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Youth in Transition

From High School to Work:
Voices of Students with
Disabilities and Parents

Research Team

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I. Introduction

Connecticut's Medicaid Infrastructure Grant, known as "Connect-Ability," is designed to support the competitive employment of people with disabilities. The grant, funded by the federal Centers for Medicare and Medicaid Services, was awarded to the Connect to Work Center at the Connecticut Bureau of Rehabilitation Services, Department of Social Services. A major goal of Connect-Ability is to develop a comprehensive system of employment supports for people with disabilities, including youth with disabilities.

Connect-Ability's "Youth in Transition" initiative seeks to smooth the way for students with disabilities who are in transition from secondary education to employment or further education. It emphasizes practical solutions such as promoting the development of more internships and summer employment, encouraging mentoring opportunities, and making tools available for identifying areas of interest and strength. Priority areas for this initiative include school transition programs, the integration of assistive technology that can follow people from school to work, work-based opportunities, mentoring, increased understanding of benefits, and increasing independence. Transition activities are coordinated by the Connect-Ability Transition Work Group.

Connect-Ability contracted with the University of Connecticut Health Center (UCHC) to provide research and evaluation services related to grant activities, including the Youth in Transition initiative. Although many activities lend themselves to evaluation through the collection of administrative and programmatic data, the Transition Work Group proposed that one key element of the research plan was the "voice of the consumer," the collection of rich data about the beliefs and experiences of students with disabilities and their parents concerning work and the transition process. The work group and researchers from UCHC developed a plan to gather information directly from students and parents on transition-related subjects including employment aspirations, attitudes about work, employment related school experiences, and their desires and needs concerning school employment and transition programs. This data is designed to inform not only the Connect-Ability transition efforts, but also education officials at the state and local levels, as well as students, parents and advocacy groups.

II. Methodology

Given the challenges of reaching a random sample of this population, the sample was developed as a purposive convenience sample in order to include individuals who had knowledge or direct experience relevant to the school-to-work transition process for students with disabilities. Parents of students with disabilities were either referred by school systems administrators at the request of an official from the State Department of Education, or solicited directly at a parent information session by a member of the UCHC research team.

The sole method of data collection for parents was the telephone interview, administered by a trained interviewer from UCHC. Twenty parent interviews were conducted by telephone, and lasted between 30 and 45 minutes. The interview guide for parents is attached as Appendix A. All parents interviewed agreed to have their telephone conversations tape-recorded. Parents were assured by the interviewer that their names would not be associated with any of their remarks, and that complete confidentiality was assured. Tape recordings were subsequently transcribed.

Two methods of data collection were used for students: individual interviews and focus groups. As with parents, the sample was developed as a purposive convenience sample. Recruitment of students for both individual interviews and focus groups was by referral from members of the

Transition Work Group, school transition personnel, and an official from the State Department of Education.

Twelve students were interviewed individually by a member of the research team, and each interview lasted between 20 and 30 minutes. Eleven of these students were interviewed by telephone, and one student was interviewed in person. In the case of one telephone interview of a student with autism, the student's mother also participated on another line to help and prompt responses. The in-person interview was completed with a young person with cerebral palsy who communicated through a communication board. That student's transition coordinator was present to help facilitate the interview.

Three focus groups were held with a total of 30 students. Each focus group was held in a private room at high schools in Hamden and Meriden, Connecticut, and lasted between 60 and 90 minutes. All were facilitated by two trained facilitators from the research team. In all cases, a transition coordinator or guidance counselor was also available during the focus group to help prompt the students or to clarify questions or answers. They also added to the understanding of their school system's transition programs.

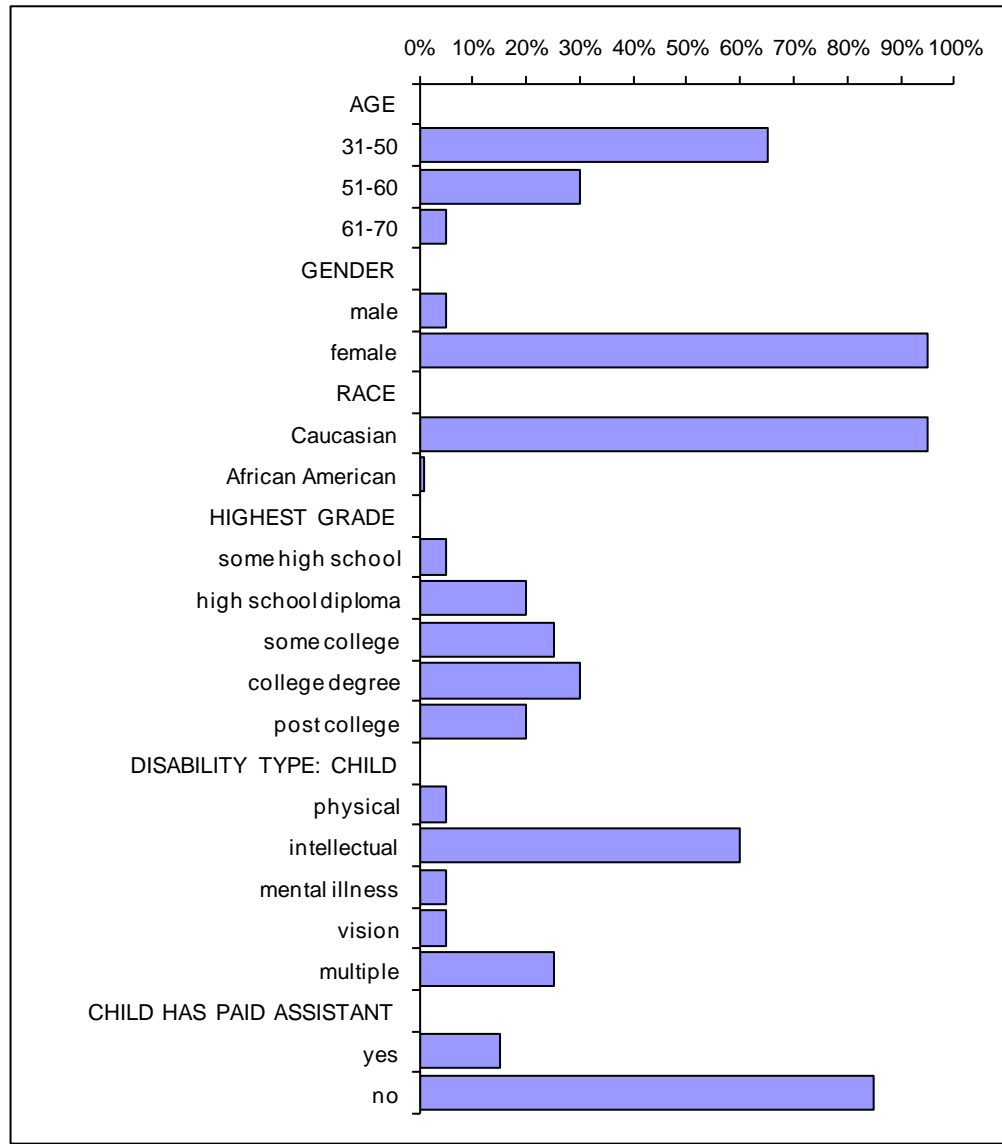
All students, whether participating in individual interviews or focus groups, were assured that the information they revealed would be kept completely confidential. All individual interviews and two of the three focus groups were tape recorded with permission and later transcribed. One student at one focus group objected to the tape recording, so detailed notes were taken by one of the facilitators. The University of Connecticut Health Center's Institutional Review Board approved this research. The student interview and focus group guides are attached as Appendices B and C.

Qualitative responses to all interview and focus group questions were entered into Atlas ti 5.2, a scientific software program designed specifically for the analysis of qualitative data. The content from these open-ended questions was analyzed using standard qualitative analysis techniques (McCraken, 1988). Major areas of interest or concepts were organized into common themes using the constant comparative technique (Glaser & Strauss, 1967). Additional themes were included until no new topics were identified. Similar statements were explored and compared to refine each theme.

