LINDSEY: Again, my name is Lindsey Whitcomb. I am a social worker for the National Spinal Cord Injury Association and will be moderating today's presentation. This webinar is one of several that National Spinal Cord Injury Association will be hosting and all of our webinars are recorded and archived on our website at www.spinalcord.org. Today's webinar will discuss what makes up self-esteem, positive and negative factors in the lives of women with disabilities that can affect it and techniques for improving it. It will also share the results of a study the tested the self-esteem enhancement interventions and the Internet-based 3D virtual world of Second Life.

Our speakers today are Peg Nosek and Susan Robinson-Whelen, both from the Center of Research on Women with Disabilities at Baylor College of Medicine; Rosemary Hughes from the University of Montana Rural Institute on Disabilities; and Pam Mackie who is a consultant for the Center for Research on Women with Disabilities.

You will have time at the end of today's presentation for questions, so, please, at any time during the presentation, use the questions window chat box to write in your question and hopefully at the end we will be able to get through everybody's questions. So without further ado, I'd like to turn the presentation over to Peg.

PEG: Thank you very much. I would like to welcome everyone and thank the United Spinal Association for giving us this opportunity to talk to you about our work. I'd like to welcome my colleagues. The research that we're going to be presenting to you today is funded by the National Institute on Disability and Rehabilitation Research. At the end of our presentation, we're going to be giving you the results of this study, although what we're really presenting is 20 years of research that we've been conducting.
First, we'd like to start by going through each of us so you can see what we look like and tell a little bit about our stories and why we're interested in self-esteem and women with disabilities. That's a picture of me. I hope you are able to see the slides on your computer screen. I'm the one with the tracheotomy and the purple hair. That's how I'm known. But it was interesting because I've had a disability all my life, spinal muscular atrophy, which is a progressive condition. About 10 years ago, my lungs collapsed and I started using a ventilator with a tracheotomy, and that really changed my body image and we're going to be talking more about body image. Suddenly I became very interested, I don't know why, in wearing more low-cut blouses and doing interesting things to my hair. I don't know what's going on here but somehow I wanted to get everyone out there something else to look at besides the tracheotomy.

So anyhow what I figured is that... a quote that I came up with very early in our research is “If you truly believe you're a woman of value, you gain tremendous strength to forge your way through the most stubborn of barriers.” I learned very early on that everything that matters in life is in your head. When I started my dissertation research, which was on independent living, I found that there was this thing called independent mindedness, and that's what made the difference as to whether people were able to burst through those barriers to their independence or not. It was whether or not they were able to take control of their lives and that was something that existed in their heads, how they manage barriers. And then when we went on to form the Center for Research on Women with Disabilities and do research on the health of women like myself I found that, wow, women with very minor disabilities or conditions that some would call a disability and some would not
were living lives that were very dependent or they were very
dominated by their health condition, and other women who had
very severe disabilities weren't. So again, it's got something more
to do with what's in your head than what's going on in your body.
It's how you manage that, how you think about yourself. So that's
how I came to be interested in self-esteem.

So, we'll go now and hear from Susan. Susan, could you talk a
little bit about your quote and your interest in self-esteem?

SUSAN: Sure. My name is Susan Robinson-Whelen and I am with the
Center for Research on Women with Disabilities with Peg, and it's
a pleasure to be part of this webinar today and also to be co-
presenting with my wonderful colleagues and friends, all of whom
I've learned a great deal over time about self-esteem and also about
the important role that social relationships can play in your self-
estem. As my quote conveys, in part from the intervention work
we've done and intervention studies we've conducted over many
years, those studies and the women participating in those studies
have really shown me that there really can be this tremendous
power and healing in the support and encouragement and
friendships that you receive from other people who have similar
shared life experiences. And so I guess one of the things I've
really learned is just how very important it is to reach out and
connect with others, particularly others with whom you have much
in common.

PEG: Thanks, Susan. And next we'll hear from Rosemary.

ROSEMARY: Hi, I'm Rosemary. I know there are some of you out there that
know me and that I know you and I'm so sorry I can't see you and
talk with you. But anyway, I'm really happy to have this
opportunity to share our work on self-esteem. I wasn't prepared to
talk about my own interest in self-esteem, but as Peg and Susan
were talking, I was thinking that in my early 20s, I was in a major accident and had a head injury and many other injuries. That period of time kind of caused a temporary blow to my self-esteem, so I had to work really hard on kind of working on my adjustments related to body image and self-esteem and my feelings and my sense of self and so on and actually worked on that for several years.

And then when I got into doing the work that's related directly to self-esteem was when I was at the University of Houston Psychological Services, and my colleagues and I there developed a self-esteem enhancement program for women, women in general. It also did include women with disabilities. So I worked there for several years and worked around issues with self-esteem and lots of other psychological issues and then moved from the University of Houston to Baylor College of Medicine with Peg. One of the first things she said to me is, “Oh, my gosh, you developed this program on self-esteem, we have to do this and we have to focus on women with disabilities,” and so, that was really exciting. Disability has been a part of my life my entire life through my family and lots of different relationships and so on, so it all went together really well and we got really excited and got a grant. The first grant to develop our first self-esteem intervention program, and we'll talk about that later today.

So, for me, I'm saying I believe that it's really important for us to love and esteem ourselves with both our strengths and our weaknesses and to love and esteem others in the same way. I think if we just try to focus on just our strengths and so on, we kind of miss something. It's really important to love the areas in ourselves that are limitations or are areas that could stand some further
development and improvement. So that's kind of where I'm coming from when I think about self-esteem. Thanks.

PEG: Thank, Rosemary. Okay then, next we'll hear from Pam.

PAM: Hi, I'm Pam Mackie. I'm a licensed professional counseling intern and I've been a consultant and contract employee with CROWD off and on since I think it's been about April of '99, so it's been well over 10 years. I first became interested in self-esteem because before I had a disability, I had a lot lower self-esteem than I have now, which is extremely interesting because you would think a disability would bring out less self-esteem, but actually for me, I remember reading a poem one time and one of the lines in it was “I wouldn't trade the disability for the woman I've become.” I think it's from having to live with the challenges and find out that it's not the external approval or what other people value is important, it's what I value, an internal locus of control and how you think about things.

