center; and the mentoring, or Big Brother/Big Sister/Buddy-type program.

Two more points: one is I think support for staff is very necessary because they witness so many angry and frustrated parents. So, they need support in their ability to help the whole family. Lastly, as Rex and others have mentioned, illness is just one factor, but drug use and multiple sex and relationship partners create a lot of chaos for the children at the home. So, this means we really must address issues such as drug treatment, relationships, and parenting.

S. Lewis

Thank you very much.

Giving the point you made about the fact that the parents came and asked, "Where was our art table?" – I think that having considered the needs of children, it's time for us to turn our focus to their mothers and her needs, both as a woman and as a parent.

So, the first question I'll ask to Jan Kriebs. What are some of the issues women may bring to care that impact their willingness to receive services?

J. Kriebs

Well, first let me say that, as a midwife, I sometimes find myself in the situation of giving someone her new diagnosis even before she becomes a mother. I see that well after the birth of her child she's still dealing with her own issues of accepting her infection. So, one of her issues may well be that she is still struggling to face these issues and bringing her child to care, much less bringing herself to care. Brings it back up to her.

Additionally, these moms who do often have just basic needs, like transportation, access to their clinics, may, in balancing their needs and their children's needs, put their children first. In fact, I commonly see that we have moms whose kids come to clinic and the mothers come back for their care when the pediatric clinic staff reminds them that they also need care. So, one issue is just balancing.

Another issue is previous experiences the woman may have had. We hear stories of prejudice even from clinicians who ought to know more than they reflect back to the patients they care for. If you're not sure how you'll be treated, or if you believe that you will be given negative messages about yourself, why should you go for care? With moms whose first experience of HIV may be around a pregnancy, many of those mothers get negative messages first so that that carries over into their perception.

These moms also may not be ready, psychologically, to walk through a door that says, "AIDS Clinic." I know that the labels on the door don't really say, "AIDS Clinic," but in the women's minds, they often do. So that finding a transition into care where they can feel safe, respected, confidential, is an important part of helping to maintain women and let them feel safe receiving services for themselves.

Finally, I think that that piece about continuity can't be stressed enough, that all of the care providers be aware of the family as a whole so that women and their families are not repeating their story to every new clinician they see.

- S. Lewis You also made an important point when you said that women first come to HIV services often at the point of pregnancy, which brings up an important question, which is that there are reproductive concerns which women may have. I'd like you to comment on what might be the reproductive concerns and special health issues that need to be addressed with HIV-positive women.
- J. Kriebs Well, first, I think it's important for us to acknowledge that women with HIV are very like every other woman who makes a decision, consciously or unconsciously, to bear a child or who finds herself pregnant. The mothers that I have worked with want their children for all the same reasons that the rest of our mothers do, yet often get a disproportionate, negative message around childbearing. So, we have a responsibility, I think, as clinicians not to prejudge either people's intentions around childbearing or their ability to effectively have a healthy pregnancy, maintain the medication or other regimen that's going to help them bear a healthy child, and realize there are many other chronic diseases that carry as much risk, if a different type of risk, to a child they might bear. So, many women are now well-informed and may choose to have a second child even though that may be hard for some of their caregivers to hear.
- The other thing is that women with HIV are no less interested in sexuality than many other women. These are women who are, quite probably, going to maintain a relationship of some type or another, sexually. In many of them, they are caring relationships. I think we have to be careful, recognizing as we do, that these may be women with multiple partners, but they may equally be women in a committed relationship. Not all contraceptives work equally well in women with HIV. For example, I don't use intrauterine devices with these women. Some of the medications she may be switched to may conflict with her oral contraceptive, making it less effective. So, that as clinicians, whether we're seeing the mother or the child, we need to provide the same kind of health messages we would provide to any mom about the importance of planning a family and making conscious decisions ahead of time about whether or not to bear children, about how to protect oneself effectively against an unintended pregnancy, and about getting prenatal care whether, it's an intended pregnancy or an unintended one.
- S. Lewis Thank you.
- Linda Horton-St. Hubert, what do you see as the issues that are most central, or important, for mothers living with HIV infection?
- L. St. Hubert I guess in agreement with Jan, whether women are infected or not, I think the most important thing that I, in talking with other women, hear is that women take care of others first - natural caregivers for whatever reason. But most women, when I'm talking about HIV, I hear most women talk about HIV not necessarily being their up front-type issue in their life. They're really looking at the day-to-day needs of their family - women trying to make sure that their family is secure, that their housing and food - those are the primary things that they have to do on a day-to-day basis. Actually, women, whether they're using drugs, whether they're not using drugs, or whether they're infected or not, making sure that their primary needs for their children are taken care of. Again, when we're talking about women who have children that are affected, around the issue of their permanency planning,

what's in place? What's not in place? I don't know how to do any of this, so where can I get help with doing it? Where can I get help doing it that's going to work with me. A lot of women talk about people going to people for help with things like that. People are trying to do it for them versus trying to show them because it's important. I know myself as a mom it's important that I make those types of plans. It's important that it be my decision. Making decisions may be new for some of us – making good decisions and having the support to be able to do that, that's what I really think the most important issues are, making sure their households are in order.

