

## **Transcript of African American Experiences of Self-Help Teleconference**

Sponsored by the STAR Center

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Moderator: Maggie Scheie-Lurie, Acting Director of the STAR Center

Panelists: Derrick Adkins, Dr. Roderick Waters, Jacki McKinney

Technical facilitation by the call Operator.

MSL: Good afternoon. I want to warmly welcome you to the STAR Center's teleconference on African American Experiences of Self-Help. We have about 65 people, I believe, from various backgrounds listening in to our call today. Thank you to all of you for taking the time to call in and to join us and for your interest in this topic. I believe not nearly enough has been shared on this topic so far, and we're glad to be able to contribute to the discussion in this area.

My name is Maggie Scheie-Lurie; I'm the acting project director for the STAR Center which is sponsoring this call. The STAR Center is a consumer-support technical assistance center sponsored by the federal Center for Mental Health Services. STAR stands for "Support, Technical Assistance, and Resources" and our mission is to promote consumer self-help and leadership development among diverse communities, both ethnically and culturally. You can check out website if you'd like to get more information about our programs: our address is [www.consumerstar.org](http://www.consumerstar.org). That will give you more information about our activities, including other teleconferences like this one that we have done before and that we have scheduled down the line, leadership forums that we've conducted, scholarship programs and a variety of other resources.

Also with me today is Lynne Carter, who is going to be facilitating a STAR Center African American Leadership Forum on Building Self-Help Capacity. Do you want to say hello?

LC: Hi, I just wanted to greet everyone and thank everyone for allowing me to sit and learn from you all what some of the issues and topics are of concern.

MSL: Thank you, Lynne.

We have a wonderful expert panel of speakers with us today to share their experiences and insights on self-help and peer support. I'll be pleased to introduce them very shortly.

First, I'd like to go over just a few housekeeping items on this call. One: the agenda of our call is that we'll have this presentation and discussion from the guest speakers from 3:05 or 3:10 to roughly 3:40. Then we're going to open up for questions and answers until we end at 4 o'clock. All of you, the audience's phones are on mute right now until the question and answer period so that we can

keep extraneous noise to a minimum. If you want to ask a question, press \*1. The last thing is that an audio recording is being made of this call, and it will be made available later on through the University of Chicago and our website (which again is [www.consumerstar.org](http://www.consumerstar.org)) will contain instructions on how you can access that recording. You're more than welcome to pass on this information to anyone else you know who might be interested in listening to this call. We hope that this call and this information will be spread as widely as possible.

And now, without further ado as they say, I am very pleased to introduce our guest speakers today: Jackie McKinney of Philadelphia, Pennsylvania; Derrick Adkins of The Bronx, New York; and Dr. Roderick Waters of Plant City, Florida.

By way of introduction, let me say about Jackie: Jackie McKinney is well known throughout the country, and probably a lot of you have had contact with her or certainly know of her. She's an award-winning, nationally-known advocate of recovery for people with mental illnesses and co-occurring disorders. Formerly a homeless woman, she's recovered from mental illness and is co-founder of the National People of Color Consumer-Survivor Network. She also coordinated the first People of Color Conference held at Alternatives, which is a national conference for people with mental illness and survivors of the mental health system. Jackie, do you want to say hello?

JM: Hello everybody, and welcome to the call.

MSL: Thank you again Jackie for being with us.

Secondly, Mr. Derrick Adkins of the Bronx, New York: Derrick has said, in information that he provided to us, that he is a consumer of mental health care and a motivational speaker. In spite of his mental illness, he's been able to accomplish many things, including an Olympic Gold Medal in track and field. He says that self-help means believing that you can achieve despite your illness. He says, "I believe that all consumers have beautiful minds and can accomplish great things." Welcome, Derrick, and thank you for joining us.

DA: Thank you.

MSL: Finally, Dr. Roderick Waters (it's a Ph.D.) from Plant City, Florida: He is a former college professor who has taught courses in African-American History and Culture, and facilitated workshops dealing with diversity. As an active consumer-member of the NAMI Tampa Florida chapter, Dr. Waters has given several lectures to fellow consumers about how to advocate for oneself and how to plan for a better quality of life while dealing with the difficulties of mental illness in daily life.

Again, thank you all for joining us. We appreciate you taking the time to share your thoughts and experiences so that we can all learn from you.

To set the stage for our discussion today, I will mention a couple of things. One is that people who have lived with psychiatric symptoms have often found that self-help and support from their peers is extremely valuable, if not essential, in recovery. Secondly, disparities in the way mental health services have been delivered have been well documented, and we know that they can adversely affect the quality of care people of a variety of cultural and racial groups receive. So today our discussion is centered around these two issues and we hope to shed some light on both these topics, so that we all can understand these issues better and so that mental health and self-help services can be improved in the African-American community.

