

Oral History Usage Guidelines

Oral history is a method of collecting historical information through recorded interviews between a narrator with firsthand knowledge of historically significant events and a well-informed interviewer, with the goal of preserving substantive additions to the historical record. Because it is primary material, oral history is not intended to present the final, verified, or complete narrative of events. It is a spoken account. It reflects personal opinion offered by the interviewee in response to questioning, and as such it is partisan, deeply involved, and irreplaceable.

Acknowledgement

Development of this oral history was supported through the Mary E. Switzer Research Fellowship program, under a grant from the Department of Education, NIDRR grant number HF133F070013. Contents do not represent the policy of the Department of Education or endorsement by the Federal Government.

Permission to Quote Requests

All literary rights in the manuscript, including the right to publish, are reserved by the interviewer and interviewee. Quotation from this oral history interview transcript is allowed without explicit permission if it falls within standards established for fair use of copyright materials. Permission to quote must be applied for in writing.

Requests for permission to publish should be addressed in writing to:

Joe Caldwell
Adjunct Research Assistant Professor
Department of Disability and Human Development (MC 626)
University of Illinois at Chicago
Jcaldw3@uic.edu
selfadvocacyhistory@gmail.com

List material to be published and how the material is to be used, including:

- a. Type of publication
- b. Proposed title
- c. Publisher's name
- d. Expected date of publication
- e. Nature of publication, e.g., scholarly, commercial

Max Barrows

11/1/2007

9:00 AM – 12:00 PM

Montpelier, VT

Caldwell: The first thing is to talk a little bit about your childhood and growing up. First, how old are you now?

Barrows: I am 21, 21 years of age. You gotta love it.

Caldwell: Yes, it has been a while since I was 21. It is a good age. So, really, if you could go back and think about your childhood and growing up... What are some of your earliest memories?

Barrows: Ah, it was an interesting time. It has been like a rollercoaster. Clearly... Well, one time I remember celebrating I think it was a birthday. I think it was like I was in kindergarten or something like that. We had like quite a bit of people over. Like 12 or 14, maybe of that over. And as I look back at that, I always wonder, you know, about one thing I was really good at. I have a twin brother and he is a fraternal twin. Both him and I were the same age. But during those parties, my brother had all the boys over and I invited all the girls over. I had nothing but girls over. And I don't know why that was, but I had nothing but girls. I was like the guy who invited a bunch of girls and my brother had all the guys over. It was pretty interesting and as I look back; I always wonder: why was that? Why was the fact that? Was it the fact that I had more of a connection with girls or just had to do with my sensitivity, or whatever. But anyway it was a blast. The girls were sweet to me. I remember during the party we always had these projects. I remember one time we would build these cardboard boxes within the house where we had the party we would have these cardboard houses. And it was funny because after we would build them we would trash them. And I remember one time we built this submarine, I think it was out of cardboard. But that ended up getting trashed because we decided to take it outside and roll down the hill in it. And I don't remember if it was me or my brother, but a group of his friends or a group of my friends we rolled down the hill and I remember smacking into a tree because we couldn't see where we were going. Yeah that was a pretty interesting time. Yeah, now I am 21, but I was probably flashing back 15 years, maybe a little less than that. I had a pretty interesting childhood. Yeah, the birthday party, those birthday parties were very interesting – always me with the girls and my brother with the guys. And stuff like that.

Caldwell: Are you really close with your brother? Were you guys close?

Barrows: Hum. We talk. I wouldn't consider us too close. Whenever we talk we talk. He is pretty much... Me and him are kind of running different lives even though we are living in the same house. There have been times where him and I have talked about things in life, but we are not tremendously close. The good thing is at least he loves me and I know that; and I love him. Nothing beats family.

Caldwell: What about the rest of your family? Your mom, dad, or other family members?

Barrows: My mom. My mom and I are close. My dad... My dad and I are close. Family members... There are a few I am close to and then there are a few I am not close to. It is pretty interesting. Because sometimes it can be hard because I always wonder, "Why am I not close to some of my cousins?" And sometimes I ask my dad the question about you know brothers or siblings being close or not close. I always ask him, "Why is it that my uncle, which is your brother, is not close to you? I mean, how long have you guys been kind of separated?" And you know sometimes I talk about some of the struggles you can face when you are not close to your siblings –because my dad is not that close to his brother. Time to time they talk but we don't see him that much. So, in a way, I can have something in common with him: we both have brothers that sometimes we feel we are not that close to. But at least we know that we love them because they are part of the family. My mom's side... I think that my mom's side is a little closer than my dad's side. I know that my mom has a sister in Virginia, my aunt, and even though they haven't talked in a while my Mom does say that she's close to her. That's pretty much what I like to, that's where I like to go. I wish there was more of, but everyone's different, sometimes it's not always a perfect relationship with some parts of your family. So if I were to put it in a perspective, it depends on the family.

