



Transcript of Conference Call Presentation

IEPS and Transition: Hear it from the Students

presented by

Sheryl Burgstahler, Ph.D., Director, DO-IT (Disabilities Opportunities Internetworking Technology)

DO-IT Scholars: David Benedict, Trent Marshall, Mike Neil, Amanda Johnson, and Laura Walizer, college-capable high school students who are self-motivated and have leadership potential. They attend two live-in summer study programs at University of Washington and participate in work-based learning experiences.

July 27, 1999

Dan Linneman: I would like to welcome you to the National Transition July audio conference. This month's presentation is entitled *IEPs and Transition: Hear it from the Students!*

My name is Dan Linneman, and I am a professor of special education at the University of Illinois at Urbana Champaign. I work with the National Transition Alliance, and I am located at The Transition Research Institute.

Today we are honored to have some experts in the field of transition from school to adult life. In fact, when we began planning this audio conference, we wanted to use the word "experts" in the title instead of students. But I was afraid that if you saw that you would think, "Oh, business as usual. Adults talking about what students ought to do." But today isn't about business as usual. We have some scholars from DO-IT, a project located at the University of Washington. *They are our experts.*

We spend a lot of time thinking about transition, identifying best practices, funding them, implementing them, and so on. But our experts today are the consumers who ultimately hold us accountable.

At this time it is my pleasure to introduce Dr. Sheryl Burgstahler, DO-IT's director, who will, in turn, introduce our panel of experts. Sheryl?

Sheryl Burgstahler: Thanks for inviting us here. I am the director of DO-IT. DO-IT stands for Disabilities, Opportunities, Internetworking and Technology. DO-IT began in 1992, and we were first funded by the National Science Foundation to increase the successful participation of people with disabilities in science, mathematics, engineering, and technology careers. We use technology as an empowering tool and have a focus on transition from high school to college and employment. We also include work-based learning experiences along the way. Now we receive funding from the State of Washington, the U.S. Department of Education, and many other sources.

Today we have five participants who are DO-IT Scholars, one of the DO-IT programs funded by the National Science Foundation and the State of Washington. In addition to other activities, they have been involved in several summer programs where we focus on college and career transition. As we speak, they are participating as interns in a

work-based learning opportunity that we have here on campus, helping with program operations and mentoring our younger Scholars. We have high school students living in the dorms learning about college life and technology. Today, you are going to hear from students who have succeeded in the program and are now working for us as interns. They may sound a little tired because we are giving them lots of work to do.

These students are the experts. They will tell you about how they were included or not included in their transition experiences from high school to college to work. They will share with us what helped *and* what did not help. Our first expert is David.

David Benedict: Hi, my name is David Benedict. I am a sophomore at Eastern Washington University. My high school memory of my IP chairman was that I had a meeting with him once a semester. It wasn't much else. As far as the accommodation I received, I did most of the work on my own. I talked to my teachers beforehand about my disabilities and asked for the accommodations I needed. When I got to college it was quite a bit different. Every quarter I get a letter from my DSS office that I handed out to my professor about my disability and they have helped a lot with preparing my professors and getting accommodations from my professors for my disabilities.

Trent Marshall: I am Trent Marshall. I had two really helpful teachers in high school that were IEP teachers, and they were trying to drive me into the IEP meetings every chance they got. I guess I was just sitting back listening to what my mom, my dad, and the teachers were talking about. They would ask me a question to get me involved. And I thought this was very good because they just would

not let me sit back and let them take over, or take over my responsibilities. I needed to learn how to be more independent. The teachers were friendly, but they could also push me just the right amount at the times I needed it.

Mike Neil: I am from Denver, Colorado, and just graduated from Denver University High School. I am eighteen.

