

In-Home, Physical Activity, and Independent Living: What's the Connection

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Presenters: Katherine Froehlich Grobe and Dorothy Nary

LAUREL: Good afternoon. This is Laurel Richards with ILRU in Houston, and we want to welcome you to today's webcast. The topic today is "Physical Activity and Independent Living: What's the Connection?" Before we begin, I want to acknowledge the support of NIDRR, the National Institute on Disability and Rehabilitation Research, for its support of an initiative such as this whereby they wish to promote the use of research among those of us who are not researchers but have a stake in the findings that the researchers come up with and also to acknowledge our colleagues at the University of Kansas Research and Training Center on Independent Living. They and we jointly operate the RIIL project, the Research Information for Independent Living. Our presenters today will field questions and this is meant to be interactive, and they are expecting questions to be submitted or comments to be submitted. So please exercise that activity. Before we get started, I want to welcome our presenters today. We have Katherine Grobe and Dot Nary. Katherine, I believe you are a Ph.d. in behavioral psychology, right?

KATHERINE: That's correct.

LAUREL: From Kansas University. Looking at your bio I see that you've been doing research in this area for nine years altogether in disability areas and in health promotion type stuff for the last six; is that right?

KATHERINE: Yes, that is correct.

LAUREL: How did you get involved in disability-related research?

KATHERINE: Well, actually I had a wonderful mentor. After college, I had gone to work for the National Institutes of Health and was there at the time that the National Center on Medical Rehabilitation Research had just been opened and was working with David Gray who is now a faculty member at Washington University and is also himself a person with a disability, and he introduced me to not only the

areas of research, but the great need that existed in terms of improving the lives of people with disabilities. So I had a passion to continue doing work in this area and came to work with Glenn White back in '94. I believe it was '93.

LAUREL: I didn't realize that you were affiliated with David Gray, and he does do remarkable work, but I didn't realize the impact as far as that.

KATHERINE: Yes.

LAUREL: That's excellent. And your interest in the research area is on improving health, health promotion?

KATHERINE: Yes.

LAUREL: Dot, I noticed on your bio that you had worked with some independent living centers in New York before taking the position as director of training at the RTC on IL.

DOT: Yes, I came in as a research assistant and came out to Kansas to work with Glen White because I'm really interested in health promotion for people with disabilities.

LAUREL: And the centers in New York, which ones were they?

DOT: I worked at one in Corning and one in Binghamton for about nine years all together. At the time the ADA was passed so it was pretty exciting.

LAUREL: And it continues to be so.

DOT: And challenging.

LAUREL: Now you're working with a center there, Independence, Inc., and another board.

DOT: Yes.

LAUREL: Dot, now, be honest, didn't you have reservations about moving to Kansas when you have a name like Dorothy?

DOT: I had a lot of theme parties for going away and one of them had a banner on the ceiling that said "Surrender, Dorothy," but I survived.

LAUREL: I'm mighty glad. Why don't we segue into the presentation? This is a subject that is receiving a lot of attention these days and not just physical activity and the importance of physical activity, but the whole issue of health promotion and maintenance. So, please let me turn it over to you and welcome to the presentation.

KATHERINE: This is Katherine. I think I'm going to get started off to talk about why physical activity is important to independent living, and I'm going to start off talking at a global level or sort of a general population level. We know in 1996 that the surgeon general's office released a report on the health benefits of physical activity, and we're able to see that even moderate amounts of physical activity had substantial health benefits. It could help reduce the risk for cardiovascular disease, some cancers, stroke, as well as help people maintain healthy weight, healthy cholesterol levels and healthy psychological, lower depression. So the nation sort of began to focus on physical activity as an important factor for improving health outcomes because cardiovascular disease and stroke are two of the leading three causes of death in this nation.

But the short-term benefits of physical activity are particularly important to people with disabilities. The short-term benefits include things like increased strength, endurance, and stamina so that it's very possible through physical activity that people with disabilities cannot only do the things that they need to do to be able to do all of the transfers they need to do if they are a wheelchair user throughout the day or be able to navigate on crutches with enough energy to do that; but also to have enough energy to do the things they want to do, socialize, play with your kids, things like that. So the short-term benefits are also important, but there can be some specific benefits that are related to those short-term benefits. They can help improve function.

So maintaining strength and balance and endurance can really help with engaging in activities of daily living and the ability to do those and not have so much fatigue that you would be wiped out for the rest of the day. And I have two examples of types of disabilities that physical activity can help to improve. One is COPD (chronic obstructive pulmonary disease), for somebody who has that, it is possible through starting in small and short time segments of physical activity and increasing over time to not only increase endurance, but to increase lung capacity. The more somebody is inactive and sedentary, the more deconditioned they become and particularly this is problematic for people with COPD because it continues to diminish lung capacity. So if it's possible to start to increase activity back up, start with two minutes a day and increase to five, maybe ten, over a period of time. It's possible to have an effect on lung capacity as well as energy in general.

And for severe obesity, it can help people not only begin to start to move more often, but to increase their muscle and their ability to stretch their legs and move around and get their heart rate up. And potentially, you know, over time, if weight loss is an interest, then, you know, structuring more intense physical activity can help with that. I can talk about these specific programs about a woman who had severe obesity and had a lot of problems with circulation through the obesity in her legs and had problems with pressure ulcers and just increased circulation was decreasing the severity of those pressure ulcers by her self report.

DOT: I'd like to add a few more reasons why it's important for independent living. One of the participants in the study I did is a woman with quadriplegia and she is studying to be an elementary school teacher. She was glad to be involved in the study because she commented that in order to have the stamina to get through a school day with a group of second graders, she would need to exercise to achieve the stamina level she would need. So I thought that was good. And I think all of us, now that we have opportunities to work and to have lives, especially because of legislation like the ADA, people need to feel good enough to do it for a long period of time.

We lost some disability leaders in the 90's, much sooner than we expected to, men in their fifties. I can think of a few people. We need to be looking at our health now that we have reasons to live. We can have a good quality of life. So I think a lot of this has to do with general health and remembering that as Katherine mentioned we're susceptible to the same diseases such as heart disease as everybody else who is not disabled.

