

## Introduction to Excerpt from Testimony of Dr. Peter Blanck

Dr. Blanck was our second witness. When we first took Jenny's case, we knew that we would be operating against society's powerful and persistent opinion that people with disabilities need "protection" – and that, too often, "protection" means taking away a person's right to make decisions. When we entered the case, the Judge had already put Jenny in a temporary guardianship, taking away all of her decision-making rights, including where to live, what to do and who to see.

In this excerpt, we ask Dr. Blanck to focus on the importance of self-determination and autonomy for people with disabilities, focusing on studies showing that people with disabilities who have more control over their lives live longer, have better jobs and are better able to resist abuse. In particular, he cites studies showing the effectiveness of Supported Decision-Making as a less restrictive alternative to guardianship.

1 independence and self-reliance for people with  
2 disabilities and to give his opinion on the way  
3 some of the things we've discussed in this case  
4 will or will not maximize Miss Hatch's  
5 independence and self-reliance.

6 MR. BARTON: No objection, Your Honor.

7 MS. SWANSON: No objection.

8 THE COURT: All right. So ordered.

9 BY MR. MARTINIS:

10 Q. Dr. Blanck, first, in your opinion, why is  
11 it important to maximize the independence and  
12 self-reliance of people with intellectual disability?

13 A. Well, in a nutshell, it's true for all of  
14 us, to the extent that we have a reasonable capability  
15 in our lives to make decisions and to follow our own  
16 unique preferences, it's related to a higher quality of  
17 life, it's related to better health outcomes, it's  
18 related to better social interactions, so it's just a  
19 normal element of human interaction, which we would  
20 hope to maximize.

21 Q. Is there -- you mentioned studies. Are  
22 there studies or literature in your field indicating  
23 that the more independence a person has the better  
24 their quality of life?

25 A. Yes. A matter of fact, most of the studies

1 show that that, of course, is the impetus for the  
2 Americans with Disabilities Act and modern disability  
3 law in the United States, that integration is an aspect  
4 of the human experience that should be fostered and  
5 leads to better human flourish.

6 Q. Now, historically, how has the legal system,  
7 including the guardian system, done that? In your  
8 opinion has the legal system maximized historically the  
9 independence and the self-reliance of people with  
10 intellectual disabilities?

11 A. Well, without going too far back into a  
12 history class, as you probably know and as the Court  
13 knows, historically, there's been an overly-medicalized  
14 approach to disability, which was kind of a cure and  
15 maybe rehabilitate model, it was typically other driven  
16 and not consumer driven, and that was reflected, of  
17 course, and segregated to living environments,  
18 segregated work environments, out of sight, out of  
19 mind, and a lot of -- much less control or input by the  
20 consumers.

21 The modern model of disability, which is  
22 reflected in out-of-state law as well as the Americans  
23 with Disabilities Act, is much more individual focused  
24 and consumer focused and fostered -- and to foster  
25 independence that's reasonable in the circumstances

1 with a particular focus on the individual's preferences  
2 and needs and interests in life.

3 Q. I've heard the medical model described as  
4 follows, it seems to focus on the diagnosis and says,  
5 because you have condition or diagnosis A, you must get  
6 intervention or treatment B, without actually looking  
7 at what the person can do or can want or can need; is  
8 that an accurate description?

9 A. Yeah, that's a fairly accurate description  
10 of the medical model. Today's model has, for example,  
11 under the Americans with Disabilities Act, has moved  
12 away from diagnostic categories in defining disability  
13 more towards functional person-centered outcomes, and  
14 that means that those sorts of outcomes are determined  
15 in context with appropriate supports, with  
16 accommodations to maximize the individual's  
17 independence.