For me, the successful transition to school and work came primarily from my parents. I think that they fostered a sense of expectation that I would go on to college. It was never really that much of a question. I had so many people going on to college around me that it was never something that I was worried that I could not do. I think part of it is also that, even though some people with disabilities have family that do encourage them to go to college, they fear that they cannot control their own environment. And one of the reasons I am lucky in that respect is that I got hooked into technology very early. For example, I have been working up the ladder, and I just got myself an environmental control system that is voice-activated. And that has been really a helpful item. I got my first computer from my original IEP and that is probably the most successful thing that series of meetings produced. I have not had an IEP in ten years.

So, on that front, it was not as helpful as it could have been, nor was my school, since our high school had a counselor that was simply a guidance counselor. And she was young and new and simply inexperienced, not just toward me, but towards the entire school, which was really small. We had a lot of interaction with the teachers, so she did not need to do much anyway.

But from the parental standpoint, it really stands out. I was taught that someone would have

to prove to me that I could not be doing something for me to believe it. It's rarely been shown that I can't do something. So, from a positive mental attitude standpoint, I think you have to go in and face life with an attitude that you can do everything until you are shown otherwise. And that I think comes from parents, friends, and from just being a self-actualized person. So I think that is my main advice and my main lesson.

Amanda Johnson: Hello. My name is Amanda Johnson. I am eighteen. I just graduated from high school and am in a wheelchair. Throughout my education, I have had an IEP. I have had an IEP ever since I began school in kindergarten. And mainly, in high school, it has been altered a bit. My IEP team would meet every year, but quite often the things written into the plan would not be accomplished, so it would have to be written down the next year also. And when my transition from high school to college arrived, my parents helped me make the change. The transition from high school to college went smoothly. Right now I'm in college. I mainly have no concerns about my collegiate experience.

Laura Walizer: Hello, I am Laura Walizer. I am eighteen, and I will be a freshman at Hendricks College in the fall. In general, my high school years were a little bit hard. It was my mom, me, and my guidance counselor versus the school administration. Every year we would look at the schedule and see what would need to be changed because I have a little bit of a mobility impairment. We would present the assistant principals with changes we were going to need them to make. And they were always unapproachable and would wait until the end and hold out as long as possible before actually making the accommodations. That guidance

counselor was the one who worked with my mom and me the most. She would be on our side. She would always be along side us, and she had the power and connections to get some of the things done that we needed done. Whenever my mom and I were frustrated, she was always there to talk to.

And I think that the way high school went helped prepare me for college. If I ever run into a situation where it is tough to get accommodations, I will know how to handle it and won't just back down. I think that will be very, very valuable as I go on in life.

Sheryl Burgstahler: You have heard the bad news and the good news. I've been taking notes to summarize what our panelists have had to say.

First, the needs of each student were different, and the process of transition is an ongoing process, one that needs to be reevaluated at various steps along the way. We've heard that it is important to involve students at every one of those steps. It is helpful to the transition process to be conscious of transferring parental responsibilities to the students as they move from high school to college, careers, and adult life.

Promoting self advocacy is very important. It is important to have a plan and, more importantly, to follow through with the plan.

And, finally, don't make assumptions about what the students can or can't do. Remember at all times that they are the experts or at least they are becoming the experts about their interests, about where they are going in this life, and about their disabilities.

Are there any questions?

Janis Chadsey: Yeah, this is Janis Chadsey with the National Transition Alliance. Trent, I had a question for you. You talked about how your

teachers were so helpful during your IEP meeting and that they would not let you just sit there, but they would want to make sure that you were involved and participating. Do you think there are things that we could do with students that would better prepare them before they even entered into the IEP meeting so they would feel more comfortable about participating? It is one thing while you are in the meeting, for questions to be directed to you, but I am wondering if there would be some things that we could do prior to the meeting that might be helpful before the meeting even took place. Would it be helpful to talk about what goes on in meetings, do some role playing, or help students to ask questions so they feel comfortable with it? I don't know about you, but maybe, for some students, it is a little bit scary to have to go into a meeting with a whole bunch of adults who are supposedly experts. Is there some way of helping students to feel more comfortable?

Trent Marshall: You can try to improve their public speaking so that they are more confident. Maybe that would be helpful. To me, that has never been a problem.