S. Lewis Along those lines, you made an important point that women often take the role of the natural caregiver and certainly making sure that their children's needs are met.

Jan, in your work with women, how does a woman's health influence her relationship with her children?

J. Kriebs Well, if you think of it purely from a medical standpoint, HIV may not, for a period of years, have a large affect on that relationship. Eventually, if moms are on complicated medication regimens, the side effects of those medicines, or the side effects of HIV, may leave her unable to participate in some kind of activities for their children, or with less energy. But, I think, the other issues goes all the way back to what Rex started out talking about, which was a negative impact of HIV of children who didn't know the diagnosis yet. I found myself wondering if he was talking whether we have data that compares the children of HIV-infected moms to the children of other mothers with long-term, chronic, potentially fatal illnesses. Because we see the issue of stigma or negative perception in so many areas around HIV care that it made me think that, perhaps, some of these issues with children picking up on the family mood, if I can use that word, may have some other commonalities that we may not always acknowledge as clinicians. I think that there are a couple of key points for us to remember as clinicians.

One of those is to always individualize our assessment when we're providing clinical care to moms and children and be sure we're not making assumptions that are based on HIV as opposed to based on the mother's medical and psychological health generally and to positively validate things that moms are doing right. These are systems issues, to look at how our interventions promote or interfere - what messages do we send?, so that we work individually in clinical settings to improve that relationship between health and ability to parent effectively.

S. Lewis You, along with the other presenters today, have hinted at the issue of disclosure and how that might impact children and the relationship between mother and child.

Barbara, a mother's choice to disclose her HIV diagnosis to her children can be on a continuum from not disclosing at all to giving the child some limited explanation of illness to full disclosure of HIV infection. In your experience, what influences a mother's approach to disclosure of HIV to their children?

B. Draimin I think mothers wisely choose a number of factors that help them decide. In our research, when we've looked at what parents tell their children, it's not an all or nothing. We've actually looked at five, different steps, one of which is, "I tell my children nothing;"

another of which is, "I tell them I'm ill;" the third of which I tell them, "I'm seriously ill;" the fourth of which, "I tell them I have an illness that I might die from;" and the last, "I have HIV or AIDS." So, I think we have to look at it right away from a continuum. When we're discussing the whole disclosure issue with parents - explain to them how many different choices they have along the way.

Just to give it a little context, from our research, we've found that about a third of the moms have told none of the children, about a third have told all of the children everything, and then about a third tell some of the kids in their family, but not others.

The other important point about context is that we know what mom has said that she has told, but we don't know what the kids have heard or what they remember. So, we have an example of a child in our video who came to the video and was asked, "Well, what is it like for you that your grandmother, who takes care of you, has AIDS?" She said, "I'm not really sure. She told me she was sick on the way here." The clinician said, "Oh! Is that the first time that you knew?" She said, "No, she's told me a few times, but I keep forgetting." So, we put all this emphasis on disclosure as if once a parent says something, then it's clear a child understood exactly what they said, when, in reality there are big differences between what parents say and also what children hear.

The other example is that there are many parents who will tell us that they have not told their children anything, but we don't know because, of course, we can't ask what their children actually know from the fact that they see all their medications or from the fact that they attend clinic with them.

Well, how does a mom or dad decide whether to tell? It's in combination with our workers who, I might add, do not ever lean on one side or another toward disclosure, but are only there to help the parent and the mom, in particular, decide what, if anything, and when, if at all, she wants to talk about her illness with her children. The parents decide usually based first on age. How much will a child understand? What's the best language for me to deliver anything I want to say? Will my child re-disclose to others?

The second factor is other losses. How have they reacted to other losses from possibly death of another parent or grandma or an uncle or a sibling?

The third is severity of my illness. "I think I'll wait until I'm more ill," or "I think I should tell them now based on the fact that I'm not ill."

The fourth is whether or not there are others with HIV in the family. That is another parent or a perinatally infected sibling.

The fifth is, "Have I told others in the family beside my children? Will those people I have told support my children and help them if I should decide to disclose?"

The sixth is, "How mature is my child?"

The seventh is, "Has my child ever initiated the discussion, or is it only me who initiates? Have they asked any questions? I think I really better learn how to respond."

The last and final one, which is I think very complicated is, “What roles have professionals made? Have professionals told me I ought to disclose? Have they cautioned me against disclosing?” We have found that an active professional sometimes encourages people when families aren’t ready and sometimes discourages them because they are reacting against it. So, I think we have to pay a lot of attention to the role professionals play in how a parent decides. Ultimately, we believe strongly that it’s the parent’s decision. We should support any way that they make that decision.

S. Lewis Jan, given that mothers make various choices about disclosure, how do a woman’s choices about disclosing diagnosis influence her own health?