18 Q. Has there been a recent report from the  
19 Senate on the importance of integrating into  
20 communities?

21 A. Yes. Senator Harkin, when I worked in Iowa,  
22 he was my senator, Tom Harkin, who was one of the  
23 drafters of the Americans with Disabilities Act,  
24 recently has come out with a very important report  
25 through his committee in Congress citing the importance

1 of independence in living with regard to quality of  
2 life and, in fact, if I might add, that it's much more  
3 cost effective in terms of costs for the Medicaid  
4 Program.

5 THE COURT: Is he still with us?

6 MR. MARTINIS: Let me --

7 THE WITNESS: I'm sorry?

8 THE COURT: Is he still with us?

9 THE WITNESS: Senator Harkin is still with  
10 us, and he has announced that this will be his  
11 last term.

12 THE COURT: Okay.

13 MR. MARTINIS: He is the father of the ADA.

14 THE COURT: I know he was getting up there  
15 in age but I enjoy him tremendously, but go ahead.

16 BY MR. MARTINIS:

17 Q. This case, as I'm sure you know, is about  
18 whether or not Miss Hatch should have a guardian, and I  
19 want to ask you one very important threshold question:  
20 Are guardianships always bad, do they always adversely  
21 affect a person's independence and self-reliance?

22 A. No. I would say, without being too glib,  
23 and you can tell me if I am, it's really not about  
24 guardianship or not. It's about how do you maximize a  
25 person's independence that's appropriate for a given

1 situation in light of his or her preferences.

2 Sometimes guardianship or a partial guardianship may be  
3 appropriate, sometimes it's not. Certainly, in my  
4 opinion, the presumption should be focused on the  
5 individual's preferences, the individual's capabilities  
6 and what the individual can safely and appropriately do  
7 with supports in society.

8 Q. I've heard guardianship described as  
9 follows: It's a tool. You use the right tool in the  
10 right job, things get fixed. You use the wrong tool  
11 for the wrong job, and people can get hurt. Does that  
12 sound accurate?

13 A. Well, I'll have to think about that analogy,  
14 but certainly guardianship is a legal mechanism, which  
15 if done properly in the right circumstances, can be  
16 helpful. If done, obviously, in the wrong  
17 circumstances cannot help in human flourishing.

18 Q. Based upon your research and your work, what  
19 do you consider to be the most important factors or  
20 components when you're creating a system to maximize  
21 someone's independence and self-reliance?

22 A. Person-centered focus. That was an easy  
23 question for me to answer very quickly, because  
24 person-centered focus in terms of preferences and  
25 abilities and supports is really what the modern

1 disability model is about, and in the past, it's been  
2 other focused, it's been providers, and no offense to  
3 the Court, but courts or monitors like myself, and,  
4 historically, that has led to the isolation and  
5 segregation of persons with disabilities.

6 Q. So when we're developing systems to maximize  
7 independence, should we put someone in a situation  
8 where they're in a situation that may be more  
9 restrictive than they need and give them the chance to  
10 earn their way out, or should we look at less  
11 restrictive settings first and give people an  
12 opportunity to do well?

13 A. Well, with regard to your former point, it  
14 sounds a little bit penalizing to me from a human  
15 experience. We're not talking about prisoners, we're  
16 talking about individuals who, with appropriate  
17 supports, want to flourish in society, just like you or  
18 me or my 92-year-old mother. And I think if I  
19 understood your question correctly, what my research  
20 shows is that the first presumption can be  
21 independence, choice, the ability to control what  
22 people do and what they think about, but that is not to  
23 suggest that that is done recklessly or without  
24 appropriate supports.

25 Q. So in your experience, what is the import or

1        what is the effect of a person's past ability to make  
2        decisions or demonstrate independence on prediction of  
3        how they will be able to do that in the future or on  
4        creating a system to maximize their independence?

5            A.     Well, as a general matter, the research and  
6        psychology shows, again, you don't have to be a  
7        psychologist to know this. The best predictor of  
8        future behavior is past behavior, and to the extent  
9        that future behavior can be supported and appropriately  
10       recognized, the preferences of the individual, then you  
11       learn from your mistakes, you learn from the past.

