

August 7, 2001

## Transcript of Conference Call Presentation

# Parent Involvement in Postsecondary Education

presented by:

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**Ms. Schoeller:** I want to welcome everyone to the National Center on Secondary Education and Transition (NCSET) August teleconference. My name is Kris Schoeller, and I am the transition technical assistance staff for the Parent and Youth TA network. I am also the parent of a young man who has mental retardation and a seizure disorder who was able to attend a full year of technical college under what we called a “selective objective” as part of his transition program.

Your presenters today will be Teresa Whelley from the University of Hawaii. Teresa is a research coordinator for the National Center for the Study of Postsecondary Educational Supports and has been conducting numerous focus groups with youth and parents and support staff regarding parent involvement in postsecondary education.

Along with Teresa, you will hear from Sheryl Burgstahler, who is the Director of DO-IT, which is out of the University of Washington. DO-IT stands for Disabilities, Opportunities, Internetworking, and Technology. It serves to increase the participation of individuals with disabilities in challenging academic programs and careers. Sheryl and Teresa will share some of their individual work and also some of their collaborative work.

I would also like to let people know that Julia Washenberger, who is also on our staff, is on this call. She is a young woman who works at NCSET and has spina bifida and a learning disability and she just completed her four-year degree. So, I thought it would nice for people to know that they can ask Julia any questions in terms of her parent involvement with her success story.

But before Sheryl and Teresa talk with you, I would just like to take a minute to share some additional information that we thought might be help-

ful regarding parent involvement. Deborah Leuchovius, from PACER Center, is also on the call today. Deborah is a parent but she’s also the coordinator of the TATRA Project, which provides technical assistance to many of the PTIs around the country regarding transition for the Rehab Act. PACER is also the lead of the Parent Training and Information centers in the country, and a partner in NCSET.

In June we conducted a capacity building institute. During that three-day conference, we held three separate discussion groups to address the issue of parent involvement in postsecondary education. All of the participants were parents, PTI directors, or additional staff from PTIs who work with families. All but two of the participants were either siblings or parents of persons with disabilities.

**Ms. Leuchovius:** And people with disabilities themselves.

**Ms. Schoeller:** And people with disabilities themselves. Right. Thanks, Deborah. We have some of the key issues from those discussion groups to share and hope to do something more with this information down the line. Some of the key issues include, first of all, that the parents in the three groups really had a difficult time thinking about their role in postsecondary education. That first question asked about their role was really a challenge for them because of their previous role as advocates for their child within the school system. This didn’t easily translate into involvement after school and into the college or postsecondary setting. In fact, many felt that it was not their role to be an advocate as much as it was their role to be a mentor during those years when their kids phase out of high school.

They did see themselves as providing the behind-the-scenes assistance like financial assistance, paperwork assistance, medical needs, and help with

career development decisions. They also felt that it was their role to have discussions with their sons or daughters about their disability and to support them and help them to identify what kinds of things they would need when they got to a postsecondary institution and then how to communicate and disclose that information so they could actually get the accommodations.

The question was raised that maybe parent involvement or advocacy at the postsecondary level seemed a little contradictory to self-determination and that we, as parents, may need education to learn how to allow our kids to fail so they could learn how to do some risk taking and then some real determination about what they wanted to do with their life. There were several stories from parents who let their kids fail in their first attempt in postsecondary and that was an important step in determining what they really wanted to do with their life.

A couple of other points, participants did say there seemed to be very little coordination between high school and postsecondary and that accommodations or modifications were not automatic at the postsecondary level. Regarding who provides the support in their mind and their perception of who is currently supplying that support, they didn't feel there was any consistency. These key points were made from, I think, representatives of multiple states. How many states, Deborah?

**Ms. Leuchovius:** There were 20 states.

**Ms. Schoeller:** And some of them said they were getting some support from the Office of Student Services, from VR, some from special education transition staff, and some didn't know or they weren't receiving any support in making that transition to postsecondary and getting accommodations at the postsecondary level.

They also felt that the accommodations that were looked at in high school were so focused on the curriculum and individual assignments that it didn't consider the whole career development picture for families or for the person with the disability.