Caldwell: So you mentioned that your, you said that your childhood was interesting. What do mean by that? What are some of your best memories, and what are some of your bad memories versus some of your good memories?

Barrows: Some of my good memories was well of course the birthday parties that I had... Let me see... It's hard to think of good... I probably had a lot of good memories, but for some odd reason I don't think of them too much; I don't think back to my childhood too much for some odd reason. I don't know why... But definitely the birthday party. Let's see.... Well I always had a love of weather. My mother says ever since I was a little kid I was involved in weather. I've liked weather a lot. I would always go outside and watch thunderstorms like I do now. I don't know how that started, but it started when I was a little kid. Let me take you back to middle school. I would pretty much mock the weather guy, like I would do his hand motions and tell the weather forecast. Some teachers remember when I was in middle school when I would predict when a storm would hit, and it would be like the timing of it? And there was one time that I said a storm would hit my high school campus in five minutes, and it actually did –so I was right on target.

Caldwell: So you've always been interested in that?

Barrows: Yeah, since I was little.

Caldwell: Did you always grow up here in Vermont? Have you always lived here in Vermont?

Barrows: I've been living here in Vermont since I was five weeks old. I was actually born in Florida right outside of Orlando, but since I was five weeks old I've grown up in Vermont, in my town of Worcester, for pretty much my whole life.

Caldwell: Is that pretty close to Montpelier?

Barrows: It's about seven miles north.

Caldwell: You do get interesting weather patterns here in Vermont.

Barrows: Yes we do. But one thing I can't stand is the cold, when it gets so frigid out below zero. But I do like the winter for this particular reason, because I always love the wind storms. Hearing the wind howling through the trees, it sounds like a jet but it's really soothing. And in watching the trees bend and stuff. That's one thing I've been interested in. Weather has always been my number one entertainment. I probably would substitute television for weather, because weather is something that always happens when Mother Nature does her thing, it's so entertaining –that is never boring, and television drains you.

Caldwell: How would you describe your family? You talked a little bit about them...

Barrows: How would I describe my family? My family is... Some of them... They're... I have a pretty good family. Since my adoption, they have really have had support towards –my mom and dad –having both my brother and I raised in their family and they have always had passion for us. They have always been there when we needed them. So I would say that my family is a good family, because I know that deep in my heart, they have a lot of love and respect for both of us, both my brother and I.

Caldwell: So you were adopted when you were young? You were born in Florida and adopted?

Barrows: I was actually adopted in Florida when I was five weeks old, and then I was brought to Vermont.

Caldwell: So it's mainly your Mom and Dad, and you and your brother?

Barrows: Yeah. I've always been curious about my biological mom and my other siblings, biologically. I've always been curious about that.

Caldwell: Do you know them at all or have any contact with them?

Barrows: No, I don't, but I've always been very curious about them to the point where I would like to get in contact with them. I'm at the age where... But yeah... But I don't think I've ever met them or know them, I just...

Caldwell: Did you have a lot of friends growing up? You mentioned that you invited girls to your party; did you have a lot of friends in school?

Barrows: Not really. Elementary school was very rough. My childhood, when it came to friendship, was really rough. I think it has to do with my difference. But since I was such a young age at where I didn't realize of how different I was to everybody, but as I look back on it, I think that was one of the reasons why I didn't have that many friends. But I always thought that having most of my friends, the friends I did have were mostly girls, and I just figured that as a sensitive guy myself I just connected with them, connected with girls better because they had similar sensitive feelings like me. So when I look back, I think that's the reason why –so when I mentioned the birthday party, inviting all the girls over. I talked about it with my brother. My brother as he looks back at that I had the right idea. My family said, "Girls were really sweet to you. They were there for you in case you needed them. They understood your sensitivity more; they were just kind to you." As I look at that, that is why most of my friends were girls. But overall, I didn't really have that many friends. That kind of felt awkward. I think at the time I wasn't really aware of why and how, because I was so young.