So, for me, I've really come to realize that our culture actively promotes low self-esteem for women by sending messages that we're not enough without buying a certain product or if we have a man in our life or a significant other or if we look a certain way and that we need to have that in order to be deemed worthy. And so, for me, I've come to believe and actively have to remind myself not to buy into the messages that are being sent out in our American consumerism culture. To have a healthy sense of self-esteem, we have to actively dispute these messages and recognize when you start to think them, say, “Whoa, that's not true, that's not really true,” and learn to think and live in a manner that is basically in total opposition to our culture.

PEG: Thank you, Pam. Okay, now a roadmap – by the way, I've included some small pictures of who's talking in the upper left
corner of each slide, so that you can follow us with our pictures. We're going to talk today about the overall term for everything that we're talking about which is the sense of self. Then we'll talk a little bit about body image and focus mostly on self-esteem with a definition, we'll talk about influences, both positive and negative, on our self-esteem, and talk about the research. We've done interventions to help women with disabilities enhance their self-esteem, and we'll finally end at the top of the hour with comments and questions from the audience.

**The sense of self** – When we started our center, we did a study that many of you probably participated in. It was a study about sexuality and reproductive health for women with disabilities, particularly physical disabilities. In that study, because it hadn't been researched very much at all, we started with a qualitative segment of the study first and that's where we interviewed 31 women and we just listened to them. When you don't know what questions to ask, the best thing you should do is listen. So we did, we listened, and the women talked to us for anywhere from 45 minutes to 5 hours and we transcribed those interviews and analyzed them. What we kept hearing over and over and over was how the women thought about themselves, and it had many different elements. They talked about their emotions. They talked about their body image. They talked about their mental aspects of having a disability and mental aspects of just being a woman, their intelligence, about being a woman, what that meant to them, their personality, their ownership or their lack of ownership of themselves, their social being, their personal identity, their ability to exert self-control. Spirituality was another thing. They went on
and on and on, there were so many themes that came out that related just to their sense of self.

So, what we're going to start talking about next is body image, and then we'll go on to talk in more detail about self-esteem. So, Rosemary, could you talk to us about body image and who is this wonderful woman?

ROSEMARY: This is a wonderful woman. Some of you, I'm sure, are familiar with Alison Lapper Pregnant. This is a photo of the Alison Lapper Pregnant marble sculpture. She's a critically acclaimed British artist and a member of the Mouth and Foot Painter's Association in London. Back in 2005, she models for this sculptor of this 16-foot marble statue of her. At the time, she was like 81/2 months pregnant and she modeled for the plaster cast, her body was made a plaster cast for the statue. This statue was placed in the famous Trafalgar Square in London for 18 months on one of the four pillars, and the other three pillars had statues of male military heroes. So, you can just imagine there were a lot of controversies around this and it was a really exciting time. It stayed there for 18 months. She's quoted about the statue as this, "I regard it as a modern tribute to femininity, disability and motherhood. It is so rare to see disability in everyday life – let alone naked, pregnant and proud. The sculpture makes the ultimate statement about disability — that it can be as beautiful and as valid a form of being as any other." So Alison, as you can tell from her quote here, she is and continues to be an outspoken advocate for people with disabilities.

One of the reasons Alison is so important to me is that I had the pleasure of becoming acquainted with her at an international women and disability conference held in Spain a few years ago. And so, what I'm sharing here in the next little bit is information
that Alison shared with me but she's also shared publicly and included in her biography. Her biography is called *My Life in My Hands* and it is really really good. Just briefly, she was abandoned by her parents at birth and spent most of her childhood and adolescence in institutions, where she experienced—as many other people in institutions as we know too well—a great deal of abuse at the hands of the staff. When she left the institution, I think, at age 16, she became a student of the organization that I mentioned earlier, the Mouth and Foot Painters Association, so that provided her income and then she became focused on disability as the emphasis of her art.

She gained her independence at 19, again describing herself as really carefree, fun spirit—she is a fun person—who got her driver's license, began dating, marrying a man who became abusive almost immediately and divorcing him. So very involved with her art, she became inspired by the statues of Venus de Milo, she used her own body in art. One day, she was paging through some art books and she saw that and she thought, “Oh, this is interesting,” and she then began realizing that she had not been focusing on disability in her own paintings and her own photography. So she said to herself and I quote, she said, "God, you're different but you're not that different." This is how she looked at a cast of her body. She said, "God, you're different but you're not that different," and concluded that the whole her body seemed quite beautiful in its own right. She said to herself, "It was quite a revelation. I thought, ‘Wow, you look pretty good here girl.’"

So then at 18, she became pregnant, she had her son and she said a really important part of her self-esteem and her sense of self was she was saying to herself when she was pregnant that if her baby
would be born with an impairment that no one would be better able to understand and care for her child than herself. And so, anyway, she talked a lot, when I met her she talked a lot about her son, very very close, very proud of him. I think he's probably about 11 now. So basically to kind of end a story that I could go on for hours and hours is, as an artist, Alison wanted, she said, able-bodied people to come to terms with what she looked like. She said, “I want them to have a sense of my journey towards self-acceptance and experience the idea that disability could be artistic and beautiful.” And I quote from her, "I think it's wrong for me to complain that people don't understand disability and then refuse to talk about my personal life. Telling my story is the best way I know to make issues I care about understood." If any of you ever want to have more conversations about Alison Lapper, I'd love to have those conversations with you. Thanks.

So now, **body image**, as we just heard, is a lot about a person's feelings of the aesthetic and sexual attractiveness of his or her own body. It's an awareness and it's a product of personal experiences. Like for Alison, it was a product of her art school, her dating, her marriage, her awareness and her personality, so a product of personal experiences, personality and various social and cultural forces, usually in relation to others or in relation to some cultural ideal. We always read so much about the problems that young women have, young people have in comparing themselves to celebrities and to models and to what our culture seems to really approve in terms of thinness and so on.

So body image is also a reflection of a person's self-esteem. I think that it's a reflection of self-esteem and I think self-esteem is a
reflection of body image and you can't pull them apart. I think we can see that from Alison's work, right?

