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*The stories of real people
and employment*

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A. Introduction, History and Methodology

1. Background: Connect-Ability

Funded by the Centers for Medicare and Medicaid Services (CMS), the Medicaid Infrastructure Grant, now known as “Connect-Ability,” was awarded to the Connecticut Department of Social Services (DSS) in 2006. The grant is designed to enhance and support competitive employment for people with disabilities. The Medicaid Infrastructure Grant Needs Assessment Final Report, published by the University of Connecticut Health Center, Center on Aging, describes the purpose of the grant:

The grant is intended to facilitate enhancements to the state Medicaid program and services, to promote linkages between Medicaid and other employment-related service agencies and to develop a comprehensive system of employment supports for people with disabilities (Robison, Gruman, Porter, Kellett & Reed, 2006, p. i).

Connect-Ability included, as one of its first components, a needs assessment survey sent out to people with disabilities throughout the state of Connecticut. Respondents included Connecticut citizens who were participating in any of the Medicaid waiver programs designated for people with disabilities, the Medicaid Buy-In program, and some individuals who were participating in the Connecticut Benefit Offset Demonstration project.¹ The survey included both quantitative and qualitative (open-ended) questions about their experiences, expectations and needs regarding work and personal assistance. In addition, separate surveys were sent to employers throughout the state to obtain information regarding their attitudes and practices in relation to hiring people with disabilities.

The results of the Connecticut citizen survey, in addition to providing information about living situation, ratings of overall health, transportation and neighborhoods, yielded a sequence of challenges or barriers to working as expressed in an open-ended question. The most frequently mentioned barriers or challenges faced by workers included physical health problems or physical disability; transportation; lack of personal assistance either at work or at home; intellectual or cognitive disability; emotional difficulties or mental illness; work place accommodations; training or education; assistance to find a job; lack of jobs with benefits or good pay; concerns about loss of benefits; and older age (Robison, et al., 2006).

In addition to the survey, more complex, qualitative information was derived from focus group and key informant interviews. Representing the voices of 320 stakeholders, including people with disabilities, family members, service providers, state agencies, and employers, these in-depth interviews revealed several themes. One of the predominant themes was the fact that many Connecticut residents with disabilities are still struggling to gain employment. Another theme was the perception that people with disabilities are still experiencing discrimination in many employment practices.

¹The Benefit Offset Demonstration Project is a pilot program sponsored by the Social Security Administration (SSA) that affords people who are receiving Social Security Disability Insurance (SSDI) the opportunity to earn more than the maximum amount usually allowed for those receiving SSDI without losing all of their cash benefits.

2. 2008: The Birth of the Pathways Project

Results of the surveys, focus groups and key informant interviews provided significant information about the employment barriers and challenges faced by people with disabilities. The Connect-Ability team sought to enhance that information with more in-depth insight into the journeys of individuals, over time, in their struggles to find meaningful, competitive employment. The *Pathways to Success* project was initiated in early 2008 to follow a group of individuals with disabilities through periodic in-person interviews in which they share their employment stories, including their aspirations, successes and failures. This qualitative research was designed as a way of describing the personal experiences of people with disabilities in their pursuit of employment.

Initial interview participants for the *Pathways* project were recruited from the pool of callers to Connect-Ability's toll-free assistance number, which was set up to provide a common point of information for both employers and job seekers. Several hundred calls were made to the toll-free number during 2007 and 2008 as a result of Connect-Ability's wide-ranging public information campaign. The early calls came overwhelmingly from people with disabilities seeking competitive employment.

A researcher associated with the University of Connecticut Health Center (UCHC) made calls to 121 of the several hundred inquirers who had called the number during the period from July of 2007 to May of 2008. Although the primary purpose of the initial calls was quality management (respondents were asked several questions about their experiences when they called the Connect-Ability toll-free number), one question was designed to recruit individual callers who might be willing to participate in the *Pathways* study.

During 2008, the first year of the *Pathways* study, nineteen men and women agreed to participate in an initial interview and follow-up interviews at regular six-month intervals. Since participants were chosen on the basis of their willingness to participate, the sample is not representative of those who called in; neither is it representative of people with disabilities who have a desire to work. The majority of first-year respondents were men (n=15) and the respondents represent a wide variety of disabilities including back injuries, stroke, spinal cord injuries, traumatic brain injuries, visual impairments, cognitive impairments, and mental illness. In two cases, a proxy related to that person answered the questions. In another case, both the participant and his mother contributed to the interview. The ages of the 2008 group ranged from 21 to 61. Demographic information for the nineteen original interviewees is presented in Table 1.

Table 1. Demographic information on the original participants

Type of disability	N (%)	Age	N (%)	Working status	N (%)	Gender	n (%)
Physical	14 (74)	21-30	3 (16)	Full time	2 (11)	Male	15 (79)
Mental	1 (5)	31-40	4 (21)	Part time	1 (5)	Female	4 (21)
Cognitive	1 (5)	41-50	7 (37)	Not working	13 (69)		
Vision	3 (16)	51-60	4 (21)	Self-employed	3 (16)		
		Over 60	1 (5)				

An in-depth look at the results of the first-year interviews was compiled in a research report available from UCHC (Reed, Shugrue, Robison & Ducharme 2009).