J. Kriebs Well, in the first place, women may be less likely to seek effective care if the treatment she receives will inadvertently disclose her status to anyone, but particularly to her children. These mothers often bring children with them to their visits because they don’t have reliable daycare. So, she may not be willing to come at all. She may choose a different place to seek care. She may elect episodic care rather than a steady, more health-giving regimen so that the issue of her status may not come up. She may also change how she communicates with her care provider, particularly if she believes we will react negatively to what choice she has made. So that you can find yourself in a setting where you can’t get the mother to come to you for care, or where she chooses a less beneficial setting for care or a less effective therapy so that it doesn’t give away her secret. Or, she may not tell you the truth about how she’s feeling if it’s going to suggest to a child in the room with her that there is something wrong.

Also, her emotional and her psychological status are going to affect day-to-day issues that are going to affect her health. If you’re depressed, you don’t eat as well. You don’t go out and exercise your body. You don’t participate in daily activities that are positive. You begin to, I think, set up sort of a negative feedback cycle. So, you can’t discuss things like that with your care provider if there are children around who might hear. So, again, you have that feeding in.

Finally, I think there are some non-medical kinds of care, for example, getting on to a special housing list, that women may not ask for or may not accept if they believe that in doing so they will reveal themselves to others in the community or risk their children finding out from a third party what’s going on.

S. Lewis Rex, would you like to add anything from your work regarding a mother’s disclosure of diagnosis to their children?

R. Forehand I think I could just echo some of the things both Barbara and Jan said. Disclosure is a very complicated issue. In terms of examining what the effects are on the children of a mom with HIV infection, disclosing to those children, it’s really in its infancy – that the research in this area. Our work, again which is based on relatively small samples because most moms do not disclose, but it indicates that disclosure really doesn’t appear to be associated with a child’s adjustment, but I think that’s a very tentative finding.

What is the most important point to make, though, I think, is that what is very important is timely functioning, like how moms parent and how much social support they provide for the child. So, I think that the emphasis, and I think this goes along with what Barbara said about supporting parents' decisions whenever they choose to disclose or not disclose, is exactly the right one: that we want to support parents when they make those decisions. Then, we want to emphasize to them that it may not even be the most important decision. The important decision really is your relationship with your child and being there for your child to the extent you can.

S. Lewis

Thank you.

You made an important point that family functioning is key and relating to the child and shoring up and supporting that family relationship is key to functioning.

I'd like to begin discussion of some of the family meetings and family interventions that have been successful by asking Linda to share with us what kinds of support or services she feels are needed by families where a mother has HIV infection and the children are uninfected.

L. St. Hubert

Sandy, I may have to definitely start off saying, again, that having on-going, supportive counseling services for mom – and I always say that and I always tell people the best thing happened to me when it was very early on in my diagnosis ... that I had issues beyond HIV and introduced me to a counselor. It was a place where I could begin to address me and some of the things that kind of impacted my life. So, it also gave me avenues to be able to see what my child needed and how to change some of the norms that I may not know how to do. Parenting classes are definitely types of things that I did early on. Again, being able to get parenting classes in a safe and in a non-judgmental type of thing – that is, parenting class not as a negative types of view, but very much – like, let's just say, early on HIV, being viewed very positively.

Also, as they were talking about earlier, moms taking care of themselves, the issue of childcare, being able to have supportive childcare. When we're talking about affected children, a lot of places where, if your child is infected, they may have childcare and they may have mom care as well at that particular setting. But as for myself and a lot of women, when our children are diagnosed uninfected or never been through that perinatal process, when I go to the clinic, there's no type of environment where I can take my son and he not be affected or hear something about HIV or whatever. So, even being able to open a door for women to be able have support in adult-type settings for childcare where children can be not so much around adult conversation because it's not always a problem bringing the children to the clinics with them. Sometimes, I don't want them to hear what other people are saying around them because I have been in parenting classes. I don't say, necessarily, how those kinds of conversations around my children, but I don't want to expose them to those types of environments. As well as the ability to have more social-like events with children. Because, again, being a parent whose child was diagnosed unaffected, when my child turned 2 ½, we were recommended to go to a private pediatrician or whatever, it also disconnected my son for any type of social event that happened with the normal people who are affected by HIV because we're no longer connected directly with that pediatric world. So, you were having events around that that

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children can be involved with as well as talking to moms who have kids that are infected as well as uninfected.

The issue comes up and...two children say to me – how one child may give so much attention. They get to go to camp. They get all these other services. I've had two kids say to me, "Well, I probably would go if I had HIV." That's a real alarmer to me when we're talking about young pre-teens thinking that because so many services and things are available for their sibling, they're getting nothing. They're going to the bus every year while the sibling goes off to camp and comes back with all of these toys and gifts and wonderful stories. Every year, because of the poverty levels, they never get to go anywhere. There are Christmas parties. There are all types of things all year long happening for their siblings who have this terrible disease, but getting all these wonderful rewards. That's always a problem as well as to be able to help some of the kids that also are uninfected with mentor-like programs, as someone was talking about earlier. I'm always trying to get something going, some type of mentorship. Again, someone else that they can look to, someone else to come and help mom with the kid because there are different stages in mom's disease. She may feel good. She may have med. There may be days ... beyond the Buddy that can come and teach my child beyond what's happening in our direct community who can take them and give them dreams and plant seeds into them of knowledge, the new experiences. Maybe my mom and my sister can't do it because they're caught up in the same mess that I'm in, but who's are they willing to give their time to this child to be able to impart some things in them that they otherwise may not have had?