So that leads us to our first question, which is: What does self-help mean to you as an African-American? Jacki McKinney, would you like to go first on that?

JM: Yes, I don't mind. What it personally means to me is: once I understood, really understood, what the symptoms were, I could recognize in advance, before I needed "outside help," that I was becoming symptomatic, getting sick, acting difficult, having difficulties – however different people phrase it – I could recognize that it was happening and I was able to do the things that would either stop it or slow it down to the point that I could take my time and think about where I wanted to go and who I wanted to see. I could actively participate in choosing who and what method I was going to utilize to take me through what might, at that point, be an episode. It was truly a miracle. And it was truly through talking with, and being around, other consumers that this very important lesson was taught to me. It was not something that I discovered on my own. That's it.

MSL: Thank you, Jacki. Derrick, would you like to go next?

DA: Yes. Self-help, as it regards to mental health, I believe deals largely with educating yourself with regards to the symptoms of mental illness as Ms. McKinney was saying. Education is key. When I first began to feel the way that I started to feel, I didn't know why, I didn't know what mental illness was all about. I began doing some research, learning the different causes of clinical depression and the ways of getting healing. There's just so many different ways. Some have to do with medicine, and some do not. Some have to do with electroshock therapy, some are just psychotherapy and counseling. There are a lot of spiritual methods of getting healing. It's important to educate yourself on the many different methods and then, as Ms. McKinney was saying, go forward with the path that you think is going to help you.

MSL: Thank you. Dr. Waters, please?

RW: Greetings, everyone. I believe that self-help, to me, is a very human enterprise. I believe that every human being needs and wants food, clothing, and shelter, but in addendum one also needs the sense of self-preservation. And that last of those

criteria is what I want to emphasize the sense of self-preservation. To me, that means to do that which is going to maintain or enhance my well-being. And all that means is that, first, self-discovery. In the African-American community one thinks of self-help as synonymous with self-reliance. At one end, that's quite good. At a bad extreme, that can mean denial. For example, "I am self-reliant, therefore there can't be a problem. I can lift myself up by my own bootstraps." That is part of the African-American culture, but when it pertains to mental illness, that's very deleterious. And so the first thing that has to happen is an awareness that there is a problem; two, finding the help; and three, pursuing that help; and then four, doing that which is helpful for you for maintenance and for enhancing well-being.

MSL: Thank you. I've got a number of questions, of course, and rather than call on each of you individually to talk about the question, if you'd like to jump in we can proceed that way and just give everybody an opportunity.

Tell us about how self-help and peer support have made a difference in your recovery. Can you share some examples with us?

Any of you like to jump in? Okay, back to Ms. McKinney.

JM: You want to know how self-help helped me in specific?

MSL: Yes, can you share some examples of how self-help has made a difference in your recovery?

JM: Let me see, what I can say that would be the most telling. For people that don't know me, I think the first thing that you should understand is that I'm seventy years old. And like many African-American women that are older, for years we struggled with being the person who could not, would not, should not ever be sick or have a problem, because we had all these responsibilities and roles that we took on and were given to us, both in our families and our communities. So I fluctuated between being ill and being well, and constantly was in – as Dr. Waters used the word – denial. It didn't mean that I wasn't feeling badly, it just meant that I had to get so sick that I would actually be *taken* somewhere rather than *going* somewhere.

The self-help movement introduced me to people who had a different point of view about mental illness. They were not always the ones, but for the first time there was a full discussion with myself and other people about mental illness. As I was growing up, and in my community, in my lifetime I never had a full discussion. Psychiatrists and psychologists always told me what to do. I suffered from many distorted diagnoses. Self-help, for the first time, put the responsibility on me to be a partner in my search for both treatment and wellness. And it also gave me the *modus operandi* for staying well. In other words, activism is really what fuels this balloon, and in the self-help movement I discovered that not only

could I work hard on being well, but also I could work hard on carrying the message and delivering it to other people. I did not want to continue seeing people to be 45 or 50 years old before they could obtain for themselves what we are calling today “recovery,” before they felt that they were a partner and a part of their own wellness. So self-help, I think, really saved my life. I also have mental illnesses in my family; I’m not the only person and the only generation that the mental illness has showed up. It helped us all, because we’ve been able to follow the steps that both the other speakers have spoken about. Mostly, it was the activism. The activism really fuels me to stay well and to exemplify that this is really something that I not only can manage, but I can turn this “scar” into a “star.”

MSL: That’s great, I’ll have to remember that. Derrick, do you want to go next?