**Ms. Leuchovius:** I think that was not—I mean, exclusively high school transition, but a kind of disability support that they get while—

**Ms. Schoeller:** At the postsecondary level too. Okay. They did see value in mentors. It was mentioned several times that there was great value

in providing a peer or mentor or person who had made that transition to postsecondary as a resource for high school students and their families.

NCSET hopes to continue to address this topic with PACER, the University of Hawaii, and the DO-IT Project, putting together some publications or presentations on this topic in the near future.

But for now I would like to welcome Teresa and Sheryl, who are on. We will have time at the end for questions and comments.

**Dr. Burgstahler:** Okay. I direct the DO-IT Project at the University of Washington. I am going to get started here and then Teresa is going to pick up the ball. We are going to focus the presentation and discussion today on how we can develop self-determination skills within our children. We don't believe that providing parent involvement is contradictory to self-determination skills because we look at self-determination not as an end product but as a continuum and a process, something that we are working toward. Even us parents, we are becoming more and more self-determined, hopefully, as we learn more things in our life.

So, one thing we'll start off with is one definition of self-determination. It's rather short and a large group developed it, so it includes a lot of the concepts that you would see in any definition of self-determination.

*Self-determination is a combination of skills, knowledge, and beliefs that enable a person to engage in bold, directed, self-regulated, and autonomous behavior. An understanding of one's strengths and limitations, together with a belief in one's self as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults.*

Now, one thing I personally like about this particular definition is that it focuses on three areas: beliefs, knowledge, and skills. We or our children can be moving toward a more self-determined life as we develop those three areas. Just looking now at them individually for a moment:

1. If we take a look at beliefs. In order for our children to be self-determined, they should be able to say things like—and believe it of course—I am

competent, I can succeed, I can speak for myself. Many of these statements would relate to the broad set of literature on internal locus of control—that they have a sense that they have some control over the things that happen to them and the results. They realize that some things are out of their control, including perhaps the disability that they have, but they can take charge and they are competent and they can manage certain activities in their lives and they can speak for themselves. So, the beliefs part I think is critical, and something that we can all work on with young people, disabled or not, to help them develop that sense of self-worth and competence.

2. The second one is knowledge. One of the big issues we work on with students in our DO-IT program, which I will talk to you a little bit later about, is knowledge about their disability, how it affects their learning and work environments, how it affects them in those environments, and what accommodations are most appropriate for this person. We have a summer camp going on right now at the University of Washington. We have teenagers and we have opportunities where they have to describe their disability to a faculty member and describe how it affects their learning in a class that they might be taking from that faculty member, and what accommodations might be needed in order for them to be successful. We emphasize the roles of the disabled student services office, the faculty member, and the student in all this.

This is a very difficult thing for these students to learn. In my experience, a lot of high school students don't have that experience, that practice that we are giving this particular group of kids before they get to college. We expect them to be self-advocates. So that's knowledge. We have beliefs, we have knowledge, and the last one is skills.

3. I have to say when I first thought of self-determination, I only thought of the skill part, be it learning how to be a self-advocate, learning how to speak up for yourself, learning to be a good presenter, learning things in school, developing skills that will serve you well when you are in college and ultimately in careers, job skills and academic skills such as study skills. So that one

I actually early on was more familiar with—the list of skills that we have to have to lead self-determined lives. But I am thinking more and more how important it is to have the beliefs and the knowledge as well. All three need to be covered as we are working with students with disabilities.

So, that's going to get us started here. Now Teresa is going to pick up the ball and talk about theory and studies, etc. Right, Teresa?

**Dr. Whelley:** That's what I am doing. I've had the opportunity over the last six months to talk to four groups of people in Oahu, the most populated island of Hawaii, then the big island, which is the least populated but we have the university there and then New England and New Hampshire and in Massachusetts. The study we conducted was in Hawaii in two groups here. Let me give you a little design. The point was that we saw from a previous study at the National Center for the Study of Postsecondary Educational Supports that there was a conflict between what students reported to us in national focus groups—that they felt they had mixed feelings about families. They felt that families were helpful and important and then some other students also strongly felt that they were overprotective and not helpful. So we wanted to go further and we developed another study. In this one we wanted to contrast opinions of families as to students as to disability support coordinators, and hence we have those groups.