S. Lewis Thank you very much.

Rex, I'm wondering if, in your research, there have been any findings regarding the needs of families where mother is HIV infected and children are not?

R. Forehand Well, let me begin by saying that I think anything I have to say pales in light of what Linda has to say with her experiences. So, I would like to begin on a positive note by pointing out that there are several things that one might think would be needs in the families we've worked with, which actually ended up being met by the extended family. That is, extended family members, particularly grandmothers and aunts of children are often very involved in the life of the children we've worked with. These same family members are often the choices of the mothers to become caregivers for the children after her death. For those mothers who, unfortunately, have died during the course of our project, these grandmothers and aunts actually have become the caregivers. Importantly, they plan to permanently raise the children.

Furthermore, in many of these cases, these new caregivers are able to provide a very stable, home environment for the children. As a result of all this, most, with only one exception – none of the children that we have worked with over the last six years have ended up in the custody of the state. So, that's the positive side.

However, there are also some unmet needs. One of these is that although children are ending up in the care of the relative, the mother actually won't care for the child. There appears to be little, long-range planning in coordinating with these relatives. I really

believe that there's more planning if we, as mental health professionals, can help mothers plan. This would facilitate the children's transition to new caregivers and the children's adjustment. Thus, some long-range planning is needed, but there are also, I think, three other, maybe more, immediate needs.

One is that we need to recognize the adjustment of children whose mothers are HIV infected may be disrupted even if these children themselves are not infected. This means we need support programs for these children. As Linda said earlier, parenting programs for their mothers and also, in addition to their future caregivers. In other words, a service is needed which integrates support for children with both current and future parenting.

A second related, unmet need is that extended support in the parenting of childcare areas is needed for mothers who are HIV infected. Fortunately, as has been noted several times, women who are infected are now living substantially longer than just a very few years ago; however, the changes the immediate emphasis on services. Some planning for children after their mother's death - planning how to help mothers and children through an extended period of illness. This involves coordinating family resources and community services. It also involves very practical issues, like childcare during mother's medical visits. It's already been mentioned. Helping women stay on a prescribed medication schedule for a prolonged period of time.

Finally, let me end by stating that when we ask women with whom we work what kinds of services they need, by far the most common response is counseling. "Someone to listen and support me."

S. Lewis

Thank you.

Barbara, even though women living with HIV are living longer, healthier lives, 80% of them have children who are under the age of 20. As Rex just so keenly pointed out, permanency planning is a need. It has to be an essential part of the services that they receive. How do the issues and tasks related to disclosure impact on permanency planning?

B. Draimin

I have four thoughts on that. Let me just give a little context. In many cases a parent does not need to disclose in order to do permanency planning. So, there is a bit of myth that one needs to disclose first before doing permanency planning. Lisa found that that's not the case. But let me then qualify that with four points about it depends who you are talking about disclosing to.

The first one is disclosure about your illness to the potential caregiver. If your plan is so informal as to say to your sister, "Would you take care of my child(ren) if anything happened to me?", that's not a real plan. Because although it's true that any of us can get hit by a truck and ought to all have a plan, it is also true that someone with a serious illness needs to let the person know whom they are choosing that this is more imminent possibly than chance. So, the first thing is, "Are you going to, or have you disclosed to the potential caregiver?" Without that, I think the plan is very vulnerable.

The second thing is that without any disclosure to children there's going to be no or little input from the children. That's an important part of planning, that they have a chance to say who they would want to live with. Not that you would always choose that, but that you would always have their input. So, it does make it more vulnerable when you don't have their input.

The third point is, "Are you going to disclose to the father of the child(ren)? How is he going to be involved in the plan? Like it or not, for women whose – the father of their child has possibly been estranged from both them and their children, that gentleman has a lot of significant, legal rights. A woman has to decide, "Does she want to contact him? What does she want to say to him?" He legally must be involved, either at the court level or earlier, which is when we prefer to do it to find out what plan he would like for his children and get his say and his needs met.

Lastly, if a child is infected with HIV, any plan that a parent would make for that child would be very weak and potentially jeopardizing that child's health and treatment if the caregiver weren't to know that the child who they were promising to take had a critical illness.

S. Lewis

You made a crucial point in noting that the plan can't be to your sister, "Will you take my child if something happened to me?" I'm wondering, what do you believe are the steps and resources, or strategies, necessary to develop a viable, permanency plan? You mentioned some, but I'm wondering if there are other steps.

B. Draimin

Right. Well, first let me say that there have been about 30 of us who have been working for five years just on figuring out the steps and resources so that I invite everybody on the conference call to either write us or visit our Web site at "thefamilycenter.org" to find out a little more and see some articles printed on it. We do have an article on what ten steps to viability that I wrote with Carol Levine entail; but, let me just give you about five points that we have found very important.