DA: Okay. I believe that self-help and peer support have helped me in that, when you’re suffering from certain symptoms of mental illness, the hardest thing to do sometimes is to explain to others, who aren’t suffering from the same thing, what you’re going through. I have found that no one is able to relate to me, with regards to the symptoms, as much as others who may be peers of mine who are going through the same thing. And it wasn’t until one of my peers, who was going through a similar condition (although there was also an addiction on her part to marijuana as she was trying to self-medicate), explained to me what she had gone through and the healing she had gone through in the past (before she fell into addiction) that I found the right treatment to help me. No one was able to explain to me the problem as well as one of my peers did. Doctors who’ve gone to school for many years gain so much knowledge, it’s sometimes condescending and sometimes you’re not on the same level. You’re on the level where you’re experiencing it and they’re on the level where they have infinite knowledge about it. When you speak to your peers about it, your peers can relate on a level that others cannot.

MSL: Thank you. Dr. Waters?

RW: As a student of history, and a son of the South, my experience may be quite different than some of the listeners of this program. I must say that I believe that self-help, obviously, is quite important, but that next step of finding peer support, I guess that’s where I found my Cyclops on the way to finding the golden fleece. And the Cyclops is, in the South there’s an old saying: “Black people get the blues, white folk get depression.” Part of this is because of economics, because one could not afford to see a physician; another was lack of confidence in others and speaking of issues that should stay “in the family.” You did not discuss mental illness, that was seen as a moral weakness or – even worse – a demon, and so it was not discussed. It’s a very Southern tradition – not to say that the rest of the nation is anti-religious by any means – but this is a very “religious, pious” region of the country and certain things were never discussed. So even looking for a

support group is difficult. That is one of the reasons why I'm an activist, to facilitate change in that.

So, yes, it is important to find people, which I did serendipitously, and it is important to be able to relate about, "Oh, this medication did this," or "You're not the only one." I believe that knowing that you're not the only one out there is so important, knowing that when you're down another's up and helping you to say, "Hey, tomorrow's another day." But I say with great sadness that finding that support group – once you come to terms that this is not a demon, this is not a bad day, I'm not feeling badly because this is the high price of being Black in America and you're supposed to be depressed (uh, no!) – I hope to facilitate groups so that people of all ethnicities can come and feel welcomed and know that they're not the only one.

MSL: Okay, thanks! Next question is: Can you describe organizations or facilities that enable you to give and receive peer support? Are they specific to African Americans?

JM: The first organization that I belonged to not only was not specific to African Americans, but had absolutely very few African Americans. And for the most part, traveling nationally, that remains the truth. We have come a long way, but we are nowhere near the level that would give us parity. This is a big issue for me. That is, the resources that have been developed for the consumer movement have basically not been spent, for the most part, in and on people of color. And what little has been spent, the lesser part of that has been spent on African Americans.

When I joined the movement, I joined as a professional who wanted to come out of the closet. As many of you will find out, if you don't share that, you'll find out that many people – especially African Americans – have gotten degrees and worked in their profession and have lived with the shame and the blame that the other speaker was referring to and have hidden their illness, even within their family. I exemplified that. So I belonged to this group because I wanted to stop hiding. I was to the point where I was more fearful of being found out than I was fearful of coming out. But the place that I found my most hope, and most help, and got to feast my eyes on many, many diverse people of color – or at least a larger group than I'd ever seen – was the first Alternatives conference that I attended fourteen years ago. And that was an eye-opener for me.

Because it wasn't just enough to be in the consumer movement, let me tell you. That was the beginning of saving my life: I always say, whenever I make a presentation, "consumers saved my life." They changed the whole way I felt about myself, my illness. But when I got to see the African-American people... By the way, most of whom are no longer around, because they did their time in the movement and they never got to the front of the room (those are my words) and so they disappeared, nobody ever heard from them again. I'm probably one of the longest to sustain this kind of activity, because Blacks have just not felt welcome

over long periods of time and have dropped out. But Alternatives was the place that I found the answer to the question that you asked “what consumer group?” It isn’t a group, it’s a conference where consumers come from all levels. You can be a brand new consumer and come with someone from your organization, you could still be living in a residence or in a partial residence and you can come to Alternatives. And the hope, and the joy, of seeing people like yourself, so that you don’t feel like you’re the only (my word, not theirs) “betrayed” of your people – outing yourself in a place that your family and your relatives would be embarrassed if they knew you joined. It really made a difference to me and I support Alternatives from the bottom of my heart, and I really wish there were more opportunity for more people of color to be at Alternatives.

It was never one group, never. It was Alternatives that really turned me around.

MSL: Thank you. Derrick?