Janis Chadsey: I see. Not for you, anyway. So, no one had to really do anything to help you practice?

Trent Marshall: No, but I am thinking that could possibly work. I don't know.

Janis Chadsey: Thank you. Do any of the other students on the line have an idea about that or if they ever worked with anybody prior to these meetings?

David Benedict: I have some opinions on IEP. I saw my IEP person once a year and, after that, I did not see him until the next year when we did the IEP again. So, one of the other things that you

might look into is having monthly meetings with the IEP persons. Or you could try to get to the teachers more involved in this if the student is mainstreamed.

Also, I notice that they always managed to schedule the meetings during times that we had tests or projects that we would do in class, so you might also want to double check with the teacher to make sure that there is not something really important going on in the class that day.

Janis Chadsey: Yes. That is a good idea.

I have another question. Laura, I was interested in your comments. One of the things I am very interested in studying here at the University is people's social skills and their social behavior. I thought it was interesting when you said that one of the things that you had learned was to persevere and to not give up or back down when obstacles are in your way when trying to get accommodations and other things accomplished. But there are different ways of doing that. You can persevere and do it in such a way that you are kind of aggressive or annoying, or you can persevere and do it in a way that is still pleasant. You seemed to have learned a lot from your guidance counselor. What type of approach did she take? Or what is the approach that you are going to take when you go to college?

Laura Walizer: We would be polite about it, but we would tell them what we needed and wait a few days. If it did not look like that was going to be effective, we would say we still needed it to be done. Then we would be quiet about it and give them a chance to do what they needed to do.

Janis Chadsey: So the main thing is just not to give up.

Laura Walizer: Yes.

David Benedict: What I remember from my last IEP almost ten years ago is that you certainly start out being polite. But, in my case, the principal was so unmoved that we had to escalate sometimes, and the only way my mom and I finally got it to work was to bring in the local legal center for disabilities. That worked instantly. It is an aggressive move, but I think it proves necessary sometimes to have the law really in there with you.

Janis Chadsey: Yeah, I think just in personal examples that I have been associated with that often that has been what it has taken in order for things to occur, which is really too bad.

David Benedict: Yeah, but I think people need to get used to bringing in authority and not being stopped by doing that if that is what it's going to take to get their needs met.

Janis Chadsey: Sure. I think it is ridiculous that we have to resort to that. But you are right. Oftentimes that is the only way that things will get done.

Amanda Johnson: Hello. This is Amanda Johnson again. I went from seventh grade to high school with my principal. In eighth grade, my parents and I had a meeting with my IEP team to discuss which high school I would attend. My home high school was not accessible to wheelchairs. My parents met with the school board since they had the final say about whether an elevator was installed. They said no, and my parents and I filed a complaint with the Montana Human Rights Commission. Last August, they ruled in favor and the school district appealed it to the District Court. The school did install the elevator last November.

So, I found that you should try to be nice at first, but when that does not work, get legal help.

Janis Chadsey: All right.

Laura Walizer: Hi. This is Laura again. There might actually be an idea that you might want to try even before you go to a legal center. We went to our superintendent of schools. We just went over the heads of the school administration when it became necessary and that was simply magical. Michael's solution was the one that got things done a lot faster. I do remember that.

Janis Chadsey: Well, now, that is an interesting idea. I had not thought about that.

Laura Walizer: One thing we never did, but, in retrospect, we could have tried, was to have the superintendent of schools attend the IEP meeting if there was really a problem with something at school. You have them just sitting there silently watching, ready to step in if there is a problem. That is one thing to do.

Amanda Johnson: In my experience, the superintendent was involved from eighth grade on and the special ed. coordinator was also involved. That way, there were people of authority attending my IEP meetings. However, it did not have that much of an effect since the board had the final control of the elevator issue.