3. 2009: Pathways in Year 2

Fourteen of the original 19 interviewees continued their participation in *Pathways* in 2009, the second year of the project. There were 31 total interviews completed during 2009: 10 first interviews of new participants, 14 second interviews, 6 third interviews, and 1 fourth interview. Five original interviewees, 3 male and 2 female, did not continue their *Pathways* participation in year two. All were unemployed at the time of the first interview; all had a physical disability; two were in their 30s, two were in their 40s, and one was in his 50s. Three either had their phone disconnected or failed to return the interviewer's calls after several attempts. One individual refused to participate in a second interview, saying she was unwilling to give any more of her time. One person was a "no show" for the interview.

The 10 new individuals added to the study were again selected from people who called in to the Connect-Ability toll-free assistance number. As the first group had been primarily male, the researcher attempted to increase the number of females interviewed. In the 2009 group, ages ranged from 16 to the 50s, half were male and half were female, and the majority (70%) were not working. Two of the ten were aided by a parent in answering the questions.

The demographic characteristics of these new individuals are presented in Table 2.

Table 2. Demographic information on the 10 new participants

Type of disability	N (%)	Age	N (%)	Working status	N (%)	Gender	n (%)
Physical	6 (60)	Under 21	1 (10)	Full time	1 (10)	Male	5 (50)
Mental	3 (30)	21-30	4 (40)	Part time	2 (20)	Female	5 (50)
Cognitive	1 (10)	31-40	1 (10)	Not working	7 (70)		
Vision		41-50		Self-employed			
		51-60	4 (40)	Attending school	2 (20)		

4. Interview tools and process

For all initial interviews, information was gathered by the researcher through a guided interview based on an interview guide approved by the UCHC Institutional Review Board (Appendix A). The research evaluation team at UCHC received significant input into the development of the survey from members of the Connect-Ability Steering Committee. The interview assesses the current employment status of each person; satisfaction with services rendered by private and public agencies; and barriers encountered in the search for employment, such as transportation, attitudes or biases, accessibility or lack of accommodations.

At the time the participant agreed to be part of the research, a date and time were set to conduct the initial interview. The majority of the interviews took place in the person's home, with the exception of one participant who was homeless. His interview was conducted in a quiet corner of a local diner. In each case, participants were assured of the confidentiality of the information that they were about to disclose. The interviews were tape recorded and subsequently transcribed. Each interview lasted 45-60 minutes. Finally, each person agreed to follow-up interviews at six-month intervals for the duration of the study. The 2008 report was based on the 19 initial interviews conducted through December 2008. During 2009, 10 additional interviewees were added to obtain a more diversified sample, along with follow-up interviews with the initial group of interviewees. One of the new participants had both a first and second interview during 2009.

For follow-up interviews additional questions were asked of the interviewees, based on the IRB-approved follow-up interview guide (Appendix B). These questions were designed to continue the story of the person's employment journey, specifically directed toward finding out what progress the individuals had made in finding a job, what help or support they received along the way, and what barriers they encountered.

5. Analysis

All of the transcripts were entered into Atlas.ti.5.0. This program is designed exclusively for qualitative (open-ended responses) information. Content from each open-ended question was analyzed using standard qualitative analysis techniques (McCracken, 1988). Transcripts were analyzed line by line in order to identify and interpret each individual's responses. Major concepts or areas of interest supported by direct quotations were organized into common themes using the constant comparative technique (Glaser & Strauss, 1967). Additional themes were included until no new topics were identified. Like statements were then explored and compared to refine each theme and ensure a fuller understanding of each.

B. Initial Themes Confirmed by New Participants

Themes that emerged from analysis of initial interviews with new participants were remarkably similar to those from the original group. While no new themes emerged, some of the original themes were emphasized in different ways by this new group.

The major themes (each with several sub-themes) included the following:

- employment related issues (including employment status, aspirations of participants, finding a job, and problems at the job caused by the disability);
- external sources providing help (including supports, positive and negative experiences, and thoughts regarding the Connect-Ability toll-free number);
- barriers (including transportation, accessibility, need for accommodations, additional training and assistive technology, benefits, and employer perceptions); and
- attitudes (such as having a positive attitude during interviews, the supportive attitudes of families, and negative attitudes).

1. Employment related issues

The ad campaign to promote Connect-Ability continued during parts of 2009, and featured individuals with various disabilities working successfully at competitive jobs. Many interviewees saw these ads as inspiring and wanted to pursue similar avenues to employment. Each new participant had aspirations about employment, and each one had different approaches to finding a job. Some had been able to find jobs, but found that their disability interfered with their ability to maintain that position. Others were having little success in finding any job at all.

Employment status

A majority of the new interviewees were not employed (n=7) at the time of their first interview. One individual was employed full time, two had part-time jobs, and two individuals were also going to school (one full-time student and another with a part time job.)

Employment aspirations

One man in his late 50s indicated that several times he had applied for jobs and was told that he was overqualified. He was just looking for any job. He went on to say

... but you're not overqualified if you don't have food. You're not overqualified if you can't pay the rent and can't buy gas for your car. You'll do any work, and that's where the indignity occurs. And who is saying that we can't do that work or that we wouldn't be a good person to have?

The mother of a 16-year old girl with spina bifida reported that her daughter always wanted to work, but showed a slight reluctance in terms of how to approach this, probably because of her disability. The mother said that even though her daughter is a full-time student, she was able to take part in a summer work program for children with Down syndrome. This program helped her daughter, enabling her to discover the kind of work that she might be interested in doing after graduation.