DA: I just have a brief answer to that question. The only group that I am familiar is the mental health association of the county where I live, which is Nassau County on Long Island. I got to meet some of the people there, and they have a peer support program but they did not have anything catered toward African Americans although there were a good percentage of African Americans there, probably 30 to 40 percent. I didn’t utilize the programs too much, because I had kind of already developed a peer support group prior to my becoming aware of this group. That’s the only formal group that I became aware of: Nassau County Mental Health Association.

MSL: Okay, thanks. Dr. Waters?

RW: Believe it or not, there are two parts to that question. The first is, have I found a group that made inroads or programs for African Americans? Other than writing about them, and saying “yes, there is a problem here,” solution/peer facilitating-type programs targeting the African-American community... I would have to say a reluctant “no.” Now, there may exist one that I do not know about, but from my standpoint I would have to say no.

Now the second part of that question is the following: are we, or do we want, existing organizations to be more inclusive, so that African Americans can eat at the table as co-guests, or do we want African Americans to form their own groups in that sense of self-reliance? Segregation in any form is very distasteful for me. And I would hate to say that since I am dissatisfied with what is happening here, I can just simply take my ball and go home and play with people that look like me, eat some of the same foods that I do, maybe speak some of the same slang words that I do – I would hate to be that myopic. But I believe as the other presenters have said so eloquently, it really doesn’t exist. I would rather be part of the movement to help facilitate that change within the larger organizations, to help them to understand that it is just as important to have a place for me at the table, as

well as it is just for me to come to the conference. The day of the “race representative” is long gone. The day of counting how many Blacks are at the conference, where you could just look at one table and see “oh yeah, we have four, which is 400 percent more than we had last year,” those days are over.

That often happens when you go to a peer-facilitated meeting where it isn’t so much being only one, but not having your culture recognized as being co-equal, to not feel like you are part of the collective. That is very hurtful. When you’re finally coming out of the closet, and then to be put in another closet again. So the door is closed, you open the door, and the window’s shut. And I think that’s the frustration that I feel.

MSL: Thank you. The next question is somewhat related to what you’ve all been talking about, and that is: What are the stigma issues unique to the African-American community? And what are your recommendations for addressing them?

JM: This is really interesting, because it follows right on the back of Dr. Waters’ remarks, which appear to me, from my perspective from fourteen years in the movement, to be somewhat naïve. But that’s just an opinion, it’s certainly not intended to be derogatory. It’s just that when Dr. Waters is as educated as I am about this system – and I don’t want to pick him out because it may be a whole telephone full of people – anyone of that opinion really needs to be shared with, he needs more information about the movement as it has evolved and what has happened. I would like to invite there to be that discussion amongst us who really would like there to be those two places. Dr. Waters is suggesting that it is better to join the group, the major group, and actually have them treat us as equals and do the work there. What I believe is that we need our own group. And that comes back to one of the stigma issues.

I have to agree with Dr. Waters that some of the issues are self-stigma, but that comes from the way I grew up. I grew up self-stigmatizing because that’s what I was taught about mental illness. And invariably, as I watch myself in these later days dealing with members of my family who are younger than me, who are my children and grandchildren, I realize how much of what I’ve been able to *not* do with them, how much I’ve been able to keep them away from those self-stigmas. How critical it is! And sometimes, you can’t do that in somebody else’s house. You really have to be in your own house. It was amongst ourselves that a great deal of that started. And it’s amongst ourselves, in my opinion, that we need to be to get over it, to learn to treat it, to get over that self-stigma.

But if our self-stigma is 30 percent, 70 percent of the stigma comes from the outside world. I went to one meeting with an African-American presenter who said to the other consumers... And I’m publicly known for saying that consumers who are white may not be my color, but they still are my kind, and I really believe that we are in the end the least stigmatizing, the most inviting and enveloping group of people I have ever belonged to. I came out of the Civil Rights movement and I

believe the consumer movement is still more inviting at the consumer level. I think it's as we get up the pike or we go up the food chain and we start to be "involved with other agencies and resources" that's when it really happens.

So what are the major barriers and stigmas? How the federal government funds and doesn't fund our activities, how the federal government funds and does not fund our involvement. There was one time when there was another woman who – I don't know if she's on the phone or not but I'm going to call her name: Celia Brown – we used to share one seat. They would bring her in the morning and me in the afternoon, because they wanted two consumers but they only wanted to fund one slot. And we would share that slot, and that's documented. There a pamphlet that we wrote, five or six different races of people wrote a book about stigma and recovery. I suggested to Maggie that she try to get a hold of that. I don't think I followed up on making sure that she did. I'd like you all to read what we, as people, were saying about the movement, and about racism and disparities. It was all about the movement and inclusion, and it's really an interesting thesis. I'd like you all to have an opportunity to see it. You can reproduce it if you have a copier, it doesn't have any rights to it.