So, I am going to report findings of that, and I want to talk a little bit about theory and what should happen, typical development during the launching period. The period of teenage into adult life for a family is called the launching period. What should happen and what does happen in most families one way or another is that young people grow up and they go off into the world. Families' roles are always to nurture and protect and socialize their members. So this last function of raising young people is to launch them into the world.

So, this nurture, protect, and social life comes to a combination there. There are some tasks that need to be done during the launching period. One of them is that the young people need to be financially independent of their families, they need to have a social life independent of their families, and they need to make some decisions independently of their families.

So, with that as the background, we went and started talking to families and students and we have analyzed the first set of findings. I am going to talk about some findings for a little bit.

One of the findings was that families are advocates in postsecondary education. All our groups were students in postsecondary education and their families. I have some quotes, some reports. One parent reported that she was the person who went and got the disability paperwork to prove that her daughter had a disability. The parent actually did the leg work—went back into postsecondary education at the Department of Education, got the paperwork, and got it to the college. Another person reported that she was a parent. This was a mom that actually went and found the disability support office for her daughter, so that was a role she took. She found the service and coordinated it.

Another one went even further, and I guess this is advocacy. The quote is, “I studied with her, I encouraged her, and I talked to the counselor to explain her issues.” I think that’s more direct advocacy with her daughter and maybe outside of her daughter. But I see that as something that, you know, all families would do, if you had a child at home.

I forgot to say that Hawaii is more of a traditional environment in that it is expensive to live here. It’s typical for students to stay and live at home through their college years—not all students do but a lot, most do. It’s also typical for young people to stay with their families, maybe until their first child is born. Housing is expensive. It’s expensive to live. It’s also more of a traditional society and the family has a big role in making decisions in your life. So it’s a familiar mediating structure of the family. So that’s typical for here.

Our second finding was family balance, protection, self-determination, and empowerment. So there is a mediating group that helps to launch the young person. Here I have some more quotes. “A professor said the student was not able. The father went to the disability support office with his daughter.” This story works out very nice. “The student reported to me that she lied to her parent’s advocacy on her behalf. Then later she learned to collaborate with her parents and then she developed and refined her own self-advocacy skills.” So actually for her it was during this postsecondary education period that she became

her own self-advocate, and she did it with the mentorship and role modeling of her family, and that was good to see, and she is a fine young lady.

Another quote, “My mother encouraged me to keep pressing on. Any time anything horrible happens to me, I can always go back to my mother’s house.” Again this is the balancing act. There is protection. There’s that safe haven that young woman can go to, but she’s being empowered by her family to move out there and do more.

The last finding I have I want to report is about families’ encouragement versus their overprotection. There was quite a bit of discussion among the students that they felt discouragement from their families, which was surprising to me, that the families really were protecting them from being discriminated against or being let down, being in situations where they weren’t able. So, one student talked about that she actually had to go ahead and prove herself above her parents’ low expectations, and then her family was very, very supportive of her. But initially it was difficult. She had to go beyond what they thought of her.

The students reported that they wanted and appreciated support and this support was often instrumental—the financial, the reading, the drives, the transportation, and basic necessities. I have some nice quotes to wrap this up.

Here’s one: “We need food, you know, somewhere to live, and encouragement. I think positive sometimes. You know, to instill positively in me, more and then support and guidance.”

Another student: “Because of my determination and they believed in me, they said go for it. They watched me physically struggle for the last two-and-a-half years doing things that I am not supposed to be doing and not grumbling about it, but these are things that I wanted to do.”

Another two: “I was born with a disability and my family didn’t see me as someone with a disability, they saw me as a family member.”

Lastly: “So my family helps me but not as much as me. I am my biggest supporter.” I think that those quotes describe some of the evolution that happens as a young person still needs the support, and the *ohana* as we call it in Hawaii, the homeness of having a family, but they use that to go out in the world and determine their own lives.



So, Sheryl, those are my stories so far.

**Dr. Burgstahler:** Those are some pretty good stories there. Thanks. I think it's pretty clear from the feedback that you have that there is no one-size-fits-all here. Apparently the role the family should play with a young person with a disability as they move on to their studies or employment or postsecondary setting depends a lot on the particular child we are talking about and the family situation; the goals, the abilities and disabilities of that child; and their position on the road to success. We may say here at the university, for instance, in our Student Services Office, that we prefer to work with the student and hope by that point that they will have the self-advocacy skills that they need for education, etc., etc. But that's not the real world in our families with students with or without disabilities. They all progress at different rates. They all have different needs and, hopefully, we as parents have a good idea of what is best for our child and could get the resources that they need. So, I think it's real important to look at the individual situation here.

