



Transcript of NCSET Conference Call Presentation

My Future My Plan: Engaging Students as Leaders in Planning for Their Future

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presented by:

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MS. STENHJEM: I think we'll just go ahead and get started. Thanks, everyone, for introducing yourselves. I really appreciate it. My name is Pam Stenhjem. And I'm the Associate Director of the Youth and Family Participation Network at the National Center on Secondary Education and Transition at the University of Minnesota.

On behalf of our center, I'd like to welcome all of you to this month's teleconference call.

Before we begin, I would like to request if anyone is using a speakerphone to remind you to please put your phone on mute, which will tone down any background noise that may occur during the call. And I'd like to thank you for doing that.

Today's topic for the teleconference is "My Future, My Plan: Engaging Students as Leaders in Planning for Their Future."

And we're very lucky to have two people with us today who have worked on several very innovative and important projects related to student leadership and planning for the future.

We have Gerry Wurzburg, President of State of the Art, an Academy Award winning multimedia communications company that creates products for ordinary people facing health and educational challenges. Gerry is also the director and producer of two HBO documentaries - "Educating Peter" and "Graduating Peter." "Graduating Peter" has been airing on HBO for over the last two months, and so many of you on the call may have already had the chance to see this film.

We also have Dana Sheets on the line, who is a producer at State of the Art, and who has been responsible for development of an educational curriculum and video called "My Future, My Plan," which directly corresponds to and builds from the film "Graduating Peter."

MS. SHEETS: Thank you.

MR. WURZBURG: Thank you.

MS. STENHJEM: And just so people know the format of today's call, this is how we'll go through the call. We're going to ask Gerry to begin. Gerry's going to be providing us with a little bit of history on "Graduating Peter," which includes the story and the release of the film, as well as how the film is being received currently.

And then Dana will share some information about the educational curriculum, "My Future, My Plan," how it was funded, and some of the overall goals of the curriculum.

After Dana's portion of the teleconference, we'll open it up to any questions that you have for Gerry or Dana at that time. And then, at the end of the call, I will give you some information about related Web sites where you can access more information on this topic.

So, without further ado, I'd like to introduce Gerry and have her begin.

MR. WURZBURG: Hi, everyone. Thank you for joining us today.

We started with - I'm sure many of you know the film "Educating Peter," which came out in 1993. And that was a story - we filmed the story of Peter Gwazdauskas, who was at that point in third grade. It was his first experience being included in his community school.

Before that time - he has Down syndrome - before that time he had been bussed about an hour away. He was in a completely contained setting. And so this film followed him from the point when he first started being included, and the first film was about just third grade. And it was very much about Peter's experience, but also as much about the experience of his peers in that classroom.

And that film ended up with, you know, at the end of that film, that half-hour film, you're feeling a sense of, OK, you know, this looks good. This looks as though things - there's a possibility that this can work. Obviously, you know, it takes a lot to make that happen.

We then, you know - all of you know that the issues around transition planning occur and are stretched across the life of a child. And so I was very interested in - because I stayed in touch with the family - very interested in the possibility of actually following his transition planning process, again, in a documentary way.

And so, the new film that just came out, "Graduating Peter," really represents 10 years. It's following him from third grade all the way through high school and out of high school.

And so, it invariably, included a lot of the struggle. Peter was diagnosed with depression during that time. So we were trying to get at how - as you all know. You're not a simple definition of your "label." But you've got many, many levels of complexity.

And we tried to capture in that film what that family's experience was as they tried to continue to have Peter included, and try and really work on making his transition plan. And you - it's very much - the film really captures a lot of the family effort in that, particularly his mother.

And when film ends, it's kind of a mixed message. Because - and you end the film and Peter is - he does graduate with his peers. I mean, there's some years in there where it was quite frankly a tremendous struggle, and it was very unclear how it was going to end up.

But at the end he does graduate, across the stage with his peers, with a certificate of attendance. And he continues, you know, working at his job in the community.

But at the same time, you know, Peter has pretty significant communication disabilities, so it's not like there's a - unfortunately, you know, I'm off dealing with the mainstream press. So there are people out there who are expecting some sort of a cure. And that's actually in a way how they express it.

So, it ends up with a complex picture at the end, which is, reality is a complex picture. So, that's where that film ends off.

Now, since the film finished, just in the last four months, Peter has, in fact, moved out and moved into a house near his parents. He's living with two young women who are both college students. And he's continuing at his job.

And we've actually started filming some of that. I don't know if we'll make a film of it, but to our mind, that is really where the story - that, to my mind, that's the important part of the story, is, OK, now what happens? Now let's look into the adult years.

And that's true for all of us who have raised children. It's not the end of high school. It's what happens

in the next 10 years.

So the film came out on HBO. It's been - when you talk about how a film is received, it's always kind of a confusing thing. It's been getting a very strong response. I think for people it's been a real - for a lot of families, it's been getting a lot of response from families, because this is a situation that they are living through.