What are the stigmas? Self-stigma is number one. Number two is how the funding and resources are shared. Number three is about how even though we were in the room, we weren't in the *front* of the room. I had to get to the front of the room by sort of sitting there long enough for everybody else to disappear or go away. I didn't get there because people recognized that I brought something to the table. It was mostly self-push to get to the front of the room, to have an identity. When I came into the consumer movement, the agenda was what was happening to us in the hospital. As you know, now there must be 150 important themes that we talk about. We never talked in those days about being women; we never talked in those days about culture, *any* culture; we never talked about in those days about recovery. We never talked about recovery when I came into the consumer movement. It was basically the treatment in the hospital, what our doctors and psychiatrists and psychologists were not doing, what was happening to us in the drop-in centers. We've come a long, long way.

But the barriers for the most part are systems barriers, not people barriers. It's a lack of recognition that there should be. The Surgeon General's report, for all of you who have not read it, and the Presidential Freedom Commission both say wonderful things. But no one has taken up the banner to do anything about it, except to tell us that it's something that should be done. I believe in America that every time the federal government particularly wants something to happen, they give you such specific guidelines as to how they want you to do it that you don't even need to think. Yet, here we have these huge issues and all they say is, "Something needs to happen." I believe that the something that needs to happen is that they need to fund people who know how to make things happen, who understand organizational development, who understand systems change to help us – and that they are obligated to do that for us when they bring us to the table. Not

just to bring us to the table and say, “here you are,” without a voice or with a voice that is not educated.

Sorry to take so long, but that’s really a hot one for me.

MSL: Thank you, thank you. I would be happy to have you share more. We are going to be running out of time so I’d like to get on to the other two folks before we open up for questions.

DA: Maggie, can you repeat the question?

MSL: Yes. What are the stigma issues unique to the African-American community and what are your recommendations for addressing these?

DA: The stigma issues unique to the African-American community seem to me to be much along the lines of what Dr. Waters was saying. You have the Black church which, as he said, in the South is even more strong and prevalent, which considers those who are going through any type of mental or emotional issues to be filled with the Spirit or a demon, or perhaps just that they just don’t know the Lord. That’s a big stigma that I believe is very strong in the African-American community.

And then, myself being probably the youngest member of this panel, you have a growing spirit in young America, where – especially the men – are seeing it as necessary to present themselves in a very strong, bold, somewhat tough demeanor, to where it’s almost overkill. To where it *is* overkill, machismo, whatever you want to call it. And then when you have someone who says that they’re having emotional difficulties, that person is seen as weak, as soft. And that can be a problem also in getting our younger men to come out and let people know that they are suffering from something. I spoke at a school in Newark, New Jersey, it was an inner-city school. After me giving my testimony, a young man... you know, many middle-aged business men would have looked at him and thought that he was going to rob them, because of the way he was dressed, with the big clothes and the hat to the back and the corn-rows, he had a very tough image about himself. But after I spoke, he waited until all the other students were gone, and came out and revealed to me that he was going through the same thing. It was the stigma that had kept him from coming out. I stayed in touch with him, and got him in touch with the necessary persons to help him. But those things are a problem, especially in the young African-American community.

MSL: Thank you. Finally, Dr. Waters?

RW: Yes. In addition to that, I believe wholeheartedly that to understand African-American culture, you must understand the machinations of the African-American church. I am not saying that one has to be a believer, per se, but you have to understand the operations of the African-American church and how it has

contributed to the African-American culture. I will say this as an aside, that Martin Luther King was noted for stating, and I paraphrase, the most segregated hours in America are between eleven o'clock and one o'clock on Sunday morning. I will get to that in a moment. If the church is saying, "You're either very weak or you're a demon," Generation X and Generation Y are saying "You're soft," we in the African-American community are just as guilty of playing Social Darwinism – only the strongest shall survive, only those who appear tough, only those who appear masculine. Not only do we have a very myopic, very sexist, misogynistic, homophobic (you name it) nature that we call "survival," particularly here in the South... then, let's say we have an African-American male who says, "You know what? I have a problem. Despite all the minutia, and all the negative press, I have a problem and I need help."

And then you go to a meeting, and it's certainly not going to be in First Something Something or First Something Something down the street, and you certainly can't go to the mosque, the temple, the church, to mention this issue. And then you find yourself going to, as somebody might say, the "outside" of the community. You go there and you have no assistance there because that organization does not understand you. You're really in a Catch-22. You're damned if you stay in your community, you're damned if you leave your community.