I believe she always wanted to work, but kind of felt like, how do I do it, how do I get a job? She was waiting for somebody to put it into place for her and this summer program was an opportunity for a lot of help to put it into place.

Finding a job

Some new participants were working by themselves, in traditional ways, to find jobs. Others had connected with various state agencies, to help them find jobs. One woman who had worked at her last job for 18 years as a case manager was now under restriction by her doctor to drive only an hour a day. As a case manager she had previously driven 1500 miles per month.

I did and have continued to try to network through [names of state and non-profit agencies]. I have spoken to a variety as to what is out there in trying to identify how I can best transition back into the work world.

Another woman in her 30s had this to say about finding a job.

I'm doing everything on my own. I feel like I am not really getting any help. I feel like [name of state agency] could have helped me a little bit more ... but basically right now I feel like I'm not getting any help from anyone and I'm doing everything. I've called up so many different places and every time I call – it's like, I hit a brick wall ... there's not much out there ...

Problems at the job because of a disability

The mother of a young man with both bi-polar disorder and ADHD said that her son usually was able to get a job initially. This was consistent with a theme in the 2008 interviews where someone who doesn't initially present with a disability may land the job, but not be able to maintain it.

[Name] is very well put together, I mean he's clean cut. He's very good with customers and he knows the communication skills and stuff. And it's ... once you know they see

that there's no problem with that. It's just getting the job and then working with the job itself after having it ... They're all excited when he starts work and everything and, you know, as time progresses, and they start figuring out that he does have ... some disabilities, but they could see there is something that is not right.

2. External sources providing help

Most individuals who called the Connect-Ability toll-free number were looking for support in their search for meaningful employment. Some individuals had found counselors who were both empathetic and efficient while others were disappointed with their experience. As with the first round of interviews, a positive experience was usually associated with that counselor's understanding of the individual.

Support and help

Some of the new participants also expressed a need for advocacy. One man in his late 50s thought that because of his disability he would need to have an advocate.

For a disabled person, you need an advocate. You need someone ... who can run the interference, who can read, write about it, talk about it, push employers, push agencies and so forth to reach out. I mean the idea that someone's disabled – it's got nothing to do with ... their capabilities or strengths. ... we have a lot to offer.

Negative experiences

One woman with a learning disability was looking for help with finding a job as a teacher's assistant. She asked a state agency office for help, but felt that the counselor was presumptuous in expecting that she would know how to do all of the things that the counselor asked her to do. According to her, the counselor

... kept telling me, well go to Connecticut Works, post your resume on careerbuilder.com, post your resume on monster.com. But people don't even know how to do that. She was telling me, well do this on your own, do that on your own. But I'm, like, isn't she as a vocational counselor supposed to know the services out there and are supposed to contact them and then contact me and say well this is what will get you started. She didn't even do any of that. I felt really bad.

Another woman was disappointed by the policies in force regarding the state agency employment assistance system in Connecticut. She said that she was told in an orientation meeting that Connecticut is one of the states that is not open to everyone who has a disability.

There are other states where ... if you have a learning disability you can automatically get help, or if you have bi-polar or if you have something wrong with you, there is an opportunity there for help, and this seems like, well you can get help but only if you fit A, B, C and D and I am hoping that ... I don't have to wait all this time just to be told "no."

She added that the waiting period for approval or disapproval is 60 days.

Positive experiences

One man who had been a social studies teacher and guidance counselor had taken early retirement because of health reasons. Now that his medical issues have stabilized, he was looking to get back into the workforce perhaps on a part time basis. He had spoken with a counselor at a state agency and had a positive experience.

I forwarded her my resume and she asked me a number of questions about the type of work I am interested in, and about my background and then she spoke with ... the person they have up in their office in Hartford who does a lot of the work with employers and they looked for positions that might be available that would be somewhat of a match ... You call, people call you back. They spend time with you on the phone, they follow through – so it's refreshing.

The Connect-Ability toll-free number

As with the first group of interviewees, this group also hoped that the Connect-Ability toll-free number would be their one stop for finding a job and were sometimes disappointed. One of the participants said,

I was hoping that with Connect-Ability, they would have something that they had figured out, to see this fellow who was in the wheelchair ... who had lots of experience, become the president of a trucking company. I figured somebody figured out how to put two and two together, but turned out it wasn't the case.

The mother of a young man with Asperger's Syndrome was very disappointed with Connect-Ability. Her son had been working with Connect-Ability for several months with no results. The mother said,

I must have had delusions of grandeur, because my concept was that they must have jobs up there and they're going to help you. Maybe it's a state job or rather than have you be collecting disability or on Medicaid that they could give you an opportunity because [name] is bright. But because of the Asperger's there's a few little oddities that if you don't know that this is going on. And I am wondering if in his interviews where he was off on his own, if people had second thoughts, not knowing what that was all about even though he was very responsible and confident. And I thought that Connect-Ability was going to be able to open doors, let people know, he's got something going on but he could be a great employee for you.

The mother of a 16-year old called the Connect-Ability number, and after two years was just starting to piece together a plan for her daughter. Now that her daughter is getting closer to 18, the mother explained that she needed to get connected to multiple agencies to help provide for the daughter.

I didn't know all the departments. I didn't know where to go and I kind of felt like once I got connected with your service, I was looking for maybe a step kind of thing: this is what you apply for if you need this, this is what you do next, and I kind of pieced that together myself and did a lot of calling and asking, but it would be nice if there was something more, a "to do" kind of packet. If you are looking for transportation this is where you go. If you are looking for skill training this is what you do.