And so finally, they're seeing something that is close to their situation. And they maybe haven't had the same disability issues, but they're having the same issues around planning for their child's future.

And we're getting the same response from people with disabilities. They're letting us know that it's - they're frustrated with things in it, but they're very happy to see that the display of what's involved is in there.

Some people, quite frankly, are, you know, it's not picture perfect. And there is certainly some pushback we're getting from people because it isn't picture perfect. But, you know, it's - that, in fact, is the reality that people have to work with.

What we're doing with the show is we also have a facilitator's guide that is going to be released. The show is now in distribution, but the facilitator's guide is in release. So that kind of can give you some guidance in terms of how to use this in a community setting or a school setting or training setting, which is a good place to be using it.

Now, out of that film, as soon as we knew - you know, we did the first film, "Educating Peter." And one of my real frustrations with that was that, you know, we had the film but we didn't have enough outreach materials.

I worked on some things with Syracuse, but I felt as though it was kind of put together, not to my satisfaction. Because people need to understand the background and the complexity of trying to do full inclusion.

In this one, we really wanted to make sure that something came out around the same time that really captured, what is transition planning all about?

So from the time we started working on the second film - so we're now talking, you know, nine years ago, 10 years ago - we really started to try and find, how can we raise money to have a companion piece? And so, you know - because I really felt it was very, very important that families have some tools, that schools have some tools to support them in supporting families.

And so, through a combination of funding from Department of Education and then ultimately the National Institute of Child Health and Human Development, we were able to raise funds so that we could do the piece "My Future, My Plan," which is a video.

It's a whole - it's a curriculum, so it could be used for training of staff. It can also be used to work with families and to work with young adults, so that they can start to see, OK, here are some faces. Here are some people who did the transition successfully with a range of disabilities.

And then he - and then also, very important, is a notebook, which is a low-literacy, very accessible notebook that families can really use to walk themselves through, and schools can use as a way of guiding families and adding their own information.

So that's kind of my handoff now is to Dana, who has done a superb job shepherding "My Future, My Plan" to life.

MS. SHEETS: Thank you, Gerry. The crux of the effort to develop the curriculum, starting from recognizing that Peter's experience was a struggle, not only for him, but also for his family, in terms of finding out what exactly transition planning was going to involve, how many people it was going to involve, what does it look like in the school, what does it look like outside and beyond the school setting?

And we started off doing many, many interviews - many interviews with youth with disabilities, with their family members, with professionals who work with students with disabilities, with people who, at an academic level, sort of review what is and isn't working.

And what came out of those interviews overwhelmingly from the families was that they just didn't even have a place to start, without going to 17 different Web sites and talking to nine different people, and having a meeting to have a meeting.

And so, the overall message that came very clearly to us was that people wanted a comprehensive resource that touched on all the areas that were going to be involved, that it was not going to give them all the answers in one place, but it was going to let them see all the different areas that need to be considered.

And also that it was written to youth, that it is their life and that self-determination and student-centered planning is very, very important.

In the video, the three youths that are profiled are Brandon, Frances and Peter. And the stories were chosen because they represent students who are very engaged in the process, who have family members who are very engaged in the process, and who either started early or understand the importance of starting as early as possible.

The ideal target audience, the first primary audience for the three sources - for students aged 14 and their families, who were in the process of transition-

ing into high school. So at that point - and students who have an IEP, so that they're getting support from the school, and at 14 is when the transition planning process, from the school's standpoint, really needs to kick into high gear and start looking at what's going to - what's going to happen after high school's over? What's the next step?

And we were originally going to have a very small booklet that came along with the videotape, and it got to the point where a very small booklet was going to be a very useless recap of a lot of material that was out there.

And so, we kept pulling in content areas. We kept pulling in topics for the notebook of things that people wanted to know about.

And we cover - it starts off with questions, you know, to begin exploring the process of what is my life going to look like? After high school, what are my visions? What are my barriers to my vision?

And we do have a big section on advocacy. We have a big section on rights - legal rights and responsibilities, where we go through the laws that protect students in school and their families, and give them the right, you know, to services and records and protections and equal opportunities.

And then we talked about people. And there's several chapters on different people involved, the importance of records. Services, college, job training, health, recreation, housing, transportation.

We really tried to cover all the bases, because that's what people were asking us for. And in the - these materials are - have been qualitatively evaluated before we brought them towards completion. So we sat with a group of people and had them look at them and give feedback.

And I'm happy to say that several people did try to steal the resources from the focus groups. Other people were kind enough to ask for their copies after we get done.

But people really dug into the notebooks to the point where they were very frustrated when the moderators asked them to stop working with the notebook and start talking about them to give us feedback, so we can make it better.

And we just had - we just took them, "My Future, My Plan" materials down to the Pacific Rim conference in Hawaii and screened them there and had a couple of people there who felt that perhaps that was the time for them to acquire the notebook.

But they held off until they're going to be able to order a copy. And we are going to be accepting orders at the Web site for it, myfuturemyplan.com.