III. Parent and Student Demographics

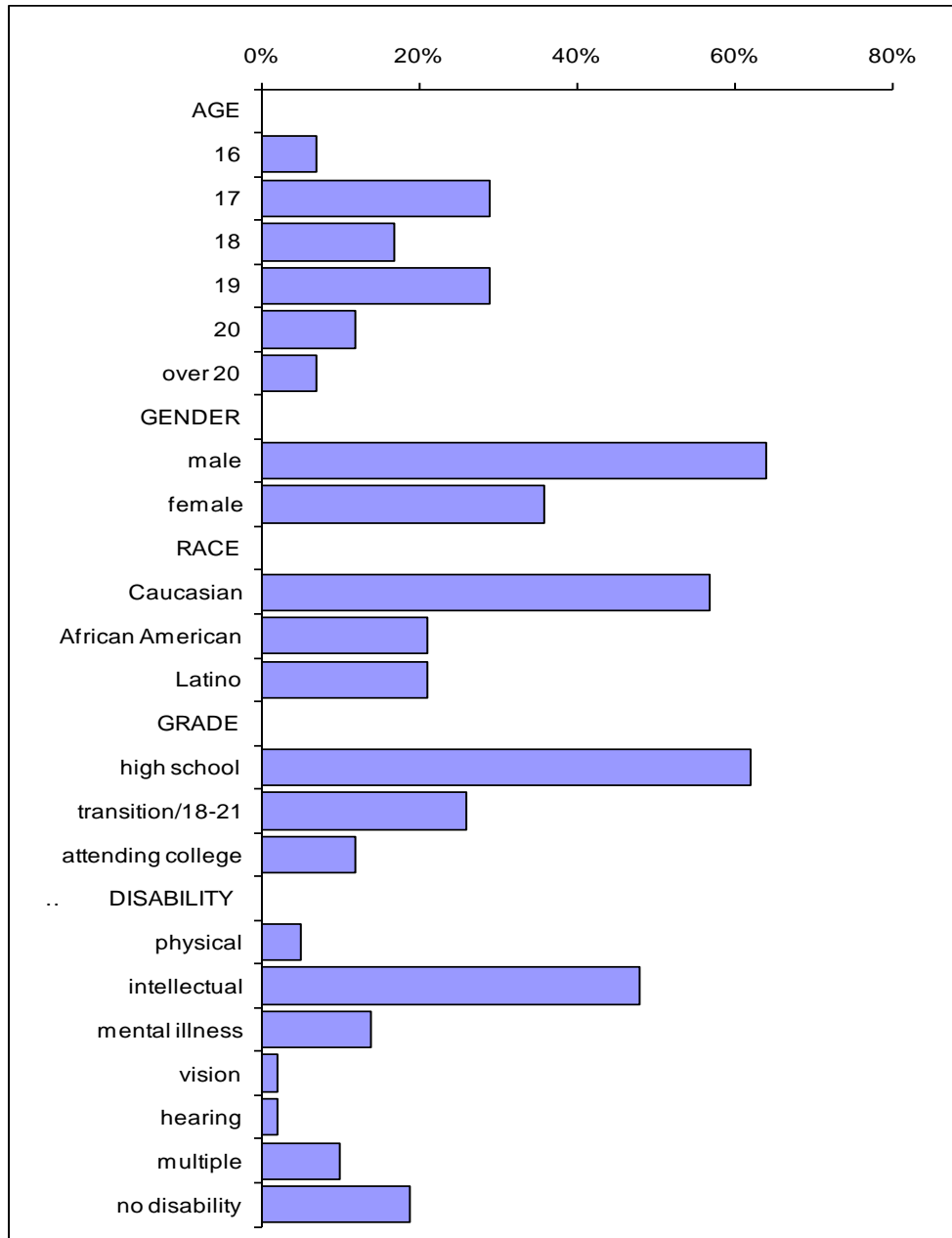
All parents and students filled out a questionnaire containing demographic information at the time of their interview or focus group. The majority of parents interviewed (n=20) were female (95%), white (95%), age 31 to 50 (65%), with at least some college or a college degree (55%). In addition, the majority of the parents (60 %) had children whose primary disability was intellectual: either a learning disability, mental retardation, or a diagnosis of autism or other related autism spectrum disorder. Only 15 percent of the children of these parents had paid assistants that helped the child in the home or at school. Parent demographics are summarized in Figure 1.

Figure 1. Demographic characteristics of parents



Most students (n=42) were ages 17 to 19 (75%) and were currently in high school (62%). Sixty-four percent were male and 36 percent were female. Slightly over half (57%) were Caucasian, and nearly one-fourth (21%) were African American, while another 21 percent were of Latino or Hispanic background. Almost half (48%) had an intellectual disability, which could include mental retardation, a learning disability, or autism. Fourteen percent indicated that they had a mental health disability, including schizophrenia, bi-polar or personality disorder. Only five percent had a physical disability; 2 percent had a vision disability; two percent had a hearing disability; and 10 percent of the group had multiple disabilities. Nineteen percent indicated that they had no disabilities. Although these students indicated that they had no disabilities, all students had been previously identified by transition coordinators at their schools as being in the special education program or having another identified disability. Nearly two-thirds (62%) were currently in high school while one-quarter (26%) were in an 18-21 transition program. Twelve percent (n=5) of the group were attending or at least taking a class at the college level. Student demographic information is summarized in Figure 2.

Figure 2. – Demographic characteristics of students



IV. Results of parent interviews

Seven major themes emerged from the interviews with parents.

- The school system. There were both positive and negative reports about the school systems made by the interviewees. Some parents thought that their school system should be offering more to students with disabilities.

- Parental involvement. Many parents spoke about their own involvement with their children both in the school system and in the job search. Most agreed that certain things could not have been accomplished without their efforts and their personal involvement with their children, both within the school system and within the potential work place. Some parents believed that there was a need for some sort of centralized information system where they could find out about what is available to help their children and discover other services for which they might be eligible.
- Accommodations. Most parents believed that their children had some abilities and indicated that some of the jobs being offered were not challenging enough for their child's level of understanding or ability. They described various accommodations that would have to be in place for their children to be successful in a job, and some indicated barriers that would have to be overcome in order for them to succeed. Certain parents, particularly of children with an autism spectrum disorder, mentioned that the lack of social and communication skills poses a barrier for their child in trying to apply for any job. Parents of children with physical disabilities mentioned the need for personal assistants and other accommodations in order for their children to be able work.
- Employment. Many parents believed that employers had certain preconceived notions about what it might be like to hire a person with a disability. Some parents actually were present with their children when they experienced discrimination by a potential employer.
- Transportation. Another barrier described as paramount was that of transportation. Parents spoke of the hardships posed by not having adequate transportation, but then praised certain institutions for providing travel training to young people so that they could learn how to navigate public transportation.
- Supports and services. Parents spoke about certain service agencies whose purpose is to help their children find meaningful employment. They mentioned things that were positive about these agencies, but a number of participants had complaints about the system and the way that it worked. Some offered suggestions to these agencies.
- Parental worries and fears. Finally, parents spoke of their worries and fears regarding their children and their apprehension with regard to the ability of their children to eventually live on their own. For many parents, one of the most commonly mentioned themes was "what will happen to my child when I am no longer around?"

The following sections detail the scope of parents' experiences and attitudes in each of these dimensions.

A. The school system

Positive reports about the school system

Some parents had very positive remarks about their school and the transition program within that school, the job training, the involvement with agencies, and the work experience that their children were receiving. Three parents had children enrolled in the ACES (Area Cooperative Educational Services) school programs, a school specifically geared to train children with disabilities in a variety of career skills. Other school districts were also perceived as exceptional in providing transition services and other special programs. The mother of a child with a developmental disability said of her child's school system,

I got to say [name] school system has been very proactive in getting the kids placed with agencies. I think they tend to use two agencies. It wasn't too long ago where they pretty much had all the kids going to one agency. They have been very, very good that way. I also

have DMR which is now DDS come to her PPTs since she was 15 or 16 working towards the transition of school to work.

Another mother whose child has attention deficit disorder and is enrolled in a public school was very positive about the help that her son was receiving, both from a job coach and through special courses offered to the students.

They had a job coach that was assigned to him and they helped him to spruce up his resume and stuff which he also learned how to do that. In that class ... "Me and My Independence" helped him do resumes and letter of acceptance and that kind of thing with his job coach. They helped him develop that a little bit more and they kind of went over ... grooming, you know, what you should wear for an interview and how you should act and that kind of thing and then they went to the library and went online and looked up things. So that areas that he was interested in – and then they took him out on a couple of interviews, and then he ended up getting a job which was one of the interviews that he had but it was more like the company that he worked for.

The mother of a young man in the ACES school spoke of the emphasis that the school places on training young people with disabilities towards a variety of different types of job situations. She indicated that the school offers a variety of trainings for different skills so that each student can find a niche for him or herself.

[Son's name] school does an amazing job. They have in house – they have a work floor that has assembly and packaging jobs that are available to the kids. They also have in house all kinds of different business machines you know whether it be shredders or copy machines or whatever so they get both kinds of experience in house but then they also take the kids out into the community and [son's name] has been to US Surgical and Hewlett Packard and all different places. One of the first jobs that I had was at US Surgical only not that location so you know he is getting a wide range of different job opportunities from working with animals to whatever so it's given him the opportunity to see, you know, what is he good at what he is interested in and then things like that.

Another parent of a child who is also enrolled in the ACES school system commented about the opportunities that are offered to students with disabilities. The mother believed that not only did the school provide specialized training for job oriented skills, but also the school had realized specific connections within the community that would help open more doors for her child.

It's a great thing for him and I think that the program he is in will be a better fit for him as far as getting him focused on his job skills where I wouldn't be able to get him there. They have more openings, more options for him. If I was just to walk in and say my kid is this, this and this, do you have anything that might help him. Where these opportunities that he has through the school, they have more doors opening for him because they are set up with these job sites.

One mother of a child with Down syndrome said her child's public high school had also made arrangements with different work sites within the community where a variety of skills could be obtained.

The school had built in to its educational program, opportunities to go to different work sites. Ever since he was a freshman in high school, he went, he did his scholastic classes that he had to do, but then he would go and work in the community as well. At the beginning it was

like community work experience, they had different venues set up with companies that they had agreements with. But this last year he went with an agency for 2 days a week. And then he was just supposed to be able to flow into that job after graduation, but with the budget he was not able to do that.

Negative reports about the school system

While some parents were satisfied with their school system, other parents believed that something was lacking in terms of preparing their children with actual work experience. Some parents believed that too much emphasis was put on academics, which, for their children, was perceived as less important than practical skills that would enable them to be self-sufficient and to obtain a meaningful job. One parent noted,

Even though he is 16, he only just completed his first year of high school, and they tell me that eventually they do that. But that right now what they're focused on is getting him the courses that he needs to get the high school diploma because of the 'no child left behind' thing. He's actually got to take courses that, to my mind, really aren't that practical for him, like he's got to take world history, got to take things like that, but they say that he'll go to school until he is 21 anyway so they'll do that later.