DOT: And now, Katherine, do you want to talk a little bit now about who can do it?

KATHERINE: Who can do it?, the second item on the agenda. Really, everybody can be involved in physical activity. And I want to go back to highlighting the surgeon general's report that came out in '96. That report really highlighted that moderate levels of physical activity were all that were needed to achieve the substantial health benefits. When the different national organizations looked at physical activity guidelines, they said, it used to say we needed to do 20 to 30 minutes of high intensity activity, but the new data suggests that even 30 minutes of activity accumulated throughout the day. So you could do as few as five to ten-minute bursts of activity, walking through the parking lot, gardening, and things that weren't as high intensity to be able to gain these benefits.

So that's really good news for people with disabilities who may have more severe impairments and more substantial barriers to activity. I do want to say though there

should be a caution for people who have things like progressive disabilities or episodic disabilities or who might experience other health complications like cardiovascular problems or respiratory problems. You want to start off in smaller time increments at a very low intensity level because it's a matter of needing to condition the body and the muscles to start getting active in those ways again. And it's always a good idea to consult with a doctor before beginning a program just to make sure there is not some health complication that you're not aware of that might be a risk factor.

One example might be hypertension. So that if that is going on, you can get that treated before progressing too quickly and putting yourself at risk for heart problems. But really, breaking it down and beginning at a level that's feasible is possible for anyone. Is there anything you'd like to add, Dot?

DOT: No, I think you covered it. I think there is probably something that everybody can do, even in one training we did where we had Terry Chase in, she said a person who has difficulty breathing and has little movement can put books on their chest and use it to help them do deep breathing. So we're talking people with all types of disabilities and all levels that they can probably all do something.

KATHERINE: Right, and that reminds me, too, for folks who might have paralysis in their lower limbs or not enough strength, even passive range of motion exercises are good to help with keeping the muscles and tendons limber and able to move and ask potentially help also with circulation, just even the passive movement. Shall we talk about the barriers?

DOT: Yeah, why don't I start off. Katherine, can you kind of finish it up? The good news is I think people are starting to realize there are barriers and are starting to remove them. The bad news is there are still a lot. That's everything from what women in Katherine's study called "Fair Spandex," you know, people don't want to go in those tight costumes and exercise at a gym, lack of welcome in public settings. I was at a hotel recently and they asked me about a pool lift and they asked me "why would you be interested in a swimming pool?" because I use a wheelchair. There are a lot of physical barriers like that. A lot of places you can get in to a facility, you can park and there is no aerobic equipment available for someone who uses a wheelchair. There is a cycle you use with your arms instead of your legs is good, but most commercial facilities don't have them yet.

There are also hassles around getting recommendations from health care providers. A lot of providers simply don't know how to recommend safe useful activity for people with disabilities, even though there are some books on the market now that give precisely that information. There is an effort on the part of fitness facility

management to remove barriers, and I think their incentive is somewhat altruistic. They are looking at the market in the future. And we have an aging society.

Many people will live longer and these are the folks they are going to market their centers to. So that's on our side. It's a good thing, but certainly it's not happening soon enough for a lot of you us.

KATHERINE: I'd like to say that barriers to activity exist for everybody. The national datasets indicate that about 75 percent of people with disabilities, that includes all types of disabilities, you know, hearing and sight and back problems almost and things like that as well as the spinal cord injuries, are either sedentary or not active enough to achieve the health outcomes. And nearly two-thirds or about 66 percent of people without disabilities are also sedentary or not active enough to achieve the health benefits. So this is truly a national problem that we have a lot of people who are leading very sedentary lives, and in the general population types of barriers are also common among the types of barriers people with disabilities experience, things like lack of time, safety in neighborhoods or communities where you can be active, and cost of fitness facilities or proximity to your home.

So these are some of the types of barriers that we know are cited in the general population and can also unfortunately pose problems for people with disabilities.

DOT: I think we might be ready for some questions.

RACHEL: Okay, we've gotten a couple of questions. One, Dot, you started to address there. This person wants to know how can advocates gain greater access to fitness centers and improve the use built of the fitness centers for people who use wheelchairs?

DOT: First, I would talk to the management and explain that they would be wise to increase access, and you might want to contact someone from the local independent living center to do a walk through. I believe that the access board, the national architectural barriers compliance board has done some work recently on fitness facilities so you might refer them to that.

But basically, I think it's not clear under ADA exactly what they are required to do, but certainly the building has to be accessible in terms of equipment, you're on less sure footing there because they may not be required to do it, but I think if you can develop a relationship with them, explain that this really will help. Refer them to magazines that discuss accessibility in fitness centers. So that might be good information for them, too.

RACHEL: It sounds like also, even teaming up with some advocates for people who are aging might be helpful because, you know, I think that fitness centers definitely respond and see that that's a large constituency. And they don't always recognize how large a constituency people with disabilities are because there are so much media about baby boomers and aging, they understand that. Another question is: have you found that informing people about the importance of physical activity and the dangers of not exercising really helps motivate them to exercise?

KATHERINE: This is Katherine, and I'll just begin by saying, and we'll talk more about it when I talk specifically about the study that we conducted here at K.U. I think education is very important. People need to understand the health consequences of physical activity, and need to understand it has day-to-day practical improvements in health outcomes from improved sleep to just feeling like you have more energy. But, unfortunately, just educating people is not enough.

We need to do other things to really help them create a program, figure out ways to overcome barriers, and then continue with the program over time as, you know, life intervenes and we get sick or family members get sick or we just don't feel like it or we have injuries. So, we need to use different tools or strategies to help people both begin and maintain activity programs.

DOT: I think that's a really good point. This is Dot, because in a lot of places we've crafted communities that don't facilitate exercise. We have to drive everywhere. So I think it does take a lot of work on the part of a person wanting to adopt that habit to find ways to do things and to work it into busy days. So I think that's good information.

RACHEL: Okay, I have another question that takes us in a slightly different direction. There is some interest to know if a tens unit is a viable way of exercising muscles in people with paralysis.

KATHERINE: Dot, do you know about...