But even now - and we've begun the second part of the evaluation, which is a quantitative evaluation, where it's going to be placed with parent/student pairs, or dyads, and we're going to review their experiences about transition planning over a three-month period, so we can see, you know, what were their attitudes before they got this, and then, how do their attitudes and knowledge about transition planning change over the course of time.

So we are going to know, when we get done with this, you know, if this resource has moved in the right direction, and I'm very confident that those results will be very positive.

And just last week we had a pilot test with a small group of families. We're going to have another one this weekend. And in the pilot test, again, there was a family that dug right into the questioning process at the beginning of the notebook, because - and they, you know, when asked why they were, why they didn't leave the first chapter of the, you know, 16-chapter curriculum, they said, well we've never had this conversation. We didn't know where to begin.

And we've also had several students, in watching the video, identify having seen the student's model, their choices of work and college, come up with choices, of possibilities they want to explore college, and they want to explore work. And their parents being stunned because they had no idea that they thought of those things.

So we're really seeing some positive early indications from our research efforts that we've gone in the right direction.

And the goal was not just to make a thing and sell it, but really going back to what Gerry said before, it's really about creating awareness on the importance of transition planning, and using the broadcast of "Graduating Peter," and building an alliance of outreach partners. And if you go to the Web site you can see all of the partners that we have there.

National Center in Secondary Education and Transition, of course, has been amazing in the development of this. They've also participated in - Pam, if I could ask you to speak a little bit about your role in developing the parent's guide that comes along with the student notebook.

MS. STENHJEM: Sure. Well, when State of the Art approached us and said, I think initially you approached us and said, would you mind looking at the content that we have for "My Future, My Plan" and just give some feedback.

And we were happy to do that - we love seeing new resources and love being able to help with stuff like

that.

So, Kris Peterson and David Johnson and myself reviewed that, and gave feedback on "My Future, My Plan" just in general, and thought it was great.

And based on our feedback, we started talking and saying, you know, it would be really be nice if there was some kind of a guide that helped the teachers and the parents to support the young adults, to be, you know, self-determined, to use the student notebook in a proactive way, to be able to be leaders in their own transition planning.

And we felt very strongly that young adults would not be able to just grab this notebook and just jump into it and work their way through it and just take it and run.

We felt that they needed a circle of support of people that would be there for them and help them to work their way through that notebook in a constructive and proactive way.

And so we suggested that a parent/family/teacher mentor guidebook companion be developed to the student notebook, so that adults working with youth would be able to have some guidelines and some ideas about how to work with youth as they go through the notebook and start planning for their future.

And so really, the companion - the adult companion is really, it follows the same sections that are in the student notebook. And it's just written toward adults. And it gives them some helpful hints and some ideas about, you know, what would you be doing with a young adult when they're going through this section?

What kinds of things should you be thinking about? What's important to bring up and not forget to do as the adult in this young person's life? What are some additional things you can help them to think about?

And, you know, so we proposed this to State of the Art. And, of course, they were like, that's fantastic. Would you guys help us develop that? And we said, of course.

And so now we've added one more thing that needs to go out with this package, but which we really feel is a critical component to the success of "My Future, My Plan."

MS. SHEETS: So this whole package, "My Future, My Plan" - that's a curriculum, the video and the notebook - is going to be available in late April, early May.

And you can go to myfuturemyplan.com to get more information on what it is and to find out about ordering it. And there will be - there are bulk discounts. And, like that.

And one of the elements I haven't mentioned yet is that the video does come with a video discussion guide. And that came out of, also in talking with NCSET about, you know, having a facilitator present at screening and using the video, and using it in a workshop setting where the video can inspire people to become engaged in the process.

That students and families really get excited, and their curiosity gets piqued by, you know, maybe they aren't exactly sure that they know what an IEP is supposed to have in it. And maybe they didn't, you know, if their 504 plan is an option. Maybe they've never heard of that before.

And what does that mean and, you know, what is this adult services? And how do I get accommodations at college if my kid's going to go there?

And then just really start to ask questions of everyone around them. I mean, it's not always a quiet viewing of this film. People start talking when they're watching the film, because they're so full of interest and questions about what will come next.

What do we do now? What is the next step?

MR. WURZBURG: So to increase the reach of the project, also it's available in Spanish - both the notebook and the video is available in Spanish.

MS. SHEETS: And those will be released for fall of 2003. So for this coming fall we'll have those materials.

MR. WURZBURG: Right. I think we're probably at a point where we can take questions or talk ...

MS. STENHJEM: OK. That sounds really good. So anyone that has any questions for either Gerry or Dana, just go ahead and ask a question.

MS. HALL: Hi, this is Sandy Hall from UW-Whitewater. How much does it cost?

MR. WURZBURG: "My Future, My Plan," the package is going to be under \$100 for the video and the notebook. We're - we don't have the exact - we're waiting to get all of our bids back from the printers. But it's going to be under 100.

It's going to be - you know, it's probably going to be about 60 for the video and the notebook, in that price range. And that's basically a cost recovery price.