So it's important for women with disabilities, or for a woman, to:

- Assert her right to make choices about her body – That can be what one wears, what a woman decides to do in terms of having family, in terms of partnerships, in terms of a career, in terms of what her body and her career would map.
- Feel ownership of her body – Restrict the limitations resulting from her disability to physical functioning only and not impose those limitations on her sexual self.
- Be accepting, not ashamed of her body – This is why I wanted to talk so much about Alison Lapper because she definitely makes a really strong point of that in her life and in her willingness to do what she has done with her art and herself.
- Take action to enhance her attractiveness – I know I've heard Peg talk lots of times about the importance of owning one's attractiveness—and you can see that in your picture, Peg, with your purple hair—so I think that's really important too.

PEG: Oh, by the way, that picture was taken on my 60th birthday; I'm not ashamed to say that. But with my hair turning white, gray and white and all various shades, I figured I think I got to do something different. So okay, Pam, when you talk about self-esteem with disability, you got to add aging on there too. Okay, Pam, can you talk to us about what is self-esteem?

PAM: Okay. What do we mean whenever we bring up the topic of self-esteem? Well, it's basically how we value ourselves. And so self-
esteem would involve how one's sense of worthiness, their adequacy, their self-respect and whether they feel that they're just as important as other people. According to a feminist perspective, women's self-esteem may be based on participating in mutual relationships or caring for others or having a sense that they can influence and that they can also be influenced by others and the perception that they are really visible to others, that others see them.

So what is self-esteem? Do I think of myself as being worthy? Do I value myself? Do I like myself? What do I think about myself? Do I think others are better than I am? Am I deserving of love or respect? Am I worthless? Am I capable of giving and receiving love?

Some of the positive influences on self-esteem that we found would be:

- Greater age – But I would counter that maybe it would be maturity, because you can have a sense of maturity and a better perspective on yourself and how you fit into the world at any age. So, it may not just be as we get older that we get higher self-esteem but often times it goes that ways because we have more life experiences to draw from.

- Another positive influence would be if we have affection – If there's more affection in our home; positive expectations from our family and from ourselves; a positive school environment.

- I would add positive social environments, whether it be at work or volunteer or a sense of community or support from friends.
Some of the **negative influences on self-esteem** that we have discovered would be:

- If we feel pain, whether it be physical, spiritual, mental or emotional
- If we experience fatigue, where we feel like we just cannot accomplish the things that we want to accomplish
- Whenever we need to depend on other people and we cannot be as independent as we may want to be
- Being perceived either by ourselves or by others as being a burden to the family, to our friends, to people we work with or the people that are there to help us with the things that we cannot do for ourselves.
- Another negative influence would be overprotection, when people want to keep us from what they perceive as struggling to accomplish something or do something and they think that they're helping us by doing it for us.
- The developments of secondary conditions can really have negative influences on self-esteem.
- Losses such as employment, health insurance, personal care attendants, relationships, whether it be a family member or a long-term relationship or a friend relationship, work relationship, any type of relationship, because so often as women we identify ourselves and receive self-esteem through the relationships that we have with others.

We have found that there's **no real connections with self-esteem** concerning about whether how severe a disability a person may have or how long that the person has had the disability. There have been mixed findings that there can be just as low self-esteem with women who have no physical, mental or emotional disability.
We've also found that there's no connection between self-esteem and how much education a woman may have.

Some **strong connections with self-esteem** would be things like:

- If we're socially isolated – That will have a negative effect on our self-esteem and there are some strong correlations there.
- If we're in an abusive relationship with somebody or if we abuse ourselves in some form or fashion by either having negative thoughts, by thinking less of ourselves, by comparing ourselves to others.
- Depression is also a strong connection; that being depressed has a negative effect on our self-esteem.
- The quality of our intimate relationships – That can determine whether we think we have value or whether we do not.

So when we realize that we may not think of ourselves as highly as we think of other people and that we are experiencing low self-esteem, we can start to **take steps to improve our self-esteem**. But it's very challenging because a lot of times we're going against the culture, against what other people may value or think is valuable. It takes work on our part, hard work, by constantly questioning and challenging and getting in touch with ourselves in what we find valuable and strengthening that within ourselves. Start with small changes because if we try to start too large, it's really easy to fail or to fall short and that could have a negative impact on our self-esteem. Improving our self-esteem is a lifetime process and they may be one reason why we talked about it seems to be higher when we get older and we get a sense of maturity and
life experiences because we become aware that we can rely on ourselves and that we're there for ourselves and that we can accomplish things if we don't give up and we continue to try.

So, in summary, when we're talking about low self-esteem or high self-esteem, it's not really the disability per se, but it's rather the whole enchilada, the whole picture, the contextual, the social, the physical, emotional dimensions of the impact of the disability that may influence our self-esteem. Women with disabilities face numerous barriers and challenges, as a result of both disability and the gender biases and must continually cope with assaults to their self-esteem that are propagated by negative societal attitudes.

PEG: Thank you, very good, excellent Pam. I'd like to add to that too that our self-esteem could be situational. In other words, I know for myself there are some situations where I feel really good about myself, really positive when I'm with other people who are positive or in a situation where I have a lot of self-confidence, but there are other situations where my self-esteem could be really really low, so you never know. Or like in a medical situation, sometimes there are some medical professionals that can just make me feel very insecure and so I get very defensive and that just feeds a low self-esteem. It could be one way in one situation, one way in another situation, so it's a very mixed bag. It's a very complicated thing and you did an excellent job of describing that, thanks Pam. So we'll move on now and talk about what we've done to try to make the situation better for women with disabilities. And we'll get back to Rosemary.

ROSEMARY: Okay. Hi, this is Rosemary again. So we did a lot of studying what the women told us in the earlier interviews that Peg was talking about and realized that there was a need for intervention
but an intervention that would really be safe and inclusive – and by safe I mean respectful and a place is safe for women who a lot of times have been in very unsafe situations of abuse and mistreatment as we talked about with Alison Lapper.

An inclusive personal development program for women with disabilities – Now, you know, it's really interesting these quotes that are on this particular slide. I just glanced and they were all made pre-ADA which tells me that the folks that we're talking about the importance of these interventions were probably, and as I look at them, drivers of the ADA as well as were some of you out there in the audience and Peg. Anyway, so that was Michelle Fine and Adrienne Asch saying a need for safe inclusive personal development programs for women with disabilities. The next point was made by Mary Joe Deagan and Nancy Brookes back in 1985 who said women need an environment where women with disabilities can serve as role models for one another. And finally, our colleague, Martha Saxton said that also opportunities to share important information about resources and confront internalized multiple oppressions including ableisms and sexisms.

