Empowering People with Mental Illness through Treatment Planning

with Donald M. Linhorst, PhD, MSW

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Summary

People have the right to participate in their own lives to the extent they can, and this applies to people with mental illnesses and other vulnerable populations. In this presentation, Dr. Linhorst defines empowerment, lays out the conditions and circumstances under which empowerment is likely to take place, and provides concrete examples of applying the principles of empowerment.

Transcript

or comments and I can be reached at my e-mail address: Linhorsd@slu.edu and then they can also call me at work 314-977-2745.
TP: All right, thank you. We will also put links to those references on our website at MIMH trainging.com. Dr. Lindhorst, thank you for your time, and the information we've gotten from you today.
DL: Very good. Thank you for the opportunity.
TP: And if you have any questions regarding this topic or any ideas regarding this topic or other topics you would like to see in this or any other format you can drop us a line at feedback@MIMHtraining.com. At the Missouri Institute of Mental Health we're always looking for your ideas on topics or speakers that you would like to see in this or any other program format. If you are watching this program on line and would like to receive CEU's for this program click on the post- test button and complete the post -test and you will be able to print your certificate directly off the website. If you are watching off-line, say on a DVD, the information regarding the post-test and the CEU application should have been included. Again, we encourage you to check out the other references on this page and look at the other programs we have available as well. Thank you for your time. And thank you for your time, Dr. Linhorst.
DL: You're very welcome.

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setting clients up for failure, so these opportunities can be successful. And then again, an organizational culture is imperative to empowerment. I think there has to be a bottom down belief that mental health consumers can make decisions that they have information that they can provide that the organization geniunely needs to be successful. We have to look at resources as well, again, whether they be money or time or training resources. Then the provision of treatment and rehab activities is critical to empowerment. Some people with mental illness are not going to be able to be empowered unless their symptoms are managed to the degree necessary for particular activity and then to develop the skills they need. Finally, empowerment is all about relationships--that for people who do not have power to participate with people who do have a degree of power, that there must be some sense of trust on both sides that this is possible and will be taken seriously.

TP: You've used the word resources a lot in talking about money and time, those sort of things, but are there informational resources for people as well?

DL: Sure. You mentioned the book at the beginning "Empowering People with Severe Mental Illness"—that's available through Oxford University Press as well as other sites, Barnes and Noble or Amazon.com, and that book also includes an extensive list of references. So for particular empowerment area--whether it be treatment planning, organizational decision making--there are many many references that people can turn to. And the audience should feel very comfortable in contacting me if they have questions

Presenter

Donald M. Linhorst, PhD, MSW is a Professor of Social Work and the Director of the School of Social Work at St. Louis University, and is the author of the book Empowering People with Severe Mental Illness

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implement them when we can."

TP: We've spent a lot of time talking about people with severe mental illness as being kind of a group of people that benefit by this, but I get the sense this can cross populations.

DL: Absolutely. Certainly kids in foster care, the frail elderly, people with substance abuse issues, crime victims. These conditions can certainly apply. Now the internal conditions may vary somewhat, so if we're talking frail elderly, you know their health conditions have to be looked at in terms of what activities that they can do, but the basic conditions certainly do apply .

TP: A lot of the people who are going to be seeing this presentation are going to be mental health professionals, what kind of message would you have for them and suggestions would you make for them.

DL: I think it starts with first of all realizing that you are in a position of power. We often don't think in terms of power and lack of power. So be aware that you are in a position of power and look for opportunites where you can involve consumers in the decision-making process, and particularly those in which they can actively make decisions. Next, I think that professionals can use the conditions kind of as a checklist, so if there is an opportunity, that they look at, first of all, are their symptoms managed enough? What kind of skills do the clients need? Do they have it? Do we need to provide training? What incentives are there for clients to wanna participate? Is this culture going to support it?