The first one is to assess the readiness, or what I call, "Why don't they want my wonderful service that I have to offer?" Most professionals set up a wonderful service, but the first point is really, "The professionals are ready, but are the parents ready to do the planning?"

The second one is knowing the family, both by visiting their home and doing the genagrams so that you can find out everyone in the family. Even when you know the family through the genagram and visiting in the home, we find lots of things happen, such as sometime we're in the home, someone wanders out of one bedroom into another. One of our attorneys said, "And who might this be?" "Well, he's an uncle who lives in the household." Well, that's a very important fact that we hadn't gotten through our other ways of knowing, so it's very important to know the whole family.

Next we need to coordinate the professionals. Generally, on almost every case, we need three professional involved: a social worker to do the psychosocial, an attorney to do the legal work, and an entitlement person so that both the parents and the caregivers know what entitlements they stand to gain and lose by any kind of arrangements they make. I

think it's incumbent upon agencies to coordinate the professionals and all their different rites and passages and training rather than expect the client to do that.

We have the advantage of having all three of those professionals under one roof at the family center, but I think that if they're under different roofs, that's fine as long as the professionals have made ongoing relationships about how they're going to deal with issues such as information sharing, confidentiality, and other things.

Realistically, it takes us six to eighteen months to do a plan for a parent. I know that when we started, we hoped it would take much less time, but we need to admit that it's complex and time-consuming. We believe that we must be pleasantly relentless in our follow-up with clients - that most parents tell us that losing a child or planning a life for a child without them is the hardest and most painful life experience they've ever had. So, we need to help them through this process and through each step.

We have to assume that, in working with a family, we will probably have to create two to three legal plans. Sometimes we call ourselves the Sisters of Perpetual Planning, but that's because we need to have the energy to help a client identify a caregiver and then find out that that caregiver might not be right and help them to find another one.

So, I invite you to call us or to e-mail us for any of the details that I didn't fill in in that kind of two-minute answer to a long question.

S. Lewis

Thank you very much, Barbara.

Sandy, I'd like you to give us a little bit more of the real world, family life perspective. Describe some of the concerns you have addressed with a family where a mother is HIV positive and children were negative. How did you intervene? What was the outcome of your interventions?

S. Walker

All right. Well, I'm going to describe a family that we worked with for several years, but I must note that every family, all of our families, ourselves, and our clients, are very complicated. So, in two or three minutes, I'm obviously going to leave out a lot of the information. I also, obviously, have changed a lot of the information to preserve the confidentiality of the family.

Very briefly, this is a family that consisted of a mom in her mid-30's who had AIDS and her two daughters who were ages 5 and 9 when I met them. They were both HIV-negative. Mom was diagnosed during her pregnancy of the 5-year-old. The family was referred to me by a case manager from an AIDS, community-based organization because the mother had concerns about both her daughters and how they were coping. The mother had been unable to follow through with other referrals to a local, child guidance clinic. Even though transportation and other kind of support was given for her to bring the children there, she never showed up. She also never was able to follow through with the support at the girls' schools that did have services for families, but she wasn't able to follow-up with recommendations there.

Anyway, the older daughter, who was 9, was mentally retarded and had set some fires. The younger daughter had some problems with lying and stealing and had a pretty serious speech impediment. So, she was hard to understand. Neither child was attending school regularly. In fact, when I had met them, both of them had over 50 absences in that year. They were both, obviously, doing poorly in school since they weren't going very often.

The mother had told both the girls her HIV status several months before I met them at the pressure of her attending physician.

Both girls, after I met them and met the family, joined long-term support groups for HIV affected kids. They were separated by their age. They both did very well in the groups, really connecting with the other kids in the group. They, in fact, attended every single session that there was. I must note that we did provide transportation so that wasn't an issue for the mom at all. She was very satisfied with what was going on in the groups for them.

At that point, that seemed to be enough support as the kids needed; however, a few months later, the youngest child's father died of AIDS after having a really horrible time with dementia where he had become very aggressive towards many people in the family. Soon after his death, the mom called me up and reported that the younger girl had wanted to join her dad in heaven. She had wanted to hurt herself to join him and was playing dead – come in the living room pretending to be in a casket for hours at a time.

We did a quick home visit to do suicidal assessment and initiated individual therapy with the younger girl. This was done both at home and at school, depending on the time of year. She met with her therapist once or twice per week for 1 ½ years. In her play, her therapy reflected scenes of violence and aggression. These scenes seem to really worry her immensely when she would play or write stories. In aggressive and violent scenes, she'd get very worried about what would happen to her. She really struggled with issues of life and death, and good and evil. She expressed a lot of hope through her play that if only she and her sister and her mom were good enough that they would not die and her father would return to her.

We also provided a lot of parent guidance and a lot of parent support. This included helping mom and developing her parenting skills, helping her advocate for her kids at school, and accompanying her to her healthcare provider.

When we first met, her mom had no plans for her kids. She was quite conflicted about where her kids would go, thinking that no one in her family would want to take them because of their problems.