The mother of a young girl with both an intellectual disability and bi-polar disorder said that her daughter had a hard time in high school, which is why the mother decided to switch her over to an agency contracted by the Department of Developmental Services.

When she was in high school it was more at that time an academic role and then when she went to the agency, I think her junior year, we were leaning more towards vocational.

Need for additional programs within the school system

Other parents suggested that there should be special programs or vocational offerings in their school. Some examples of things desired by the parents included job shadowing programs, a vocational department, and one-on-one involvement with the child to determine their aptitudes. Parents from different schools had different experiences with their school district. Some schools offered programs such as job shadowing and internships, so the experiences reported here are from parents of students whose school system did not offer the desired program.

I would love to see him have a - I know they have a job shadowing program which they say later they'll [do that]. I would love to see them have a program where they take them with a job coach to try different things out for a couple of weeks at a time. You know what I mean? Like this is what it is like to work at the grocery store, this is what it is like to work at Walgreens, this is what it is like to work, I don't know, where else would you. I think that would be nice but, on the other hand, I'm sure would be tremendously complicated for them to do that in the school program.

But I could imagine if there was [a] vocational department. We used to have things, like I joined Junior Achievement in high school even though my career track was aimed a different way ... so we could practice some vocational skills and that wasn't even within the school. It was sponsored by the school.

One parent of a child with a visual disability agreed that the high school did offer community experience for her child, but indicated that the program needed to be expanded to include other opportunities for learning. The transition coordinator had made connections in the community, but the offerings of skills were limited.

They have done so so much with folding towels and doing laundry. I think that they need to expand the program to different companies in [name of city]. I think that they need to give the kids more options of types of things to learn. ... There's not enough companies to offer their services and say, "Hey, they can do this – folding envelopes, stuffing envelopes – " I think that it is too repetitive what they do – and every year it's the same jobs – it's community experience – They need more companies to open up their doors. So that the students can learn new skills beyond folding towels, teaching them new skills.

The mother of a child with Asperger's Syndrome wanted someone to help in determining her child's aptitudes, through some kind of hands-on experience.

One of the things I would love the school to do is to help me puzzle through what he can do, you know what he is good at because I am his mom, I am a different context. And whether that be a vocational program within the school that either observes classroom, or understands how he works, or help him tease out his interests. I think hands-on experiences. Some people with various disabilities learn a lot more by the hands-on experience because when the words are being spoken they just hear "wah wah wah" I don't know if that makes sense to you.

Other parents thought that because of the size of the school, their child was being overlooked and just herded out so that the school would no longer have any responsibility. One parent thought that her child was getting overlooked not only because of the size of the school, but also because the child was *not* a discipline problem.

But the goal in his special ed. program seems to be to get him out of high school and so he never had any experiences, there was not a thought of it in his program of how to get him some experiences. I have had to pull the team together to talk about him and these are not bad people, it's not a bad school it's just a big school and kids that don't misbehave get lost. So it gets all the way to the end of the gray card and they are failing something and nobody has really noticed and then his special ed. teacher didn't know, you know what I mean?

So anyway, I don't know what the school's to do but I think that schools have many mandates and so to add another one is always terrible but the idea of high school, high school is not just an academic thing. I realize that a lot of our society goes on to college but a lot don't and the school has gotten away from, I think the high schools, of course I came from a working class town, [name of town], we had a lot of vocational programs in the high schools.

The fact of the matter is the year he's 21 their obligation to him has ended and if he hasn't in fact learned anything useful there is no way we can go back to them and say look you're supposed to do this.

I don't think ...his special ed. teacher who is ...the case worker has enough support to do as much as she would like to do because she is only one.

Some parents believed that certain transition programs or targeted classes should start much earlier so that their children would be able to learn the skills that are valuable in the work place and for life in general.

They have what it is called Connecticut Works, you know things like that if they could kind of make it more towards like the teenage years if they could somehow have something at the school I would think

I think that would kind of make more of a transition if they could start, you know, trying to do things earlier.

Oh you know when he gets to high school this can be – none of that was ever discussed and I think that should be when a child gets to be in like 9th grade – they should start to prepare him for when he is out of school.

B. Parent involvement

Parent involvement in the school

Most parents believed that it was only because of their involvement in the school that certain things were attainable for their children. In other words, most parents felt that if they were not proactive on behalf of their children, they would not be receiving the proper educational and vocational skills.

I did find out the hard way, that for the most part unless the parent goes in and asks, they actually may send a bunch of papers home in the kids' backpack that they hand to them, but unless the parent goes in and asks actually most of the time you don't have any idea what they are doing. They don't like say we have these programs that we are offering to your kid. You have to go in and say what about this program. ... I am not being a cynic I just learned with my second son that if you didn't go in and advocate, often the schools don't offer and it's a two way process. It's really not a criticism it just seems to be the way it works.

But I have always felt like it is often a scramble, and they go, "oh, we did that last month" and I look at my son's bag and at the bottom I find a note and I might have been able to tell that this is what I should have done. You know what I mean? So there is a little bit of outreach when a school has special ed. students that maybe would be helpful, and, I think, maybe there are parents who don't respond to that and then there are parents who do. I went to this meeting and I was shocked. It is a huge high school and only six parents showed up.

Actually it's the parent that actually has to do something. I realized when he was a junior that oh my goodness we only had one year left we have to do something and that's where I started looking for what we could do with him things like that, and I actually got him signed up for classes when he was a senior at his PPT meeting, the last one we had for his junior year.

No I did it on my own. Yeah, when you have to sign up for your courses for the next year they give you the book, and I thought, "oh that would be a good one for him." I also put him in a culinary class thinking, you know, maybe if he learned to cook, thinking if he ever got a place, he would be able to eat. Those are the different things that I thought that he would benefit from.

Parent involvement in the job hunt

Parents were involved not only within the school system, but also in helping their children to find and maintain a job with the proper supports and accommodations.

He gets you know like the mentoring that he has and the job coaching that he has. He got those services because, because I was very diligent. Not everybody knows how to, you know, do that. I was able to kind of unearth the services that not a lot of people know about. I knew that volunteering services through DCF were going to be switching over to DDS, so what I did was I got him into volunteering knowing it would be very short lived, and whatever his budget from volunteering would be transferred over to DDS. So, because of knowing the system, [name] has the services he needs.

Other parents who were not as knowledgeable about the system were just starting the process of finding out about what services are available. Some of these parents indicated frustration with continually trying to find answers to their questions, or even to find the right questions to ask.

I am trying to seek out as many people as I can to help us pave the way and get us connected with the people that we need to get us to where [name] can be independent.

Every year, now I forget who sponsors it in [name of town], they have a huge transitions fair which I went ... which I got great information on from all different agencies from all different programs after high school that I never knew about. And, you know, other friends that I have, that I know, that are in that field, didn't know about, and, you know, so I find that it is, for me, it's a constant struggle to go and search to find whatever it is out there that I think might help my son.

Many parents believed that they themselves were the primary teachers for their children in terms of succeeding in their jobs. Some believed that the schools were not teaching these skills effectively or at all.

You know just let him know the basics you got to get there on time, you have to be on your best behavior, you can't get mad at a job when you are there, you have to do what they tell you to do.

Need for centralized information

A number of parents said that part of the problem with helping their children was a lack of information or some kind of central agency that could direct them to the different services that are available beyond high school.

Well you know, I think it's good to have them there and everybody on the same page because as a parent, it's overwhelming, you know, and you don't know what's out there and as far as the school system goes they know everything and everything is confidential. So as a parent you really don't know much. You don't know who is getting what, you don't know what's what. Sometimes I didn't know what to ask for.

I am constantly, I go to as many seminars and things like that. I see from different lists, dealing with employment or intellectual disabilities or inclusion, that I can find out what is actually available out there for people, because I don't see that there is a central easy source to go to as a parent to find out what those things are.

I am not sure if this is really just me, constantly grinding the wheels at the different stages that he has gone through to find out what's there, what's available, you know, what is there, out there that the state or whomever has to offer that I don't know about.

Right it's not just the work, it was like where do you go, who do you talk to? [Son's name] had a birthday party and one of the children that he invited he is severely disabled and [name] wanted to have a play date with him and his mom said, "oh he has to work" and I am thinking work, where does he work at? And then we started talking and that's how she told me about ARC and how they helped him and all that, and that's how I ended up finding out about that, just from talking to another mom.

One parent was very involved in the workings of the system and had gained a lot of additional knowledge in her efforts to find the right avenues for her son. As a result, she now offers support groups for other individuals who are in the same position of trying to find out what help or supports are available.

A knowledge of the system and how the system works is very important because there are a lot of individuals out there, for example, those that have autism, that the family went through 'birth to 3' when they were young and then they end up in my support group. And I say, "Is little Johnnie still getting DDS services?" and they say, "What do you mean, we never got DDS services." Then I'll say was he in birth to three – yes, well that's from DDS - oh really? You know, and then they find out that they signed their rights to DDS services away. They signed a paper that says I don't need DDS services anymore instead of staying on, or instead of seeing, at age 8, if they qualify again.

C. Accommodations

Types of accommodations

Concerns about finding jobs for their children were joined with concerns about having the proper accommodations to support them on the job. In some instances, these accommodations were seen as being very simple, particularly for any child with a developmental disability. Desirable accommodations included things such as allowing the individual to work at his or her own pace, having frequent breaks, or having a job coach. Job coaches were seen as being essential especially in the process of finding and interviewing for a job.