12           Q.     In your research in your work, have you  
13       become familiar with or had a part in implementing less  
14       restrictive alternatives to guardianship with an eye  
15       toward increasing or maximizing independence?

16           A.     Yes, particularly as I've said in my  
17       responsibilities to the federal court.

18           Q.     Can you give us a couple of examples of what  
19       would be a less restrictive alternative to guardianship  
20       that would maximize support, while also providing  
21       assistance for a person to make decisions?

22           A.     Well, if I understand your question  
23       correctly, there is a term that probably has been  
24       discussed called the supported decision-making, and  
25       that's, essentially, in today's literature and



1 research, it's just a term for a vehicle to allow the  
2 individual to have his or her preferences and wishes  
3 implemented in terms of his or her life with  
4 appropriate supports, whether they're provided by the  
5 government, Medicaid Services, or by families or by  
6 friends.

7 Q. I've heard supported decision-making  
8 described as follows: It's the method of describing  
9 something to someone in language they can understand so  
10 they can understand the choices before them and make a  
11 choice themselves; is that correct?

12 A. Yes. Again, I'm sorry, if I understand your  
13 question, but, essentially, it is enabling the person  
14 to fulfill her or -- his or her preferences with the  
15 maximum aid, choice, independence possible, as opposed  
16 to making the decisions for that person, essentially,  
17 if I understood your question correctly.

18 Q. Well, yes. I get confused with supported  
19 decision-making, because it just sounds like something  
20 we all do every day, every time we go to a mechanic who  
21 has to explain to us how the car works so we can decide  
22 whether to get it fixed, aren't we engaging in  
23 supported decision-making?

24 A. Yes. In my case, I have quite a bit of  
25 supported decision-making when it comes to automobiles,

1 and I have four teenagers and who have resulted in my  
2 paying particular attention to that.

3 Q. So this supported decision-making, it's not  
4 just some kind of theoretical model made up out of thin  
5 air, it's just what we all do every day applied to  
6 people with intellectual disabilities, right?

7 A. Yes, certainly.

8 Q. Have you done personally or do you know of  
9 any studies showing the effectiveness of supported  
10 decision-making for people with intellectual  
11 disabilities?

12 A. Yes, there are studies which show the  
13 effectiveness of supported decision-making for people  
14 with Down Syndrome, people with intellectual  
15 disabilities, with outcome measures such as quality of  
16 life and independence in living.

17 Q. Have you done any research on the effect of  
18 supported decision-making?

19 A. Yes, I think I have in this sense. I've  
20 tracked thousands of individuals in one study, for  
21 example, published in the Iowa Law Review of  
22 individuals who moved from segregated settings and from  
23 segregated work into integrated settings and integrated  
24 work and looked at outcomes in terms of their  
25 behaviors, in terms of their quality of life, and so

1       forth, with appropriate supports, and the results show  
2       terrific improvements in those areas.

3               Q.     So for people who are able to engage in or  
4       have a history in engaging in supported  
5       decision-making, is it fair to say that your study  
6       found that they had better lives?

7               A.     I would say as a general matter,  
8       independence in life, choice in life, personal focus  
9       leads generally in the research to better quality of  
10      life outcomes.

11              Q.     Are there any -- is there any case law in  
12      this country looking at supportive decision-making?

13              A.     Yes. I believe, for example, in New York,  
14      there is a judge who has -- I forget her name -- very  
15      much supported the concept of supported  
16      decision-making, who has written opinions on that.

17              Q.     Are there any other studies that you're  
18      familiar with conducted by *The Arc* or Professor  
19      Wehmeyer discussing the effect of independence and  
20      choice on quality of life?

21              A.     Yes, there are studies. Professor Michael  
22      Wehmeyer is a leading person in Kansas on these issues  
23      and consistently the results show, as I have said, that  
24      choice, independence, lead to better health, quality of  
25      life affluence.