Before mom died, she was able to make a permanency plan for both her kids. She was also able to make several videotapes, including times that she spoke directly on the camera and about her hopes and dreams for her kids and, other times, that she wanted the social worker to videotape family activities that included special things, like a birthday party or outings to the park. But, she also wanted her videotapes to include everyday activities, like getting ready for school or just hanging out in the living room.

Both kids moved in with their grandmother before the mother's death. The grandmother was very open to permanency planning once that was approached to her. Although the grandmother lives more than an hour away from the program, she and the kids wanted our program to continue to be involved. So, the grandmother actually comes down every week for a caregiver support group, stating that she really needs this time for herself. We decided to transition the kids therapy closer to home and found some good therapists up there near them, but we still keep in touch per the girls' requests because continuity seems to be important to them. They really seem to need that connection with the past. Thinking about our program is connected to their mom.

The youngest occasionally tells her grandmother that she wants to join her parents, but her grandmother works very closely with her therapist and with our program about these concerns and ... quite able to allow this child to express her really sad and despairing feeling but is able to keep her safe.

Lastly, although everything's not ideal in this family – there's lots of struggles financially and with all types of support, I think things are as good as can be expected. In fact, kind of the proud thing that this grandmother has is that both kids are doing extremely well in school. Their teachers love them.

S. Lewis Thank you very much.

S. Walker You're welcome.

S. Lewis A very touching story.

You all today mentioned a number of issues and a number of needs that families have. You've talked also about interventions that many of you have implemented to address some of the needs; but, based on your clinical or research experiences, what do you feel are needs that are currently going unmet? Sandy just gave us a wonderful story, telling us about services she is implementing, but what needs might be going unmet? From your perspective, how might these needs be addressed most effectively? Maybe Barbara can answer first.

B. Draimin I have three thoughts. One is that we need to help caregivers and their new families. The second one, as Sandy just described, is the need for the child to stay connected in some way. Some families don't want to be connected to us and want to move on to a world without HIV, but many do want to be connected and do need the support services.

The third one is mental health services, specifically innovative models and not just counseling. We find that when we do the other activity-based groups that that can often be a transition into counseling. And that even though, as Rex stated, moms will tell us that the number one thing they want is counseling, it doesn't mean that that's the way they will necessarily vote with their feet and be able to either be there when we go to the home or come to the center. That sometimes they don't have a strong enough relationship with us or trust us or therapists in general enough and we need to transition it by providing other services.

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Lastly, I think the drug treatment world is very single-focused, but we are all dealing with families. A disease such as HIV, which is a family disease – well, drug use is another disease that's very much a family one. Yet, the models for the treatment world act as if it's just one person who needs to be the target of our health.

S. Lewis Thank you very much, Barbara.

Sandy, do you have any thoughts about this?

S. Walker Yes, I do. Actually, I agree with everything that Barbara said. I'd like to add that, I think, many of the children do need grief counseling. The mothers do need counseling. However, we do have a problem with managed care covering costs. I think many times we think of counseling as preventative. It's hard to bill an insurance company if you don't have a psychiatric diagnosis. I think most of us would like to prevent that psychiatric diagnosis.

Lastly, also, I'd like to kind of reiterate that services must be made available to every kid and to every family and that even though parents and caregivers may want their kids to receive a service, they might not be able to get them there. The kids themselves, obviously, can't get themselves to service. So, the services need to be non-traditional. They need to meet the kids where they're at, whether it's at school, at home, or community centers, in the park, wherever they might be. I think it's up to professionals to take the responsibility to ... in this area.

S. Lewis Thank you very much, Sandy.

Linda, what about you? Your thoughts on unmet needs and how we might address them most effectively.

L. St. Hubert I guess I want to go back and just, agree with the long-term custody, permanency planning-type thing, looking into the future as well as planning for today. HIV may be a diagnosis, but we also have known people for other incidents, accidents do happen. So, we don't need to look at it as HIV is the only reason why we need to do some permanency planning. As well as to build in more educational opportunities for families to get education about the diagnosis, about life, around the parenting classes. Just about living life on life's terms. A lot of the population that we're working with are from poverty levels ... population. Again, doing some basic skills on budgeting, basic skills on how to run a household, things like this – as well as begin, which is a major issue with HIV, enhanced training from Day One, from diagnosis. This is an inevitable part of HIV. We know that versus starting it at the point of medication. This is something that I really strongly feel needs to be built in as early as possible, emphasizing worked into someone's daily life. Again, as well as looking at helping women to identify HIV as, not necessarily the worst thing that ever happened in your life, but something that they can take control of and help manage so they think it's a positive. So, therefore, they can present it to their children, their families, and their communities as a positive something that they are willing to work with. They may need the support of others to help him, but it doesn't have to be the worst thing that ever happened.