So he knows a lot of programs, a lot of programs that I don't even know and he has the capabilities but he is just slow. He's got to do it at his own pace. So is there a job out there for him, I'd like to think so.

We have had kids whose physical stamina wasn't up to what they needed on the job and if they had had more breaks or maybe part time work they would have been able to do it.

Yeah or some coaching, probably coaching around an interview I don't think eliminating it, but coaching it.

Like he would like to be working, but there is no way that he could work on his own – there are no supports. For his level, he needs supports. He needs someone to keep him on task, he needs someone there with him. Not one-on-one, like for some other individuals, like he could be in a group of 4 or 5 – but he needs to be directed.

[H]e would need a job coach to get him started and to help interface with the employer. I don't think he would need a job coach for long but it would be good for him to have someone. You know when the mom goes along it changes things, you know, so it's really better for

somebody, for not to be me, to do that. And its my hope that eventually over the next year he will get some kind of part time job while he goes on to college and takes college classes.

One parent spoke about her son who was working part time at a library. Because the people he worked with were very helpful, her son, who has autism, was able to maintain his job and continue working at this position.

[W]ell the fact that, you know, in a two hour shift he gets breaks. It's like a 10 minute break or whatever it is, but they actually, they say it could be as long as he needs it to be, you know, and if he needs more of a break they'll let him. The job itself, the folks at the job, will allow him to take as many breaks as he needs as often as he needs. He has been sticking to the one break a night though for 10 minutes and that's the only accommodation that he's really needed.

Another parent whose son had a job explained to her son's employer about his particular needs.

But, I said, it's more than that, with having the ADD he has short term memory loss and things like that. He doesn't remember things, he has got to be constantly repeated to. We have lists everywhere that we write down, you know, this is what needs to get accomplished. And so I just made all these other suggestions to her [the employer] because she also does that with other children that she has there.

Accessibility, need for personal assistance

Other barriers were mentioned by the parents. One parent, whose child has a cerebral palsy, spoke of accessibility and the need for a personal assistant at the job.

You know what I see as a hassle the biggest thing in his whole day is. No, I think he could get on the van, I think he could get there. I think hopefully it would be accessible and he could get in. But the biggest problem is having to use the toilet. Anything, even to go to the mall for more than a couple of hours, and he had to use the bathroom, who's going to do it for him? Or even to eat? He is not independent eating either.

Communication and social skills as a barrier

Finding the right kind of job to suit the person was seen as essential. For an autistic child, the inability to communicate and lack of social skills were viewed as impediments to making that first positive impression of their true abilities. Getting past the initial interview was considered to be the hardest part of the entire process. One parent was hopeful that if her son could get past the interview, he would be in a position to find a job that he might enjoy.

And then, I also think, I look at my son, with his particular disabilities and he is going to have a hard time articulating his strengths and his value to an employer because of his social skills. Although I think that he is capable of doing a full time job and actually maybe finding something he could enjoy.

Other parents echoed those concerns.

[A]nd you know the work itself he does not need any help with the work itself. He needs help with the odd ball social things that come up.

Well I, its clear to me, having been a special education teacher and supervisor, that all kids in high school need some help kind of moving on beyond high school, but my son is particularly oblivious and naïve. I mean he kind of has the oblivious and naïveté of a kid with an intellectual disability except that he has been in honors level classes at the high school so he's, you know, he's quite a history scholar, and he's very verbal, and he likes to write, and all that stuff. But when it comes to you know just negotiating the real world, he's really very immature, very undeveloped. And so I realized that I had to really, I mean, we worked a lot on social skills and trying to develop friendships and get out and do things and that kind of stuff, but all of a sudden I realized that the whole notion of getting into a work place was really something he didn't have any, not only any preparation, but he didn't have any aptitude, any particular skills. And so that's why I retired early from the school system, so that I could work more with him in that.

Let me speak to his situation. As I said, he presents like a young man with many more limits than he really has because of his social kind of awkwardness and bluntness, and so, in an interview or with somebody who doesn't know him, you would immediately assume that he couldn't do anything.

D. Employment

Employer perceptions

Most parents believed that the employer's perceptions, and stigmas in general associated with anyone who is different, would prevent their children from being accepted, and that it would also limit their ability to gain employment. One parent mentioned the stigma that goes along with having a disability and the perceptions and skepticism that any employer may have with regard to hiring a person with a disability.

I work at a mental health facility and so for our people here with mental health disorders, it's just layer upon layer of stigma and all that stuff. I think that employers struggle with it, with hiring people, because they afraid to make the adaptations, or afraid they are going to be more expensive.

Yeah and a lot of places aren't willing to work with them. I mean, I have even dealt with the general public where it's like, you know, well we have to take care of this, or we have to accept him with a disability, we have to make accommodations for him to be able to do this job. I don't see why they just can't hire somebody that can just do the job. I don't think the general public is ready to hire the handicapped. I think they feel that they are more coerced or more forced to do it because they are in fear of the repercussions of it.

Ignorance – of employers. I think that there is not enough (I don't want to say training) exposure – it's really hard for someone who doesn't know anything about disabilities to be willing to accept it. But I think that with more exposure I think that they would become more willing. I think that there needs to be more liaisons but I think that DDS is doing a lot with the community, but I think that there needs to be more support for them in the community and more integration. I think that early integration helps.

One parent had experienced this apprehension within the school system. She thought that possibly the fear of hiring someone with a disability was a result of never having been exposed to anyone with a disability.

I think to some extent maybe fear of employers. You know, even I have seen this from the teachers that haven't had many, I guess, many kids of special ed. in the classroom. They were like initially oh they actually said that in one of the star team meetings, "oh I didn't know what to expect. I thought it was going to be a lot of work. I thought that he would just sit there and take up space and not really get anything out of it." And then they were pleasantly surprised that with proper support modifications or whatever he fit in just fine.

It's not even so much the employers it's the employees of the employers that make it hard on these kids.

Just give them a chance

Some parents felt that their child just needed to be given a chance to work and to prove that they can do the job. They longed for employers to be more accepting and employers who are more willing to just give their child an opportunity to show what they are capable of.

Just give them a chance and I wish people would just kind of, you know, if more people were more accepting, then there would be more opportunities for them and I know the market's tight so ...

I think it's just the people, in general, be more open to people with disabilities that they are able to do a job just as well as somebody else. Yeah, they may need a little bit more prompting but you know?

Abilities of the child

As far as finding a job, parents expressed certain concerns regarding their child's skills and abilities and the practical applications of those skills. While most of the parents interviewed were very positive about whether their children could or would find meaningful employment, they considered it very challenging to get a foot in the door.

[H]e has some skills that with the computer and things like that that he loves to do for his own purposes. I don't know. I mean, you know yourself that part of work is taking the skills you have and applying them to a purpose that someone else has set before, and I don't know if he ... is going to work he is going to have to understand that that ... when you work, you are not there to play, you are there to do what they tell you to do. Now, I mean, he does that in school ok but I also know that in school there is quite a varied routine and he probably doesn't get bored in school.

Particularly the parents of autistic children and parents of children with intellectual disabilities were skeptical about their children's ability to understand what would be involved in finding a job, and they questioned whether the child would ever make enough money to be fully self-supporting.

To me, his best shot for getting a job would be if somebody who really knew him, and knew what skills he had, and knew about autism, knew of a job that might be good for him. I don't see him going out searching for a job. I don't think he would even understand what is involved in that. To tell you the truth, I don't think he will ever make enough money anyway to support himself or have benefits or whatever and I'm hoping he'll qualify for social security disability, but I don't know that he will.

Offering jobs that are more challenging

Other parents expressed their concerns about certain jobs that are available. They expressed a desire for their child to have more than a mundane, unchallenging job.

I mean there's I have seen many successes you know and I have seen situations where it hasn't been so successful. So I think that one of the downfalls is there just aren't enough jobs out there and workers out there to help support individuals with disabilities.

Right they can do more than vacuum a rug. To me, you know, they have skills that they can do. Maybe it takes a little longer but they do get [it] done and they are generally very capable and they want to work. So I know my daughter loves to work and wants to work. She loves her paycheck.

[Something] that's challenging and interesting for her, because I do find sometimes in my experiences that they underestimate their abilities, and they are really stuck doing really jobs that are very boring to them, you know, and I think they have to take a look at the whole package. It's just not about work. It's about who they are and I think that's forgotten sometimes.

Goodness of fit

Finding the right employment was seen as being dependent on finding a goodness of fit. If the job is specific for a certain skill, the young person applying may be good at that one thing, but not able to complete other tasks as well. One parent noted:

I think for kids with learning disabilities one of the tricks is that is that when they go in, if they are choosing wisely, then they choose something that they are a pretty good match for. And so when you are a good match for something on the surface of it people assume that you have comparable skills all around. And so you say oh this guy's pretty sharp he can, you know, fix this radio in a heartbeat. That's great and then they assume that you have comparable skills in taking phone messages or something like that, and then you find out the kid can't write very well, or he misspells things, or he can't take a message on the phone because his auditory processing is poor. And so then they get disgusted and lose jobs for that or kids don't apply for jobs because their afraid someone will find out. And so they rather than apply for something that would be really perfect for some ways, and then ask for an accommodation, like don't make me answer the phone and take messages, they just don't apply for something where they might have to do that because they don't want to admit that they have a problem.