What I am going to do next is just talk about some issues that we have found reported by parents either in the literature or focus groups or in programs like the DO-IT program, and kind of throw these issues out, and then I am going to give you an example of some of the things we do in the DO-IT program, which includes our summer session that is in session right now. Then we will have a nice discussion hopefully after that.

We have more questions than answers, but let's start with some of the issues. One issue that has been mentioned—and I will underline it again because it is such an important issue to think about—is that the lives and the management issues and the services and accommodations provided in the pre-college setting and the postsecondary setting, whether it's a college or a technical school, or an employment setting, are different. It's very difficult for families to negotiate services, etc., for their child. I am on a discussion list with our disabled student services coordinators in all of the Washington state schools, and just this morning—and this is not unusual—there was a message that a parent had called and he was quite angry because his child was not getting the services that he expected. And he documented the—I think quoted the IDEA and

also mentioned the many support services that he had in high school. Anyway, part of the discussion was what role the parents play in this and, of course, the child needs to give permission before the parent can get specifically involved with a disabled student services office. Most of the schools in our state that would require a letter signed by the student.

But also the confusion on his part about the legal climate in a postsecondary setting compared to a high school setting. Anyway, it was a lively discussion that could take the whole hour here. But the whole idea is that the laws that come into play in these various settings and the services are different. I know from a postsecondary view it's rather shocking to some students with disabilities when they come to places like the University of Washington and find out they are not going to get the same support services that they received when they were in high school. So, part of what we do in the DO-IT program and others like ours is help the young person learn what the differences are between getting support in a high school setting and in college and employment or postsecondary settings.

Another big issue is this whole thing we have been talking about as far as advocacy. Some people feel very strongly that the parents are their advocates in high school, and the moment that the graduation diploma is present, then they need to be their own self-advocate. I think it's much more of a continuum and a gradual process. I think for some kids that would be reasonable when they get to the college setting. But I find a lot of situations where it's not reasonable that the parent withdraw that much from their child. So it's a challenge, of course, to figure out exactly what role that parent can play.

During our program yesterday, one of the parents showed up. Her first child is an intern in our program and he is now going on to college. She was sharing with him a short letter that he needed to sign so that she could talk with the disabled student services office. He is a very competent young man, and he went to the disabled student services office and is having kind of a difficult time communicating about his learning disability and how it might affect him in the classroom. He actually asked his mom if she would come but, of course, she couldn't get involved unless he gave her permission. So the mom helped him write the letter and

then he signed it yesterday. Then they were going to meet in an office together. After talking to him, I thought this is a wonderful thing to have happened because he is one of these kids I think, particularly because his disability is invisible, that he would have just said, "Well, I don't really know. I guess I will just try to do it without any accommodations because I can't really, you know, work through this." I have a feeling, knowing this family fairly well, that she can get him on the right foot and start to get those accommodations he needs but also work with him so he will be able to do this the next time, the next quarter. So, in one sense she said she was a little disappointed because she thought he could do this, but then I really appreciated the fact that she jumped in and didn't take over the process—I mean he made the choice to include her in the process—but was right there to help but still looking at this as a process towards self-determined behavior, not as something she wanted to continue to do forever.

Another issue that comes up quite often is lack of successful role models with disabilities. I see two types of role models that are important in this area. One, the older adult who has a disability and is successful in employment or perhaps in college, but also the peer mentor who is perhaps a little bit older, maybe a year or two older, perhaps even the same age, who has a challenge that they are facing and can share their successful experiences and some of their unsuccessful experiences in negotiating the system. It's not easy to find role models and mentors for students with disabilities. Much of what we do in DO-IT involves using the Internet to connect mentors with protégés and that works successfully. We also have some on-site programs, as I mentioned in our dorm right now, where we have young people, let's say after their sophomore year in high school, who have disabilities, living in the dorm with adult supervision, of course, but also with students who have disabilities who are just graduating from college and even a few who are in college. I have really seen the power of that role modeling and mentoring when the student is just a few steps ahead. I think that that really helps young people toward self-determination when they see someone who is a year or two older. It's too much of a leap in that area to be looking at someone who is fully formed and off in their career although that

type of role modeling is important as well.