So, using those nine conditions or other internal ones that may apply as a checklist to make sure that you are not

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client needs.
Now there's a range of choices that are important. The choices of structures--organizations should offer consumers multiple opportunities. Not all consumers will sit on a board of directors, but most clients should be able to participate in the evaluation process in some way. So a choice of mechanisms to improve, to provide input, and as well as what issues are raised. Clients should not just react to opportunities that are given to them, but they should be able to say, "Hey, I think this is an issue that we need to address at the board, or do more research on." And in the decision making process there should be a range of options, not just, "We're going to do what the board of directors wants or the executive director," but there are a range of alternative actions from which to choose. Again, resources are important--training of both clients and staff. Board members may need training on how to effectively interact in meetings with consumers and what to do if some consumers are experiencing symptoms in the course of meetings—so, training of both client and staff. Having some financial resources maybe to provide stipends or to pay for transportation, or to pay for child care. And again the resource of time is important because it can take more time in the range of structures I mentioned if clients are involved. Again, having a supportive culture and for organizational decision-making in particular, this really starts with leadership--that leaders say, "this is important, we are going to set up these opportunities; we are going to listen to clients; and we're going to carefully weigh their suggestions and

References

Joel Handler: www.law.ucla.edu/home/index.asp?page=529

Empowering People with Severe Mental Illness, by Don Linhorst: http://www.amazon.com/Empowering-People-Severe-Mental-Illness/dp/019517187X/ref=sr_1_1/190-4086453-0371967?ie=UTF8&s=books&qid=1225306175&sr=8-1

"The involvement of a consumer council in organizational decision making in a public psychiatric hospital," Donald M. Linhorst, Anne Eckert, Gary Hamilton and Eric Young, *The Journal of Behavioral Health Services and Research*, Volume 28, Number 4, November, 2001, pp 427-438

Glossary

Empowerment: meaningful participation of people with mental illness in activities or decision-making that gives them increased power, control or influence over their lives in areas that are meaningful to them.

Objective Outcomes: actual power or influence in a given situation

Subjective Outcomes: The opinion a mental health consumer has of his or her role in an activity

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have symptoms managed to a certain extent so they can participate and there are a range of skills that are needed to participate in the activities that I mentioned and in some cases you need public speaking skills and you need assertiveness skills, and you need negotiation skills and in some cases too, good written communication skills. Again, they need to have the readiness or the confidence to do it. And some of these activities can be very intimidating--in doing research or sitting across from the table—sitting at a table with board members from a variety of positions. It can be very intimidating. So, there need to be activities that help build the confidence so that people can participate. And again, developing trusting relationships. Again, clients need to feel like the people they are working with in whatever organizational decision-making activity, really do believe in them and that they are willing to take them seriously in those endeavors. For clients, the benefits--there certainly are these concrete incentives. For clients, by participating, they might get more effective services; they might get a new program that they need by sharing their opinions. And participating in these activities can have real therapeutic value as well. Clients can learn new skills from participating and they can gain confidence in their ability to do these things that can carry over to other activities. And some of these activities can pay stipends. So there can be a financial benefit. Again, for the organization as I mentioned, the research is very clear that clients who have input into the organization, those organizations are much more responsive and provide the services that are a higher level of quality and that better meet

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health consumers have an input at the agency level of agency policies, procedures and what programs are offered and how they're run. Now to exemplify that a little bit more there is a range of structures that--and processes through which--consumers can have an input at the organizational level. More and more non-profit agencies are including mental health consumers as full board members. Consumers can also participate in task forces and committees as well. Another means, is through forums where consumers and direct service staff and adminstrators all get together to talk about what are the important issues and you know prioritize those and look at and develop plans of action. Another very effective means is through client participation in program evaluation or performance improvement activities. Now for that to really be empowering to clients though, it should be something in addition to just completing a survey or being interviewed. For it to be empowering, evaluation--consumers should have the ability to identify this is an issue that needs further investigation. They should have some input into how the study is conducted. There are many cases where consumers should help to collect data and analyze it, and dispense the data as well as be part of the committee that has oversight to make sure that the findings are actually--lead to change within the organization. And then there are a variety of informal means. At one of the agencies I worked with, the Executive Director always had a open door policy and clients at any time could stop by to chat or to share concerns or suggestions for improvement. So there may be a variety of informal means as well. Obviously, clients need to