DOT: I don't think so. I think a tens' purpose is to relieve pain or to redirect it. I think the functional electrical stimulation can build muscle, but I don't think that it provides cardiovascular activity, and I'm not an expert on this, but I believe that the muscle stimulation doesn't really provide much exercise. It might build muscle for future use, you know, for standing perhaps, but I don't think it gives a cardiovascular workout, but don't quote me.

RACHEL: Okay. We have a question that sort of takes us back a step to talking about public gyms. This one says that public gyms are often very accessible but limited in equipment. Are there studies or businesses that design equipment for different disabilities?

DOT: Katherine, do you want to take that?

KATHERINE: Dot, you might know more specifically.

DOT: There are companies that specialize in adaptive equipment and one place to look at that is in NEW MOBILITY magazine because they usually have some advertisements, and each year their July issue focuses on equipment. If anyone is interested, I do have an armagometer at home and I'd be happy to refer people to that website. Why don't I give my e-mail address or Laurel would it be better for them to get on the chat line after? It's an armergometer. It's simply a stationary arm cycle. So it's like a stationary bike except you use your arms.

LAUREL: Thanks.

DOT: And my e-mail is dotn@ku.edu.

RACHEL: This is Rachel. I wanted to add one thing. You guys had referred to the access board, and talking about gyms, and there are some new guidelines that are out that do deal with gyms. They don't affect the design of the exercise equipment itself or the machines itself. But they do require that one of each type of machine is available on an accessible route and that there is transfer space for people using wheelchairs next to at least one of each kinds of the machine.

DOT: That's good information. I complained at a hotel recently, and I just got a letter back. They were required to have a pool lift under ADA, but they were not required to buy an armergometer. There is a distinction there. In order to use the pool they have to get a lift, but if you can't use the equipment to begin with, they don't have to get anything adaptive at this point. Katherine, did you want to describe your study.

KATHERINE: I'll go ahead and start. This is Katherine. Back in 1997, we at the Research and Training Center at K.U. received grant monies from the Centers for Disease Control to investigate the ability of an intervention or a program to promote physical activity among women with mobility impairments.

What we did was recruit women with disabilities across the Kansas City metro area and determined their eligibility for this study. Their eligibility was primarily

determined by their mobility impairment; but they could be walkers or wheelers as long as they had difficulty maneuvering about their environment in an ambulatory way. And we talked to over 250 women who were very interested in participating, but only 93 actually were eligible and able to begin the program.

So what we ended up doing was randomly assigning these women into two groups. We had one group that was going to be the experimental group or the group that got the exercise program, and then the other group was a waiting list group. We were going to compare them to the exercisers and then they were going to be given the opportunity to participate in the exercise study at the end of the first six-month round. So this was the intervention, a six-month program where the women enrolled; we had five different strategies or components that we had programmed to help them increase their activity levels.

And the first of those components was to attend a day-long educational workshop, and we brought in two women who themselves have disabilities and are sort of content experts in either independent living or in physical activity. And they spent the morning talking to the participants about why physical activity was important, what sort of barriers they might be experiencing, how they could overcome those barriers, and started to talk about specific activities that the women could engage in over the six-month time period. That's where Dot had said one of the women talked about putting a book on your chest even if you only have some respiratory to use your respiratory muscles and to improve lung capacity. Then in the afternoon we spent time talking to the women about how this six-month period of time was going to go with our intervention or our physical activity program and getting them set up.

After that educational workshop, we had one-on-one phone calls between every woman that enrolled in the study and the exercise physiologist. This is a professional who knows about exercise science as well as knows about disability and they were able to give individualized prescriptions to the women about what things they could do for physical activity, where they might be able to do that in the Kansas City area if somebody wanted to do water aerobics and had ms [multiple sclerosis]. The person tried to help them locate a pool that had the correct water temperature or talked to them if they wanted to do a home program, talked to them about if they wanted to do some sort of strengthening exercises if they didn't have weights, what things could they use in their home to use as weights to create resistance.

And so that was about a 30 to 45 minute phone call. After that, we then asked women to self-monitor, and basically it was just keep a daily record of physical activity, and we asked them to mail those records in to us on a weekly basis. That

way, we could be following their activity levels over time. Two other components that we thought would be helpful in promoting activity were to pair them with another woman in the program who was also attempting to begin an exercise program and ask them to give themselves some sort of reward each week they met or exceeded their physical activity goals.

So that was the program, and we had the women do it at home or in their community for six months. We were tracking their weekly activity levels and we were looking at not only their physical activity, but we were looking at different physical health and psychological health parameters, things like their weight, their body fat, their cholesterol levels, blood pressure. We looked at depression levels, and we looked at their self-reported experience of secondary conditions, and we were asking about 18 different conditions, things like sleep problems, chronic pain, bowel and bladder problems, things along those lines. And we were hoping that, you know, physical activity would have an impact on some of these health parameters. And we were comparing the exercising group with the group who didn't exercise.

What we found was that about 25 percent of the women across both groups withdrew from the study for a variety of reasons, including injuries, needing to care for others, whether it was their children or family member, or even exacerbating problems with their own disability and other health-related issues. So we had a variety of reasons people left the study.

But of those who stayed in, we found that the exercisers actually just about doubled the total amount of time. The women doubled their total amount of time spent in physical activity over the six-month period. And we told them to count the things like, park further and walking or wheeling to the door, things that were stretching and strengthening activities as well as anything that was cardiovascular related, if they were walking or wheeling or swimming or doing water aerobics or seated aerobics. Those things got counted at cardiovascular activity. And the women in the physical activity program were able to go from about 15 minutes of activity before the program to spending more than – about 100 or plus more minutes per week in cardiovascular activity.

So they really substantially and significantly increased their time spent in cardiovascular activities, which was great. And when we compared that to what the new physical activity recommendations are, they suggest engaging in about 150 minutes or more cardiovascular minutes of activity each week. And so our participants were engaging in just under that, but when you add the amount of time that they did other types of activity, things like stretching or strengthening activities or, you know, if they could walk, anybody walking the stairs in their

home or things like that, they actually were doing more than 150 minutes of activity a week. So when we count all the activity, they were doing more than the surgeon general would recommend or other national physical activity guidelines. However, when we looked at the health data, unfortunately, we did not see that the women had significantly changed things like their body weight, their body fatness, or their blood pressure. And so there are a number of reasons why this is possibly true, but I think one of the important ones for this study is that we did include women with a variety of disabling conditions. We had women with arthritis and a woman who had a double amputation below the knee. We had several people with ms, spinal cord injury, and so some were ambulatory as I said earlier, but others were using power chairs and really only had arm mobility.