Sheryl Burgstahler: I would like to make one comment about including the students in their IEP process. One thing that we have found helpful in the DO-IT project is to encourage students to invite DO-IT staff to their IEP meetings for Scholars that are in Washington State. Most of the people here today are outside of our state. But, those who are local can invite us to their IEP meetings. It is really an interesting dynamic when we arrive. When one of our staff members arrives at an IEP meeting for one of our students, the other people in the group are usually very suspicious. They think we are lawyers or something.

But we just come and share and support the student. And I think it has been a very positive experience, and it sends a very strong message that the student with the disability should feel welcome to invite people to be in the meeting. And that is probably the best outcome of all in that process. But I think that one thing that the rest of you could do if you are involved in that process is sit down with the student and ask them who they would like to have in that meeting and then respect that wish.

Any more questions?

Janis Chadsey: I have one more question. As I recall, many of you have just graduated and are on your way to college next year. You talked a lot about the kinds of things that had happened in high school. But I was wondering how you were feeling about going to college, and whether or not there were people in place at the college who had been identified to provide you with support or to help you if you need any services in any way.

Sheryl Burgstahler: Two of our students have been in college, and then three of them are going on to college this fall. Several of them do have comments about this. We will start with David.

David Benedict: I found the DSS office at Eastern really helpful for getting accommodations at the school. They were right there, located at the school. If I had any problems, I could simply walk into the DSS office, and normally the counselor was not there, but I left a post-it on her desk. They were also a lot more helpful about doing accommodations. As I mentioned before, the letters for my professors told them what my disability was and what accommodations I was requesting. And I never had any problems in getting accommodations from the DSS office. I talked to some professors. They also were right there when I was getting books

on tapes. One of my books was so new that they did not have it in the main library, so they taped it on site for me and that was nice. And also they kept calling and checking up on me and making sure that everything in class is all right.

Laura Walizer: I would like to say, because I will be a freshman this fall, we have been working with several people at Hendricks College, and it is such a wonderful change from my experience at high school. They literally said that they were ready and willing to do anything that is necessary to work with whatever accommodations I need: to make sure that the walks are accessible and that doors are ramped or have automatic openers.

This is such a wonderful attitude, and I think part of the thing that helps is that we choose our college. We crossed off the list of our choices any colleges that have a poor attitude toward accommodations. I think that eventually we'll have a lot less pressure than in high school. It should be nice.

David Benedict: I am going to South Seattle Community College and I found that if they won't do the services of a full university, I have been hopeful that I will get extra time for tests or assignments that we are doing in class. And sometimes they are not there, but I will get back to them later and they just are more than willing to talk to whoever you need to in order to get it done.

Mike Neil: Hi. This is Mike Neil. In one sense, I think I am in – on the face of it — a worse position in terms of my college. I am going to Colorado College in the fall, and it does not really have a DSS office. However, I think that it more than makes up for it in the willingness of the professors and the physical plant to immediately and effectively remove barriers. And it really helps also that class sizes are never going to be over

twenty-five. So, a very personal relationship with the teacher can be developed. And in that sense you can really get a lot changed much more quickly than in a large school.

Amanda Johnson: I am attending the University of Great Falls in Montana and it is a very small private college. When I first applied there, I talked to one of their admission counselors, and he gave me a tour of the campus. And then later on, I also was seen by an occupational therapist, and he wrote them a letter about accommodations that have to be made or that would be helpful, and they have made nearly all of them, except for the ones that require an elevator or something. And one of my classes that I am taking is on the second floor, and they have already made arrangements to move it down to the first floor for the time that I will be taking it.

Sheryl Burgstahler: Do we have anymore questions?

Janis Chadsey: No. I am really struck by how accommodating all of the colleges have been for all of you in contrast to your experiences in high school. I was also struck, Laura, by what you had said regarding getting to choose the college that you are interested in. And, of course, you are going to pick the one where they seem to be willing and supportive and helpful. In contrast, with high school, especially if you are in a small town, you don't really get much choice. It is really something for me to think about.

Sheryl Burgstahler: One thing that we are very much involved with in the DO-IT program in working with young people as they transition to college is helping them make good choices.