Obviously, if you're a school system and you get bulk, that price completely changes.

MS. HALL: Thank you. That's very reasonable.

MR. WURZBURG: Thank you.

MR. HERSE: This is Tom Herse from Florida. I wanted to compliment you on the film. But I did find it to be kind of depressing.

But I appreciated the blunt honesty of not trying to paint it with rose-colored glasses.

MR. WURZBURG: Right. Thank you.

MR. HERSE: And I think it really did bring home a lot of realities that families are thinking of, and just wanted to compliment you all on that effort. And certainly hope that it continues.

And my question was, has the response been big enough that they've considered doing a - broadening the base, you know, having another person that they follow, maybe from early intervention on?

MR. WURZBURG: No. That's the sort of - I don't know. I mean, I certainly am talking with them, because I really want to make sure they - I'd like to continue to follow Peter, because I think that where the story has turned has been very positive, even in just the last couple of months.

Because he's moved out of the home. He's having some real success, and he's having some success - fears.

MR. HERSE: Well, I think a lot of guys would think if they're living with two college girls ...

MR. WURZBURG: Well, tell me about it. Not a bad ...

MR. HERSE: ... you know, I'd be feeling pretty successful.

MR. WURZBURG: Right.

(LAUGHTER)

MR. WURZBURG: You picked up on that right away. I can - but I agree with you.

We're actually trying to get funding to do another project on early intervention that really looks at best practice models. And we're trying to get funding from NICHD (Nat'l Institute of Child Health and Human Development at the Nat'l Institutes of Health) on that. So we're trying to get funding for that.

"My Future, My Plan," that video is very positive. It very much looks at a very positive perspective. It's a very different perspective on Peter, because it's a lot about kind of the meetings and the process that was involved. You get a lot more detail on his experience.

And then the other two stories are very much from the point of view of the young person, and family, as family was involved.

Anyway ...

MR. HERSE: Bravo.

MR. WURZBURG: Thank you.

MS. PETERSON: Could I ask a question or make a suggestion? I'm on the Web site.

MS. STENHJEM: Sure.

MS. PETERSON: This is Colleen Peterson in Nebraska. And I can appreciate all the work you guys are doing. But I know that you've said you've had kind of overwhelming response from the film.

And I see there that you've got a list of resources, and you can't list everything. I know that. But you've got PACER Center and the Piek Parent Center in Colorado. Is there any way under the PACER Center's entry you could put, please go to the PACER Center Web site to find the parent training information center in your state?

Because there's a parent training information in every state in the Union.

MS. SHEETS: Absolutely.

MS. PETERSON: ... if they go to PACER, they can get to us, because they also house our national technical assistance ...

MS. SHEETS: Right. Because they have the Alliance and they have FAPE ...

MS. PETERSON: Right, but ...

MS. PETERSON: ... people don't know that. They're going to think, oh, there's a parent center in Minnesota and one in Colorado.

MS. SHEETS: Right.

MS. PETERSON: But under PACER, if you could just list, you can get to your state's parent training information center.

MS. SHEETS: Absolutely.

MR. WURZBURG: We'll do that.

MS. PETERSON: That would be wonderful.

MR. WURZBURG: Thank you very much.

MS. SHEETS: And we, actually, just to let you know, in the resource section of the notebook, we have all the coordinating offices for the parent training and information centers are listed in the resource in the printed material... and then we have, as current as we can get it, the state information, as well. So that the families who may not have access online ...

MS. PETERSON: Would have it on written ...

MR. WURZBURG: Yes.

MS. SHEETS: At least try for their state. And if the state doesn't work out, then they do have that regional office listed.

MS. PETERSON: OK. And if it was on the Web, that would be great, too.

MR. WURZBURG: Yes. Thanks very much.

MS. PETERSON: You're welcome.

MS. STENHJEM: Other questions for Gerry or Dana?

MR. WURZBURG: I guess I have a question out to you. You know, we've developed this resource, and we think, I mean, based - and we developed it by including conversations with a lot of people like yourselves.

And, you know, what advice - or do you think that this is something that you can use in your communities, in your efforts?

MR. HERSE: This is Tom Herse from Florida. And I was wondering if there was discussion about kind of a snippet of versions of "Graduating Peter," "Educating Peter" to be able to use in kind of conjunction with doing training, so you can use a, you know, a few minute clip to demonstrate - or a five-minute clip - to demonstrate a specific concept you're trying to convey.

MR. WURZBURG: Yes, you mean from "Graduating Peter."

MR. HERSE: Yes.

MR. WURZBURG: Yes. Yes, you can go to films.com, and they are licensed to sell that show. And so that is available.

MR. HERSE: OK.

MR. WURZBURG: And then you can use it however you want to use it.

MS. SHEETS: Yes, the price includes performance rights, I believe ...

MR. WURZBURG: Yes.

MS. SHEETS: ... what the Web site says.

MR. WURZBURG: Yes. They have an institutional price that's on the Web. And then we've been working with them to come up with a family price, too, which will be, you know, closer to - will be much more reduced.