Caldwell: And you think it's related to your disability, or your difference, and how kids react to that?

Barrows: Absolutely. As I started transitioning from elementary school to middle school, I started kind of realizing, slowly, that it had to do with the fact that I had a disability. And as I look at middle school, I at first thought I wasn't going to have a problem with it, but now as I look back on it, at first it was easy, but then it just got really rough. Because, it's just my social life, at that time in my life they didn't understand me one hundred percent; I was just so different. I've been the victim of bigotry; I've been called nasty names. I've... When you look at the friends you thought you had, they weren't really my friends because most likely the friends I thought I had weren't really that nice, but I didn't know it at the time. I do believe it had to do with my difference. In middle school I started thinking about it a little bit, but I still wasn't fully aware how different I was. Growing up in Vermont has been a challenge because as you can see it's not much of a diverse state. So I've experienced racism as a result of that, growing up as one of the very few black kids, not only in my state but in my school. That's what kind of started me thinking about my difference a little bit more. The fact that I was just wasn't respected well or not as understood as I wanted to be.

Caldwell: Do you think you experienced that both for being black and having a disability? Do you think it was separate or together?

Barrows: At first I thought it was separate. But then once I started talking... I thought that... Looking at how teachers... When I started looking at it academically, there were teachers who didn't understand how I learned, and so they were impatient and they didn't take the time to have me learn the way I thought I was good at learning. And that's when I put it into perspective. So when I started being bullied by a bunch of kids, that's when I started thinking, saying well, "You know, I think it's not only the color of my skin, but that my disability might have something to do with it." So when I transferred from middle to high school, that's when I really started wondering if it could be my disability as well. With the way I was treated not only by students but by teachers who didn't understand me, I started putting all that into thought, and started thinking well how I wanted to be treated better as time goes on, and I started saying to myself, "Maybe it is my disability as well." Maybe I really started thinking about the fact that I had a disability and the way that I learned was part of the reason why a lot of teachers didn't understand the way I learned.

In high school is when I really started thinking about it, especially in the first two years. This is before I started transitioning into special ed courses. I was just taking normal courses, and I would always ask for extensions of the homework, and some of the teachers would say it would be a waste of their time to do that, and I would say that I have the type of brain that I can't do everything at once. I wasn't given a proper explanation of the homework assignments so that I would either have to ask for more of an explanation or an extension if the teacher couldn't give me a clear explanation of what to do. So, then my parents could help me out, but then the teachers would say, "It's due this day, and it would be a waste of my time. I would have to give you an extension or two." And I thought that was ridiculous. And also in a way, that related to in class. I was afraid that a lot of the students in class were looking at, were thinking, "If Max can't do this then why is he in school?" That made them kind of wonder if "Max isn't fit for school," and things like that. I was afraid that a lot of kids would start looking down on me even more because sometimes struggles in class would show, and they didn't think I was that smart. It would add to the bigotry that I would receive from kids who didn't understand me. My brain couldn't process the information that was being spit at me from the teachers in front of the room. "Whoa, I need this broken down," but they couldn't do that. It would make me crash sometimes. It would be embarrassing sometimes, it would add to the bigotry that I would receive, and that was part of my struggle.

Caldwell: When you say bigotry, how did you experience that? What were some of the forms of that?

Barrows: People saying that I was stupid, retarded, the “R” word –looking at me like that, not really helping me out like they would help each other out with assignments, they would avoid me. Whenever I would ask a student for an explanation, they would say, “Dude, why don’t you just look at it yourself? It’s right in front of you.” It was an excuse for them not to help me. They weren’t really too pleasant about it. I remember this happened in ninth grade. I had this science teacher; she was really nice, though. This teacher, she would give us an in-class assignment; we would have to get it done by the end of the class, and if you didn’t finish then you’d have to take it home and finish it as homework. I remember one time I wanted to work with a couple of kids, because they were all working in groups because they wanted to get the assignment done. So they got it and would help each other out by working in groups. And their answers would be like, “I’m sorry, but we’re almost done,” or like I said before, “Dude, it’s right in front of you just do it, get it over with. God, it isn’t that hard!” They weren’t really too nice about it. They were just using that as an excuse to avoid helping me out. Plus, with the other type of response I would get. I would have to talk with my teacher and say “I’m struggling with this assignment, what to you recommend for me to do?” And she would say, “Just finish it for homework and we’ll look at it tomorrow.” So I would have to take it home which sometimes I didn’t want to do since I also had homework from all my other classes. I would get it done with the help of my parents. Even though my parents were supportive of me, I still felt a little bit down because I wanted to do my homework myself. But because of the way I learned, my disability and how I learned, which makes me learn differently than everyone else, I can’t do it all by myself. It kind of felt excluding a little bit because I always wanted to be the smart one, the one that could get everything done by myself. It would be a way to prove to these kids that I’m smart, but I probably am not smart like you. I have my own way of being smart. I just had trouble doing that.