Now, as an academic, I believe that if it's teachable, it's learnable. And I have learned, and I have taught students that – guess what? – this Black skin does not preclude my Ph.D. It is just as important for someone to know that I can be in a position of authority, or that I can learn from somebody that looks like myself. So therefore I will not let other communities off the hook, saying, "We have to take care of ourselves." I believe it's a given; I make no apologies for saying I'm a proud African-American male. I do not think that is discrete from saying that I'm also a member of the mental health community. I don't think those have to be mutually exclusive. I believe, yes, some of my support base is African American, for those issues I believe that African Americans can understand, great.

But I do believe that other organizations... and to answer the question, why does the government not fund African Americans, why there are so few, I may give this answer: because they don't get it. Part of it may be that they don't care, but part of it is they don't get it. I believe we have to educate them in saying, "Guess what? These are our unique needs, these are our unique challenges," and bring it to the table. I don't want the excuse "Well, we didn't know there was a difference, we didn't know there was a cultural construct." I believe they know, but I don't want that excuse out there. So I'm not going to let anybody off the hook. I believe if there's a peer support group, whether I'm the only African American there or not, someone should recognize that I'm just as special, and I have a place at the table, and I deserve to be treated as such. And if they do not what the needs are, find someone else or help lead me to a place which does.

So, I do believe in a two-pronged approach. I believe in working within the community, as well as out. Because as anybody who studied the civil rights movement will know, if we thought that only African Americans helped themselves, that's a very naïve point of view. There were too many people who were not "of color," too many activists like the late Marlon Brando, John Forsythe, ??? Rivera who sat by Dr. Martin Luther King when he spoke, too many whites who helped when Blacks stayed at home, for us to sit here and go: "Well, we're going to have to help ourselves." Because if that were the case, the civil rights movement would have never gotten off the ground.

MSL: Okay. Thank you, all three of you, very much for your rich thoughts and experiences. At this point we can open up for some questions. We've got about fifteen minutes. If you want to ask a question in the audience, you press "\*1." If you'd like to address your question to anyone in particular on the panel, please specify that, or if you just want to address it in general you can do that also.

OP: And our first question comes from the line of July Rose.

JR: Hi, my name is July Rose and I'd like to ask Dr. McKinney a question.

JM: It's Jackie!

JR: Pardon?

JM: Jackie isn't a doctor.

JR: Oh, I'm sorry.

JM: It's all right.

JR: At any rate, I really enjoyed what you had to share. I am very new to the movement, and you mentioned something about an Alternative Conference? How can I get information about that? First of all, I'm a little bit overwhelmed being a new person getting involved and coming out with my mental illness, graduating from Yale... I could go on. However, this feels like I'm starting a new life. If I can get some information about that conference, so that I can start getting the support and help that I need, I certainly would appreciate it.

JM: Well, I certainly thank you for addressing that issue, and thank you for being bold and courageous enough to make the choice to be out, because it is a choice. The Alternatives Conference is going to be in Denver. I think that Maggie can give us websites so that we can all get that information.

MSL: Yes, we can email to all of you the link to the website.

JM: Is that all right?

JR: Yes. I also want to thank all the rest of the speakers again. Bye-bye.

JM: Thank you.

OP: Our next question comes from the line of Maxine Cunningham.

MC: I had the same question, I wanted to get additional information the National People of Color Consumers Alternative Network.

JM: “National People of Color Consumer Survivors Network”

MC: I’m sorry.

JM That’s alright, the name is a mouthful I admit. When we got to Alternatives (maybe the third time I went), we realized that while we have Black caucus and we have other caucuses – we now have women’s caucuses and people can pretty much have caucuses on whatever they think is important – we were having the caucus every year. We decided that what we needed to do was at least have some kind of network where we could talk about state-of-the-art things that were going on, where we could talk about research that was turning into practice, where we could inform communities of color about things that were going on in their neighborhoods. For the most part, when research is being done, even if it’s something that you can use, it’s done in such small numbers – there may be two-three-thousand people in the community that need the service and there may be forty-five slots for a whole city. Because often we’re not included in it, we don’t get the information which gives us an opportunity.

So what I’m saying is, we actually are an information broker. We do most of our work by recruiting and organizing and supporting people who are one, two, three, four, maybe up to ten or twelve in a group that feel like they need a national presence. We don’t have a website, any funding. We are a network of people; what we used to call ourselves was “The Wannabes.” If you wish more information, if you wish to contact me, you’d really have to try, for the next three months to just call me on my phone. I’m hoping that Maggie, again, will share that, my name, telephone number, and where I can be reached. After the next three months, hopefully, we will have a place that is more sustained. We will have something, I’m not sure exactly what because we’ve asked for many, many things and so far we’ve got a lot of feelers out there... but we’re trying to get some kind of connection, hopefully a website, so that we can all share. The website, although it’s called “people of color,” it’s for anyone who wants to share information *with* people of color, not just *for* people of color. That’s it.