MS. STENHJEM: And then, Gerry, was that a question you just asked of the participants?

MR. WURZBURG: Yes, I just was curious about, you know, from your all personal points of view, from the places where you all sit, ways that, you know - do you think this is something you can use?

How can we get it to you? How do you find out about these things? Is it something that you can see in your budgets? And, you know, how can we really work to get this out? Because, you know, clearly, the need is there.

And, you know, I, you know, we feel that we have a very - with "My Future, My Plan" - a very good tool to kind of complement what a lot of you are doing.

MS. STENHJEM: Anybody?

UNIDENTIFIED CALLER: That question was too hard.

(LAUGHTER)

MS. SHEETS: And one of the things I do want to mention about the notebook is that it is going to be released in a three-ring binder format. And that is so that it can be customized, that local places can put in local resources. Or, you know, school systems can put in school information.

And we went with the ring binder, the three-ring binder format, because it is modifiable. It is flexible. It's

not, you know, this bound book that never changes. It's meant to be a part of a very dynamic process.

MR. WURZBURG: Because we felt as though from talking with people that a lot of times there are always things that you want to tailor. And it may be that you want to tailor, you know, depending on whether a kid has a developmental disability or a learning disability, there may be different things you want to tailor in there.

But it really gives you that flexibility, plus it gives the family and the young person, most importantly, that flexibility.

UNIDENTIFIED PARTICIPANT: Will it be possible, you know, you buy one notebook, if you were to be able to duplicate that locally. Or do we need to buy - in other words, is it copyright - that'll be copyright protected?

MR. WURZBURG: It's copyright protected, unfortunately. Because a lot of - yes.

UNIDENTIFIED PARTICIPANT: OK.

MS. STENHJEM: Although - this is Pam Stenhjem, the moderator. I've looked at this curriculum a number of times myself, just from the editing standpoint in helping State of the Art with this. And I would say that what you'll receive if you do - or if a family, or if a school district purchases a number of these, is well worth - well worth it.

And is just cost recovery, but it's amazing. It's - you'll really get your money's worth. I mean, it's just - there's everything in there. Everything you wanted is in there, so it's - I mean, it's definitely worth it, if you can swing it, if you can do it.

MS. SHEETS: One of the people at the Pacific Rim conference who was examining it had been charged with coming up with a proposal for what is transition planning to explain all the funding needs in areas that are to be involved, because their school system is looking at reformatting how they do transitions.

And she was so desperate to take this notebook away. Because it had done all her work for her, is what she said. Because it really did - you know, there's a lot of wonderful resources that are out there on how to make IEPs effective and how to make good IEPs.

This curriculum does not do that specifically. The IEP is a chapter and included in this.

But it really, really pushes everybody to look at a big process, a big process that starts before high school and well after high school and includes many things that are beyond the IEP, so the family can start accessing community resources, community school to work programs, community health resources, and exploring

what is actually out there for them in a realistic way, not trying to, you know, get them started down a path where there's nothing there for them.

And that's been - that's been an important thing, too, in talking with people. Just realizing, you know - of course, all of you know the big change in services from school to after school, but parents are still not as aware of that as they need to be.

MR. WURZBURG: No.

MS. SHEETS: So that's a big message in both the video and the notebook. Is, you know, you've got to go call these people, and you've got to find out early, and you have to talk to them.

And there's telephone scripts in there. There's sample letters for advocacy, for writing letters. And in the parent section there's a special section on estate planning and a special section on letter writing, and a section on getting legal services and legal help.

So, we really did try and just, you know - it's something everybody does. But with these populations in particular, it's something that really needed to be made explicit, to really spell out, you know, this - you know, you should get accommodations for the SAT if you need them. And this is the number you can call.

It's that kind of a resource.

MR. WURZBURG: Before we start losing people, I do want to say that, you know, we'd love to hear from you. And if you think this is of interest to you, it's myfuturemyplan.com, and then you can send us an e-mail, because we'd love to kind of hear from you who have been out here on the phone, because I couldn't capture all your names.

But you can send us e-mail through that site.

MS. PETERSON: Could I ask a couple more questions?

MR. WURZBURG: Sure.

MS. STENHJEM: Sure, go ahead.

MS. PETERSON: I need to know if, within the manual, any part of it, did you deal with the risk of choice, and how staff and families deal with that?

MS. SHEETS: We talk about, in the parent's guide, I believe, Pam, that when we talk about it, it is a time of transition in the role for the parents in terms of concerns about facing well-being of their child as they make choices about their independence.

So we do address that in the parent's guide - parent/teacher guide - that it is not always a comfortable process of allowing a young person to choose the things that they're most interested in.

But, and the difficult balance of the roles of moving between being the decision maker to supporting a

decision maker.

MS. PETERSON: OK. We're dealing with that at a state level here in the adult system.

MS. SHEETS: What state are you in?

MS. PETERSON: Nebraska.

MS. SHEETS: OK.