Another issue: Lack of access and practice with empowering technology, including computers. Sometimes students come to the university having used adaptive technology in computers but to such a minimal degree that they are really not proficient. As you know, when they come to the university or a two-year college or a technical school, they are going to have a lot more work to do in an independent way. They really need to be experts on that technology before they enter that step.

Students need opportunities to make decisions, to request accommodations, to self-advocate, to make appointments, to experience the consequences of their decisions, to fail once in awhile. We encourage our students to get more involved in their IEPs. One of the things that we invite them to do—and they often take us up on this—is to invite one of us DO-IT staff members to be on their IEP team. I'm less concerned about us being on their team than I am about them making that decision. It's really difficult for these kids usually to even figure out who they would ask in order to have permission to put this person on their team. So they need to be encouraged to do that.

We are not troublemakers, by the way, we are just very supportive. But when I see these kids step forward and find out who to talk to and just say, "I've invited Sheryl to be on my IEP team because she's associated with the DO-IT program." Just taking that action is empowering. We have to keep looking for things like that.

One thing I like about our DO-IT Scholars program, we have kids come in multiple years, and as they get older we can give them more and more responsibility to make decisions, even if it's something as simple as helping an instructor in one of the workshops or putting out the treats and making sure they get cleaned up afterwards. I think it's really important to find those opportunities.

Another thing is keeping communication with the child going as a family during those postsecondary years. Of course, this is true for any family situation. But to make sure that there is positive communication going on between the child and the parents and the siblings before the child moves on to that postsecondary setting so that positive ways of interacting have been developed and can be built

upon. If there is not positive interaction at that point, it's not the right time to be developing it. It's difficult to do anyway.

I think it's really important—I think I have said this before and this came up with Teresa's comment as well—that if your child or the child we are talking about needs direct involvement of the parent as they are moving on to the postsecondary setting, they find a positive way to do that but also provide a way for the child to be in the driver's seat as much as possible whether it's writing that letter to get permission to be communicating with the disabled student services office, to help the child write the letter for you to sign, etc., and make the appointment and get involved during the discussion as much as possible. I think we can help young people move toward more self-determined behavior, even as we are supporting them.

So, those are some of the issues that we have thought of and we can discuss some of these during our Q and A period. But now I just want to tell you briefly about the DO-IT Scholars program and then Teresa will wind up and then we will have some time for questions.

The DO-IT Scholars program started in 1992 with funding from the National Science Foundation. Its purpose was to encourage young people with disabilities to enter and be successful in academic programs and careers. Because of its funding source, we are particularly focused on fields such as science, engineering, mathematics, and technology—fields where the National Science Foundation has a particular interest. Since then, the program has been funded by the State of Washington. Although we still focus on challenging careers, including those four, we encourage our students to enter other professions as well through much of our mentoring and so forth.

We take about 20 students a year. It's very competitive. They apply to the program. It's just Washington State now that the state is funding it. It used to be national. We select them based on their motivation to participate, their interest and aptitude in going to college, which can be a technical school or a four-year school. They have to have a disability, and again, be motivated to participate. We have taken one out of every three or four students per year. So it's competitive.

We have had experience now with nine summer programs. During that time, we surveyed the parents and asked them to comment on some of the benefits they see for their child. Some of the findings tell us a lot about what the parents consider to be important, so I am going to share some of those with you. We decided to ask them about the program overall but then also about the different components of it. The program involves multiple summer programs where they live on campus, reach peers and mentors, eat cafeteria food, go to lectures, maneuver on campus, and participate in extracurricular activities. We try to do it all in a couple of weeks. Then they come back the next summer again to do different types of activities. The third summer is an optional work-based internship.

During the year we loan them a computer and they communicate via the Internet with each other and with over 50 mentors who are college students and people in careers who have disabilities themselves. We ask the parents a few things after the child has participated for awhile in the program. We ask them, first of all, to what degree the participation affected their child, changed their experience, changed their child in a number of different areas. So I don't have to throw a lot of numbers at you, I will just list them in order. They are all rated fairly high, the ones I am going to share with you, but I will list the order that they were indicated in.