Two interviewees did note that Connect-Ability referrals (one to a non-profit agency and one to a transportation resource) were useful aids in furthering the job search.

3. Barriers

Similar barriers were identified in the second round of interviews as in the first. Often barriers were related to the individual's type of disability. Consistent with findings from the Medicaid Infrastructure Grant Needs Assessment, certain additional barriers were perceived by individuals as roadblocks to their success in finding employment. Transportation, accessibility and lack of assistive technology were common barriers for anyone with a physical disability. For others, the need for additional accommodations was identified as a barrier. Many participants also described the attitudes or biases of potential employers towards people with disabilities as a barrier.

Transportation

Lack of transportation poses a barrier for those who do not drive, limiting the places where they could apply for work. For example, any job that was not on a bus route could not even be considered. One student had her first work experience as part of her school program. Her mother said that finding transportation was not a straightforward process. The mother called the Connect-Ability line and through searching the internet, she was finally connected with her town's Transportation Department which sent her an application. She described this process.

[The Transportation Dept.] had someone come out and talk to me about getting [my daughter] a van card and then calling up ahead of time and setting up transportation for her. So that was helpful. I didn't get that immediately as part of the searching out employment, which would have been helpful to say OK this is how we can get her a job, this is how we can get her back and forth.

A woman in her 30s said that transportation was also a barrier for her. Although she is trying to get her driver's license:

... transportation is a barrier to me because, let's say, for instance, there was a good job in Canton, CT, and the bus doesn't run there, then there would be no way for me to get there ...

Need for Accommodations

A woman who had worked as a case manager for 18 years was in need of a dictation machine for any new job that she might get in either the management or administrative field. She was not sure whether she would have to supply that herself or have her potential employer make that accommodation. In any case, she was willing to purchase it on her own if it might help her obtain a job, and was very proactive in her quest to make herself marketable.

I do expect it to be a barrier with the dictation machine, but I have called up Yale, I have utilized their Dragon, looking into that. I have called up the VA, I have called up a variety of different agencies. Again, I am going to go to this [seminar] on Friday to learn what is out there that can, I guess, that I would have to purchase personally to keep me abreast of the hiring process, that it won't preclude me from getting hired.

A man who uses a power wheelchair explained that he would need very simple accommodations.

Something that helps me when I am working at a desk is having a desk chair with arms just because of the way I have to stand up. An accessible bathroom that has maybe a higher toilet seat.

A woman in her 30s has a learning disability and indicated that since she has trouble getting organized and following directions, one necessary accommodation for her would be to have a supportive work situation which would allow her to ask questions.

I have to get myself organized. A barrier to me is remembering this, remembering that, and you know basically trying to remember what to do, keeping it all in my head and staying organized to me that's such a barrier ... but my learning disability has become a problem because I have a learning disability when it comes to comprehending, such as following directions, or someone explaining something to me then they'll have to explain it like maybe 3 or 4 times and I'll have to finally get it.

She was also realistic in her job pursuits. Instead of wanting to be a teacher or a substitute teacher, she was setting her goal of becoming a teacher's assistant.

I'd feel more comfortable being a teacher assistant than being a substitute teacher because a substitute teacher, you have to take over the class yourself, and I have trouble. Like, if the real teacher leaves directions for me, I have trouble following that and I cannot follow up on a class alone by myself – that's a big responsibility. Whereas, if I am a teacher's assistant, if I ask questions to the teacher that I don't understand, and the teacher says, well, this is what we need to be done, so yeah.

Employer perceptions

As with the original group of participants, new participants who had reached the interview phase of employment also perceived some discrimination. One man had applied for a position as a greeter at a car dealership where he would greet customers and connect them with a salesperson. Although he was in a motorized wheelchair, he was able to drive and get to the dealership. This participant said,

This manager looked at me and just – he sort of didn't get it about how I would be able to function in a position and do the position competently. When I explained how I would do it and it was probably using a power wheelchair most of the time, because there was a lot of getting from one point to another and on your feet, it just didn't ... I could just see that he didn't get it, and I never heard back from him despite numerous follow up calls ...

Another participant, a young woman with a weight problem in addition to bi-polar disorder, spoke of the attitudes of potential employers toward someone who is overweight.

A lot of people look at ... somebody who is bigger sized and they don't think that they can do what most people can, and ... I think that that's a big misconception that a lot of people have about certain people who are big. There are some people out there who will use their size as, you know, a hindrance, and I don't see it as that. I just see it as more ... I am going to prove you wrong and you know most of the time I am able to prove people wrong, because I can do, but it's just getting your foot in the door ...

4. Attitudes

As with the first set of interviews, a majority of participants talked about having a positive attitude and keeping their sights set high. While frustrated at being rejected for some jobs, these individuals kept their optimistic outlook and this was seen as a positive reinforcement to their confidence level and potential success. Likewise, having a negative attitude would ultimately lead to failure. Participants who felt well-supported by their families also felt uplifted and remained optimistic. The attitude of positive thinking could be present specifically during the interview or, in general, throughout the whole process of finding a job.

Positive attitudes

A woman in her 30s with a learning disability reported on the challenges of having a disability and the need to think positively.

Well, it's a challenge when you have a disability, but I would always leave it as ... when you think positive that's the best thing. When you think positive and you just take one day at a time that's the best thing.

Negative attitudes

The mother of a young man mentioned that her son had been somewhat depressed and negative after searching for a job for so long.