MS. PETERSON: And so I was looking for more resources, because what we're finding is that basically there's those types of statements - and don't get me wrong, there's nothing wrong with that. I fully believe in that statement that you just made in the book.

But the state level people and people in professional positions are often looking for something in black and white that says, I'm liable or I'm not for allowing this choice.

And so we're struggling a little with finding information on how people have dealt with that. So, ...

MS. SHEETS: Yes, that is not ...

MR. WURZBURG: Yes, we don't get into that.

But that's a very good - that's a very good point.

MS. PETERSON: It's going to be Peter's next step.

MS. SHEETS: There's already been quite a few discussions.

UNIDENTIFIED PARTICIPANT: I'm sure there might be some people who would appalled and shocked that Peter is living with two college girls.

MR. WURZBURG: Exactly.

MS. SHEETS: Yes.

MS. PETERSON: That, what kind of a precedent are we setting? Who is going to be liable if something happened in this house?

You know, those are the kinds of questions that come up.

MR. WURZBURG: Right. Right. And that's already been ...

MS. PETERSON: Wow.

MR. WURZBURG: ... that's already been ...

MS. PETERSON: On how you're working with that?

MR. WURZBURG: Yes. That's what we're talking with them about.

MS. PETERSON: Good. Good.

UNIDENTIFIED PARTICIPANT: And I certainly hope that the message is, this is that Peter has just as much rights as anybody else ...

MR. WURZBURG: Absolutely is.

UNIDENTIFIED PARTICIPANT: ... to be able to have mistakes and have failures, and have things not go according to plan.

MR. WURZBURG: That's right.

MS. SHEETS: Exactly.

MR. WURZBURG: That's right. Thank you for saying that, yes.

MS. HALL: This is Sandy in Wisconsin. Going back to how to get this out better. I don't know. Just one thing that pops into my mind is, we have our upcoming transition and rehab conference at the American Club in Kohler, Wisconsin.

And, you know, this would be a great exhibit. And there'll be lots of school districts in Wisconsin, you know, ...

MS. SHEETS: Sure.

MS. HALL: ... represented there.

MR. WURZBURG: Can you send us an e-mail about that? And maybe - obviously, we don't have the budget to travel to places like that, but we could send you fliers and information on it. Would that be possible?

MS. HALL: I set up - I set up an exhibit for UW-Whitewater. I mean, if you could send me stuff so people could look at it, ...

MR. WURZBURG: Yes, we could.

MS. HALL: ... that - because I think people need to touch this and look at it.

MR. WURZBURG: And, yes, absolutely. And we could send you - because the video is all finished and packaged. And we have a mockup of the notebook.

MS. HALL: OK.

MR. WURZBURG: So that - yes. Yes. Can you e-mail Dana about that?

MS. HALL: Sure. Dana?

MS. SHEETS: Yes. Just e-mail the - the e-mail just on the Web site. It's office@stateart.com. It's on the how to order page. Contact us.

MS. HALL: OK.

UNIDENTIFIED PARTICIPANT: Did Peter make money ...

MR. WURZBURG: Yes, yes.

UNIDENTIFIED PARTICIPANT: ... off of this experience.

MR. WURZBURG: Yes, he absolutely did. From very early on, he was making money.

UNIDENTIFIED PARTICIPANT: So he gets residuals on the ...

MR. WURZBURG: Oh, you mean on the show?

UNIDENTIFIED PARTICIPANT: Yes.

MR. WURZBURG: We don't make any money on this show.

(LAUGHTER)

UNIDENTIFIED PARTICIPANT: So HBO doesn't - HBO doesn't pay every time it's played, or anything like that, like they do ...

MR. WURZBURG: No, basically what they did is

- this film never would have gotten made if they didn't provide us with the production funds.

UNIDENTIFIED PARTICIPANT: Right.

MR. WURZBURG: And so they did that. And certainly, if we make - if we recoup more than the cost of it, Peter will absolutely share in it. But basically, they have bought the rights to be able to air it.

UNIDENTIFIED PARTICIPANT: Has this impacted Peter as far as opportunities for public presentations? That type of thing? Is he becoming a star?

MR. WURZBURG: Well, he is, because he has gone with me to several conferences.

MS. SHEETS: We were at the ARC ...

MR. WURZBURG: We were at the ARC conference in the fall. And we've been at some other conferences. And then also his mother has been at conferences.

UNIDENTIFIED PARTICIPANT: Is he being paid?

MR. WURZBURG: Either with Peter or alone.

UNIDENTIFIED PARTICIPANT: Is he being paid?

MR. WURZBURG: Is he being paid? Yes. If anyone's being paid, Peter is being paid. His expenses are always being covered, if our, you know, kind of - there have been several events where basically our expenses are paid.

UNIDENTIFIED PARTICIPANT: Great.

MR. WURZBURG: Meaning our hotel, transportation and things like that, and meals.

MS. STENHJEM: And, Gerry, can you explain a little bit about your relationship with Peter? Kind of what his verbal level is, like if someone wanted him to be a keynote speaker or something, at a conference. I mean, is ...