So it's very likely that within six months this group was not doing enough activity to actually reduce body weight or reduce cholesterol levels, but that they were doing enough to just start to begin to increase their stamina and strength and sort of ability to keep moving. And so I think this was a preliminary study to allow us to see that, yes, we were able to create some sort of program that would help women to begin to engage in more physical activity. But as I said, we had used originally five components that we thought would help people engage in activity. Two of those components, which were the pairing up of a partner in the program for social support, and the reward component, the women really didn't actually do that. Most of the women told us that most weeks, I think out of the 26 weeks of the intervention, at least 11, an average of 11 weeks, they actually got support from somebody else in their life rather than their partner.

I think it was maybe three weeks on average they got support from their partner, and they really didn't use the reward system at all. As a matter of fact, those who did, often told us they rewarded themselves with cake, cookies, sweets, things that were probably counterproductive to an activity program. And I think there are other sort of methodological programs. We had so many different types of impairments that were experienced by the women in the study; we made sure that women had programs that were going to be appropriate for them. So we had some women that were doing walking programs, some that were doing wheeling programs, some who were primarily doing passive range of motion and they were resuming some of their own activities of daily living like bathing or transfers, but they were doing less typical physical activity-related activities.

So I think another reason we didn't see a larger effect on health outcomes was because nearly everybody was doing a different type of program. So we really ended up comparing apples and oranges. So I think the real strength of the study is that we did find that the women increased their total activity levels as well as doubled the amount of time they were spending in cardiovascular activity. And we

did interviews with all of the women at the end of the intervention and asked them about how things went. And 75 percent of the women who had gone through the program told us that they did experience other improvements and things like their strength, their endurance, their ability to sleep better, their ability to engage in other activities that they now had energy for.

Things like that really mattered to them in their daily lives, and so I think that gave us researchers' ideas about how we might structure a new set of measures that are going to be more sensitive to functional impacts of physical activity. We, with using weight and body fatness and cholesterol, those are very important health measures. But with the types of activity this group was doing, it probably would take a longer period than six months to impact some of those outcomes. So we might want to think about using other functional type measures as intermediary measures as we continue to look maybe over longer periods of time at the health impacts. So, I think that I will conclude my discussion of the study and let Dot turn to hers.

DOT: Well, that's good, Katherine, and I have to say mine is much smaller and simpler than Katherine's and we based some of it on what we learned from her study. So I had the benefit of learning from the larger study that she did. For this project, we tried to devise an in-home, low cost, very adaptable physical activity program for some participants in the Kansas physical disability waiver here. The PD waiver is an HCBS program. It's home and community-based services where people can have a tendency to be in the community and not in an institution. We had five people start.

One dropped out soon after due to illness, and one person had the type of disability where this program was not appropriate for her, but three people stayed in, and really did very well. They increased their activity each week from none basically up to 27 minutes, three times a week, which is good. They did the activity in their home. We used adaptive aerobic videotapes. We went to their home each week, viewed them doing the program, asked questions, had them fill out health logs similar to the ones that Katherine used in her study and just basically checked in and gave them support every week to keep up.

Each person started at the number of minutes they thought they could do easily and after two weeks we increased the minutes, maybe three minutes to five minutes, so by the end they would have five regular increases every two weeks. The good thing about the study was it was very accommodating in terms of people needing time out.

We had a woman with diabetes, and she had an infection and had to take a few weeks off. We had a woman with multiple sclerosis, and the temps were in the 90's for part of it and she had a week where she couldn't exercise. So this study design, which is single subject, is for very small numbers of people but allowed us to be very flexible with the program, which is what people needed.

We measured also things like stamina, heart rate. We didn't see big differences in this group, but we really focused on providing support so that these people could increase their physical activity on a regular basis in a very cost-effective manner using maybe a 30 dollar videotape in their homes. They didn't have to go anywhere to do this.

So, as I said, we went every week and charted their activity and gave them feedback. But we also tried to set them up at the end of the program with people in their own environment, perhaps a personal assistant who would help them chart their activity, on a chart on their refrigerator or a friend who would go walking with them. Again, we had a woman with ms. We had a woman who had an orthopedic impairment, was very obese, and also had diabetes and asthma. She had multiple disabilities, but she stuck with it. She wanted to make the gains from increasing her physical activity and the third participant was a quadriplegic. So she had very high levels. She could move her arms a bit and she used that to get aerobic activity. It was just a few participants, but by keeping it small and having people measure their progress against their own baselines so regularly increasing their activity every two weeks, it helped us to be flexible and to make it work for everybody. Are we maybe at a question point again?

KATHERINE: Yeah.

RACHEL: Okay, we've gotten a couple of questions in. The first one is for Katherine, referring to your study. The questioner says she understands that the women in the study did not use buddies or chose effective rewards; but which of the components did prove most motivating?

KATHERINE: Interestingly, it was the keeping track of their daily activity logs. When you think about it, what we know from sort of behavioral research, it's a wonderful way to motivate someone, and weight watchers actually uses this. You have to log everything that you're eating and you get points for it.

DOT: It does make you be honest. I know.

KATHERINE: And that's what the women told us because when we had the workshop, the women were very motivated. It was a wonderful day. We had a lot

of camaraderie, a lot of great sharing, and they learned about things that they didn't know they could do to really have an impact on their health. So they left being very motivated, and we thought that was going to be the most important component. This is why I said when I talked about the study, it might help understand why the education alone isn't enough.

They learned a lot. But six months, 26 weeks, is a long time and a lot can happen day-to-day and things that are related to the disability. As Dot said, they had somebody in their city who had an exacerbating ms. We had the same sorts of things of people with arthritis where they would have a flare up and really be unable to work out. So things happened that kept people from working out. What this monitoring, these daily logs did, what the women told us when we talked to them by phone in those interviews was “I started out doing great and my motivation may have come or go, but I was able to look back at the logs and see my progress.”