And I thought that Connect-Ability was going to be able to open doors, let people know, hey, he's got something going on but he could be a great employee for you. And [son's name] was enthusiastic. He was so anxious to get to work, and after six months of nothing happening, he got more and more depressed. ... He was getting more and more depressed ... nothing is happening.

She did report that her son was connected with a non-profit agency through Connect-Ability and is now working at a part-time job that he got through them. In addition, he is planning to go back to school to become an auto mechanic.

C. Follow up interviews (themes)

The process of interviewing participants for a second, third, and in one case fourth time allows deeper examination of the person's employment journey over time, and expands the insights gleaned from one point-in-time discussion. The fourteen initial participants who had more than one interview expanded on many of the same themes they began in their first interview.

1. Employment related issues

Employment status

Of the original 19 individuals who were interviewed in 2008, 14 had at least a second interview, six had a third interview, and 1 had a fourth interview. Eight original participants are still unemployed; one who was working at the time of the first interview lost his job because the company went out of business; six participants are currently working part time, full time, or are self employed. A man who was working two part time janitorial jobs has not found another job;

in addition, he thinks that one of his part time positions is decreasing hours and may be eliminated because of a school closing. One person who was in the process of applying for Social Security benefits at the time of the first interview was able to find a part-time job with a former friend. A man who was working at a radio station has maintained his full-time job and still enjoys it. A man with epilepsy has decided to pursue a job working at his home, providing health information and selling health care products for diet and nutrition. A man who owned his own business was in the process of evolving from that job to a new kind of self-employment as an author. Finally, one individual who also had a business that he was trying to keep afloat found a position in telemarketing. This started out as part time, then increased to full time, and eventually he became the head of that department.

Health reasons

Most of the original themes persisted for those individuals who agreed to continue their *Pathways* interviews. For one individual who remained unemployed, health issues prevented him from seeking employment and he suspended his job search until his health improved.

Finding a job

For some of the original group, finding a job had become even more urgent than before. A man who was working two part-time janitorial jobs reported that one of his employers was in danger of closing down. They had already cut back his hours when he said:

... so I will probably lose that job and that will be a loss of three to four hundred dollars a month ... and my financial situation can't handle that, so it's getting a little more desperate to where I would probably take anything that came along now.

Another man who had been looking for a job at the time of the first interview was told that he would jeopardize his disability status if he were to look for a job while applying for Social Security benefits. While one state agency had encouraged him to look for a job while applying for SSDI, his lawyer informed him that he would have been denied SSDI if he was even attempting to try to find a job. Fortunately, a childhood friend needed some help. He said,

This just happened ... he needed somebody to come in on a part time basis, so I got lucky. It just happened to work with me. Had that not worked, I needed to stop looking for a job through the state, wait until my social security ... the whole situation got played out and then go back to the state [for help with finding a job.]

Applying for a job

One former truck driver was still applying for jobs from time to time. He went for an interview in the fall of 2009 and the interviewer told him that he would call back the next day. He went on to describe the rest of the experience, which had been the same for several jobs that he had applied for.

You know, he did not call back, so I called back the day after, and he wouldn't even answer. He wasn't around the secretary said. "[the job] has been filled. Sorry, good luck." ... know what I think what clinched it was I mentioned... I didn't say disability, but I said that I get medical benefits, didn't go into detail. Because he had said, "we offer medical after 6 months." I said, well that's important to me, and I think that's what blew the interview right there.

The interview process

One mother of two young children is still struggling to find a job. Whenever she has applied for a job she has hidden the fact that she suffers from anxiety. For her the application part is easy, it is the interview process that she said is "horrible."

I always have a very big fear that I am going to have an anxiety attack in front of my interviewer and he'll say she is not fit for this job, and I have to pretend that I don't have that problem so that I can get hired.

Problems at the job because of a disability

A young man with epilepsy reiterated the difficulties he had had with employer reactions to his disability.

Any other work I had found, aside from a home business, has only come short on me. If I did succeed in passing all the interviews and being hired, it was only within time that a seizure, that the medication could not control, would occur on me. And one thing led to another being that the employer was either going to give me a reasoning such as that I am scaring the employees or that they cannot have an occurrence such as a seizure in their office and I would end up losing the job.

2. External sources providing help

Support and help

A former truck driver, who lost his vision and was receiving services from a state agency, said that the agency was more of a help in preparing him for a job, but not necessarily looking for a job. They helped him with household training right after he lost his eyesight. He said

... their mobility training is excellent. The gal that comes here to teach me computer skills and house training, she's excellent.

But he has been pursuing the job hunt on his own. Realizing that it would be more advantageous to work from home rather than in the community (because transportation would be an issue), he had taken a course for becoming a freight broker, which would allow him to work out of his home.

Negative experiences

In their second and subsequent interviews, participants continued to emphasize the need for advocacy and counseling in their search for employment. A man who was looking to replace his two part time jobs said that finding a counselor that is really knowledgeable in the field of assisting people with disabilities is the key.

The people that I have experienced so far don't seem to be any more knowledgeable really than I am, at least don't seem to be.... Somebody that can really give some assistance, a real background in that area ...

The mother of a young man with epilepsy had talked about trying to find help for her son through a non-profit agency. She eventually took her son to that agency's New York branch, which was connected with an organization that helps evaluate the individual and works to help that person find a job. She had this to say about the agency's Connecticut branch.