So we did it; we developed a program and this program that you're looking at is one of the programs that we developed to enhance women's self-esteem. So, some of the people in this picture here were people that were actively involved in our early intervention work. You can see right there Pam Mackie in the blue shirt and myself. Oh, my gosh, I look so much younger, Peg. Myself there and other close friends and women with disabilities who were so involved in the beginning of a lot of our intervention work.
**Theoretical frameworks** – What are the philosophical and theoretical drivers of the work that we've been doing to develop our interventions, including our intervention on self-esteem?

- Well, first of all we drew a lot from social learning theory. Social learning theory takes into account self-efficacy; by self-efficacy we mean a belief in one's ability to influence outcomes for desired goals, so the belief and the confidence in our ability to get things done, to influence what's going to happen in order to reach our goals. So that was an important thing and we'll talk about how we did that a little later.

- Feminist psychology – We're all feminists and we're very interested in women's rights and women-with-disabilities’ rights and realize the importance of supportive relationships that can offer a sense of connectedness and mutuality so it's not just going in one direction but we learned and we realized this early on in our work with our interventions that we learned as much as we gave. In other words, you also teach what you learn, learn what you teach – boy, was this ever true with our early work!

- Independent living philosophies – Concepts of personal autonomy and independence and interdependence and empowerment and advocacy were all extremely critical in the development of our interventions.

When we developed the programs, we started out and we're still doing that with small groups of 8-10 women, two pure facilitators when that's possible. Sometimes when we're doing interventions, we find that, especially when we're working with small ILs—we work closely with independent living centers—so sometimes there
will be one person who is a woman with a disability, a physical
disability, if that's the case as it has been with our interventions on
self-esteem, so we strive to have two pure facilitators. Our self-
estee m program met for two hours per week for six to eight weeks.
We have provided the intervention and done research on the self-
estee m program when it's done face-to-face in small groups in the
same room, physically present with one another, and we've also
done it over the Internet using Second Life, which some of you
may or may not be familiar with Second Life but it's a free public
virtual 3D world and we'll talk about that a little bit later too.
So we developed leader’s manuals and participant’s manuals. The
programs are highly interactive. Sometimes we'll get feedback that
they're not interactive enough, that we're providing a lot of
information, but what participants really like to do is really talk
with each other and learn about resources from one another and
learn about one another and how they address various health issues
or overcome environmental barriers in their lives, and so we
started working so that the breaks would be a little bit longer and
inviting people to come in earlier and stay later and so on to
enhance that interactive element.

Homework – We would ask the participants to go home and try
out some of the things that we were trying in class and then come
back and say how they did when they came back for the next
session.

Our topics – First of all, we would start out with:
• An overview of self-esteem – Just kind of like Peg did
today, you know. What does self-esteem involve and what
is the sense of self and what really contributes to a sense of
self-esteem and what doesn't? We know, for example, the influence of abuse and violence on a woman, on a person's self-esteem is really critical. So kind of what really contributes to a high level of self-esteem and what has kind of operated to reduce self-esteem in women with disabilities and then how to heal and how to strengthen one's sense of self.

- The role of gender in disability socialization – when I was talking about, I think it was back when I was talking about Mary Jo Deagan and Nancy Brookes' work on women with disabilities, I mean they talked a lot there about women with disabilities having a double whammy. I mean I think they were at that time identifying the double discrimination that women with disabilities experience through gender discrimination and through disability discrimination and kind of those messages we talk about here in the workshop about how do we get the sense of gender from our families, sense of gender and disability from our families, from our schools, from our peers and how that kind of all goes together to make us who we are.

- The third topic is connecting to self and caring for self – And so we would have a lot of opportunities there to really build self-awareness and to understand and cherish one's strengths and also learn ways to care for self, so self-nurturing was a big important focus.

- Relaxation skill training in every session – Sometimes, it would be progressive relaxation or it might be a meditation or it might be visualization, lots of different methods that we introduced so that women could take away whatever it
was they wanted to and practice that relaxation in stressful periods in their life.

- Connecting with others – including healthy and unhealthy connectedness, boundaries, improving relationships, improving communication skills including assertiveness skills
- Planning for the future – So what's going to happen after we leave this workshop? Because the workshops tend to have a lot of cohesiveness and relationship building and an opportunity to look forward to one week after another to get with the same group of people, usually it's a very positive experience. So then, what happens when participants leave the workshop? So we spend some time talking about how to maintain the growth and so on from the workshops. That's a very brief overview of our topics.

The kinds of **intervention strategies that we use** – Well, we first of all present information, the information I was just talking about.

- We would go over some of those topics and just provide information, research-based and clinically-based information.
- We would invite group discussion and group exercises and role playing – Role playing, for example, when we do a service training, kind of practicing saying no, practicing asking for what you want and letting people know what you don't want, so the whole importance of self-determination.
- Goal setting and weekly action planning – This was what I was mentioning before. At the beginning of the program, we work with people to develop goals, set goals, and then choose a particular action that will help them reach that
goal. So, their goal may be to have more, not to feel so isolated, to build the social connections. A weekly action plan for one participant might be to contact an old friend and meet that friend for coffee. So then, in the workshop itself, they will say they plan to do that and when they plan to do it and how they plan to do it and how many times during the week they might want to reach out to somebody and their confidence in doing that. So on a scale of 1-10, “Well, I'm confident at about a level, a confidence level of 7 that I can do that.” We know from other people's research that that's the optimal level right there because you don't want it to be too easy because if the thing is too easy then they often don't get done, but not too difficult, not that they would involve too many barriers to completing the action plan. And so in the workshop, when they come back in and they say they didn't do it, well, what were the barriers that got in your way of doing it, and so kind of work to make the action plan more reasonable and go back and try it again. Homework exercises – Basically working on their action plans.