E. Transportation

Transportation was also seen to be a major barrier in terms of finding employment.

I think there is more of a difficulty finding a job that is near public transportation.

I would have to say the state should do something about transportation. Here in the valley there is Valley Transit but it doesn't accommodate as much as it should and I just think the state in general has transportation problems.

Transportation is a big one. Right and maybe if the price of gas goes up another couple bucks there will be more buses I don't know. I mean I don't wish for the price of gas to go up 2 more

bucks but I don't know what it will take to get a better system so that more people can get around.

The buses don't run as frequently as they need to and they don't go to as many places as they should and they don't run as long into the evening as they should. I would say that's where I see my son probably having the most difficulty in the future.

Utilizing public transportation

Many parents expressed other concerns related to utilizing public transportation that would pose a barrier to their children.

Part of the issue is in order for him to be able to take the bus, he is not capable of crossing the street safely yet, so you know we have to work on that too. We have to work on that simultaneously. But, yeah, I am sure that eventually he will be able to pick up the bus down town and, you know, if he had to go to you know if he wanted to go the Y, or if he wanted to go to the library or whatever I think you can do a dial-a-ride and get on their schedule. But then you're at the mercy of the bus as far as when you can work ...

He doesn't drive and we did have a driving assessment and they had a few concerns about whether they think that he really isn't ready to drive now so we have been doing more bike riding and following some of their instructions for improvement and we're hoping to do some travel training for him to go to his college classes and maybe to get to work.

Yes, I see the transportation as being a problem in terms of getting to [name of community college] because the bus is an hour and fifteen minutes and really the drive is only 20 minutes. So if you have to it's one thing but of course you have to change so you have to ride into the city and then you have to take another bus and you have to make sure you don't miss it. And, you know, he would need to be carefully trained about bus etiquette, you know, not striking up conversations and just kind of maybe sit up near the bus driver and mind your own business read a book or listen to your I-Pod or something ...

Travel training program

Some parents looked into a travel training program which assists people with certain disabilities to navigate their way through the transportation system.

I found out at the transition fair that they have this travel program that you can sign up for that's absolutely free that teaches – they come, you know, you have to pay for the actual train [or] bus fare – and they teach the clients how to go from where they have to either from here or work or whatever for free.

I'm going to sign him up to learn how to and I'll do whatever they have to do as far as making whether its cards or symbols or whatever so they know what bus to take or what train or where to get off and I never heard of that before.

Certain school districts or geographic areas provide transportation programs for youth with disabilities right in the school system. One mother of a student with a visual disability described the program.

Actually, they have [name of transportation company], where you call up and you call for a ride – they know him, he's got an account number, he calls up, he's been practicing his

communication skills and listening, “I need a ride, I’m going to [name of store]– or to a Doctor’s appointment” and then they come and they take him where he needs to go and they either wait until he’s done or they come back for him. And he’s done grocery shopping – and he’s done this practicing through the school. But [name of transportation company] actually goes to the schools, makes sure they all have a special ID cards, and that they all have the benefit of having this number. ... He does have one class which focuses on what they need to do – and he’s gotten some certificates from [name of transportation company] for being able to get out into the community based on what he knows about getting himself transportation. I don’t think that that will be a problem. The transportation dept. is great. Like coming into the school, helping them out and taking trips with them, and showing them how to use the different things that are available.

Driving

Some parents suggested that at some point their child might be able to drive and gain increased independence. Still they had their reservations.

I have no doubt that he could work the car he probably already knows how to work the car that wouldn’t surprise me at all. But it’s the processing and understanding laws and anticipating what other people might do, those are all things that I think are going to make it very difficult for him to ever be a licensed driver so there is that problem.

Now that he is out of school I do all the driving. He tried to learn to drive, he expressed that with my husband and we were kind of leery. A few weeks ago my husband let him get behind the wheel of his truck and I am like, ohhh no.

F. Supports and services

Strengths of service agencies

Many parents felt optimistic about the agencies that exist to help people with disabilities. They applauded the efforts of individuals and agencies for their expertise and their efforts and endeavors to help people with disabilities.

That they exist is great, certainly that there are BRS people who come out to schools to meet with young people before they leave school, I think is really important.

Certainly I think they work with people to help them be compassionate and supportive and accepting of people so that people aren’t, the clients aren’t, on the defensive thinking this person is going to mock me or be impatient, because I don’t get things quite the way other people do.

I am just starting to get involved with them but I can say I had my first meeting last week and you know they have connections. So even if they don’t have all the answers, there are enough people around them that maybe somebody will. Just through the school and dealing with the transition case manager in my son’s situation, she’s already gave me names. OK, so there is the beginning. I get BRS, I get a whole trail of people start to come into play and I think from there it just starts to branch out.

Well the people that I know are really top notch workers who really care about the workers.

[The] strengths of it is, you know, helping these disabled people that, you know, they have disabilities they are unsure of themselves, help them out there, to get a job, you know, make them stronger and realize you know what? I am just like anybody else on the street.

We are working with the Department of Bureau of Rehab Services to get him a job coach and getting him a job. So that's coming along.

Weaknesses of service agencies

But service agencies were also viewed with a degree of skepticism by some parents.

I think its strengths are that it exists. I think that if you are talking about BRS and some of that stuff - my impression, because I haven't had direct experiences, that it exists and there are people there who want to help. And that they know the system. But I think that it is under-resourced and the eligibility time frames are probably too short and too stringent.

Oh, I will say in terms of strengths that his Bureau of Rehab Services case worker has, you know, kept in regular contact, been willing to be flexible about appointments, been willing to, you know, keep the process going. We started meeting with her last fall. I have a mild concern that we started meeting with her last November, and we have only gotten to the level of an employment goal in June. And we met with her monthly anyway. I hope that that was a process that took that long because he was in school still, because if you were out of school and you had to wait that long to get this far I think, wow, that would be very discouraging.

Other parents were bothered by the length of time that the entire process would take and how difficult it would be for families who live a distance from the agency office to continue to work with that agency.

Well she just you know we'll have an appointment and she'll well we need to make another appointment, we'll make another appointment for a couple of weeks away and then we keep making another appointment and it just seems like I just don't - to my mind it has taken an awful long time to get to this point when I could have gotten us to this point like in February. But so I don't fully understand their process.

I would like to see more involvement. Call me once a week let me know how things are doing follow up right away even with the DDS or DMR it's the same agency let me know what's going on - don't keep me on hold for a month or six weeks.

I wonder how it is for families that don't even live within half an hour of a BRS office, you know, and what do parents do who work? You know do they have to take off - I would have had to take off probably between one afternoon a month anyway to get him to all the appointments in the last 6 months - well there are some people who don't have that option so I am concerned about those things.

Suggestions to service agencies

Some parents had suggestions for agencies that would help improve their successes. One parent thought that doing things in groups might be a way of more effectively reaching more kids.

I don't think it is such a bad idea to do things in groups. I don't think everything has to be individual, you know, in other words, using the resources differently - so maybe groups of

young adults who are aimed this way or seniors having that as part of their curriculum, the BRS part of it. Starting then and working with groups of kids because I think they can problem solve and they can aim their efforts more effectively maybe, reach more kids. The resources are pretty limited.

Another parent thought that BRS should support volunteer positions as a way of getting job experience for these young people.

You know I went to a presentation that was given by BRS that talked about the importance of young people doing volunteer work and that made sense to me. And, you know, my son has done some volunteer work, but when I asked him if they would support him in a volunteer position in a field of interest of his, I was told, "oh no we don't do that." So I think that there is a disconnect there. What do you do with kids who get out of high school who aren't ready to work? Who will work with them?

Still, another parent was baffled at the approach of the BRS counselor. This parent indicated that instead of just finding her son any entry level position, the BRS counselor was quite insistent on narrowing the search to a specific skill.

Another thing that I found kind of mystifying is that like many 18 year olds I have said you need to get a part time job. He's like, ok, alright, many entry level positions would be fine. You could stock shelves, you could work in an office, you could like custodial but BRS won't allow him to work with agency to find some entry-level job. He had to narrow the focus to a particular field either light custodial or office work or stocking shelves or and I think well that's a crazy system all he needs is an entry level position so he can get some of the entry level experience. It is BRS that's saying, "oh, no we can't just help you find an entry-level position doing something doing one of say 5 things. We have to find you know like the job that you say you want.

G. Parental worries and fears

Child being taken advantage of

Some parents expressed a concern about their children being out on their own, in particular the possibility that people could take advantage of them because of their vulnerability. There were also concerns about whether their child would ever be able to be on their own.

I have known, of course, this is because I am his mother and I am protective of him, but I have concerns because his communication ability is so poor. I have concerns about people taking advantage of him. Like if he were put in a job by like one of our friends or by like one of his teachers who knew him that would be one thing, but I just I worry because he is naive he is very naïve and he could be very easily taken advantage of.

And even though he is disabled he is very good looking he is tall and handsome and I worry about maybe some girl taking advantage of him. I worry about a lot of things.

I mean my concerns are just that he has a socio-communicative disability that's going ... we live in a language-based society and my concerns about him working are the same concerns I have about him in almost every other area of his life, which is what is going to happen to him? Is he really going to be able to work? That's my thing. I think while he is higher functioning than a lot of retarded people, I still think that we're looking at some kind of sheltered employment thing. He is going to need a job coach, he is going to need to be closely

supervised. I think that if there is a place like that for him in the work force that's great, but I don't know if there is.