Caldwell: Do you think that things got better or worse as you moved from middle to high school?

Barrows: At first I thought things were getting worse as I went from middle school to high school, academically, but I think that after my parents started realizing that this system of having assignments thrown in his face isn’t working, then they started considering ways that I can learn, ways that I can learn that would make it easier for me to complete homework assignments and make through a class. So in my sophomore year I started taking special ed courses. When I started taking those special ed courses in high school, at first I felt comfortable because there were other people with developmental disabilities in these special ed courses. When I got the descriptions of the type of classes they were with, not that much homework, but homework that you can do in a way you can do it, that’s what made me feel good at first. And once I when I start taking those

courses in high school, I was thinking, "Okay, this might work," but then I ran into another problems, socially. A lot of those people in those classes had disabilities that were more visible, and because mine is considered to be invisible or can be invisible. Well, I have a lot of self control. The kids that I started getting to know more at first, well they didn't understand me, because my disability was more invisible than theirs. So academically it was good, but then it was kind of a flapjack, at first it was social, then it was both, and the academically it was easier, but then socially at first it was harder. Because when I started taking those classes, the kids were like, "Whoa, who is he?" They started looking at me like I was a kid who didn't have a disability, or they didn't think I had a disability at first, so at times I had conflict with them. They would sometimes use that as a weapon against me, and that's when it really made me, kind of wonder, "Even though academically the classes are right, socially are they working for me?" So, that's when I really started realizing and thinking about my disability even more. And I started asking myself questions like, "What kind of disability do I have?" Because first I was bullied by those who didn't have disabilities, but now I'm in the course where academically it was easier, but socially it was harder, and that's when it was like, "Wow!" That's when I wanted to become more aware of my disabilities.

Caldwell: How did you form your understanding of your disability? Can you walk through that a little more, if you can remember how you formed your thoughts about your disability?

Barrows: The way I would do it, I did it was... It took time, but it started when I started getting to know people in my classes more. I started explaining. At first we would talk about some of the experiences we had been through as a result of being so different and having disabilities, and I was also curious to know what some of these individuals had been through themselves. So we started sharing, as we got to know each other more, some of the challenges we had faced at that time. At first I heard everybody share theirs and then I shared mine and that's what started the connection. Then when we were all comfortable enough to tell our disabilities and what they are, and get a little understanding as to what they were, as time went on we became from what once was just understanding to friends. As time went on, we got to understand each other even more and started talking about challenges on and off, and then telling our own disabilities to each other and what they were, and then the past two years that's when these individuals and I started connecting. I was thinking, "Whoa. I'm not the only one with disabilities or the only one with challenges." And it just, as time went on, it was like, it felt amazing, it felt really good to get to know people that were like me in a way and had been through the same kind of challenges as me. So I was thinking that, "Wow! I would like to connect with these people who actually want to be friends with me, because now we have stuff in common, as we share

more and more about ourselves. It is how we united as friends." And then the friends that I told you I thought I had, I kind of, my friendship with them faded. So really my closest friends became those that had something in common with me, and that's when I started realizing that maybe my way of friendship is to meet people that are just like me, even though we're all different, they've been through the same challenges as me. And when we started getting to know each other more we all united as friends and I became friends with people I didn't think I'd be friends with. And those I thought were my friends in the past, weren't really my friends. They were mainly acquaintances because they didn't know me one hundred percent.