I thought that their support was weak, and understandably, they have small staff, but what struck me was sort of like the lack of inter-agency or foundation working with each other. It seems like ... it was all about protecting their own existence as opposed to enlarging themselves through their interactions with other agencies so when a consumer comes to them, they have the breadth of information.

3. Barriers

Transportation

The parents of one young man with Williams Syndrome who is still in school decided to move to a different school district since the initial interview so that their son could benefit from programs offered in the new school district. He was recently interning as a music teacher's assistant with 5th and 6th graders at a local grammar school, and his parents were hopeful that this might turn into a possible career. But they went on to say,

I think the big problem for us, we both work full time, so transportation is an issue ... we also made the transition to come back to [name of town] for him because there's a bus line, because there's a group of stores he could walk down, maybe he could get a job in [name of store] where he could walk himself.

A 60-year-old woman who had just completed college classes has so far not found employment and has stopped aggressively looking. One of the barriers for her was definitely transportation.

Even if I found the most perfect job in the world, I would not be able to get there or get home if their hours were after the time of the public transportation. So I got a little discouraged, a lot discouraged, and I said to myself, well, what's the point? So I haven't even tried.

Need for accommodation

A woman who is fearful of having an anxiety attack during the interview thought that having an employer who is understanding and compassionate would be a dream come true.

That would look awesome ... an employer that could understand that I have anxiety and that ... I have some things that are worse than others, and maybe that employer could work with me .. and help me out. I mean that would be wonderful.

Benefits

One participant also spoke about not wanting to take a job for fear of losing his unemployment. He said that there were positions available through temporary services, but they were part time positions paying minimum wage.

I can't keep my house and do that. If I take that job then I lose my unemployment and I make three-quarters of that on my unemployment, You know, as crazy as that sounds, I

mean I would rather work, but ... I'll lose everything if I do that. I mean my family is more important than anything right now, so I'll take care of them – so I'll just do what I have to do.

Another participant faced a similar dilemma regarding Social Security and medical benefits. He believed that if he earned too much money then the medical would be an issue. He went on to say,

It sort of makes you wonder if you should just be one of the statistics and maintain disability and not search. But being the type of person I am, I can't do that as far as just sitting around collecting a check ... The biggest thing, it's not the income itself, it's the medical is the biggest question in my mind because obviously I need the medical help.

A person not presently pursuing a job because of health reasons indicated that another issue for him would be having medical benefits. He described a friend who is in the same predicament.

Finding a job that he can get adequate medical insurance that will pay him enough compared to what he is getting now and it's ... he told me point blank, that he's had two jobs and he's quit both of them because he has had better benefits through not having a job.

Employer perceptions

One man with an amputation and prosthetic leg who had gotten a job on his own lost the job because the company went out of business. He spoke about this at the initial interview, but now that he was in the process of again looking for work, it seemed to be an issue in applying for another job.

Like how you get a physical test by just getting that nod when you come in the door, you know, they look at you and then your pant leg comes up and then they look at you and then you know the meeting is shot. ... But the first thing that pops in to my head is, oh this guy is hurt, he's going to be taking days off or something like that. I mean crazy things go through their heads ... but if they really knew me, I don't take days off, I don't take vacations unless I have to ... that's the real me, but they don't see that. They never give me the chance.

D. Pathways to Success

There were a few cases where individuals who had not been working at the time of their first interview succeeded in finding employment. Their pathways are described below in greater detail.

Carl²

One individual at the time of the first interview had his own business, but was just managing to keep it afloat, and was in the process of looking for another position. Because he had a family, his business needed to do more than just stay afloat, and he was looking for the security of

² Actual names have been changed to protect confidentiality.

working for an established business. He did not have the additional resources to give his own business a boost, for example, the funds to advertise. He was working with a state agency on his job search. He described his original business.

I think I love it, but I know I am unique and exceptional at it, but I am wide open to any other possibilities. I am a company man without a company – that is the way I look at it. I have got my business that I have been holding on to for over eight years. Now that I have been on my own, alone in this business, I am losing my love for it.

Carl had experienced many of the same barriers and attitudes that other participants had experienced. The fact that he doesn't drive is definitely a barrier. He and his family did move back into the city to gain better accessibility to public transportation. When Carl applied for jobs there was a good deal of skepticism on the part of potential employers.

I am not legally blind in the conventional sense. I can see what I am looking at, but once I tell you I am legally blind, the rest of the interview is, "which eye is he looking at me – what is this guy?"

By the time of the third *Pathways* interview, 15 months after the first, Carl had obtained a part time job. He described how he worked with an agency hired by the state agency that does coaching for people with disabilities. He was given the chance to work 30 hours as an evaluation for a job working in telemarketing. He excelled during this evaluation period and the company hired him, at first part time. Carl continued to excel in his job and soon became the top salesman in the telemarketing department.

During the fourth *Pathways* interview, Carl described his ambitions and the opportunity to prove himself in that evaluation.

I mean no disrespect to anybody who's been involved with this, but I feel as though all I've really looked for is the opportunity to show what I can do and I might be clinging to this opportunity, but you know, I am a company man and I like to make the most of what I got to work with because, like I said, I am not getting knocked down with job offers.

He went on to speak about his job.

... I don't adore it, but I am proud of what I have been able to make as far as being successful goes and getting the results that I set out for I am proud of what I have been able to accomplish with that.

He was also adamant about not wanting to stay on SSDI. He said,

... and I am not going to be so preoccupied with what I am getting from the government that I would keep my salary down to a point where I can still collect full disability benefits. I want a full time job and that's that.