1. The number one effect they said was interest in college.
2. Number two was their perception of career options.
3. The third was their self-advocacy skills were improved.
4. The fourth was, it affected their self-esteem in a positive way.
5. Fifth, it affected their scholastic interest and participation.
6. Sixth, it impacted their social skills in a positive way.
7. Seventh, their level of independence. That one, by the way, I think would probably be very, very hard for the students who had some issues because of a mobility or sensory impairment, but since we have a lot of students with learning

disabilities, that particular group was rated lower than that independence category.

Then we asked them to separate a little bit the value of the computer and the Internet communication as compared to the summer program. We asked them to compare those as far as their impact on their child's social skills, their academic skills, and their career and employment skills. Again, they rated each item fairly high. What we could conclude from their ratings is that the parents thought that the computer and the Internet communication had a greater impact on their academic and their career skills, their academics and careers, rather than social, that was the third one. Academic and career is for the Internet part. The summer study they rated most highly in the social skills—that it really helped them in their social skills.

So I think we could conclude from their comments and from their ratings that both were important, the in-person, get-to-know-you kind of stuff, as well as the online support. But they perceived them to be important in different areas.

A few of the comments from parents provide greater insight, not only regarding how their child benefited, but again, what they consider to be important in developing in their child. So I will give you a few quotes and then I will turn this back to Teresa.

When the parents were asked what the most noticeable impact of the DO-IT activities were on them, that would be all the activities that they do in preparing for college and careers through the DO-IT program. Here are a few. These are direct quotes.

- “Being able to socialize more independently without having this disability get in the way.”
- “For self-esteem and ability to do things for herself.”
- “Increased self-advocacy skills.”
- “Increased knowledge of rights as a person with disability.”
- “He is more willing to advocate for himself in school.”
- “He is more comfortable in social settings.”
- “I have watched the computer and software bridge this gap between my daughter's IQ and her academic skills.”
- “He is more accepting of his learning disability.”

- “He advocates for himself.”
- “He has a better understanding of the accommodations he needs to be successful.”
- “Increased self-confidence.”
- “She is able to go to a college professor and talk about her needs.”
- “The DO-IT camp allows students to bond.”
- “The computer networking allows them to continue to support each other throughout the year.”
- “He came home talking about his college plans with confidence that he could manage it.”
- “It helped my son get a part-time job for his first year of college.”
- “His orientation to computers was the greatest gift. He excelled and wants a career in networking. It was a life-changing experience that will have a major impact on the quality of jobs and career opportunities my son selects to pursue. It has had a significant impact on his ability to be a self-advocate and also on his commitment to fulfill responsibilities.”
- “The first day of school last fall he walked up to each of his teachers, introduced himself and told them of his learning disability. They were impressed with his forthrightness and his poise. For the first time he had peers—other very bright, motivated, ambitious students who also happen to have disabilities. This was very powerful.”
- “My son returned with a specific career goal in mind. He has a real sense of being able to live independently.”
- “The program has added much quality to his life.”

If we wanted to summarize all of this in a sentence, it would be, how can we maximize the quality of life or improve or increase the quality of life for these students, socially, academically, professionally, and how can the family play a role in doing it?

So, Teresa, can you sum up for us?

**Dr. Whelley:** Well, it's a challenge but here we go. So, there are three points. I am going to speak mainly of some similar themes among the three points, the basic studies, my studies, and Sheryl's ongoing work.

The one thing I see is there is a process. All of the folks talked about the advocacy role clearly in



the IDEA and secondary, there's a process of that self-determination in young people. Perhaps that doesn't happen as a person graduates high school and enters college, but it's a continual process. In Washington State, it happens in a different way maybe than it does in a family in Minnesota or it does in New England, so that process. But the goal is still that young people are able to define themselves and advocate for their own wants and needs.

I see clearly that there is a role that families play with students in postsecondary education with disabilities. Both of the PACER groups and my group talked about basically behind-the-scenes roles and an instrumental role and the financial and driving around and getting stuff together—that role. So the behind-the-scenes roles and more an effective range. I interpret that to mean that the encouragement, the support, the always knowing that you had a home to go to, a place that you were loved, the sense of family that is important in people's lives.