So, as I look back on it know, if I could put this all in a... I didn't really make it clear to you, when I was in elementary school, transitioning into middle school, socially it was hard because a lot of kids didn't understand me. I probably skipped a little bit, but socially it was hard. But then in middle school it was academically. I did have teachers that really appreciated me, and liked me and I learned a lot from them. So, academically it was easy in middle school, but socially it was hard. But as I was transition from middle school to high school, it was both, as it was turning from one side to the other. My life was vertical, when I was transitioning from middle school to high school, it was both hard socially and academically. So not only the kids, the teachers didn't understand me either. And then as I got further into high school and when I started taking special ed courses it went from being... Well, first it was socially hard but academically easy, but these were kids... Like if you look at the other side of it, it was like other individuals with disabilities at first didn't know me or understand me, they didn't know me as well even though they had disabilities. Their disabilities were kind more visibly shown than mine, so it was like they didn't understand me because they didn't think I had a disability because mine was so invisible to them. Then as we all got to know each other better, and share stuff, everything just became easy, and then as high came to an end for me, junior and senior year, it was socially and academically easy, because I began to make friends. I made friends with people who were all different from me, but we all had something in common. That plus the special ed classes that I took, it was academically easy. So it went from being socially hard, you know, one side or the other. Kind of hard to explain...

Caldwell: No, you're doing really good. This is important. It's important for people to know about. Did you have any prejudices against other disabilities that you had to come to terms with, like when you went to class and there were those with visible disabilities? Did part of you say that they're not like me, or did you have to accept their disabilities? Did you learn about them?

Barrows: I had to work on accepting their disabilities. When it comes to prejudices, maybe I can put it in this term. I wasn't trying to be prejudiced towards

them, but I was never thinking when I was younger of people with disabilities that were more visible than mine. So even though I had seen it, I was never, I wasn't used to being around it. So it was like I've never experienced being around them, so I guess it comes from your experience with being around those individuals. And once you're around those individuals long enough you get used to it and you understand and accept it more. So maybe that may have been the case. But did I have prejudices? I never had hatred towards them. But maybe I was a little timid maybe, or maybe uncomfortable, so like, because I just hadn't been around those people. I wasn't thinking about those people, so maybe uncomfortable, I just hadn't been around them. But maybe I never hated them for who they were –as a result of how they probably thought of me. I'm sure they didn't hate me for who I was; and maybe they had never been around someone like me. I think it all came from experience since I've learned. But I'm glad you asked me that question. Maybe with individuals with invisible disabilities, they haven't really seen or maybe even heard of or both, depending on the person, experienced people with invisible disabilities. Because maybe what disability means to them is visually shown: slur your words, sometimes you do weird things, like physical things that happen to somebody. And they didn't see that in me that much. And maybe with me, as a young boy, I probably wasn't around people with more visible disabilities more visible than mine and physically shown than mine. So, I think it has to do with uncomfortability. Maybe we were all uncomfortable with each other at first, like, "Whoa, I've never seen this in somebody." So yeah, maybe that's what it was.

Caldwell: When you look back on your school, do you have any ideas that you would recommend that could make things better for kids in schools now? Some of the things they are struggling with now that you went through, or dealing with that you went through, do you have any ideas about how to help them? How to make the schools better?

Barrows: First, what I would do is I would probably talk to that individual to see what they are struggling with or what their challenges are, and get an understanding. Maybe that would give me some ideas that would help them socially and academically. But what would help me out, if I knew an individual that was having the same type of struggles as me, I would talk to them about what it was, and then I would think of ways, I would talk to them about ways you could improve that relationship, academically, and socially with your students and your teachers. That's what I would do.

Caldwell: What about bullying, almost everyone I've interviewed and talked to so far has had experiences with that in school. What can be done to improve that?

Barrows: I would probably say educating kids better about difference, diversity in an individual. It doesn't have to be one thing. Maybe what I would do is... When I look at bullying, I think of name calling. I will put physical violence in there, too, because that's what ends up then. What I would do, I would educate them on what some of the words might mean and why. Then they can probably get an understanding of what they might say when it comes to the name calling so they could understand why it might hurt that individual that they say it to. Like for example, the "R" word. Bear with me. For example, the "R" word –"retard," you know, a lot of people say that a lot to each other to express that they think they're stupid. But really what it means is that it is similar to a racial slur directed towards someone with a developmental disability of any sort and it's just disrespectful. And what I would do is educate them on the meaning of that word and what it really means. First, I would probably say, "Why do people say that?" Get their answer as to why, and then after they got their answer I'd probably tell them what it really means and why it should not be said. Not just about the "R" word but other words that can be used and hurtful and why. Then I think it would improve a little bit. It's a crazy world, I will admit, especially when you're a young child. But I think those would be some things that would help to improve bullying.