OP: Our next response is from the line of Leo DiValentino.

LDV: Thank you. I have a question about the inclusion of the topics that we have been discussing in the education forums for our future doctors as to the sensitivity that they should be developing, and to get it far enough in their curriculum so that it's not forgotten because it was taught in the first semester or the first year of their program. The sensitivity to work with all minorities... because I have seen it in probate court hearings where a young African American was kind of explaining his position to the judge in the final part of the deliberation. And judge said, "You have to promise me that you'll not take drugs." And the young man, in a very youthful, childish way said, "I don't know if I can do that, judge." And the judge said, "Well, if that's going to be the case, you're going to spend another week in this hospital."

I think it's this lack of sensitivity and understanding between the cultures that we really run into a problem. It's an education process. I think the APA should pick up the ball on this thing here and NAMI National is having a very good program in their September national conference to directly address the issue of the African American. And thank you for your program.

RW: May I, as an academic, answer that question? I've taught courses on diversity. And although, *de jure*, your comments are welcome, and true, and to the point, *de facto* the university (and that prefix "uni" means "everything," it means "all") really is quite, and I use the word, conservative and very myopic. When you mention the word "diversity," people think you're watering down standards. There is a certain standard, it's called (and it's a mouthful) "able-bodied, rich, white, Anglo-Saxon, Protestant, heterosexual (or at least appear to be), and male." Everything else that deviates from that is going to cause you to not even get tenure. So someone like myself, who may by definition teach African-American history, women's history, if I teach a course in general U.S. history and I mention something about African-Americans other than that they were slaves and Lincoln wrote an emancipation proclamation and Martin Luther King did a wonderful speech, then guess what happens? That diversity goes. We're not going to even mention the women's movement, the gay rights movement, the anti-war movement. We're not ready for that.

I'm not saying don't do it, but that is a major fight. We're talking about education. You're talking about a paradigm shift in academia. And although I have not taught for a while, I can tell you that I have many colleagues who tell me that the tea leaves are saying to get away from it. You hear of titles such as "The Declining Emphasis on Race," which is another way of saying, "let's just wipe out differences." You hear words such as "this is a color-blind society," that's garbage. That's equivalent to saying, "I don't see color." What you're really saying is, "I don't want to recognize difference, because I have to learn how to deal with those differences with dignity and respect."

I live in a *colorful* world, and that includes a beautiful, colorful mind of mental illness, a beautiful, colorful mind of African-Americanness, a beautiful colorful

mind of *all* people. As my Spanish brothers and sisters would say “para mi es la raza humana,” for me there is only one race – the human race. But there are many ethnic groups and there are many different interests. I think it is finding the commonality *and* embracing the different colors of humanity that really makes it special. As for the NAMI conference, I hope to see you there. I have been blessed to have been able to attend that. But in doing so, I hope to also (since you mention NAMI) start seeing people that look like me in leadership positions.

It’s important, as I said before, to see people that look like me standing before you speaking about issues of diversity. I hope you call people in Florida, where I live 25 miles east-northeast of Tampa, Florida, and say, “Guess what? Dr. Waters taught diversity. Let him show you how to be more diverse in your pedagogy, in your teaching, in your group dynamics. And so, I love that question, but let’s be honest. How many people are willing to do that when you set a standard and everybody else is seen as “other?”

JM: Maggie, do you think that we could put a call out to ask people to identify some of the products that have been developed that actually do attempt to (and I say this tongue-in-cheek) speak to the university? There are a couple of programs, and I know that the leadership in those programs are African Americans. I had the opportunity to make a free video that’s somewhere around, it’s probably five or six years old. It was made not just by myself, an African American, but was made by a woman from the Pacific Islands. This video was made directly for medical students to have some understand of how we “people who were consumers of color” saw our needs. And I think there are a number of products that, if we could put out a call, we could identify more other than the three or four that I know of specific to that question.

MSL: Sure. I think that’s a wonderful idea.

JM: I think these things exist. But again, they’re very small and no one’s every asked to put them together in one place.

MSL: You’re talking specifically about projects that would educate medical students?

JM: Well, I would broaden that to projects that were intended to educate *anyone* who would be working with consumers, and who might be in a university or a teaching environment. Students, you know?

MSL: We can definitely talk about that here, and what might be the best way to do that.

OP: Our next response comes from the line of Patrick Brown.

PB: Hello. I had a situation in my past where I wanted to seek help for myself, but I didn’t get the attention that I needed at that time. So I just wondered are there

preventative measures, before becoming institutionalized, as far as getting self-help?

JM: Are you asking for material, or for strategies?

PB: I was in college, I went to a doctor. I didn't get the help then. When I came out of college, that's when I had my episode and I got institutionalized.