Financial concerns

Other parents had worries about financial considerations, such as being able to afford assistive technologies once the child no longer is in school. In addition, there was concern that providing housing for a child to enable him or her to live on their own would ultimately disqualify them from the other benefits they might receive.

And that's another problem once my son graduates from high school I have to figure out a way to continue and find the money to pay for stuff like that because it [assistive technology] won't be mine anymore so that's another big obstacle.

Who will be there for him/her when I'm not around?

For most parents, their biggest fear was the well-being of their children in the outside world, especially as parents age and are not as able to continue to take care of their children.

Well the biggest thing is as he gets older is he going to be able to live on his own at all. That's our biggest fear I think as parents. When we leave this place is my kid going to be taken care of? I think we have all tried to do trusts, special needs trusts, for our kids and what not, and I have tried to do that for him, but in the end is he going to be taken care of? It's a scary thing because you just don't know.

And who is going to be looking at that? Yes, he has a sister, but I don't want to put that on her shoulders the rest of her life either. If she were to move away or something like that you know? So that's scary for me- what happens to [name] when we go?

You know he said to me he wants to drive, he wants to move on his own into an apartment in New York. His sister's out there, and get a job out there, but I'm, like I don't know if this is ever going to happen.

V. Results of student interviews and focus groups

Six major themes, many similar to those discussed by parents, were highlighted in the student interviews and focus groups:

- The school system. Most students had only positive things to report about their school and how it was providing them with ways of gaining experience and helping them to prepare for a transition to the work force. Some students already in college spoke about how their college was especially sensitive to the needs of students with disabilities and how that college continued to provide accommodations for them.
- Employment. Students were far more optimistic than parents regarding their expectations from potential employers. Students with disabilities showed resilience to ordinary obstacles in their lives. They had already overcome so many obstacles that finding a job seemed like just another hurdle to overcome. The majority of students thought that employers might be a little bit more altruistic and actually give them a chance to prove themselves. Some mentioned that employers just needed to be made aware of their limitations and that the rest would fall into place. Despite their disabilities, many students had a definite career plan in motion and were eager to pursue it.

- Accommodations. The students talked about different accommodations or assistive technologies that they utilized in school. For many students, there were computer programs used both for communication and for helping them in writing papers and organizing their school work. Many students worked with para-professionals in the classroom to help them organize and keep track of assignments.
- Transportation. Transportation was again seen to be the biggest barrier for most students, although there were some who had completed the travel training and felt that there would be no limit to their ability to get wherever they needed to go.
- Participation in the community. Many students spoke about their involvement in their community, and were contributing by doing volunteer work and helping people who were less fortunate.
- Parental involvement. Students generally agreed that having supportive parents was paramount for their plans to be successful. For the most part, parents had been involved in getting their children established in various programs that would eventually lead to success, but their main contribution was encouragement and believing that their child would succeed.

In addition to the themes identified through student discussions, a final theme concerning some of the weaknesses of the system emerged from the adults (transition coordinators or guidance counselors) who participated in the focus groups or assisted students with their individual interviews.

The following sections explore student reactions and discussions in more detail.

A. The school system

Positive reports about the school system

Most students had good things to say about what their school systems were doing to prepare them for transition into the work world. Two of the focus groups and one individual interview were completed with students who were enrolled in the ACES (Area Cooperative Education Services) school, a school exclusively devoted to training children with disabilities in a variety of career skills. One student who attended the ACES school spoke of the variety of activities for students.

We go to a lot of places, like different businesses, to get some experience. School helps me prepare by doing academics stuff, and preparing me for a career by watching career videos - so I can find out what different careers are all about and what is allowed on the work site and what is not. Getting paid is the best part.

Another student described the job that he worked on at the ACES school, which is only one of a variety of job experiences. He said that the school prepared him for different work experiences so that they could determine which one he would actually like doing the best.

Well, the work that I did at school were gas caps, rods, stamps and caps. I put them together. I sorted them out. It was part of the class. It was an assembly job. It's putting a gas lock together - it's assembly at your own pace.

Another student described the variety of experiences available to them.

There are two or three of these jobs that we do in the community. [Company name] - I type the company name and make covers for the binders. At [company name] in New Haven I put

the invoices in their correct company folder. I like working in the office. I also work at the nursing home [company name]. I fold the towels and put them in piles.

Other school systems provided skills training to prepare their students with disabilities for working in the future. Some school systems had either job shadowing experiences or internships in place for students in addition to career centers. One student with a learning disability described the job shadowing experience that her public school provided.

My school takes me on job shadows to certain places of interest that I am interested in after high school. I'm interested in nursing and I want to eventually want to go into the neo-natal unit. So they set me up with a lady at a nursing home in [name of town] and I went there and I job shadowed, like I got a tour about it, and they're willing to put me through school for the six-week course, and pay me to go to school for them to be a CNA. That would be my first step.

Another student with spina bifida plus a memory problem as a result of it, described how her school encouraged her and made accommodations for her disability so that she could pursue her dream.

I think that this program at school really helped me a lot to be able to decide what career is best for me. Being able to have services through the school, like having extra help and extra time on quizzes and being able to have job shadows, and brought to the places to see real life experiences, one-on-one to see if this is what you would like to do and I think other kids should definitely have an opportunity to be able to have the opportunity to go out with a person and go on a job shadow, and see if this is really what they want to do. And not to let their disability hold them back - just go for what they believe in and go for their dream.

Students from various school districts described what their school systems were doing. One district offered internships and two students within this district described the importance of having these internships.

I think that because I had those internships, that I have gained a lot of work experience. I would say anybody who wants to do the internships can do them. It gives you the experience that you need to eventually find a job.

Another student had already started her career planning at college. She was planning to start her internship in the fall.

I'm going to be interning actually - so I'm a social work major - and I have an internship set up for next fall at [company name] - working with adults with mental illness.

Students also spoke of their training in independent living skills either in classes or by actual hands-on experience. At one school, there was a practice kitchen and practice living room for students to try out some skills, including cooking, cleaning, and paying bills.

It teaches you auto mechanics, budgets, how to interact with people, how to create resources, and we have employment skills, math and English courses that do help us with the business area.

A university attended by one of the interviewees has a Disability Resource Center. A student described the benefits.

...and I have weekly appointments there with a specialist who helps me think about what jobs would be good for me or how to be more prepared with things like, how you should dress, or what you should be prepared for. So it is the DRC does the most in preparing me as a disabled person for in the future, entering the workplace.

Other high schools prepared students in classes designed for that purpose, to help in finding a job. One high school student described his class.

“Jobs for the Future” - I took a reading class, and the teacher told us what to do when we go to an interview. I know that [teacher’s name], she is in charge of - she just helps people find jobs for the future - like we go on job shadows.

Another student who was enrolled in a public school described his work experience and school classes that were helping him to prepare for his future employment.

I work at the computer company, [company name] and [arts organization] - two different things. This is primarily what is giving me work experience. But I also take a class, “Career Connections” where I learned how to make resumes and other things that might go into your portfolio.

Negative reports about the school system

Most students had very positive things to say about their school in terms of preparing them for transition. Only one student who is now in college had a negative comment about his high school.

I think that on the high school level, I think that they should do more. I think that they should do more in just preparing people for other skills sets, like money management, other things that could just help make it a little easier, like independent living skills - things that aren’t really taught at high school, but would be just as important.

B. Employment

Employer perceptions

Most students were apprehensive that potential employers might think that they would not be able to accomplish the job because of their disability. However, many remained optimistic that employers might be willing to give them a chance. One young woman put it very well. She said,

I think that a lot of employers (it’s what I have learned or I have been told) employers - especially people with physical disabilities, they will look at you and they will be like, “Oh - she can’t possibly do that job.” So we need to be able to explain to their employers that, “Yes, I have a physical disability, but can do the job this way instead of that way.” People with disabilities need to be able to advocate for themselves, explain to the potential employer how they can do the job. I would hope that most employers would extend the opportunity to show them that you can do the job. I think it probably depends on the employer, but I am hoping that most people are willing to learn.

One student who was already working at her part time job as a hostess at a hotel told of her experience working with her employer.

I think that the employer might discriminate against people with disabilities thinking that they might not be able to do the job. I never mentioned that I had bad knees at my work - they would probably say, "well, you're on your feet all day at work, so I don't think that you would be good for the job." So they probably wouldn't have given me the chance to work. It's not obvious that I have bad knees except for if I've been working a lot, I can't stand up straight because I don't have good balance, so I slouch a little bit and my feet turn in and sometimes I limp. But you don't really notice that at the beginning - My boss now knows about all of my medical problems and he said that he would never have guessed that I had any of these problems because I hide it so well.

A student with a learning disability commented:

For example, I have a learning disability. So I should just sit down and explain to them [employer] and tell them that you may not understand things like at first, but it may take a few times to get it stuck into your head where you can understand it and process it. And maybe if you explain it to them then they would be able to train you a few more times to make sure that you have it. Just a little bit of extra time.

Another student with a learning disability said:

Well, they have to understand that we are disabled, that we are a little bit slower than normal people, but you got to give us a chance. We will catch on, but we will catch on slowly. Once we catch on, we're good.

A young man with muscular dystrophy thought that he would have to go above and beyond to convince a potential employer of his abilities. He said:

I think that one factor is that they have to go above and beyond, because otherwise the employer might just see the wheelchair. They might not see the person - the actual person. They will just see the wheelchair. I suppose that if people aren't vocal enough about who they are and what their abilities are - that they are pretty much like everyone else, they just have their limitations.

One of the teachers in the focus group pointed to the issue of self esteem. The students agreed.