The American with Disabilities Act requires that the campuses be accessible, but certainly some

are more accommodating than others.

Janis Chadsey: Absolutely.

Sheryl Burgstahler: And so we encourage them to choose their battles. Some students are ready to go in and face a war situation and actually enjoy helping a campus become more accessible for students with disabilities; others do not. And so I think it is very important that the student get good guidance from adults in their life so that they know that each campus is different. They need to find one that matches their academic interests and their career interests, but also is comfortable for them.

Janis Chadsey: Right.

Dan Linneman: How many DO-IT Scholars have played a leadership role at the colleges or other schools, like being on advisory boards or councils, to help the colleges formulate policy regarding how they treat individuals with disabilities?

Sheryl Burgstahler: We don't have a firm number for you, but students in the DO-IT program have done many of these things. There have been over one hundred and fifty Scholars to date. We do have some other programs, too. But in this particular program, the students, once they have been in three summer programs and move on to colleges, are encouraged to continue participating in the program as DO-IT Ambassadors. And they do a couple of things: first, they are to take some leadership positions in their community, in their churches, and in their colleges to make a difference for other people with disabilities. Secondly, they mentor the younger Scholars in our program. The students that you have met today are now sharing their expertise with the younger Scholars, in person this week and throughout the year via electronic mail. We have an electronic discussion list where we encourage them to help the younger kids who are

still in high school benefit from what they have learned in the process of transitioning to adulthood.

Dan Linneman: That sounds wonderful. Are you keeping track of the Ambassadors and others once they leave DO-IT?

Sheryl Burgstahler: Yes, we do. We have contact with our students year-round, but we even have what we call our “October One Report” to document what everyone is doing on October 1 of each year. We know where each student is and how they are doing, and collect anecdotal information about their achievements and activities, including the work-based learning experiences that they have had along the way.

Dan Linneman: Wonderful. I am thinking back to when I was at the end of my high school career and getting ready to go to college and I think there was an assumption that my parents had that I would wind up in college. I don't know if I owned that. There wasn't too much planning there on my part. When I think back on it, it's almost like I might have been derailed fairly easily just by all the distractions of adolescence.

You sound like you each had to fight the system the whole way. What I am curious about is, how do you maintain the energy to do that? In my work as an advocate, I've talked with families a lot and some of them get kind of depressed and angry about “the system.” What kind of resources, personal or other, kept you alive and fighting?

Sheryl Burgstahler: We have a few who are going to make comments on that, and I'll just say, speaking for the whole DO-IT group, I often hear comments about the importance of accepting the fact that life is not fair. This is an ongoing process and having a sense of humor helps.

David Benedict: One of our Scholars from a

few years ago had a quote that said, “Life is sticky, but it certainly is one heck of a ride.” I agree with that.

One of the reasons that I keep citing it is that, for all intents and purposes, my teacher gave up on trying to teach me anything. So, what that says to me is that it gave me a purpose. I was going to succeed, for nothing else than just to prove her wrong. And, after awhile, it got to the point where I stopped trying to prove her wrong and started to prove to myself that I could do it no matter what the world or anybody else wanted to throw at me. I'll eventually graduate college and go on to get a Ph.D.

Trent Marshall: Personally, I think that it's not fair to assume anything about a person with a disability. Having a disability doesn't mean they can't do stuff like everyone else. I've known some people that can do some amazing things and so you have to never give up. It's just one of the lessons that you have to learn.

Mike Neil: I've always gone by the personal philosophy that “To be is to do.” And so if you are not doing something and are not actively participating in your own life, you are simply not being. You are not part of your own life, and that's probably the worse thing that can happen to you. So that's what keeps me going. To do otherwise would be to deny one's own existence. That's my theory on the matter.

Dan Linneman: Michael, what are you going to major in when you go to college?

Mike Neil: Actually I'm looking at history and philosophy.

Dan Linneman: I was getting that picture.

Amanda Johnson: I am happy to say that my family helped me get to where I am now. They

stood behind me. I also have a core of friends who helped me cope through the difficult times.