MR. WURZBURG: Yes, yes. Peter ...

MS. STENHJEM: ... is that type of thing possible? And, you know, like at what level is he participating in these things? So, you know, I mean, there's a lot of people that ...

MR. WURZBURG: Peter has - if anyone has seen the film - Peter has very low communication skills. I mean, in terms of verbal communication ...

UNIDENTIFIED PARTICIPANT: Well, that's why I was wondering about something like augmented communication and some kind of facilitated ... communication and that type of thing. And I was a little disappointed that that didn't appear in the film ...

MR. WURZBURG: ... he actually ...

UNIDENTIFIED PARTICIPANT: ... to be happening.

MR. WURZBURG: Yes, no. And that was actu-

ally something early on when he was in middle school. But I work with Judy and to kind of, you know, give her information on that. And then actually someone came in to work with him on facilitating communications.

And it's one of the things where - I mean, if you know about facilitating communication, we've done a lot of work in that area with Doug Biklen (Prof at Syracuse University, Coord. of Inclusive Education Program).

You know, you have to have people who are believing in and supporting it. And it didn't happen.

UNIDENTIFIED PARTICIPANT: I'm just wondering, now that Peter is - may not have his, as much opportunity to have folks that always know him well enough to understand.

MR. WURZBURG: Right.

UNIDENTIFIED PARTICIPANT: That is sad - in, you know, living with Peter part of the next step. Is that becoming now a need that may be being recognized more?

MR. WURZBURG: From what I've seen, it - you mean, are they now trying to see about facilitated communication?

UNIDENTIFIED PARTICIPANT: Yes.

MR. WURZBURG: Is that the question?

UNIDENTIFIED PARTICIPANT: Exactly.

And is now - is the pressing needs of communication greater as a result of him now being in the community living with roommates and having maybe even greater independent access? But may be limited by the lack of communication.

MR. WURZBURG: Yes. I mean, I think that the issue of his lack of communication is a major barrier. In terms of finding some other ways of assisting him, like through facilitated communication, at this point they're not pursuing that.

But a number of years ago, there was an effort to try and, you know, get that going. Unfortunately, yes.

UNIDENTIFIED PARTICIPANT: Great.

MS. STENHJEM: You have other questions?

UNIDENTIFIED PARTICIPANT: That was my frustration in watching the whole thing. It was like, oh ...

MR. WURZBURG: I know. Yes, tell me about it, yes. It was very hard, because, you know, when you know that certain things, you know, if certain things happen differently, the outcomes can be different. And certainly, you know, from the very beginning, if they had figured out his hearing problems, ...

UNIDENTIFIED PARTICIPANT: Right.

MR. WURZBURG: ... early, it would have been

a totally different picture. And that didn't happen. And facilitated communications is not, you know, going on there.

If they were living in Syracuse, it would have been different.

UNIDENTIFIED PARTICIPANT: Is there any plans as the tracking continues on, to provide possibly any kind of a narrative updates, if there is not film, you know, a definite next phase film?

MR. WURZBURG: That's a good idea. I hadn't thought about that. But that's a good idea.

UNIDENTIFIED PARTICIPANT: You know, like you said, you just had indicated there was, you know, some good things happening here and ...

MR. WURZBURG: Yes, exactly.

MS. SHEETS: Yes, those are actually on the - the HBO Web site does have a couple of clips from when we went down and videotaped with him last summer. And you can sort of see - see his new house and see him very happily moving in there.

MR. WURZBURG: What we did - and because this all happened after we finished the film - we set dates, you know, I mean, you know, this is very important to have on the Web site where he is now. And so, those clips are on the HBO Web site.

They're clips of Peter from when we filmed him this past summer, when he - at the time that he actually moved in. Or moved out.

MS. STENHJEM: Other questions from anyone?

UNIDENTIFIED PARTICIPANT: You know, I'm calling from a hospital, from Shriners Hospital. We're very, very committed to transition. And I actually wear two hats. I work with the Healthy and Ready to Work National Center, too, out of maternal and child health bureau ...

MS. SHEETS: Oh, great.

UNIDENTIFIED PARTICIPANT: And I was just wondering, I know you've got a section on health. Is - would you - how would you describe that section?

MR. WURZBURG: Yes, that actually - that section was very important for us to include, because often, as you know, what happens is you shift - you make the transition from being with a pediatrician to, OK, now you're 18. I don't take care of you. I've gone through this with my own children. I've seen this first hand.

Dana's just pulling that section out and she's going to talk about it.

MS. SHEETS: Yes, because we talked quite a bit with Patty Hackett down at the Healthy and Ready to Work Action Center, and she helped us ... Yes, she's great.

UNIDENTIFIED PARTICIPANT: Yes. That's fantastic. Well, if you worked with Patty, I'm sure you've got it, then.

MS. SHEETS: Yes, and what we did - you know, we started off with the good basics of, you know, living a healthy lifestyle is health and exercise. And then we actually have materials in the notebook used by permission from the healthy and ready to work national center.