I could actually go back if I had had a bad week. I could go back two weeks and see how I had been doing and that helped my motivation get back up. Or if people were trying to increase their amount of time, and they were wanting to bring back and see, gosh, I could only do five minutes of this activity a couple of weeks ago, I'm now up to ten. I've doubled that time. I bet maybe I could keep increasing it. So it was a really good way for participants to see on their own their own progress, and that's what they shared with us.

And I think they also shared how we could have improved that component. One of the things we did not do, well, we didn't think about it really, was provide feedback to people about how they were doing. So some women said they would send them back saying they did no activity. So some women said “whether I told you I did a lot of activity or no activity, the response was the same, nothing.” And they said it would have been really helpful if we had given them some sort of feedback, whether by mail, by phone, in person, so I think we learned from that. But surprisingly it was not the educational workshop or even the one-on-one phone calls where they got individualized prescriptions: it was the daily logging.

RACHEL: Very interesting. That's helpful. Dot, there is a question for you that is sort of along the same lines. Are there any lessons from your study which we can generalize?

DOT: Yes, there are. I think that if you don't provide the support element, I think it's going to be very hard to change people's behaviors or for them to change their own behavior. So it's really important to pay attention to someone noting their progress or a person doing it themselves, and also that an in-home program can be

effective. You don't have to go to the gym or even to the park. There are things people can do in their own homes that are convenient and that address barriers like resources, lack of transportation, scheduling, things like that.

RACHEL: Okay, that's actually a nice transition to another question. This woman wants to know if there are any on-line or printed guides on moderate exercise? And if yes, can you provide some contact information?

DOT: Katherine, you want to take that and mention your booklet?

KATHERINE: Sure. Out of this project we did through CDC, we did create a self-guided exercise manual where we talked about all the different strategies we had used in that study that people can use on their own, and that is available. You can log onto the RTC website, and I believe that website is www.rtcil.edu.

KATHERINE: That's one guide. There is also a website actually, NCPAD, which stands for the National Center on Physical Activity and Disability that is operated by the University of Illinois at Chicago. Is that correct?

DOT: Yes.

KATHERINE: And they have lots of information in their website. It's a project that they plan to continue expanding. Lots of information about the importance of activity, and I believe they're starting to put information on there about different types of activity and equipment you can use.

DOT: And they're putting up exercise modules also. So that might be a really good source. I have the website, too. It's simple: www.ncpad.org.

KATHERINE: And, Dot, you know of some exercise videos that are really good that I know we cited. I think we put a table, based on the background work you did on all these eastbounder size videos of some really good ones.

So we have a table of good aerobic videos or strengthening videos that people can use in our workbook that had come out of the work that Dot did in compiling a library of materials for her study.

DOT: Right, there is that nice table in your booklet. I like aerobic videotapes because they're easy. You don't have to go anywhere, and you can increase your activity gradually. So I find them helpful. I don't like the disco music, so we need to get some new ones out there. I'd love to get a grant to do one that would have a warm up and exercise in five-minute increments. So that is a possibility, also.

RACHEL: Speaking of funds, you have a question here about funds. This comes from someone. If I understand this correctly, they're at an independent living center, and they're looking for funds to conduct health promotion programs at the center. They would like to know if you know of any grant programs out there.

KATHERINE: I don't know of a lot. I know there is the Robert Wood Johnson Foundation. I know they have an interest in community coalition building, and so I would think that a CIL would be very appropriate for applying for some funds like that but I don't know the parameters of funding.

DOT: I would recommend that also. I would also look at local community foundations. I would look at managed care organizations. I know that back in New York one ILC got some adaptive exercise equipment from a grant from a managed care organization. This is a real hot issue. Everybody realizes that physical activity is important, and they are also somewhat aware of the barriers for people with disabilities. So I would look at local granting organizations and use it to promote health for every one as a strategy.

LAUREL: You know, the RSA funds a number of recreational grants.

DOT: I don't know if they still do.

LAUREL: I'm not sure about that either. I know they won't fund one organization for much more than one cycle. Helen Roth in Logan, Utah, had a recreation grant.

DOT: And there was one at the Catskill Independent Living Center in New York.

LAUREL: So it's worth looking into, and I believe RTCs website would have information on that.

DOT: That might be good additional point of information for the NCPAD website that Katherine mentioned, to compile a list of sources that organizations like CILs could approach for funding.

KATHERINE: And one thing that I wanted to mention. It's a hot topic for both the general population as well as people with disabilities, and many in the rehabilitation community are arguing that it's even more important for people with disabilities than the average population. We know, based on general population data, that obesity rates are sky rocketing. It's like a 100 percent increase in the last 20 years. Don't quote me on that. Large increases in obesity and people have stayed the same in their levels of physical activity as they are continuing to

increase their weight, and recent data indicates that about 50 percent of all deaths are due to lifestyle behaviors, including nutrition and sedentary lifestyle.

LAUREL: That's 50?

KATHERINE: Fifty percent of all deaths, which the top leading three death are cardiovascular disease, cancer, and stroke. There is a lifestyle or behavior component to all of those; but it becomes important for people with disabilities because there were a couple of recent studies published in August, no, September of this year that indicate that obesity rates are even higher in the population of people with disabilities than the general population. When you think about the fact that people are living longer and functioning with higher body weights, their risks for cardiovascular disease, cancer, stroke, other type of diabetes, arthritis, things like this are also increased. So it's very important not only from the functional improvement level, but also from the possibility of having an impact on health, and I know that the Healthy People 2010 recommendations are calling for all levels of local, state, national governments and organizations to begin to address these issues.

So I'm thinking there is a possibility for community coalition building and somebody earlier mentioned getting in touch with organizations that are focused on aging issues.

LAUREL: Rachel, I've got a couple of questions, if I may.

RACHEL: Okay, and then I have two more questions that came in by e-mail.

LAUREL: Okay, Katherine, on your study, I think it's a neat distinction you make between physical activity impact on health and physical activity's impact on functional issues, which I think to a large degree, you know, have greater impact short term. And I wondered, if on the measures that you conducted on a periodic basis over the 26-week period, did the sense of wellness or the mental attitude change even though perhaps the blood pressure didn't?