Then what I heard clearly from Sheryl was, there's an impact that an intervention has, that if we help young people know earlier and their families know earlier what's ahead of them and work with them over time so that they can learn what self-advocacy skills are and develop their own knowledge and their own skills, then this has an impact on the family and the individual. And I think those are the main points. I don't have lot of time, so maybe I should turn it to Kris.

**Ms. Schoeller:** Thanks, Sheryl. Are there any questions? I have a whole bunch of things I would like to ask, but I will open it up to anybody else if there are any questions, any comments?

**Ms. Leuchovius:** This is Deborah. I am going to jump in with one question. I think Jane has a question here too. Just out of curiosity, I know that mentoring programs actually have been very difficult to set up in our experience. You mentioned that the DO-IT Scholars program is focusing on youth with disabilities in Washington State and you also mentioned that you had 50 mentors or so online? Are those mentors all from Washington State?

**Dr. Burgstahler:** No. They are actually from around the world. Actually the DO-IT Scholars program is in Washington State. But we do have a DO-IT Pals Program, which is just the electronic community of what we do. So any teenager any-

where in the world, if they can get access to the Internet and they have a disability and they are thinking about postsecondary education, they can be part of our electronic community on the Internet called the DO-IT Pals Program.

**Dr. Whelley:** Is there a Web address for that?

**Dr. Burgstahler:** Actually it's on the DO-IT Web site, [www.washington.edu/doiit](http://www.washington.edu/doiit). If you click on programs from that first page, you will see DO-IT Pals. Again, they have an e-mail address in there, [doiit@u.washington.edu](mailto:doiit@u.washington.edu). But basically what the child does is they send an e-mail message to that address and say they want to be in the DO-IT Program. We send them a little online application and they send it back and they are in the program. We keep it real simple and they are basically just joining our discussion list. We send them lessons every week. We send them information about scholarships and things like that and they get to communicate with their mentors and also the DO-IT Scholars that I told you about earlier. For any teenagers, if they want to join us they are more than welcome.

**Jane:** This is Jane from PACER. I had a question based on what was perceived as discouragement from families and their kids in college. I was just wondering whether or not if they could go into that a little bit more to—I think you discussed it a little bit as to whether or not the family was typically college grads or this was the first generation. There were fewer successes—not being able to get the appropriate accommodations or support if they were successful, etc., etc.

**Dr. Burgstahler:** Now, we in the DO-IT program don't find that. But I think because of the nature of our program maybe we don't talk to those parents very much. Because the parents we talk to are the ones that are encouraging their child to be involved in this program, which encourages postsecondary education of some type or another. So, Teresa, maybe you can say more about that. I found that interesting as well.

**Dr. Whelley:** Actually there were some negative findings that I didn't go into that much that were surprising. This was from students. Students reported that they were discouraged by their parents for going on to college, that their parents thought they couldn't do it, that it was too high an expectation and it was parents being overprotective vs. par-

ents being encouraging. It was pretty clear that these students had to overcome their parents' low expectations of them. I can only guess why the students thought that way. This is a statistical study, so I don't have what you asked which is the socioeconomic background of the families, etc. But it was a finding.

There was another finding that I didn't talk about that was negative as well—that students really felt discriminated against by being mainstreamed particularly—they talked about their experiences in mainstreamed education and secondary school, that it was hard on them and they wanted a place where they could feel supported and be with people like themselves.

**Ms. Schoeller:** Were they speaking of peers or peers and teachers at the secondary level, Teresa?

**Dr. Whelley:** Peers. They had a hard time in high school. Then on the East Coast when I was talking to students and parents, both students were very clear they had a much better time in college. Life was much more fun. They had friends. They weren't weird. Everything was good. Parents were very clear that they were very relieved not to have the burden of the IEP and were much happier to be able to even have their child negotiate their accommodations or negotiate accommodations with their adult child.