1           Q.    Is it fair to sum up those studies this way,  
2 people who can engage in supported decision-making and  
3 can demonstrate independence with or without support  
4 and are given an opportunity to do so, can become even  
5 more independent as time goes on?

6           A.    Yes.  The research shows that it leads to  
7 greater personal independence with -- but I emphasize,  
8 of course, with appropriate supports.

9           Q.    Of course.  Now, in your work, in your  
10 research, have you come across examples of supportive  
11 decision-making or other less-restrictive alternatives  
12 to guardianship being used by people with disabilities  
13 or capabilities that are less good than Miss Hatch's as  
14 found by Dr. Burkett?

15          A.    Yes, in several instances, particularly  
16 where there was comorbidity with very severe physical  
17 disabilities as well, which were quite challenging.

18          Q.    To be clear, what is the actual difference  
19 between supported decision-making, as you've described  
20 it, and guardianship?

21          A.    Well, guardianship is a legal mechanism and  
22 essentially whereby the individual does not have a  
23 choice in his or her decision-making, for the most  
24 part, and supported decision-making is more consumer  
25 focused and enables the person to have a greater say in

1 the types of supports and preferences that he or she  
2 will undertake in daily life.

3 Q. I'd like to ask you to look at a transcript  
4 you have in front of you, and it's the one -- it's the  
5 transcript of Dr. Lori Burkett. I believe yours is  
6 going to start at, looks like, Page 18 or 19. It's one  
7 I've handed out to everyone.

8 A. Yeah. 19 is the first page on mine.

9 Q. Okay. Would you take a look at Page 47 in  
10 the upper right-hand corner of that transcript.

11 A. Yes, I see 47.

12 Q. I'm directing your attention to lines 8  
13 through 11, where Dr. Burkett says: "I believe that  
14 what would be beneficial to Jenny is that she is  
15 afforded the opportunity to have individuals around her  
16 who support and love her, who give her the assistance  
17 that she needs." Does that sound to you like a good  
18 definition of supported decision-making?

19 A. Very much so. It's well said, and the focus  
20 is on Jenny to use the name in this text.

21 Q. So in your opinion, what should we focus on  
22 when we're setting up one of these systems, these  
23 supported decision-making systems or these systems to  
24 maximize independence? What's the importance, Doctor?

25 A. Well, as I've said, what I've tried to do in

1 my experience is first to listen and to hear and then  
2 to try to understand perspective, and it's really not  
3 complicated from a medical or a legal point of view.  
4 The presumption is first to try to put yourself in the  
5 position of the individual and understand what his or  
6 her preferences are. It's either as simple or as  
7 complicated as that, and as you said, we do that every  
8 day.

9 Q. And when you were overseeing the state  
10 system in Wyoming, and I assume there were times when  
11 you had to make a recommendation between a guardianship  
12 or a less-restrictive alternative to guardianship; is  
13 that right?

14 A. Yes, you know, it was very challenging.  
15 I've worked with many parents, and this is not, I would  
16 add, about the good or bad intentions of parents, the  
17 good or bad intentions of courts or providers. I  
18 recall a case, if I may, if you'd --

19 Q. Please.

20 A. -- like me to go on -- with a little girl  
21 with intellectual disabilities, and I believe it was  
22 spina bifida, and she was living in the institution,  
23 and her parents were very resistant, perhaps rightfully  
24 so, given some safety concerns and health concerns  
25 about her moving into the community. The decree that

1 the state entered into was to move all kids into the  
2 community with appropriate supports, and we had a  
3 hearing like this in a federal courtroom like this,  
4 listening to the parents who had very valid safety  
5 concerns. And my job was to ensure without a fault  
6 that that little girl got what she needed safely and  
7 not to put her in harm's way in the community.