KATHERINE: Yes. The women told us they felt a lot better. Not only were they sleeping better and having more energy, their sense of well-being, and we didn't use, actually unfortunately one of those measures. improved, and also their sense of empowerment improved as women. And the average age was 44. So these were women who grew up before Title 9 where before girls thought they should be physically active and the fact that they had a disability, they really never thought of themselves as needing or being physically active beings. They particularly weren't interested in sports, many of them.

So they didn't think of this as an aspect of their life. Many of the women told us, "you guys told me I could do something I never even thought I could or should be doing, and I tried it and I could do it, and it felt great." Several women stated that accomplishment fed into other areas of their life, to think of returning to school, to getting involved in other activities. So that really had other very important impacts, which we didn't even think to begin measuring in that first study. So we're hoping in future studies to measure both this sort of psychological impact that's a more day-to-day impact as well as the functional improvement.

LAUREL: You know, I remember hearing some people running centers, and particularly Vickie Rennick in a center in Portland, Oregon, said the recreational program they had, and it was a small one, created more changes in a life, and it had opened up doors to people that she never anticipated happening. It was just an enjoyment thing.

I've got a question for both of you, but one is the cost of the program. Katherine, in yours, if an organization wanted to repeat what you were doing but take out perhaps the research component, we're not talking hugely expensive program if I heard you describe it correctly. It sounded like the costs were in the one-day workshop.

KATHERINE: Right.

LAUREL: And then you all follow up.

KATHERINE: Right.

LAUREL: So is this not a hugely expensive program?

KATHERINE: It really could be fairly reasonable and we didn't do any cost analysis in this study, but I think because we asked people to mail those logs back to us, you know, there were some mailing charges. But I think that was probably less than what somebody's time would be if they were following up by phone with people. But in terms of the type of benefits that can happen, those can potentially be nominal costs for the long term impact.

LAUREL: Oh, yeah. Yeah. And Dot, on the program of yours, I have two questions: one is the videotape of adaptive exercises, what was the base. What was the cost of one?

DOT: Oh, we used a couple of different ones participants could choose. Most of them are 20 to 30 dollars.

LAUREL: I assume they're not that fellow named bo, or tai . . .

DOT: They're not. The best ones are done by people with disabilities.

LAUREL: And they could be accessed through the national center?

DOT: I'm not sure. They're in the booklet Katherine did, and there is a catalog that's available that has some, but they're not the best ones. So I think it would be best to maybe contact us, and I plan to keep abreast of any new ones coming out.

LAUREL: Now, on the videotape, if a participant was older and wanted to maintain range of motion, and, I mean older like a senior, is it too aggressive for them or would there be appropriate exercises?

DOT: There are tapes of different levels and intensities and some of them recommend that if you can't do the most intense, you make your movements closer to the body so you don't stretch your arms over your head, but just to your head. So a lot of them are adaptable. They know that people have different functioning levels and you can use the tape itself to adapt them, even as you increase your stamina. You might not start at the highest level, but for doing it for six months, you might be raising your hands way over your head. There are specific tapes to build strength for people who are elderly and these are not as much needed tapes. They require the ability to stand, but there are some good ones, too.

RACHEL: We actually got a question from somebody who is describing her disability and she's looking for specific aerobic videos. So should she get a hold of Katherine's booklet and e-mail you as well, Dot?

DOT: Yes. That would be good.

LAUREL: It might be useful for us to post that question in the discussion forum and their responses so if other people are interested, that would be one source.

RACHEL: Is Katherine's book free or is there a cost to receive that?

KATHERINE: There is a cost to it and I don't recall what the cost was.

DOT: I think it's ten dollars maybe. And it's under the catalog. So if they go to the rtcil website, go to the catalog.

KATHERINE: The booklet is called *Exercise for People with Disabilities, Getting Started on Your Fitness Plan*.

DOT: Can I have a minute to address your issue about cost effectiveness?

LAUREL: Yes.

DOT: One of the reasons that I did the study was because I have been in places, including where I live now where we convinced the city rec department to do some adaptable exercise. We did, for example, a yoga class and three people came. It was a seated yoga. The difficulty is scheduling, transportation, not having enough energy at the end of the day. I think it's often very difficult to put a class together of enough people at similar functional levels who can get to the same place at the same time.

So what I thought for this program is a city recreation department or campus recreation center could have a meeting, allow people to choose tapes, try them out, have a person to consult, send people home with weekly routines to do, something they can do three times a week, contact each other by phone, by e-mail for support, log into a website with their activity and meet again the next month and maybe do that for six months to really get consultation on activities, connect with the other people in the program. It's just much easier than trying to get people together three times a week. But it does provide information and it does provide support in some ways.

LAUREL: That's excellent.

DOT: So ideally I'd like to get a grant in the future to have some community test that and see how it works.

LAUREL: That's terrific.

DOT: It is a big problem because in some places you badger the city recreation department to hold something, and they have it, and they say only three people came. That's nobody's fault, but it's the reality of living with a disability and not having transportation.

LAUREL: In some places where you live, the weather will prohibit.

DOT: Absolutely.

LAUREL: That's great. When you get the grant, let us know, will you.

DOT: Don't hold your breath, but we'll look.

RACHEL: We have some more questions. One is can you please tell us about how people with very severe impairments could increase their physical activity level? How could people with high level spinal cord injury, advanced neuromuscular disorders, et cetera, achieve an aerobic effect from physical activity?

KATHERINE: This is Katherine, and I'll start by saying Dot and I are not exercise physiologists.

DOT: I'll confess I'm a couch potato.

KATHERINE: A very active one. The number of women in our study who had severe impairments used the arm ergometer. There are some table top versions where basically it's got a stand and two rotation or cycle system and then just two little hand cranks, and so you just put your hands on it and you rotate that around. Now, this is the part we probably didn't see much change in some of our house outcomes because the cardiovascular effect with doing that type of motion is pretty low.

You'd have to increase the amount of time and the intensity over time to get more of a cardiovascular effect because your arm muscles are, you know, smaller muscle masses to get moving and if you have even impairment in those muscles so your movements are slower, your ability to get a heart rate response is lowered. So the better machines are the machines that allow the passive range of motion with the legs, but those are typically very expensive and hard to afford.