- The [Bud] Adventure – In the Internet-based program that we have been working on in Second Life, we ask participants to pair up and give a pre-plan usually off-island task to complete. Now we haven't talked about our islands yet but we have an island in Second Life and it's an environment where we have a meeting room and we have a swimming pool and we have the water, the beach, the lake nearby and everything like that and a lot of opportunities to do off-island tasks in the whole of Second Life. So there are places to go for meditation, places to go to meet people,
and remember in Second Life participants have an avatar and so that's really another thing that we will talk about, the importance of kind of having that opportunity to be anonymous and be whatever kind of fantasy the person wants to be in a program like that. It's a very rich experience for many women that have participated. The examples might be to visit a garden somewhere in the whole world of Second Life, a meditation site, a race track, so basically these adventures were designed to build navigation skills in Second Life. So it's really building capacity for Internet participation and promoting social connectedness and self-confidence. Now we started out that way choosing a buddy in doing this, but we actually went to a different method whereby the women would go on excursions with the facilitators or with one another but not necessarily with a specific buddy because that didn't always work out. There were prizes in Second Life, so a lot of times for accomplishments there would be a prize maybe to – I can't remember if we had monetary prizes, Peg help me out here.

PEG: No, just stuff.

ROSEMARY: Monetary prize, they didn't get. So basically they would get rewards for accomplishing their goals.

Our first face-to-face study was back in 1997-2000. We had a grant by the National Institute on Disability Research and Rehabilitation. It involved a randomized trial where half of the participants would be involved in the regular ongoing services of their Center for Independent Living and the other half would go into the self-esteem program. We determined the efficacy of a six-week self-esteem enhancement group intervention for women with
disability, the recruitment and intervention conducted by staff of five Centers for Independent Living in five different states. And so, in that study we had 102 participate and 51 in each group.

SUSAN: Rosemary, do you want me to take over now? This is Susan.
ROSEMARY: Oh, was I saying your part?
SUSAN: That's perfectly fine. You're doing a great job.
ROSEMARY: I'm sorry.
SUSAN: That's okay, no problem at all. As Rosemary was describing the Second Life study and some of the exciting components we had there with prizes and group excursions, we were first going to describe the face-to-face study which, as Rosemary mentioned, was [neither] funded by the National Institute on Disability Rehabilitation and Research. To briefly summarize the findings of this study, as Rosemary mentioned, we had two groups; we did this through CIL, so as Rosemary said, we have five centers for independent living that offered the program. We trained the CIL leaders to offer the program. They offered the program on our behalf. And half of the women that they recruited were randomly assigned to just receive regular CIL services. The other half were randomly assigned to receive regular CIL services but in addition to that also get the self-esteem program that Rosemary was describing.

The findings of that – The interventions groups, so the group that received CIL services but in addition also received our self-esteem enhancement program.

- We did find improvements in self-esteem which was our primary outcome of interest.
- We also measured and looked at self-efficacy – As Rosemary was describing before, self-efficacy is a very important component of the program in the sense that the
belief in your own ability to respond to new and novel and difficult challenging situations, and we found a significant increase in self-efficacy as well. And the increases that we found, both in self-efficacy and self-esteem, were very strong, very large, so even though we had a relatively small population as a whole—we had 51 that received the interventions and 51 that did not—we found very big changes over the course of just a very short, very brief six-week intervention.

We also then found improvements in depression – We found improvements in kind of overall depression scores as a whole for the group. But most significantly, we found a real reduction in the number of women who were exceeding what we classified as kind of clinically significant depressive symptomatology. So there was a real improvement not only for the whole group as a whole in terms of just average depression score, but we found a real drop in the number of women who were kind of exceeding the cut-off for clinical depression; we saw a very clear significant drop in the number of women that were classified as having significant depressive symptoms.

We also got qualitative data from the women – So we got feedback from them on their experience and got a lot of really good positive feedback. They spoke very highly of the group support and the goal-setting activities. They really enjoyed and felt they learned a lot and found the action-planning, goal-setting activities, as well as the group discussion support, to be extremely valuable. They also described learning new skills for improving self-esteem, gaining confidence in their ability to be assertive, which
was an important part of the intervention itself, increases in their connections with others and improved ability to manage stress and depression.

Okay. So for the next study that we're going to be talking about, it was similarly a self-esteem intervention, the same self-esteem enhancement intervention, but as Rosemary was describing earlier, we now took it to this new virtual world that adds all kinds of interesting fun features. So we delivered the self-esteem intervention in Second Life to women with physical disabilities who faced substantial transportation and health barriers to attending a face-to-face workshop. Because although we have done a number of intervention studies in the past addressing self-esteem, depression, health promotion, our intervention model has typically been to have face-to-face workshops, and we realized that although we may find fabulous results and we may come away feeling great about the work and we may come away with just incredibly strong support for both the efficacy and the acceptability of the program, we have always realized that we're limited in the women that we can reach with our program because only women who are able to get out and come into a face-to-face workshop once a week, committing to the same day and time each week over a six or eight-week period, we realized that there's a lot of women who we're unable to reach with those programs. And unfortunately it may very well be those who need it the most who are unable to attend our workshops, those with more severe impairments, those with less support, those who face the most serious barriers to attending a program are unable to attend our program. So, we were very excited about using the Internet as a resource to kind of
convert some of our face-to-face programs to Internet-based interventions.

PEG: I want to just go over what our island looks like. You all can go to Second Life. It's a free program on the Internet. It's at secondlife.com. So you just type in www.secondlife.com in your web browser and it will pull up the program. You download the program and go through the introduction part. Well, we've developed a tailored introduction for our intervention and we gave the women an orientation where we helped them to develop their avatar. Avatars are these characters, almost like a puppet, so you create what the character looks like. You can make it look just like you or not like you. If you notice on the opening slides for our presentation that was my avatar. You can give it a different name so nobody has to know that that's your avatar. My avatar is [unintelligible 0:57:15], so nothing connected to my real name. And you'll also notice that my avatar does not have a disability. I wanted to see what it's like to be in a world where everybody approaches me as if I don't have a disability and I'm like everybody else. And I have to tell you it's a real mind trip. For somebody who's had a disability all of their life, I found it to be really a revelation about how I respond in public, the virtual public of Second Life. It's like I want to go up to somebody and say, oh, but I really have a disability. You know, it's so much a part of me; I can't let it go. But in this world, you don't have to have a disability, so I was able to discover all kinds of new parts of my being because I wasn't accompanied by this external framework of having a disability. So that's a whole another study and I'd love to look at that more and see how women respond to having an avatar, whether they choose to have an avatar with a disability or if they choose to have one that looks like a lot of the other avatars. Now
in this world, you could also choose the avatar that looks like a fairy, I mean the kind of fairy like Tinker Bell; you can just fly anywhere in the world if you want. Any of these avatars can fly. It's amazingly liberating in all kinds of ways. So anyhow that's how that avatar is, you manipulate the avatar with the arrow keys on your keyboard or, as I do, because it's hard for me to use arrow keys, I just use my touchpad to manipulate the avatar, using a navigation bar on the screen.