By the fourth interview, Carl indicated that his employer was giving him as many as 35 hours per week, and that they had committed to offer him a full-time position in the beginning of 2010 running the telemarketing department. Carl was very proud of how it all worked out. He recalled when he first tried out for the job.

So, I didn't know what I was stepping into and I didn't necessarily think negatively or skeptically because I was just happy to put a tie on and show up for work somewhere. Certainly wasn't making much money, it was negligible to say the least, but anyway it's really panned out and I'm proud of myself.

Having an employer who was willing to give him a chance was key. Carl mentioned that his employer received him well and relied on him "without hesitation as to my disability." Carl credits his counselor at the state agency who put him in touch with the job coaching agency.

I had nothing but positive experiences with the representative at [the agency] who put me in this opportunity, and I wish she was still around because she's an excellent resource, and she had the fortitude to sort of throw me through the door there and I had the utmost respect for her too.

Harry

Another success story comes from another man who also owned his own business. At the time of his first *Pathways* interview, he was working with architects and interior designers and contractors of high-end residential homes. He was finding it difficult to go to construction sites because of his disability and wondered whether he would be able to continue. At the second interview, he had decided to stay with his business because conditions had changed due to the failing economy. Now, instead of working through architects and interior designers, he was able to pursue different avenues and have access to homeowners directly. He was pursuing the business through a different avenue, developing a website and brochures to deal directly with the consumer. He did not receive help from any agency and largely attributes his success and evolution to his own energy and initiative.

There has been no agency I have been able to go to. It's all my own personal networking, and while these people have been friendly and accommodating to me, it was only because I aggressively searched them out as individuals ... whereas ideally an agency would be able to open up a huge network for me. I am having to evolve, develop and create my own network – so it's almost like I am my own agency, self agency.

On the third interview, Harry was again evolving into different things. He had had his business for a very long time, but had let it languish several years ago in order to take care of his elderly parents. Harry had begun writing a book about his caregiving experience.

... people were encouraging me to do it, and I actually have two editors and one publisher that are pushing hard to do this because they know my writing style, they know my abilities, they know my story. It was going to be about a story of a son that took care of his parents, and what was involved with that, and I didn't want to necessarily become a writer, but I wanted to try to explain to people what my experiences were. ... so that project is going on.

He indicated that the original thought of writing this book about his experience as a caregiver has actually generated ideas for four other books. In summary, Harry was not only transitioning from what he had been doing to what he is doing now, but as his disability worsens and his mobility decreases, he was also looking at ways of using the experiences that he has. The first book has already gone to the publishers.

Donald

Donald, who has epilepsy, had had success in landing a variety of jobs, but ran into difficulties when he had a seizure at the job. Either the boss was unwilling to accept any liability if anything were to happen to Donald, or the co-workers became upset at having to witness the seizures. Everyone was unwilling to have Donald continue. Then it occurred to Donald that a “work-at-home business has been the friendliest to me.” His mother is thinking of retiring soon and would be able to help Donald in his home business. The home business involves providing health information and selling health care products for diet and nutrition. His mother also says that the seizures have lessened because he is working out of his home.

... that is probably, I think, one of the reasons his seizures have been under some control. Like, clearly a stress environment just brings on seizures for him and you know it's a routine of ending up in the hospital. His employer, understandably, doesn't want to take the liability.

One of the main barriers in having this home-based business is transportation. Sometimes, Donald needs to get to meeting sites, and his mother needs to help him. If he needs to put up flyers, having someone drive him around is essential. But, at the same time, the business is portable and mostly done over the internet. If he could move to a city, the transportation problem could be ameliorated. His mother said,

... from a portability standpoint, if he wants to move back into a city, New Haven or New York City, he can take the business with him. So that's the goal here. Get the business built up soon.

E. Conclusions and Direction for Further Research

Connect-Ability's goal of enhancing and supporting competitive employment for people with disabilities is informed in large part by the experiences of people with disabilities themselves. While significant and useful information was compiled through the surveys, focus groups and interviews conducted during the 2006 Medicaid Infrastructure Grant Needs Assessment, the *Pathways to Success* project enhances that information on an ongoing basis through periodic in-depth, in-person interviews in which people with disabilities share their stories about their journeys to find employment.

All of the individuals involved in this project have in common a strong desire to work, but each has encountered different hurdles along the way, and many described multiple barriers encountered in their search for appropriate employment. Many of the original participants continue to search for employment with no success. And many have been pursuing employment on their own, without assistance from any of the agencies designed to help them.

All *Pathways* interviewees spoke of their aspirations regarding employment, though many found that their disability interfered with their ability to obtain or maintain a job. Difficulties encountered in the process of finding or keeping a job were often attributed at least in part to the person's disability, but mainly it was others' reactions to the disability that continues to be a hindrance to the person's success. Two of the success stories mentioned in the 2009 report are about individuals who were striving toward or had already created their own businesses, working out of their home. This strategy reflects the continued unwillingness of many employers to

overcome their attitudes about hiring someone with a disability. Being one's own employer allows the individual to make their own accommodations.