DOT: Just an aside there, we do have one in one of the rec centers. Someone did some advocacy years ago and encouraged them to buy some equipment. That's always a possibility, too.

LAUREL: Any idea what the less expensive table tops might run?

DOT: I think they go from 5 to 700.

KATHERINE: The table top ones, Dot?

DOT: I think so. Mine was \$1,500 retail. There is not enough people that need them to bring the price down. Go to your local YMCA, YWCA, to your city, and you live in a housing complex, see if they'll get one. The interesting thing is I have

a friend who has osteonecrosis. She has a dead bone in her knee and she can't run anymore and she came over to try my machine and she can use it. She uses her arms so it doesn't affect her knee or the bone issue. So I think what we need to do is we need to sell this as not just for people with disabilities, but for anyone at any time who might not be able to engage in the activities they typically do.

LAUREL: All those runners who are killing their knees.

RACHEL: Are you ready to move to another question?

KATHERINE: Another one for more severely impaired individuals is also the aerobic videos because they do seated aerobics. It gets the arms doing the correct type of activity.

DOT: And a real good one will have people with different levels of functional ability doing the exercise. One I have is a person who is a quad. He can't lift his arms the same way but he is getting aerobic exercise. So that is a possibility.

LAUREL: We have about 15 or so minutes left. I don't know if you want to field some more questions now or if you want to complete that part of your presentation that is to come. It's your call.

DOT: I think Katherine had some questions.

KATHERINE: I would like to ask a couple of questions. Dot had mentioned she's interested in writing for another grant, and I am also interested in doing that, and one of the grants I would like to write fairly soon, sometime in the next few months, is improving and enhancing the strategies to help promote physical activity. I didn't talk much about it in our study, what we found was we did see a doubling in the amount of time and cardiovascular activity. But people's lives intervene and whether it's weather-related or illness related or going out of town or just life stress, people naturally had reported weeks, one to three weeks, when they were inactive. But they always got back into activity, which was the really exciting part of the study, but I would really like to structure a study – a program for the future that uses some better and stronger strategies to help promote activity.

And I wanted to ask if anybody out there had any ideas that we might incorporate some low cost ways because we want to not create a program that would be so expensive that centers or communities couldn't adopt it, but something that would be feasible. And I have a number of ideas like the one I talked about with providing feedback periodically to people's logs. But if anybody has other ideas, that would be great.

LAUREL: Would you like for them to post them to the message board or send them via e-mail or both?

KATHERINE: Either way to be great if they get a chance to post them to the message board.

LAUREL: That would be terrific because others would see it and it might stimulate them.

DOT: That's a great idea.

LAUREL: As regards to that, the discussion forum, it will be posted to the website where you can also click on Dot and Katherine's suggested reading list and a general agenda and all that. It will be on that same page. I notice that you all have a section on suggestions regarding how the results might be used and the ideas for regarding future areas. I'd like to hear some of that if it's available or we haven't discussed it already.

DOT: That was one I was going to mention the possibility of using the study I did as a possibility for an organization to do like a city recreation department. I'd like to get feedback from people if they thought that would be feasible.

LAUREL: So you're seeking feedback as to whether, for instance, working with the city to design a program that might meet occasionally, but they would have an ensemble of resources.

DOT: Right, they could do it on their own. I guess have people had other ways to structure programs where people could participate easily?

LAUREL: Good. Those of you out there who have such programs or know of them, if you'll come back to the discussion forum, message board, and post those, that would be terrific or send them straight to Dot. We have some more questions Dot and Katherine, but I don't want to cut you short on your presentation.

KATHERINE: Dot, let me know if I'm misspeaking here. I believe we've completed our formal presentation.

DOT: I'd love to hear questions.

RACHEL: Okay, we actually have gotten some feedback, some information from the audience answering some other people's questions. So I'll go ahead and throw

those two out first. The first is about the Robert Wood Johnson Foundation. Somebody actually sent in a link for the part on the website where you can look at RFP's that are coming out to grant five-year declining ratio grants to communities to increase physical activity.

DOT: Great.

RACHEL: Communities is not defined here so I'm not sure if that's a city or a county or a neighborhood or another group. Active living by design is the section of the foundation, and you can find them at www.activelivingbydesign.org.

RACHEL: Right. And then there also is a note here that the RSA grants are presently being reconsidered in Congress for refunding.

LAUREL: There you go, Dot. You were right.

RACHEL: We also got some information in for the person who was the person with the high level spinal cord injury who was looking for exercise. This person says, just so you know, tai chi, done over time will give good cardiovascular effect and it is adaptable. She's done it with as high as a c5 injury.

LAUREL: Whoa.

DOT: Wow.

LAUREL: Don't want to meet her in a dark alley, do you? Rachel, may I ask a question?

RACHEL: I've got three other questions here that came in from the audience.

LAUREL: Go ahead.

RACHEL: This is for both Katherine and Dot. Besides exacerbating disability and health issues, did the women report other barriers that interfered with their being consistent with their exercise programs and especially for those women in Katherine's study? Did the women face any barriers within the community as they tried to increase their exercise?

KATHERINE: I'll go ahead and start by saying that most of the women in our study actually ended up doing their programs at home. The handful of women who had initially attempted to work out at a community program found that what they wanted to do was not going to be as feasible as they had hoped. I know one woman

had ms and the water was too warm for her so she couldn't continue with that program.

Another woman had a problem with the pool and anybody wanting to use the pool, the pool was shut down for a couple of months, so she had to go back home and find something else to do. But I think that the types of barriers that most of the women experienced, they just ran the gamut. And most of them related to being a woman, sick kids, sick father, another woman had a family member with Alzheimer's that she actually had to be going and taking care of. Another woman was in her mid fifties, but her husband was a bit older and had fallen and gotten pretty badly injured so she was caring for him. So it was a lot of care giving stuff that was going on that was causing barriers to activity.

And then I would say some of them related to typical injuries, whether it was due to exercise or overuse injury, if somebody was a wheelchair user or just falling and getting hurt or having a hand slammed in the door. Some times they are exercise related and sometimes just regular injuries, and they had to wait for those to heal and then some problems really were exacerbations. And we haven't done an analysis to see which were which. And another interesting barrier was travel.