So in our world we created some beautiful scenery. It's a beachfront location. It's got water gardens, because I really love water gardens. That's our building at the top, on the top left, the Center for Research on Women with Disabilities. We have a virtual building there with virtual offices. There is our virtual conference room on the right. We have all kinds of recreational activities, like a hammock and a diving board into the bay. You can go underwater. The picture on the right is with my avatar down at the bottom of the ocean. There it is, walking up on the beach. You have fish swimming by. And I have to give credit to the person who designed all this for us, and his name is Dr. Thomas Nosek. He's my brother and he was working on this with us and did a great job of following our wishes to create a very nurturing and peaceful and engaging environment. We have a living room and we held a lot of the sessions in the living room. And you can see on each scene here that we've got a whiteboard and on the whiteboard, we project the slides for the day's agenda. So when we have a session, then the material that's covered is projected in outline form on those whiteboards, so all the women gather here with their avatars. They're voice-enabled so they use a headset and they talk to each other using their computers. We also have a very nice swimming pool, and at the end we have a big
party around the swimming pool with confetti and a dance ball and you can have your avatar do dances and all kinds of fun stuff. So it's a really nice venue for doing small group activities. There is like an amphitheater where you can have small group lectures and then there is a cabana, again, with a whiteboard for projecting the slides to organize the discussions. We have a cave where you can go in there and you can do your relaxation exercise. And then we also have a hilltop venue that overlooks all of these recreational spots and our building.

So, it's just fun. I mean it's not [audio glitch - 01:01:41] nature to it but it's fun because you get to explore all these different areas and you're not bound by any rules other than the rules of civility. We ask that people maintain confidentiality. Our island is private so you have to be invited to join it because we protect the privacy of all of the participants in our workshops. Susan, you want to go ahead and briefly discuss the eligibility of all the rest?

SUSAN: Sure, you bet. We had not previously done an intervention in Second Life, so this is our first venture into a Second Life intervention. In conducting the study, we were doing really a very small pilot test, so our sample is much lower than typically in our studies. But to be eligible to participate, the women needed to have a disability that affects mobility or self-care and have had that disability for at least a year. They had to have access to a computer with a high speed Internet connection and that Internet connection and the computer had to meet our minimum Second Life requirements. They had to be able to run Second Life, which was a little challenging for us. I'll talk about that in a minute. They needed to be able to understand English well enough to participate in both written and voice online discussions, and at least for this first attempt and this first study in Second Life, they
needed to not have a visual or hearing impairment that would prohibit their ability to participate in those online group interactions, group discussions and group activities. And then finally, they needed to either have an email account or be willing to obtain an email account because we correspond with them through email a good bit.

Okay. In terms of the pilot study, recruitment did prove to be a bit difficult. The primary challenge was that the equipment demands for Second Life were greater than we were prepared for, and so a lot of women that we screened were not able to participate strictly because they had a computer, they had an Internet connection but it did not meet the minimum Second Life requirements. The biggest problem there was the need for a pretty powerful graphics card. So that was a little bit of a disappointment, but we were able to get 19 women to participate in our early pilot test and complete that pilot test, participating in the program itself.

And very similar to our face-to-face workshop, we found significant improvement in self-esteem. Now here, let me just clarify, in our larger study, we did have a control group, where people were randomized; they were randomly assigned to either the intervention or the control groups. Since this was just a very small pilot test, all 19 women participated in the self-esteem enhancement program in Second Life. And we looked from this sample, instead of comparing the two groups, we compared the same group, the same 19; we looked at their pre-test scores and then compared them to their post-test scores at the end of the intervention.

Findings:
We found that over time, as a result of participating in the intervention, there was significant improvement in self-esteem.

We also saw improvement in self-efficacy, as we did before.

Again, significant improvement in depression – This is despite the fact that it's a relatively small sample that we had participating; those effect sizes were for self-esteem and for self-efficacy were moderate. So they were fairly large in improvements in self-esteem and fairly large improvements in self-esteem. And again for depression, which is what we found in the previous study, we found moderate to large improvement in depression scores. So, we found very much what we found in our face-to-face program.

We found very small, really negligible improvement in social support, but we do think that is, in large part, a function of our measurement because the women do typically describe appreciating the social interaction, but we don't always have it well.

Additional positive findings, in terms of what the women told us and what we heard from them in our qualitative feedback, they found it to be about the right amount of information. They rated the sessions and the workshop program as a whole as excellent or good. They rated it as very or somewhat enjoyable. As a matter of fact, most of them did describe that it was more enjoyable than a face-to-face program. They found it to be well organized, the information being clear and useful. Most of them did describe that they made some positive changes in their lives
as a result of participating in the program. And most of them, after having learned how to use Second Life, navigate in Second Life, did not have difficulty communicating with the leaders or their fellow participants in the groups. And the women generally loved our leaders and found a great deal of support, and the support from the leaders was excellent.

Okay. Some of the **less positive findings**: The learning to use Second Life can be a bit challenging right at first, and so some of the women did find the sessions to be a bit stressful. In our beta test, when we were getting feedback after each and every individual session, we did find that those levels of stress did decrease over time, so as they got more and more comfortable in Second Life then each week found it a little less stressful than they had the week before, so that's good news. But you did see the sessions being a bit more stressful than you would see in a face-to-face program. The women felt extremely supported by the leaders, and truthfully they did report that they felt support from the fellow group members, but we didn’t find that as universal as we see in our face-to-face programs. In our face-to-face program, women are always saying, we never have anyone saying anything other than they felt extremely supported by their fellow group members, where in this program, we did have a small, like 10-15 percent, that did not feel tremendously supported by their fellow group members.