JM: In the state, city, or county where you live, do you know of a self-help or peer support group?

PB: Yeah, there are groups now, but this was a long time ago.

JM: So now you're asking if I can recommend a strategy?

PB: Yeah.

JM: I think again, from my perspective, the answer is to, one, know what the steps are before. In other words, the education. There are books. Actually, the last couple of times I've gone to conferences where there were rooms full of books which have been written about different strategies and different ways to understand and educate yourself and "people in your community." I think the most effective teaching for beginners – and when I say "beginners" I don't mean to deprecate in anyway your learning, I mean for someone who is attempting to educate themselves or working alone – is workbooks. If you look at some of the workbooks that address this, the themes that come through (and the themes are pretty standard, you read six of them you find that most of them have the same four or five themes and after you address those themes then they may differ a little bit based on what the title is)... I think that if you could go either to a website or a place that sells materials – and again, I don't have any to recommend at this point – but I know that at Alternatives there is usually some group that runs a bookstore. They have books that are really geared toward the consumer perspective, not the doctor or the nurse or anybody professional, but really toward the consumer.

I own a lot of this self-help material, and again, I think there are websites that do cover that. I could look for something like that and Maggie could share that with this group.

PB: Thank you.

OP: Our next response is from the line of Ara Alexander.

AA: I had one response to Roderick's Social Darwinism thing. We live in a capitalist society, that's what America is. Whether you want to compete or not, it's a

capitalist society. One thing that I wanted the entire conference call to think about: all the organizations use the word “parity” – why not “equality?”

RW: I will answer that. Number one, I do not believe in treating people equally, I believe in treating people fairly. Let me give you an example. I have nieces and nephews, some of them are two years old. Sometimes I give them a lollipop. If *you* do something well, I do not expect remuneration would be *vis-a-vis* a lollipop. That’s treating somebody equally, not treating someone fairly. Everybody says justice is equal. But I have news for you: justice is not always fair.

As for the issue of Social Darwinism, that is simply an academic term to explain this ideal of survival of the fittest. I never said that I agreed with it. It is one that comes from my major in History. It talks about how people who were rich explained their richness, because they believed that they were better than other people who were not rich. That Social Darwinism that you may dismiss so quickly is the same *raison d’etre*, the same rationale if you will, as allowed certain folk to enslave other folk. So this sense of Social Darwinism is very important. It is very important for the African-American community to understand this ideal of “the survival of the fittest” and that only certain people should exist. Then you’re going down a slippery slope: you have a mental illness, you don’t deserve services... you’re under six feet, you have a certain eye-color, you have this, you have that, you’re not producing enough children, you’re not producing children of an IQ above 150, you don’t have a Ph.D., you don’t deserve this.

So yes, sometimes we may not like the terms, and sometimes we get mixed up with the terms and action. I think we like doing those actions, we just don’t like having those actions called out. The problem is, we’ve been passing over, glossing over issues. It’s time that we just step on an issue and say “here we stand.” Whether we agree or not, I believe in the ideal of discourse. Someone can disagree with me: fine! But let’s admit that there is an elephant in the room. I may not agree with the rest of the presenters, but I think we’re all in accord that there is an elephant in the room. We may, as Malcolm X and Martin Luther King said, disagree on how to deal with this problem, but both gentlemen agreed that there is a problem of racism in America. To say otherwise is academically dishonest.

AA: May I respond? Personally, for me, let’s agree to disagree. And for me, self-help is the return of the capitalist drive.

MSL: This is Maggie. I believe we’re at the end of our time. I thank everyone. I think this has been a very rich and fruitful conversation. Again, this call has been recorded and will be available for replay through the University of Chicago. We’ll post information on how to access that through our website.

Regarding the requests that have been made for us to follow through with information on Alternatives, and Jacki's phone number, and other information – we will follow through using the same listserv that provided information on how to dial in to this teleconference. We'll use that to distribute information. If you have any other questions or issues that you would like to address the STAR Center about, you can send a message to [star@nami.org](mailto:star@nami.org).

JM: I'd just like to say one thing. Because there are so many African Americans who don't use the technology, can we think about another way to disperse some of this information?

MSL: Sure. I know, Jackie, that that is a big concern. We can talk about that, I know that it's important.

JM: Thank you everybody. Thanks for the opportunity, Maggie.

MSL: Thank you very much.

RW: Thank you very much, thank you for the opportunity, thank you for the fellow presenters, and to all the callers. I welcome all your comments, and you have enriched my life just by being here today. So, I'm honored.

DA: And thank you, too. Thank you for inviting me to speak

MSL: Thank you, Jackie; thank you, Derrick; and thank you, Dr. Waters very much. We appreciate your expertise and the time you've taken here today.