When these folks went on vacation or a business trip that was like a sign that they shouldn't have to exercise. They were truly on vacation. So a lot of women didn't continue with their programs when they spent a week traveling here or there.

RACHEL: Okay, we've got two more legal questions, which I'll throw out and I can also throw out a resource for them. One of the questions has do with swimming pools because you were referring to swimming pools and they're asking for clarity. They believe the ADA does not yet require that the ADA accessibility guidelines do not yet require access into swimming pools. And the other question has to do with in gyms. Why should somebody transfer to exercise equipment and take the risk of falling? Is the gym staff required to help you transfer? Who would be responsible if somebody fell?

And I can go ahead and just let people know that these are good questions. If you do have questions like this that are related to the Americans with Disabilities Act, there is a great resource. There are information centers, technical assistance centers on the ADA that you can reach from anywhere in the country by a single 800 number, and you can ask them these questions, and the phone number is 800-949-4232. And if you didn't catch that, go ahead and send us an e-mail and we'll send it back. So I don't know if you guys want to tackle these or refer them on.

DOT: This is Dot. I'm not sure because I think there are some new rulings by the access board in the last year or so. So I'm not even going to venture into it. I always ask. I think if I pay taxes particularly that a city recreation department should address my needs as well as the rest of the population and I always go back to the idea that we are an aging society and it's just good sense. But I think you're wise to recommend the DBTAC's because I'm really not sure.

RACHEL: I think there are different requirements as to what a local government has to do.

DOT: I think a local government falls under Title 28, and it might be different than a privately owned organization.

LAUREL: How about a hotel?

DOT: In fact the DBTAC in our area had a conference and somebody complained and the hotel bought one from the vendors at the conference. I was at one who had a pool lift but thought they didn't need a buy an armergometer.

RACHEL: At this point with swimming pools, public accommodations at hotels or gyms aren't required to get access into the swimming pool. They are required to provide access to the area around the pool, especially at a hotel, people spend a lot of time sun bathing or hanging out by the pool. But the state and local governments, if they have any programs and they are programs that are water based, they have to figure out a way to make that program accessible to people who have disabilities.

DOT: Good information.

LAUREL: I'm going to change from ADA type issues. We can't let you two leave without asking you for comments on the, shall we call it the Christopher Reeve back through with regard to physical activity. Now, his position is based at the hospital there in Saint Louis. Is it Washington University?

DOT: I think so.

LAUREL: Any take on how that's going? We talked to some people who think it's extraordinary, and they have a hard time believing that intensive physical exercise could lead to the type of recovery of sensation and movement that he experiences. Do you all have an opinion?

KATHERINE: This is Katherine. I have not kept up with what's going on with him so I have heard something about it so I can't speak about this phenomena going on. How about you, Dot?

DOT: I was at a meeting in Atlanta, recently, and his wife was one of the persons up on the stage, and she talked about it, and the response from the people sitting around me, some who were scientists, was that what he experienced was not unusual as they were portraying it but I really don't know a lot about that. So I really don't know. I guess the one thing I would say is that I'm disappointed that he doesn't use his pulpit more often saying "I am very fortunate and it's very different for the people who are not as fortunate as I am."

LAUREL: I guess we'll have to wait and see if he has recovered sensation or ability to in water push off a wall, and we'll keep our fingers crossed. But meanwhile, the approach of range of motion movement for those of us who are couch potatoes. We hear the terms of health and wellness and health promotion and I'm having a trouble distinguishing between the two or is there a distinction and maybe you all can help me?

DOT: That's a good question, Laurel. I don't know if I can differentiate. I just go by the idea that we are all existing on a continuum of health. Sometimes we're on one end less healthy and then more healthy and every one can be healthy in the context of disability.

KATHERINE: Well, I can't say I've read anything that differentiates between two of them. I'm not sure that I can think of anything good. The only thing that just comes to mind is wellness strikes me as a sense of well-being, psychological well-being whereas health promotion can include components of psychological health. But it's really about promoting physical health, whether that's through nutrition or physical activity or assuring that you're getting adequate screening exams at the doctor for mammograms or prostate exams or a flu shot sort of thing.

LAUREL: Katherine, that's a nice distinction. Looks, Dot, like the University of Kansas is turning out pretty good Ph.d.'s, doesn't it?

DOT: Oh, yes.

LAUREL: And that Glen White has pretty much got a good team up there.

DOT: We are working hard.

RACHEL: I just want to say we are out of time but there are at least three or more questions that we did not get to answer. So we promise that we will post them and send you responses to them individually as well.

LAUREL: Excellent.

DOT: This is Dot. I'm heading out of town, but I will check everything on Tuesday and respond and actually looking forward to the dialogue.

LAUREL: Thank you both very much. It's been a terrific presentation and we're looking forward to seeing more out of you all, especially once you get the new grants. But do come back when you can and tell us some more. Let me close by saying that, again, that NIDRR has made the funding available for initiatives such as this whereby folks who are doing research in areas that potentially have great impact on our lives as people with disabilities. They make the funds available so that these presentations can be made to those of us who are not researchers.

Also, don't forget about the discussion forum. For a minimum of four weeks, we'll have a discussion forum active on this subject, and you can find the address, the URL on the same website where it discusses – or presents the materials for this presentation. In addition, this presentation will be archived. The audio and the transcript will be maintained on our website in perpetuity.

In closing, I want to thank our team. Our technical team consists of Rob Dickehuth who is the one who makes this broadcast physically capable and then we have Marie Bryant who is our realtime captioner. We thank both of them. Our ILRU team consists of Sharon Finney, Rachel Kosoy, Dawn Heinsohn and Mark Richards. Thanks to you all. Our question asker today was Rachel Kosoy.

We want to thank you for joining us and one last thing to our friends in the DC area, our thoughts are with you in this really difficult time, and we just pray that the sniper's plans will come to a frustrating end and he will be apprehended. But meanwhile, we pray that you all keep safe and know that we are concerned about you. So with is that, we'll say goodbye for today and look forward to you joining us on our next webcast. Thank you and good afternoon.