Some publications that I think are out now, but they weren't out by the time we got them. Just some tips on health and wellness and how to stay well.

We also talk a good deal about insurance.

About being able to talk with your doctor, how to talk with healthcare providers. We offer some forms to track health information. And we also talk about, in the college section in particular, we talk about transitioning healthcare services to college.

So we have - we have made that an integral part of this, because it's one of those areas that everybody told us got dropped off.

And so that along with transportation, we worked with the, with Project Action, and using some of their material to talk about the importance of early exposure to transportation and using it, or finding out what your choices are going to be if there's no public transportation.

So those two areas are there, and are covered because people said that they were often missed in other ...

UNIDENTIFIED PARTICIPANT: Well I know, you know, one thing that I definitely will do, once we get a copy of the video and the notebook, but I don't see why children's hospitals couldn't have this in their family resource centers.

MS. SHEETS: That would be great - a great piece to have there.

UNIDENTIFIED PARTICIPANT: Right. Not only Shriners, but I could approach Mackery about that. Because in most children's hospitals, there are family resource centers and a VCR.

MS. SHEETS: Yes.

UNIDENTIFIED PARTICIPANT: So even if you can't afford one for each patient, which would be really cost prohibitive, and a lot of families couldn't afford it, it could be available.

MS. SHEETS: Right. That's a great idea.

We'd love to work with you on that, because it's ...

UNIDENTIFIED PARTICIPANT: I would love to work with you all. It's wonderful. I can't - can we go on and order the film now? Is that ...

MR. WURZBURG: Order now and a Dana comes with it ...

MS. SHEETS: Not quite, but if you send me an e-mail, we're literally like days away from being able to sell the video and then, just weeks away on the notebook, because we got hung up in our little final edit, proof-reading, review process.

So please send an e-mail and I will reserve a copy, and the instant that we have prices and all that ordered, I will contact you all and get it to you, because I'm late. And I feel badly.

But we're almost there.

UNIDENTIFIED PARTICIPANT: I'll just e-mail you, and then you can just, when it's ready let me know, and I'll get a P.O. and we'll get a copy.

MR. WURZBURG: Thank you very much.

MS. STENHJEM: Any other questions for either Gerry or Dana?

OK. Well, we're a little bit early, but I think we'll go ahead and wrap it up.

I think what we'll do is share a few Web sites here just to recap, to make sure that you have access to information that you may need after the teleconference.

One is State of the Art. If you would like to visit their Web site, the address is [www.stateart](http://www.stateart.com) - one word -- .com. So stateart.com.

MR. WURZBURG: And you can also go to our health related is wellme.com.

MS. STENHJEM: OK. Great. And then if you also want information on "My Future, My Plan," that Web site address again is [www.myfuturemyplan](http://www.myfuturemyplan.com) - which is one word - dot com.

You can also go to the HBO Web site, if you'd like more information on "Graduating Peter," which is hbo.com. And if I understand correctly, they can also go to films.com, if they're interested in getting a copy of "Graduating Peter," Gerry?

MR. WURZBURG: Correct. And we also have a Web site, graduatingpeter.com.

MS. STENHJEM: Well, there you go. So you have lots of Web sites you can visit if you want more information.

MS. SHEETS: And you could also definitely visit Pam's group....

MS. STENHJEM: Sure. We have information, as well, on our home page, www.ncset.org

MR. WURZBURG: And NCSET will be handling the distribution, so that's going to ultimately end up where you're ordering from.

MS. STENHJEM: Yes, right. Eventually, when this is ready, we will be purchasing copies of those to then redistribute out into the community across the nation. So, eventually you'll have information about that on our

site as well.

And then, as far as transcripts of today's call, it takes us several weeks to turn that around, so I would say within the next five to six weeks, there will be a transcript on our Web site under teleconferences, of this entire call, so that if you'd like to go ahead and go in there and view that or print it, you'll be able to do that.

And then, finally, next month's call we do not have a topic or a date yet, so it will be near the end of March. And if you're interested in participating in another teleconference call, you can just visit the NCSET Web site and click on teleconferences, and you'll be able to get information on that call. It should be up there soon, it's just not on there right now.

So, I would like to, on behalf of the National Center on Secondary Education in Transition, thank our presenters, Gerry Wurzburg and Dana Sheets, for being with us today. I know everyone really appreciates it.

And I'd also like to thank everybody who called in to participate in the teleconference call.

MR. WURZBURG: Thank you very much. It was great to hear from everyone.

MS. SHEETS: It was wonderful. Thank you very much.

End of Teleconference

More Information:

If you want more information on State of the Art, you can visit their Web site at:

www.stateart.com

If you want more information on My Future, My Plan, you can visit the Web site at:

www.myfuturemyplan.com

If you want more information on Graduating Peter, go to:

www.graduatingpeter.com

If you would like a copy of Graduating Peter, you can go to:

http://www.Films.com/Films_Home/item.cfm?s=1&bin=31147

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