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- S. Lewis Jan, our last thought?
- J. Kriebs To take a slightly different tack, I think that we will better meet many of the service needs of women who are not in Sandy or Barbara's neighborhoods when we have competent, sensitive clinicians everywhere. So, if I could wish for a different kind of service need to be met, it would be for caregivers to try to be more aware to the messages that we send to women, not just with the words we use, but with the way we use them.
- S. Lewis That's a wonderful thought. If our presenters feel that they've shared all the knowledge they can share in this brief hour, I'd like to move to our question and answer period. Is anyone feeling they need to make another comment?
- Facilitator No.
- S. Lewis Okay. So, Tara?
- Coordinator Yes. Thank you, Dr. Lewis.
- One moment, please.
- Our first question comes from Michelle New. Miss New, please state your organization name.
- M. New Hi, I'm a clinical psychologist at Children's National Medical Center in D.C.
- S. Lewis You'd like to direct your question to?
- M. New To Rex Forehand and also to Barbara Draimin, or anyone else that wants to answer.
- I worked in pediatric HIV in England. I've worked here for a couple of years with children who are positive. I wonder if you could talk at all about the issue of disclosure to infected children. That's something that I didn't hear much about in this excellent conference.
- R. Forehand I think I'm going to let Barbara take the first shot at that. This is Rex Forehand. The work that we have done has focused only on non-infected children.
- Barbara, can you?
- B. Draimin Sure. Hi. I'm also not the expert on that. I would like to give you two references to people who, I think, are: Michael Lipson, who did a lot of work at Harlem Hospital and wrote a number of articles on disclosing to infected children; Lori Wiener, who works at the National Cancer Institute; and Susan Ledlie. They have done a lot more work than we have on the specific issue of disclosing to children. I do know that the issue is becoming increasingly complicated by the fact that children are living much longer, joyfully. There are some children as old as 10 and 12 and 14 who have not been told and who are active in setting up their own lives. So, it is increasingly complicated now and also by children who both know and don't know their HIV status then choosing to have children.

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S. Lewis Thank you, Michelle.

M. New Thank you.

S. Lewis Next question?

Coordinator Our second question of two questions comes from Hakimah Shariff. Mr. Shariff, you may ask your question. Please state your organization name.

G. Plumb This is Gloria Plumb from the FXB Center asking for Hakimah Shariff. I would like Barbara Draimin to please elaborate on the substance abuse models for multi-care, not standing as the single person problem.

B. Draimin Meaning a family-focus perspective on substance abuse?

G. Plumb Exactly.

B. Draimin One reference that I can give you for that is Bodega de la familia, which is in New York City and has quite a wonderful web site that describes some of their activities that Bodega de la familia – and everybody please excuse my non-accent. They involve, where they can, with, of course, the parent's permission, the children and any other adults in the household in the treatment and care of the parents. I think when we're talking about disclosure, whether and what children know about their parent's drug use and other secrets in the household become very, very important. Yet, there are few professionals, either in the drug treatment or in any other community that know how to deal with that.

I myself had experience with it as a foster parent when the three children that I took in in an emergency, their parent who was using drugs – and I asked the five-year-old, "Do you know why you're living with me now?" He said, "Well, no I don't know." I said, "Well, if I gave you a dollar to guess, could you guess?" He said, "Well, I would guess that she smoked cigarettes." I said, "Well, that's a very good kind of guess. If I gave you another dollar, could you guess anything about the cigarettes?" He said, "Yes. I guess they were funny kind sort of." I said, "But, you really didn't want to talk to me about this." He said, "Well, I didn't know what you'd think of my mother." I said, "Well, I think your mother is a wonderful woman. She's getting help now. If she gets help, then you can go back and you can live with her, too. We can all give her help together."

So, I think that's the key that children are involved in the households. They do know more and less about the drug use. We have to include them, when the parent is ready, to help in the organization of the household and in positive feelings towards her.

S. Lewis Thank you, Barbara.

Next question.

For Linda, what kind of activities have you found were successful in helping families have experiences that do normalize their lives? Like, what kind of social event?

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- L. St. Hubert One of the things that we do is that we do have a family retreat twice a year in this area. Again, we give kids that are infected and affected an opportunity to come somewhere to go away and be in a setting where we have rap sessions and conversations about how things are going personally as well as to be able to do activities and to see outside of their own household that HIV existed and that families are living as normal lives as possible. The other kids ride bikes. The other kids do things. Other kids may experience mom or dad not feeling as well. We have other activities throughout the year where kids can come together, again, just to meet there as ... coalition of them. Right now, we have a few kids that are getting older that are probably about 13 or 14. They're kind of tired of going to the family retreat, but they want to be able to do something outside. It's important that they keep that network of family of friends together even though they have their friends at school and the community. They have a need to also know what's going on with other families. So, we're trying to develop some new things to meet their needs because the retreat, kind of, is not working for them as much now. Whether it's to get together more often or do other things, we have a couple of young teenagers actually now supporting to provide childcare. They're volunteering to do the childcare allowing a couple of the support groups to happen here.
- S. Lewis Thank you very much.
- Coordinator We do have three questions.
- S. Lewis Okay.
- Coordinator Our first questions comes from Mildred Pinot. Miss Pinot, you may ask your question. Please state your organization name.
- M. Pinot It's the Legal AIDS Society Community Law Offices. Good afternoon. Thank you to all the panelists.
- S. Lewis Thank you.
- M. Pinot My question, I guess, is directed to Jan Kriebs. (1) It's not really a question. It's a salute for your comments because sensitivity on the part of service provider is, I think, a major issue; but, my question to you would be, How would you promote sensitizing providers, not just within the clinical setting, but also some of us who are attorneys, case managers, and other people who are involved, almost daily, in the lives of women who are living with HIV and trying, as best they can, to address all their family's needs and then their needs, on a secondary level?
- J. Kriebs Well, I wish I knew the answer to that question. It may be that some of the other panel members who deal with mental health issues may be better at answering that, but I think that there are a couple of things. One of them has to do with how we understand HIV as a society, both that most people understand it as a necessarily fatal disease and interpret that in the short run. Women do it when they hear their diagnosis. I think members of society do it.