... that they are afraid to reveal something to the employer about something that they are not able to do for fear that they might not get the job. They feel inadequate because they are not able to do everything and this lessens their ability to convince the employer that they could be a valuable asset for the company that they might come to work for.

One student from ACES who already had a job had this to say.

I think that there are going to be people out there who see us for who we are and I think that yeah we are going to have struggles but there is going to be support out there and I think that it's mostly with the struggle with the reading and some things we have to know when we go out there in the community. Because if you don't know where to go, people are going to target you a little bit. I don't know, I am just speaking first hand for me.

C. Accommodations

Accommodations at school

Students were asked what types of accommodation they were currently receiving at school, and what possible accommodations they might need once they enter the work force.

Several students with learning disabilities indicated that they used computer programs available to help them at school.

There's a program I use because I'm really bad at writing papers. It's called "Write out-loud" and "co-writer" helps me to write papers.

I have my own laptop that I got, I've had it since high school. They sent it over from my high school. It has programs on it to help me - it has co-writer - it's a word program where it reads me out the sentence so that my sentences sound right. It has been a lifesaver. I have keyboarding pro - it's to help me with how many things I can type.

One student with cerebral palsy who was attending both high school and community college classes was using a touch screen for communication - DynaVox – a computer plus communication device. Another student with short term memory loss due to a physical complication needed to have text read to her. In college she will probably use a computer program which has the ability to scan text through the computer and then read it out loud. Currently the teachers in her high school were reading the text to her while she read along. She said that hearing the voice while reading along helped to reinforce the subject matter.

Students with physical disabilities spoke about the kinds of devices or accommodations they use for accessibility.

I have spina bifida - I need structural adaptations, like a ramp at my house, I need ramps when I go to places. I need adjustable desks when I'm at school. I use a wheelchair (just a regular wheelchair - not electric). So then I would need also to have a lift van.

One student with muscular dystrophy needed a personal assistant at the university he attends, and described a helpful university service that recruits other students to assist. Although he uses a motorized wheelchair, he still needed assistance in transferring.

But [name of university] has a program where you - they have a listing of other students who are actually willing to be a personal assistant - and I found - I started narrowing it down and calling certain people - It was hard to find people that could help me at that particular time or at that particular location because they are also taking classes too. Most of them were very good. It provides someone that I could talk to and also them being a student, then I could talk to them about school stuff.

Accommodations in the workplace

The accommodations that this group spoke about with regard to finding and holding a job were in many cases quite simple. One student with Asperger's syndrome commented:

Well, maybe extended time to do the jobs. I would probably need a few breaks along the way too. And a little bit of training.

One mother of a student with autism who prompted her son during his interview described the situation:

He needs a job coach and possibly more frequent breaks. And also, he needs to be buffered a little bit from a lot of activity of people so that he's in a more quiet area. You wouldn't put him out as the front desk person, you know what I'm saying?

A student with spina bifida described her needs in the work world.

I'd need an accessible bathroom and a desk that I would be able to reach. I would need an accessible entrance to get into the building and get around the building, shelves that I could reach, you know to reach files. I don't think it would be too expensive. I don't think that I need too many accommodations. I can use a regular keyboard.

Communication and social skills as a barrier

Most students with intellectual or learning disabilities and those with autism related diagnoses agreed that they would need some help getting through the interview process. Many students lack social skills and admit that they would have a difficult time getting through the interview and being able to express to the employer what they are capable of doing. Several career centers at the school systems offered the students the opportunity to do "mock interviews" so that students could have practice regarding what to do and what to say during the interview. Students who participated noted that this was a very positive experience.

D. Transportation

In school, many students relied on parents or school buses to get them from home to school. One young woman who was out of school and had a job working in housekeeping at a large retailer said,

No, I get chauffeurs. I have four chauffeurs. My parents, my sister and my brother. All family members. I work Sunday through Thursday. I work four hours a day. So that is 20 hours a week.

For individuals who had a good support system at home, transportation was not seen to be an issue. However, one individual who was currently living on his own and attending both high school and college classes had a more difficult time regarding transportation. His transition coordinator explained how he maneuvered. He has cerebral palsy and can only communicate through his DynaVox.

[Name] does have ADA and he is using the Kennedy Center to receive bus training to certain places. So he's independent in transportation. He can go from home to [community college] using public transportation.

We got bus training from the Kennedy Center and we've also done training on our own. But as far as modifications, it was a problem before we got the DynaVox. You know when the weather gets cold - we have problems with it. We don't want to take it out in the weather. He has a book that he carries that gives the stops that he needs on the bus. So he can flip through that whenever he gets on the bus. So we've made modifications like that. He carries that book with him, for when he gets stuck and he needs to hop on a city bus home. And he's able to ambulate around the community.

Transportation is really an issue. The city bus - the ADA - is not convenient to get to places where he needs to go. To visit his mother is difficult to get over there. He has appointments for his DynaVox and physical therapy in Bloomfield and it's difficult to go. If he didn't have ADA - and a lot of times they're not reliable - so that really is an issue. Transportation is a huge issue. ADA is a wonderful service, but I don't understand how they can put a rocket ship in space and have people living for years and not be able to schedule transportation. It's just a shame. He's been left over in Bloomfield until 7 p.m. If he didn't have a cell phone with him so that he could text somebody to call, he would still be sitting there until someone noticed him. So they're just not reliable.

While at school, a student with spina bifida described her transportation needs.

My parents drive me when I'm at home (because I'm home for the summer) and then I have students that work for me, PCAs that I hire and they will drive me to do grocery shopping like when I am on campus - they will help with transport to my internship.

Another student who would not be able to drive herself had also accomplished the travel training program.

I have actually, I did travel training. And I went through everything and just got my certificate. So now I know how to navigate by using the buses.

One focus group participant from ACES had a job at a hospital through the ACES program, and was getting transportation provided by the school.

Transportation is one for me. I don't have my driver's license and I don't have a car plus the whole kit and caboodle with it. So that's going to hinder me a lot. That means I am going to either have to ride a bike to the train station and get a train down to New Haven, and take the shuttle to [the] hospital, or I am going to have to get a job real close to home.

A young man with muscular dystrophy was not currently driving, but had recently gone to an evaluation to determine if he might be able to drive, and the results of that evaluation were positive. When asked, "what one thing would you need to better prepare you for employment?" he replied,

Probably one thing would be being able to afford a new van. Because I went to a driver evaluation just to see if I had the necessary motor skills to be able to drive. They said that I would be able to drive, except that I would need to get a new van that would have to be modified ... I would have to purchase the van and then state agencies would pay for the accommodations. So, basically, I need to have enough money to purchase another van - the van that I would need would be at least \$20,000 or \$30,000 maybe.

E. Participation in the community

Students had varying experiences and involvement in their communities. Two were involved in Special Olympics, one as a swimmer and the other in a team basketball effort. Despite their disabilities, many students were active in their community doing volunteer jobs and gaining work-related skills. They had many comments regarding their community involvement.

Well, I volunteer and help out with this benefit for saving the park that is down the street from me. I do things like put together packages for kids and then I work with the kids. I like working

with kids, but my real interest is in medical and animals. I spend a lot of time helping out there. And I'm in Girl Scouts.

I volunteer at my food bank. I did that while I was in high school too. Mostly I crush boxes, sometimes I get perishables from the fridge. I go there once a week. I've been doing that for some time.

I'm volunteering at the hospital right now since I'm not working. And I did that when I was in high school too. I volunteer at [name of hospital]. And I'm like an ambassador - so I work in the admitting office in the children's part of the hospital. So I greet people and I escort them up to the various floors - to the labor floor, or maybe - and I also do filing.

In the summertime, my church has vacation bible studies, or vacation bible camp. So they are like little kids and I'm a camp leader. We play different games that have to do with God. I do that for a week and it's volunteer. And we sell pumpkins for kids that don't have beds. And I help out with that too. I don't have too much extra time.

F. Parent involvement

A large majority of the students perceived their own parents as being very supportive of their efforts and their dreams. Parents wanted their children to be happy, successful, and, if they desired, to be independent. One student who is now in college said this of her mother,

My mom has gone to a few workshops, like career fair workshops, stuff that I have gone to at Southern, and she brought me to my internship interview - Yeah, she has definitely has been encouraging me. My mom and dad too, have always encouraged me to get a job. I can see working full time eventually.

A young man with autism believed that his parents were truly supportive of his dreams.

They encourage me. They teach me things like social skills, and daily living skills like talking to people nicely. So they are helping. They would like me to work.

Other students expressed similar sentiments.

Mom is very helpful - she supports and encourages me and she is my greatest asset. So there's no reason why I wouldn't be able to succeed. I have been doing laundry at school. And I have been practicing at home and I can cook too. So that I can be independent.

Yeah, my parents really encouraged me to get a job. My mom actually encouraged me to work at the daycare center, to see what it would be like to work with kids, to see if that's the field I wanted to go into after high school. So that is one of my part time jobs.

G. Weaknesses of the system

Unlike the parent interviews, individual students were not asked to comment on the existing service system that focuses on helping people with disabilities to find and maintain employment. Nonetheless, several unsolicited remarks were made by transition coordinators or guidance counselors who were either present at the focus groups or who assisted students in their interviews, noting some of the weaknesses they saw in the existing service system.