**Dr. Burgstahler:** You know, one thing that has come up a couple of times in the DO-IT program is related to parents encouraging or not encouraging. This came up last night in a dorm as I was talking to a young lady. This is not the first time this has happened. She has cerebral palsy. She is a wheelchair user. Her twin sister, who does not have cerebral palsy, moved out of the home a couple of years ago actually. But this young woman in our program was discouraged from moving away and living independently by aunts and uncles and so forth. Her parents, though, were very supportive of her doing that. She is now going to move into an apartment within the next month, and she has all of her attendant care arranged through an emergency system of buttons and this and that. She can't get out of bed herself, so that will assure she'll be safe. She's managed all of this herself. Her parents have encouraged her. But what she was telling me—and I have heard this story before, from parents usually—was that her parents were getting a lot of abuse from relatives, her grandmother, other people who were

one step away from the situation because they felt that that was too much for her to take on, that she wasn't going to be safe, that she should stay home with her parents, and what are her parents thinking. This young woman was defending her parents. She says, "Well, I don't understand why these people are talking to them like that. I am the one who made the decision. I am 18 years old. You know, I made the decision but my parents are getting criticized for this." I thought that was kind of interesting. Again, it's come up in other situations too.

**Jane:** This is Jane at PACER again. Another thing I wanted to add is I don't think that it's just that parents have low expectations. When we have kids in schools, we are always being told we are going to try and fix things for our kids. So the teachers have relatively low expectations. The work experiences many students get in schools are wiping cafeteria tables, working in the hallways, sweeping halls, minimal jobs, no real careers. So, it's hard for parents to develop high expectations when the schools and the teachers are constantly telling them what it is that must be fixed with their child. They don't have any mainstream classes for your child because we can't water it down too much.

**Dr. Whelley:** Yeah. I don't mean to say it's on parents. I am in a family of somebody with a disability. I think Sheryl's example is perfect. The parent, as well as the student, exists in an environment. The environment—I mean, if you have gotten the message from the time someone was nine years old or whatever, six years old, well, that's not your child, not your child, that when a young person starts to exert himself as a teenager, what the parents are telling them is what they have heard or the environment they are in. It's very challenging for both the student and the parent to say, well, I want to do it differently at this point. But I am reporting on what students said to me.

**Jane:** I think it's very hard for students and families to go against school systems these days when everything is being measured on the outcome that the students are expected to perform, and that includes students with disabilities. I am an advocate in the schools but I've seen many students work used from performing in standard-based testing because what we just know they can't do it. That's not valid in my mind when teachers are saying that.

**Ms. Schoeller:** I have a question along that same line, Sheryl. For me, even the technical colleges have been really encouraged to raise their academic standards and provide less experiential learning. So what I am seeing is a lot of kids who want to and maybe had even some high expectations of themselves who have a significant learning disability or a low IQ or even ADD, ADHD, who are struggling to meet the academic standards. Because as you were talking earlier about the modifications, they are a little bit different than in high school. To me it's closing more doors for more persons with disabilities by making those academic standards so high that they can't complete a program where it used to be that they could maybe enter into programs that were more hands-on/experiential, that are no longer available. Any experience with that or any other level of career development that may be coming along?

**Dr. Burgstahler:** Well, I have observed some anecdotal type things, but I don't really have a good handle on it in general. But what I have seen is kind of what you are saying, I think, in that sometimes the technical schools, I think they suffer from low self-esteem themselves, and they try to become something different and maybe focus less on the experience. Well, we have academic standards, we have this, or whatever, where maybe that's not doing the service to that child and leaves some students out. But at least in some cases the community colleges focus more on two tracks, and one track is: You are here at the community college to move onto something else, let's get you into the university, let's get you into a four-year school. The other track is just sort of ill-defined and it ends up to be in some cases sort of a dumping ground that these students don't get anywhere, that they are not really focused on an outcome that can get them a job. So they end up retaking classes and taking classes that are not really focused on career skills for that particular child. So they can get left out. I run into a number of students with disabilities who are stuck in a community college with no focus on what they are doing there and perhaps no hope of moving on to a four-year school. So then what? I don't think we are serving that group very well.

**Jane:** No.

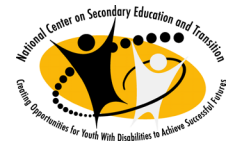
**Ms. Schoeller:** Any other questions? Any other comments? Well, I want to thank you, Sheryl

and Teresa. It was very interesting and I hope we can keep working together on putting information out for families. I think this is an area really, truly that parents don't get very much on and a lot of students are still struggling and walking in one door and out the other of postsecondary. I want to thank everybody who came on. Please feel free to contact anybody that was presenting. Thank you, everybody.

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