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Thom Pancella: Hello and welcome to this MIMHtraining.com presentation called "Empowerment of People with Severe Mental Illness". I'm Thom Pancella with the Missouri Institute of Mental Health, I am joined today by Dr. Don Linhorst (*Donald* **M**. *Linhorst***, PhD, MSW**) he is a Professor of Social Work and the Director of the School of Social Work at St. Louis University, he is the author of the book Empowering People with Severe Mental Illness and today we are going to talk about topic of empowerment. So first of all, thank you Dr. Linhorst for joining us today, why don't you starting with telling us a little bit about yourself.

Dr. Linhorst: Ok, I have been a Professor at St. Louis University for 11 years and then worked as a social worker for 18 years prior to joining the University. Seven of those years were at a community mental health center, and I worked for over 6 years at a state psychiatric hospital. My research interests include: the topic of empowerment, health and mental health policy and practice, and the intersection of the criminal justice and mental health systems.

TP: How did you become interested in the topic of empowerment?

DL: I guess as a social worker I was very aware of issues of stigma and discrimination against people with mental illness and the mental health agencies I worked at, I was really very impressed at the opportunities and the activities of the agencies underwent to empower people. But I also observed that there were many failed attempts at empowerment and many wonderful programs that never got off the drawing

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board.
TP: So how did your book evolve?
DL: When I joined the university, the first major research project I undertook was a study of empowerment at the hospital that I use to work at and I looked at what opportunites were available for empowerment at the hospital as well as the limitations that existed to empowerment and that study went very well and I repeated it at a community mental health organization and wrote several articles from those studies and then I was introduced to a theory of empowerment particularly the conditions of empowerment that was developed by a Law Professor at UCLA, Joel Handler, and that condition really helped to expand my research and provided the main structure for a book.
TP: So I like to give a little foundation too, sometimes. The word empowerment I think means a lot of things to a lot of different people. How do you use that word?
DL: Okay, to me, the definition is, "meaningful participation of people with mental illness in activities or decision making that gives them increased power control or influence over their lives in areas that are meaningful to them." Now that one line definition has certainly has multiple components. One is that empowerment is about power, but power can range on a continuum and still be empowering. There might be some situations where not having final decision-making power, but having substantial imput that is taken seriously still can be empowering, and empowerment is situational to different activities, those activities can be treatment planning, participating in organizational decision making,

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or employer, that treatment plan can be a road map for ending coercion. With availibility of choices, we're really looking at choices in terms of a variety of goals being included in the treatment plan--not just managing symptoms, but maybe employment, maybe education, social relationships, but then also looking at choices within those goal areas. For example, if they're looking at employment, that they have the option not only of sheltered workshops for example, but of training programs—maybe going to college or supported employment programs. And then there are resources that both clients and staff need to engage in treatment planning. One resource obviously are having available the treatment-rehab resources they need to manage their symptoms. Another resource is having the amount of time to participate so that they are not feeling rushed as well as a time that is convenient for them. Staff often need the resource of skill building to be able to effectively interact with the clients in a way that draws out information that is useful for them and can make decisions in a way that really does involve the consumers. And staff, too, need adequate time. Caseloads if they're high may not be the time to do that, and then finally there needs to be a culture within the agency within the program, within the treatment setting that really values and promotes and provides the resources for shared decision making.
TP: Treatment planning is a really good example. Is there another good concrete example like that?
DL: Yeah, another example would be participation in organizational decision making. By that, I mean, that mental