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The most valuable lesson I learned from one of my patients was that HIV is about living and how you live with a chronic disease. I might have understood that about other chronic diseases, but to interpret that through an infectious disease that wasn't a kid's disease, like polio, was an important step for to understanding how this felt.

The other piece is to acknowledge it as a chronic disease and to emphasize that piece. We don't necessarily penalize women with brittle diabetes, women with cardiac disease, for choosing to have a child; but, their risk to their child may, in fact, be greater than the risk to the child of a mother who uses HAART, who comes for all her prenatal visits, and who brings her child in for good care. Yet, we have this mindset that because she has this disease that somehow she's done something wrong. She may not have done anything wrong except choose to be intimate with somebody who didn't know he was infected. So, I guess, we have to change which way we look at this infection in order to sensitize people.

S. Lewis

Thank you very much, Jan.

Next question, please, Tara.

Coordinator

Ms. Johnson, you may ask your question. Please state your organization name.

Ms. Johnson

Hi. I'm calling from Moorehouse School of Medicine. I have enjoyed the conference so far. This is just to kind of reiterate what was just said. I was calling to ask the question to Jan Kriebs also and to kind of ask what would be some recommended interventions that could be implemented with clinicians or community agencies to encourage utilization of more sensitive philosophies or humanistic philosophies during practice with women and children who are infected with HIV?

J. Kriebs

I think it helps if you talk to your patients without prejudging.

Ms. Johnson

Okay.

S. Lewis

Would anyone else like to add to that?

Linda?

L. St. Hubert

I guess I have to agree with Jan on – talk to the patient. Historically, we've been making molds and putting families in them. I think what one of the things that HIV has done to the healthcare system is saying that, "We are very unique. We want to be worked with uniquely because this was what works best." The only way you can find out what's unique about that family is to actually talk with them. Because they're not fitting in the traditional molds – and meet them very non-judgmental, not based on the past. I know in my experiences, working places, working with families, a lot of times, before they can meet the family, the staff is kind of giving me the scoop on the family. Learning as clinicians, learning how to say, even though I heard of that about this family, I'm talking about today and the family that I'm going to meet. I'm going to sit down and build a relationship with this family based on our experiences and not out of others experience. I will share a story about one of the first ladies that I ever encountered. By time she gets to my office, almost

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every individual in the clinic that I was working with warned me not to be in the office by myself. Now, I've been working with her for two years. It took two years for the first time in twenty-two years of her life, she's off of drugs. For the first time, in the last seven years, she has one of her three children back. Again, being able to work with people right where they are and timing that you're not there to fix it all. You're there to kind of plant seeds. You're there to give what you have and to work with what they have.

Ms. Johnson

Okay. Thank you.

B. Draimin

Can I add two things?

Facilitator

Please.

B. Draimin

This is Barbara Draimin.

We've learned a lot at the Family Center from setting up a family advisory committee who advises professionals on what programs are needed, how well we're treating them and how we could treat them better, what activities they need more of, what is inconvenient about the way we deliver services. So, that really goes along with Jan's listening to the specific client. We also find that, though, when we put ten of them together, they're more empowered to tell us both the negative and the positive things that we can do for them.

Secondly, we have taken ten families away for the weekend a few times. We find that staff develop renewed invigoration and respect for the parents and how challenging a task both the parents and the children have by being with them in that kind of residential setting.

Ms. Johnson

Those are good.

S. Lewis

This is Sandra Lewis. We are coming to the end of our time. I know that there are several questions out there. I am going to invite our listeners who still have questions to submit them to us at the National Pediatric & Family HIV Resource Center. We do have a web site. You can e-mail us to let us know if there are questions that are unanswered for you. This information will also be published on our web site so that you can go back and read over it and refer to it to utilize in your work.

I'd like to take this time to thank our panelists once again: Barbara Draimin, Linda Horton-St. Hubert, Rex Forehand, Beth Kotchick, Sandra Gossart-Walker, and Jan Kriebs for their insights this afternoon and for stimulating such a wonderful discussion and interest in this topic among our listeners.

I think, with that, we will close our conference call and look forward to receiving any e-mail's that you have for us.

NATIONAL PEDIATRIC & FAMILY HIV RESOURCE CENTER

Moderator: Sandra Lewis, PsyD

September 29, 1999 - 1:00 p.m. EDT

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