Other notable themes that surfaced throughout the interviews include external sources of assistance (such as state agencies or counselors), barriers to employment, and attitudes of job seekers and their families. Reactions to all sources of outside assistance continued to be mixed. Some participants noted serious complaints about ineffectual agency help, while others commended individual counselors for their empathy and efficiency. Many people expressed their disappointment with Connect-Ability in terms of their ability to find them jobs. The participants thought that Connect-Ability was established to bring individuals with disabilities together with employers who are willing to work with these individuals. Clearly for many, this was not working, although two individuals did note that Connect-Ability made referrals useful in their job search. The larger issue appears to be the disconnect between the expectations of many individuals that Connect-Ability will serve as a direct link to job opportunities and the reality of Connect-Ability as a "navigator" helping individuals to overcome barriers to employment.

Barriers to employment perceived by individuals as roadblocks to their success in finding employment were wide-ranging. These barriers were frequently tied to a specific type of disability so they varied among individuals. Transportation and accessibility were common barriers for anyone with a physical disability or vision disability. The need for different accommodations was noted by other individuals, and the need for appropriate assistive technology also prevented some people from obtaining the jobs that they desire. Employer perceptions of people with disabilities continued to be one of the biggest barriers in 2009.

During the past year, the *Pathways* project added new participants to the mix, thereby increasing the diversity of the sample, representing a broader spectrum of individuals who have different disabilities, and a greater representation of various demographics. It will continue to track all willing participants with periodic interviews to follow the progress of their job search, recording, at an individual level, how supports and resources play a part in helping people connect to jobs.

The responses of those who have shared and will continue to share their journey will give the Connect-Ability team a greater understanding of how to improve the system. With information regarding individual difficulties, the findings will be used to inform not only state agency policy, but also potential employers, so that job seekers with disabilities may be successful in accomplishing their employment goals.

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Appendix A

PATHWAYS TO SUCCESS: INITIAL INTERVIEW

The stories of real people and employment

Name:

Address:

Phone Number:

E-mail Address:

.....

Thank you for agreeing to share the story of your job search with us. Your participation and the information you will share will help many people with disabilities become valuable, contributing members of the Connecticut workforce.

I have a few questions that will help us more completely understand how to support you and other people like you.

- 1) What is your work situation at this moment?**

- 2) Are you employed? If yes, where? For how long?**

- 3) Tell me what your experience was searching for and obtaining your current or most recent job.**

- 4) If you are not employed, have you received help in finding a job?
From whom?

If no, why?

Are you finding this help useful?

What kind of a job do you want?**

- 5) Are you satisfied with your current job or are you satisfied with your progress toward finding another job? (if yes or no, why?)**

.....

Please describe in more detail your journey toward a career/job of your choice.

- a) What have been (were) the helpful/supportive elements of your job search (people/agencies/services/organizations)?**

What have been (were) the barriers you encountered along the way?

***Transportation?**

***Applying, interviewing, being hired, being promoted?**

***Attitudes----your own, of the employer, your family, your school or employment counselor, other?**

***Accessibility and Accommodations?**

***Understanding your benefits?**

- b) What supports, services and accommodations will help (were helpful) in your job search?**

- c) Are there any other comments or suggestions you wish to make to fill out your story?**

Thank You for taking the time to speak with me. Your story and experiences will help so many more people with disabilities who are seeking satisfying employment.

I will be getting back to you in 6 months to continue the story. Thank You.

Appendix B

PATHWAYS TO SUCCESS: FOLLOW UP INTERVIEW

The stories of real people and employment

Name:

Address:

Phone Number:

Email Address:

.....
Thank you for agreeing to share the story of your job search with us. Your participation and the information you will share will help many people with disabilities become valuable, contributing members of the Connecticut workforce.

I have a few questions that will help us more completely understand how to support you and other people like you.

- 6) What is your work situation at this moment?**
 - a) Do you still have your job? (go to 5)**
 - b) Did you get a job since I interviewed you last (6 months ago)? (go to 2)**
 - c) Are you still unemployed? (go to 4)**
- 7) Are you employed? If yes, where? For how long?**
- 8) Tell me what your experience was searching for and obtaining your current or most recent job.**

(go to 5)
- 9) If you are not employed, have you received help in finding a job?**

From whom?

If no, why?

Are you finding this help useful?

What kind of a job do you want?

(go to 5)
- 10) Are you satisfied with your current job or are you satisfied with your progress toward finding another job? (if yes or no, why?)**

Ask all – specifically about the past 6 months
.....

Please describe in more detail your journey toward a career/job of your choice.

- d) What have been (were) the helpful/supportive elements of your job search (people/agencies/services/organizations)?

For those who are currently unemployed and looking for work ask specifically about the past 6 months

What people or agencies or services or organizations did you utilize in your job search over the past 6 months?

- e) What have been (were) the barriers you encountered along the way?

*Transportation?

For those not currently working, ask about transportation over the past 6 months as a barrier to finding work.

*Applying, interviewing, being hired, being promoted?

Ask all – specifically regarding the past 6 months

*Attitudes----your own, of the employer, your family, your school or employment counselor, other?

Ask all – specifically regarding the past 6 months

*Accessibility and Accommodations?

Ask all – specifically regarding the past 6 months

*Understanding your benefits?

Ask all – specifically regarding the past 6 months

- f) What supports, services and accommodations will help (were helpful) in your job search?

Over the past 6 months which supports or accommodations were helpful in your job search.

- g) Are there any other comments or suggestions you wish to make to fill out your story?

.....

Thank You for taking the time to speak with me. Your story and experiences will help so many more people with disabilities who are seeking satisfying employment.

I will be getting back to you in 6 months to continue the story. Thank You.