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psychiatrist, psychologist, nurse, social worker and possibly others. I mean that's the structure through which particpation takes place. Now for a client to meaningfully participate in treatment team, they need to have their symptoms managed to the degree that they could meaningfully participate and that allows them to process information, to--that gives them the cognitive ability to weigh choices and to select those goals and activities that best suit them. And they need the skills to participate, a range of decision-making skills are needed to effectively go through the treatment planning process. And they need the willingness and motivation to do it. Many people with mental illness may not be willing to, because of a range of reasons. Maybe they haven't had treatment teams that have been willing to involve them; maybe they simply don't have the confidence to make the decisions themselves and they may be experiencing clinical depression where they literally don't have the energy to participate. Now mutual trust and respect, the client has to believe and trust the individual and individuals he or she is working with and they value their opinions and that they will consider and listen to them. Likewise, the treatment team or case manager must believe that clients have something to offer and respect them enough to value their opinion. Now there are particular concrete incentives on both parties for participating. For clients they are much more likely to get the goals and activies in the treatment plan if they are able to voice their opinion and if people are coerced into treatment by—through civil commitment or through criminal justice agency or a spouse

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participating in employment and evaluation activities, but it is also situational to a particular point in time. So for example, if we are talking about treatment planning, you can have a good working relationship with your case manager, you are being empowered through treatment planning, but if at that case manager changes, he or she may not involve you. So again, it can be—it's time-limited to an activity and situation, and as Joel Handler said, "it is a very fragile state." Empowerment can also refer to a process and an outcome. The activities you are engaging in, you can refer to those as empowering activities, but we are also concerned about outcomes--are people reaching their goals, are having and influence on processess? And those empowerment outcomes can be both subjective and objective. The subjective outcomes are the opinion the mental health consumer has of his or her role in the activity. The objective outcomes are those related to--did the person really have more power or influence in the situation? Obviously you like the two to match, but there certainly are times when the subjective outcomes—one subjectively believes that he or she has power, when in reality they don't, and occasionlly the reverse is true where they are exerting power but don't realize that. I think that in defining empowerment it is important to clarify that one cannot empower another. People must do that for themselves, but others can provide support--the resources in order for that to happen.

TP: It is clear that you spent a lot of time working with that, and a lot of time and energy working on the concept and the definition. Give us a feel for why you feel it is important.

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DL: Well I think philosophically, people have the right to participate in their own lives, I think to the extent that people can, we should be able to control our own lives, and that certainly applies to people with mental illness and other vulnerable populations as well. Secondly, it enriches the experience to have people participate. We know that treatment planning goes better if clients participates and are more likely to follow the plan if they participate. The research is clear that agencies that have avenues for clients to have input into policies, procedures, the programs they operate have--offer services and programs that are more atuned to client needs. So it does enrich the experience to have consumers involved, and also it's part of the recovery perspective and an important part of that which most programs and most professions now hold. And finally, in addition to benefiting the consumer, it certainly benefits the agency and the public at large when mental health consumers are empowered.

TP: I think you referred earlier to conditions of empowerment. What would those be?

DL: The conditions are the circumstances under which empowerment is likely to take place. As I mentioned earlier, it is a fragile state and I think these conditions are hard to meet. Now three of the conditions are internal to the person with mental illness and the other six relate the individual and his or her environment. Now the first internal condition are managed psychiatric symptoms--the individual needs to have their symptoms managed to the degree that they can participate in a particular activity. Second, they also need

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the skills required. Third, they must have the psychological readiness or the motivation or willingness to participate in an activity. Now the other six like I said, are external or an interaction with the environment. One is having mutual trust and respect between the mental health consumer and the person with whom he or she is interacting with, whether that's an employer, or an administrator, or clinician that they're working with. Next, there needs to be recipricol concrete incentives for participation. That is, the person in power must have some tangible benefit to involving the person without power. Likewise, there needs to be concrete benefit to clients to be willing to take on these activities. Next, there must be a range of choices available for empowerment to occur. In addition, there needs to be particular and oftentimes formal structures and processes through which the individuals in power can interact with clients. Next, there needs to be a range of resources available. These can be anything from time to actually engage in an activity, to training of staff or consumers, to logistical resources such as tranportation or child care. Finally, there needs to be a culture, whether it be within the organization or even a program or treatment team, that is supportive of a shared participation.

TP: A lot of conditions set up there. Can we get into some kind of examples? An example of opportunity for empowerment.

DL: Sure, one would be treatment planning--and here we are talking about an individual client meeting with either a case manager or with the treatment team comprised of a