And the group excursions, as Rosemary was describing, the group excursions that we went on that were two-fold: The goal was to get them more familiar and comfortable with Second Life, improve their Second Life navigational skills, but also to allow more
opportunity for social interaction. They found them very enjoyable. I think they really enjoyed going on those, but they did not find them as valuable or as useful as other aspects and components of the intervention itself.

Also let me just add too, in terms of less positive findings, we did mention it, but the technical aspects were, of course, frustrating. In using Second Life, there's always just little glitches, certain people have trouble getting on, and funny things happen where you suddenly have a tail or you turn into a cloud, and so some of those technical issues were a bit frustrating for some women, but that's just part of the nature of learning to use Second Life.

In terms of **what they liked best**: A lot of the women described they really enjoyed exploring in Second Life. They really did enjoy Second Life. We had a lot of that feedback.

✓ They appreciated the new world that had opened up to them – I think these are some quotes here. “I never would do the traveling, shopping, going to Paris, flying over the ocean or riding whales.” “These things you can't do in your real life you can certainly do in Second Life.”

✓ They also liked the privacy – You can talk to people and discuss your problems without anyone really knowing your true identity. Your avatar is whatever name you've given your avatar and everyone talks to each other and responds to each other using the avatar name, not the real name; they don't even know your real name unless you want to, on the side, share that with someone you've gotten close to in the group.

✓ Action planning – The women really appreciated the action planning, learning the skill of action planning, and we have
found that in our face-to-face programs as well. It carried over well here to our Second Life program. Learning the skill of goal setting and action planning seemed very important and allows them to start making some important changes in their lives that they can then continue after the program is over. Again a quote, “I learned it was small goal setting, action planning, I feel better about myself, I can actually accomplish things.”

✓ And then, of course, as we always see in all of our programs, whether face-to-face or in Second Life, the group sharing and discussion – we always end up with several group members mentioning how important it was and how valuable it was to them to learn that they are not alone and to have others, where they can share similar life experiences and feel connected.

✓ They enjoyed the materials and information, and they loved our facilitators.

We did, at the end, ask the women after they had completed the program and had completed their post-test, we asked them just to do some comparison between participating in a workshop in Second Life, which they had just completed, versus participating in a face-to-face program as you normally would at a CIL. We asked them to compare those two across a number of dimensions.

➢ Hands down, they endorsed that Second Life was more convenient, absolutely, positively, it wasn't even close. But they did also say that the Second Life intervention was more enjoyable, it was fun; they enjoyed that.

➢ They described that the social interaction was about the same. In fact, most of them said that there was really no
difference, although there were a significant number who did say that they thought Second Life offered even more social interaction than did a face-to-face program.

- And then, in terms of providing the opportunity for long-lasting social connections, this was really pretty evenly split. I think the note here that the face-to-face provided somewhat more opportunity for long-lasting social connections was really based on our early beta test and experience. By the end of the study, when we had all of our data in, it was very, very much split, where about a third said this was no different. About a third thought there was a benefit to face-to-face programs in terms of lasting social connections, and about a third thought the benefit went to the Second Life, that Second Life really did offer more opportunity to keep those connections going and to maintain those long-lasting social connections.

- Now although Second Life is not for everyone, we did have one or two women who said that it felt a little odd, that they really preferred the real world. But there were a number of others who found it particularly helpful and found that they were able to take advantage of this type of an opportunity for a workshop much more so than they would be able to take advantage of a face-to-face workshop. One woman in particular who described herself as being very shy said that Second Life was such a better venue for her. It was less anxiety-provoking and it really kind of allowed her to feel safe behind her avatar and in a way hide behind her avatar until she had an opportunity to get more comfortable with the group and start sharing more. So, I think there are true
advantages for some women to participate in the Second Life program rather than a face-to-face program.

PEG: Thank you so much for directing that project. Susan was the project director and coordinated the pilot test for that. So, we'll be continuing our research and trying to do a full clinical trial and to test if this intervention really makes a difference, the face-to-face versus just regular services from the CIL. So with that, I think we'd like to open it up for comments and questions.

LINDSEY: Very good, thank you so much. That was a great presentation. We do have some questions coming in. I know we ran over a little bit but we'll get right to it. First one is what advice would you give someone having gait problems, having to try to walk with a cane, a walker and in a wheelchair for them to ignore other people's cruelty and ignorance of disability?

PEG: Yeah, that's hard. Anybody want to take, try to answer that question? All right then, I'll try. Drawing on my vast experience, I can say that you just have to keep working at it. It's not something that you can change overnight. Other people will not understand the disability like you do. Disability to them is full of stereotypes. All they've ever seen probably is what you get from the media, and the media, up till very recently, has had a very negative portrayal of women with disabilities, where we're bitter, we're always too shy, we're always too protected, we're always selfish, we're always vengeful, we're something evil, you know. [Unintelligible - 01:15:34] I mean that's where they're coming from and that's how they view us. It's horrible, we're either saints on a pedestal or we're sluts or we're, you know, we're meant to be in an institution and not to be let out. So how do you get past that? Well, really you have to create your own paradise. That's my attitude toward life. You have to be able to somehow turn the minds of people like
that by smiling at them, by showing them that you can be happy whether you're on a date or not, even if you're by yourself. But if you're with a date and you're having a good time and somebody comes up and wants to drop the proverbial quarter in your proverbial hat, you politely rebuff them and say, or make a joke about it and say, “Oh, excuse me, but I'm too busy having fun right now.” So, make light of it with humor. I know these are all kinds of trivial answers but really the only way, and I think the only way, to turn people around is to be utterly and completely positive, that if you stoop to their level and become negative and become very angry with them, you've not helped the situation at all.

LINDSEY: Thank you very much. The next question is can you use Second Life if you're not part of the study?