We've all been frustrated with BRS. I came aboard about a year ago with [name of student] and he applied to BRS. We had meetings and the staff never showed up. They were invited and said they were coming, and all of a sudden ... they make promises and they never delivered. For example, they said that they were going to do vocational assessments, they were going to do this, and they were going to do that - it's just not happening. We're going to do an evaluation, and now they say if you can find a place for us to do the evaluation, it would be much easier. And all of us are sitting there saying, "Wait a minute, I'm already spending time in your state agency and isn't this what your job is?" It's really frustrating. It was the first time I worked with that agency and I know his guardian is upset. I know you haven't gotten the things that have been promised, the situational assessments and evaluations and that's over a year ago that they were promised to be done.

The transition coordinator at one school system indicated that a BRS counselor had come into the school to meet with the students, but only rarely (almost never) came to any of the PPT meetings. The transition specialist had worked hard to get all of the paperwork completed for BRS before each student was scheduled to graduate. But all of the professionals in the career center had complained about the workings of BRS. According to her, they do their best to get the students enrolled in BRS before graduation, however BRS then complains about not knowing if they have the funding to take on any new individuals, and often do not provide any follow through for those that they have taken on. Students who had graduated called the career center and said, "You said that BRS would help me find a job." And the career counselor had to explain to the students that they must be persistent and continue to call, and call them back several times in order to get their attention. There was a general feeling of being let down exhibited by the counselors, and certain professionals in the career center indicated that BRS was not doing the job that they were supposed to be doing.

VI. Conclusions and limitations

This study had a number of limitations. Because the students and parents interviewed constitute a convenience sample, it is hard to draw generalizations from the results. There are several major ways in which the samples were not representative of the population of students with disabilities and their parents in Connecticut. The parents interviewed were overwhelmingly female and white, and the majority of their children had an intellectual or learning disability. Non-white and male parents, as well as parents of children with physical disabilities were under-represented. The student sample was more representative in terms of gender and racial/ethnic background, but once again consisted largely of students with intellectual and learning disabilities. In addition, two of the three focus groups consisted of students from the same school (ACES), a school specifically geared toward students with disabilities. These students may not be representative of students in other school districts.

Nevertheless, this study was designed as a means of capturing the "voice of the consumer," by exploring in depth the experiences, attitudes, hopes and fears of students with disabilities and their parents. Qualitative methods, including focus groups and in-depth interviews, were used to generate insights into the concerns, motivations, preferences and expectations of students and parents regarding school, transition and work. The information is by nature anecdotal. It supplements data from the 2009 Statewide Special Education Transition Services Survey (Reed, Shugrue & Robison, 2009), which provided quantitative data about transition services in the state's school districts.

Both parents and students had many positive comments about their school systems, with compliments offered for many programs and services provided to students. Students in particular were almost universally positive. Parental comments about the schools were balanced by a number of reservations regarding the timing and content of services. The role of parents in the transition

process was also seen as strong and important by both groups. Many parents believed that if it were not for their efforts to prod the schools, their children may have been overlooked or ill-served. Most students agreed that their parents were encouraging to them and served as strong and effective advocates within the schools.

Both groups also agreed that transportation was a serious barrier in the process of finding and keeping a job and that reasonable accommodations, while often necessary, should not be serious obstacles to succeeding in school or work. Parents had mixed feeling about service agencies and their ability to help the students find meaningful employment. Many parents had strong negative comments about their experiences with agencies' level of resources, flexibility, and timeliness of their assistance.

The most striking difference between parents and students was their degree of optimism about employment and employer attitudes, as well as the difficulties they would encounter in life as a result of a disability. Parents clearly worried about employers' pre-conceived notions concerning their children's abilities, and some had already experienced what they considered discrimination against their children. Students, by contrast, were overwhelmingly optimistic, had high expectations of potential employers, and believed they would be given a chance to prove themselves. Many had high career aspirations already, and thought their disability would be "no big deal."

Finally, parents worried about their children's futures, and how serious the impact of their disability would be. Parents feared that their children could be taken advantage of, that they may not be able on their own to become economically self-sufficient, and that they may have insufficient support systems when the parents were gone.

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Appendix A
Interview Guide
Parents of Students in School

Introduction

Thank for agreeing to be interviewed by us. The Bureau of Rehabilitation Services at the Connecticut Department of Social Services (BRS) is conducting this evaluation project that focuses on employment services and supports for people with disabilities or chronic conditions

You were chosen to participate because of your experience and knowledge about youth with disabilities in the school system. Your participation and any views you may express will not affect any relationship you may have with BRS, the University of Connecticut, or your child's school system. Your confidential participation is entirely voluntary. The telephone interview will take approximately 20-30 minutes to complete. Do I have your permission to continue?

- 1) Think back about your experiences when you were in school – include high school, college, vocational school or anything else. Please describe the role your school played in preparing you for employment.
[Probe: were there specific people who helped you, e.g., a guidance counselor?]
- 2) What is your role as a parent to prepare your children for employment?
- 3) What do you think about your child working?
- 4) What prevents people with disabilities or special needs from getting the jobs that they want?
[Probe: need for accommodations]
- 5) If your child has a job, how did he/she find a job?
5a). [if yes to #5] WHAT program helped your child find work
- 6) Think about the existing service system that focuses on helping young people with disabilities or special needs find and maintain employment.
 - 6a) What are its strengths?
 - 6b) What are its weaknesses?
 - 6c) What would you like to see more of?
- 7) Please describe the supports or job accommodations your child has used at school or work.
[probe: what types of Assistive Technology or job coaching, if any, has he/she used?]
- 8) If you could have one additional thing that would prepare your child for employment, what would it be? Is it too late to have it?
- 9) Outside of school, how does your child participate in your community?
[Probe – club member, recreation, church, volunteering]
- 10) Is your child able to participate in extra-curricular activities as much as he/she would like? If no, why?
- 11) In school, does your child participate in regular education classes as much as you want them to?
- 12) What difficulties does your child experience traveling to and from school?
- 13) Is there anything else you would like to add?

Appendix B
Interview Guide
Students in School

The purpose of the Medicaid Infrastructure Grant (MIG) grant is to design an inclusive workplace for the future that will accommodate a diverse workforce including people with disabilities. Your input is very important to us in this process.

1. We are interested in learning about the transition from school to work, so we are starting with some questions about your school experiences. Think about your school experiences. Please describe the role your school plays in preparing you for employment. [probe: are there specific people who help, e.g., a guidance counselor?]
2. Are you taking any classes that will help you get a job?
3. Please describe the role your parents play in preparing you for employment. [For example, do they encourage you to get a job or help you find a job?]
4. What do your family and friends think about you working (now or in the future)? [Probe: do they feel you should be currently working, working more, working less, or not working at all? Has anyone ever advised you not to work?]
5. What prevents people with disabilities or special needs from getting the jobs that they want? [Probe: need for accommodations]
6. If you aren't working, how will you go about finding a job?
7. How will you go about finding an appropriate community college or university?
8. How much of your talents and skills do you use in your school?
9. Please describe the supports or job accommodations you have used at school. [probe: what types of Assistive Technology or job coaching, if any, have you used to go to school?]
10. Please describe any experiences you have had with personal assistants or home health aides at school.
11. If you could have one additional thing in your life that would better prepare you for employment or higher education, what would be? Is it too late to have it? Why?
12. Outside of school, how do you participate in your community? [Probe – club member, recreation, church, volunteering]
13. If you feel that you would like to participate more in your community, what kind of supports would you need to do so?
14. Are you able to participate in extra-curricular activities as much as you want? Please tell us more about that. [For Focus Group leader: we are trying to get at the system's capacity to include them and barriers they face, not so much a list of activities: probe for positive and negative]
15. In school, are you able to participate in regular education classes as much as you want to?
16. What difficulties do you experience traveling to and from school?

Finish with this question:

17. Is there anything else you would like to add?

Appendix C

Focus Group Guide Students in School

The purpose of the Medicaid Infrastructure Grant (MIG) grant is to bring down barriers that keep people with disabilities from getting good jobs. Part of this is helping to design an inclusive workplace for the future that will accommodate a diverse workforce including people with disabilities. As people who will be joining the workforce in the near future, your input is very important to us in this process.

1. We are interested in learning about what the process of going from school to work is like, so we are starting with some questions about your school experiences. Think about your school experiences. Please describe the role your school plays in preparing you for employment. [probe: are there specific people who help, e.g., a guidance counselor?]
2. Are you taking any classes that will help you get a job?
3. What type of job would you like to have when you finish high school or college?
4. What do you think might get in the way of your plans? [Probe: Assistive Technology, accommodations, employer attitudes]
5. Please describe the role your parents play in preparing you for employment. [For example, do they encourage you to get a job or help you find a job?]
6. What do your family and friends think about you working (now or in the future)? [Probe: do they feel you should be currently working, working more, working less, or not working at all? Has anyone ever advised you not to work?]
7. If you aren't working, how will you go about finding a job?
8. How will you go about finding an appropriate college or university?
9. If you could have one additional thing in your life that would better prepare you to get a job or go to college, what would be? Do you think it is too late to have it? Why?
10. Outside of school, how do you participate in your community? [Probe – club member, recreation, church, volunteering]
11. If you would like to participate more in your community, what kind of supports would you need?
12. Are you able to participate in extra-curricular activities as much as you want? Please tell us more about that. [For Focus Group leader: we are trying to get at the system's capacity to include them and barriers they face, not so much a list of activities: probe for positive and negative]
13. In school, are you able to participate in regular education classes as much as you want to?
14. What difficulties do you experience traveling to and from school?

Finish with this question:

15. Is there anything else you would like to add?