8 The parents, rightfully so, took me to task  
9 on that, as they should, because this was all new to  
10 them. This girl had grown up in this institution, was  
11 totally segregated from society. Long story short,  
12 after a period of time when we transitioned her from  
13 the institution to a group home to eventually living  
14 back home with her parents, she and her family  
15 flourished like never before.

16 They had a lifestyle, which none of us,  
17 including me, could have imagined in terms of quality  
18 of life, and, you know, things are out of our control,  
19 sadly a few years after she was placed, nothing to do  
20 with the safety or security, she passed away from her  
21 illness.

22 But I remember talking with the Wyoming  
23 legislature, and some of the administrators, and the  
24 remarkable thing was, everybody was touched by this  
25 story, and many other stories like this we had found

1 where the presumption was no way, this is not going to  
2 happen, she's going to be put in harm's way, to a  
3 really nice outcome for the family, and so I don't mean  
4 to go on too long but --

5 Q. Please.

6 A. -- the moral of that story for me was, if we  
7 put our minds to it in a positive way and think first  
8 about the client and the preferences, then we can make  
9 things work, which is not at all to suggest I would be  
10 the first to say about in any way putting the  
11 individual in harm's way or not appropriately  
12 supporting the individual in the less restrictive  
13 environment.

14 Q. So in that and other instances where you  
15 were called upon to make a recommendation, for example,  
16 between guardianship and a less restrictive  
17 alternative, what was the most important thing for you  
18 to be looking at when you were making that  
19 recommendation?

20 A. Well, as I mentioned, the individual's  
21 preferences, but, of course, you have to look at  
22 carefully whether the appropriate supports exist in the  
23 environment, because we're not going to put anybody in  
24 an environment that's not safe. So the presumption is  
25 the individual's preferences and wishes, and if those



1 can be appropriately supported, then what is it going  
2 to take to enable that individual to live independently  
3 in the community, which without the -- with all the  
4 fancy legal talk is really what the term least  
5 restrictive environment is about. Least restrictive  
6 means, least restrictive, appropriate environment.

7 Q. And when making that recommendation or that  
8 choice, what effect does a person's past documented  
9 history of being able to exercise independence have in  
10 your recommendation?

11 A. Well, as I've said, it can be an indication  
12 for the opportunity for increased independence in  
13 living. If there have been difficulties in the past,  
14 it can suggest that we've got to think hard about the  
15 types of supports that are needed to make this work in  
16 the community, the presumption being that integrated  
17 living and independently living is the main outcome.

18 Q. For people who are able to exercise  
19 independence or able to make decisions with support, do  
20 supported decision-making or other less restrictive  
21 alternatives to guardianship, in your opinion, increase  
22 independence and self-reliance more than guardianship?

23 A. Well, you know, to some extent, that has to  
24 be approached on a case-by-case basis. The research  
25 would support that. I thought you were going to say

1 something else, you started -- if you don't mind, you  
2 had a couple of questions in there. I think you said  
3 something like, for people who are able to live  
4 supported, you know, that word able and disable has  
5 been historically a difficult area, because most people  
6 are able, with the appropriate supports, to live  
7 independently. Historically, we talked about the  
8 medical model and stigma and bias has been the  
9 presumption that people with disabilities cannot, that  
10 was the starting point, so able is not just meaning can  
11 Miss Hatch get up tomorrow and live in the community,  
12 it means with the appropriate supports, does she have  
13 the desires, the capabilities, the preferences, and the  
14 appropriate supports that believe in that outcome.

15 Q. Are you familiar with the work of Professor  
16 Robert Dinerstein of American University?

17 A. Yes.

18 Q. Are his opinions and writings on  
19 guardianship and less restrictive alternatives to  
20 guardianship considered to be reliable in the field of  
21 people who work with people with disabilities on  
22 maximizing independence?

23 A. Oh, very much so. He was appointed by  
24 President Clinton to serve on the President's committee  
25 on intellectual disabilities, which is the major