PEG: Oh, yeah, Second Life is public. It's got millions, I mean, literally millions of users at any given time when you log onto it. You can go to www.secondlife.com and then it will have all kinds of instructions up there for you, about how to log on to the virtual world, how to create your own avatar, it's all free. They'll try to sell you a package where you can pay so much a month, but don't do it. I have never paid a penny for anything to do with my avatar. I mean, I don't even buy expensive clothes. I just use the typical clothes for the most part. You can, once you get your avatar with the basic form and the basic clothes, then you can go shopping and you can register dollars, real dollars and buy what's called Linden dollars. That's the medium of exchange in that world, and it's like 150 Linden dollars equals one US dollar, and then you can buy stuff. Like you can buy a blouse for maybe 50 Linden dollars which is what, what would that be, 50 cents? So you don't have to because they've got a whole inventory of stuff that's free. So you can even search for free clothes or free jewelry or free shoes, or
whatever you want, and dress up your avatar like you would a doll. Really it's like having a doll or a puppet that you now can manipulate. So, anyhow, anybody can use this. The only part that you won't have access to is our island because our island, our part of the island is private for our study, but eventually we want to make that public as well, it's just not quite yet. Somebody wanted to say something, I'm sorry.

SUSAN: I'm sorry, Peg. Yes, this is Susan. I was hoping you could share the information about Virtual Ability and Gimp Girl Island.

PEG: Oh, yes. Once you get logged on and create your own avatar and give it a name, you can go to the Virtual Ability Island and that's another one where you can start with their website; it's called virtualability.org, and it's a website set up for people, men and women, with disabilities. They have an island, a public island in Second Life, so once you get your avatar, you can go there. Again, it will give you instructions on how to go to these different disability type or just general support groups, lots of activities there. Gentle Heron is the name of the developer, the creator of that island, and she's a wonderful, wonderful lady who's done all kinds of exciting things with her island. There's another one called Gimp Girl and their website is called www.gimpgirl.org. I hope I got that right; I'll look that up while I'm talking. But Gimp Girl is another island created just for women with disabilities, and they have a support group that meets several times a week. They have different kiosks where you can go and again look at things, get information. You can buy wheelchairs, spiffy looking wheelchairs. They've got a beachfront and they've got a building with art. They do a lot of things like hold dances and special events. They post artworks that are
created in Second Life. The possibilities of this virtual world are just unlimited, so I invite you to go try it out and have fun with it.

LINDSEY: A couple of questions touch on the eligibility requirements and age related to Second Life, and also in your Second Life, can women join your group or is the group closed?

PEG: Okay, first of all, age, yes. Second Life does have an age requirement, I think it's 16. I'm not sure about that, but if you go to the secondlife.com website, it will tell you that. It's not for children because just like real life, there's some kind of raunchy stuff up there too, so they don't want kids exposed to X-rated stuff without having proper precautions, so they just make it blanket that no one who isn't of age should be able to go there. So, they do have an age restriction. Our program, our test, our pilot testing of our program itself, is currently not accepting new participants. We're going to be applying for continuation funding to do more testing of this and eventually to offer it as an ongoing program. But keep in touch with us on our website, which is now on the screen. For those of you who can't see it, it's www.bcm.edu/crowd, or if you want to Google CROWD or the Center for Research on Women with Disabilities, that will lead you to our website. And so, keep in touch with us and we'll keep you informed about when we're looking for new participants or when it goes public. Someday, we may. Was there another question in that series?

LIDNSEY: Yeah, there's a few more. Is Gimp, is it www.gimpgirl.com or .org?

PEG: I'm going to look that up; give me a second. Go ahead with the next question.

LINDSEY: Okay, what impact do you think Push Girls will have on women with disabilities?
PEG: Well, isn't that a good one! That is a very interesting program. I watched the first episode. First of all, it's only about women with spinal cord injuries, so a lot of what they talk about is unique to that particular disability type, but they do talk a lot about relationships, they talk about body image, they talk about self-esteem, they talk about social attitudes, and all of that is good. I think bringing up all of those topics should do nothing but good for our movement. As far as the fashion aspects of it, I think that there may be some debate about whether or not focusing on fashion so much and being really tied up and makeup and fashionable clothing. I personally am not, so I have a little bit of trouble with that. I believe in inner beauty and I believe in healthy living and eating right and doing exercises to the extent that you can, and I think you'll notice that all of us really subscribe to that. So, I focus more on having beauty come from the inside and showing through your external appearance. So, I don't know, the fashion part of it was a bit of a turn-off for me and I don't know how other women are going to feel about that. But as far as public exposure, I think it's great; I mean the public is talking about women with disabilities in these terms, I think it's wonderful, and I'll be happy when they start talking about having children and having pregnancy issues and concerns and raising kids and all the other parts of relationships that are important to us. I was glad that they did talk about a woman who is bisexual and that's going to broaden the spectrum even more. I just looked up the website, I apologize to my Gimp Girl colleagues; it is gimpgirl.com, so www.gimpgirl.com. Thank you.

LINDSEY: Wonderful, and we'll close on one last question that I think is important. Someone mentioned that they'd really like to know more about the term that you used in the beginning of the webinar,
independent mindedness. Is it a clinical term or is it a made-up term? They love the concept.

PEG: Oh, thank you, I appreciate it. I don't like to call it made-up; let's say “discovered.” Let's say “invented” like social learning theory was an invented term by Bandura. We're paving new ground here. I'd like to see this become a whole area of research. And interestingly, I have republished on that in 1996 I believe is when that came out, and so it's not gone very far. I don't think the field picked it up. We'll see, maybe you could help us to bring it out a little bit more and get more people to start coining that term. And let's talk about it because I think it's very much connected to gender and I think it's connected with the whole independent living movement.

LINDSEY: Wonderful. Well, I want to thank all of you, on behalf of National Spinal Cord Injury Association, extend our thanks to Peg, Susan, Rosemary and Pam for that wonderful presentation and that really great information on your studies and Second Life and its impact on body image and self-esteem. And I also want to let everybody know that our next webinar will be held on June 27th, titled Breast Health and Accessibility and you can pre-register for that webinar if you're interested at www.spinalcord.org. So thank you all very much.

PEG: And please invite everyone to send any comments or questions to the email address that's on the screen, crowd@bcm.edu.

LINDSEY: Wonderful. Well, thank you all so much.

ROSEMARY: Thanks for having us and thanks everybody for listening and enjoying it./AT/pa/pt/ee