Laura Walizer: I was raised to be optimistic and pretty self-confident, which I think is extremely important for a child with a disability. It's also an important concept for teachers and counselors to promote because they have very much to do with the raising of children. For a teacher or a counselor to encourage a kid to grow up to be optimistic and self-confident is a great help to them when they run into trials, a teacher who is not that way, or an uncooperative administration, or when they just have a hard life, like you sometimes do.

Janis Chadsey: You all sound very mature in your responses. I'm fifty and I don't really have many friends who actually sound as mature as you. That's terrific.

Mike, you told us what you were going to major in and so I'm curious about what each of you want to study when you go to college or what you are currently studying right now.

Laura Walizer: I am going to major either in biology or physics.

Amanda Johnson: I plan to major in communication. Here is David.

David Benedict: I'm planning on majoring in microbiology at Eastern Washington University.

Trent Marshall: I'm not sure what my major is going to be, but I know it's going to be something in the computer field. I'm not sure exactly what. Here is Sheryl.

Sheryl Burgstahler: I haven't decided what I'm going to be when I grow up. I'm still working on it, but I think there are a lot of good ideas around this table I might pick up on.

David Benedict: Absolutely.

Dan Linneman: Okay. Does anyone have any

more questions or comments from our experts?

Tom Grayson: I have one question regarding assistive technology. We have been hearing in the past year or so that assistive technology is very important and has made great strides in helping a variety of individuals with disabilities. I am wondering if any of our experts have any insight into that or any personal experience regarding assistive technology.

Sheryl Burgstahler: Michael uses the most assistive technology in this particular group, so we will let him respond to that question.

Mike Neil: I currently am using both an environmental control system that controls about six appliances, and I also have voice recognition software so I can type as I speak. And I have a wheelchair in addition. All if those are terribly invaluable. I've been training with the first two since I just got them very recently. I can already see that they are going to allow me to do a lot more things a lot easier.

Janis Chadsey: What's the name of your voice recognition software?

Mike Neil: Dragon Naturally Speaking.

Janis Chadsey: Thanks.

Dan Linneman: Sheryl, do you have any concluding comments?

Sheryl Burgstahler: I'm never at a loss for words.

Since we have been talking about technology, I'll just mention that in the DO-IT program, at every step of the way, we use technology as an empowering tool for people with disabilities. And, we look for three things—

- 1) We want to maximize our students' independence in academics and careers;
- 2) We want to maximize their productivity so they

can compete with their peers; and

- 3) We want to maximize their participation so they are not left out of activities both in school and in careers.

As you can tell from this panel, we also have a strong focus on transition from high school to college, from high school to careers, and from undergraduate to graduate school. We are always looking for opportunities to help young people make those transitions, make them successfully, and keep their sights high.

One of the programs that we have that helps empower students with disabilities is the DO-IT Scholars program. You were introduced to that program a little bit today. But we also have two other programs where we work with young people. One is our DO-IT Campers program. In this program, we go to summer camps for young people with disabilities that are sponsored by other organizations such as Easter Seals and the Muscular Dystrophy Association. In those camps, we implement some of the transition exercises and Internet exercises that we do in the DO-IT Scholars program.

We also have a very active electronic "virtual" community of kids that are not necessarily in the Scholars program. We call this the DO-IT Pals program. So, if any of you know of young people who have disabilities and can gain access to the Internet, we would like to invite them to join our DO-IT Pals community where they can communicate with not only these bright Scholars but also a group of about one hundred mentors. Our mentors are adults who are in college or are practicing careers, with disabilities themselves. If you would like further information, please contact us at doit@u.washington.edu. We would love to hear

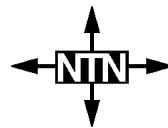
from you. We have a lot of material we would be happy to share.

Dan Linneman: Okay. I want to say a very personal thank you to David, Trent, Michael, Amanda, and Laura, and to you, Sheryl, for inviting them to talk with us today.

Janis Chadsey: Thank you.

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