Caldwell: I wanted to ask you some questions about your disability. Is it autism? Is that the label, or do you not agree with the label?

Barrows: It is called autism. The long term is autistic spectrum disorder. Autism comes in all different ways, you know. It can be invisible, close to Asperger's, or it can be very visible physically on somebody. My... I don't really know if there is a name for my type, but I know if you leave me in a room alone for more than a minute, then it will... I will do some stuff that would be physically shown if you were in the room with me. My version of it is, you know, there's a lot of things on my mind that bounce around. My brain never sleeps, like New York City. It also does affect my learning and my memory. I daydream a lot. Physically, I will admit that my disability does show on me sometimes when someone is talking to me or, no offense, when I'm being interviewed. I struggle of thinking of what I want to say and trying to say it at the same time, which is sometimes why I have problems keeping eye contact too, which I'm trying desperately hard to do but sometimes I can't help it when I don't. When I'm stressed out it becomes more physically shown, like I'll rub my hands through my head, or scratch constantly, or rub my face a lot when I'm stressed out. I will admit that sometimes in this job that I have, sometimes when there's a lot to do, sometimes I'll zone out for a minute or two, or sometimes stare out the window. It's a way to relieve the stress and drain some of it out as part of my disability. It's hard to explain one hundred percent of what it really is, but I am good at giving descriptions of what it does to me. It is

Autism. ASD is the abbreviation for autism spectrum disorder. I'm not afraid to admit that to someone who really wants to know about it.

Caldwell: How do you feel about it? Was it diagnosed at a certain point, did you have a doctor diagnose it at some point?

Barrows: That I'm not sure about. I asked my parents how I got it. I don't know if I was born with it or diagnosed at a certain age. I wasn't aware of it until I was probably 14 or 15 years old. But when I started becoming aware of it, I was 14 or 15 years old, it took me some time to be more aware of it until probably when I was in my last year of high school, very aware of it. Some of it had to do with my experience socially, but... I wasn't sure, when I was actually diagnosed with it. At a certain age, and that's one thing I would curiously like to find out.

Caldwell: How did you become aware of it? Like at age 14 or so? Do you remember how you came aware of it?

Barrows: When I started... Whenever I would come home from a long day at school or something like that, sometimes, as I do today, I think it would just be the continuation of coming home after a long day I would vent out but then, come home and I would just –there is a word for it, but I can't think of it off the top of my head. I would come home and I would.... sometimes I would lock. I would go upstairs and just process everything that had happened and then I would be away from my parents or so no one could see it, because it would be a little embarrassing for someone to see it, even though they had seen it before physically. I would talk to myself a lot, some of the things I would think about would come out of my mouth out loud so it would sound like to my parents like I was talking to them sometimes or I was talking to someone on the phone upstairs, but I would really be talking to myself. Technically it would be like a second person you were talking to. Sometimes I would look in the mirror and talk to myself. I would think about talking to someone else rather than myself but it was technically myself. I don't know if that is a clear explanation, there's a lot more to it than that.

Caldwell: How did your parents react to the disability, or did they know you had ASD before that?

Barrows: They knew from early age that I did. I think they knew it before and were more aware of it than I was. Because they noticed the physical and some verbal actions that come out of it way before I was aware of it or knew it. To some extent I think it had to do with some research into it and why.

Caldwell: Did they ever come and talk to you about it? Do you remember them ever talking to you? That you might have a disability and this is what it is?

Barrows: I remember asking them a couple of times why I do what I do and then they would tell me that I had autism. When I started becoming more aware of it, I started asking questions about the disability to them, they would help me learn but it was what I had, whether I was born or diagnosed with it. Yes they would, I would ask them sometimes why I do what I do, and they would tell me why. And some of the things they would tell me I would get embarrassed by, but at the same time, I would want to hear it.

Caldwell: Did it bother you that you had ASD at first and did your feelings change about it?

Barrows: If there were a video camera in my room and taping everything I do, when I process everything and if I were to see it, I would be very embarrassed and ashamed. I don't want to see first hand, I don't want to see myself doing... But you know, it depends on the situation. I am actually happy that I have it. It's a way of me dealing with what's going on in the real world. All the hard things I hear about in the news or on the radio or some of the things I have dealt with in the past what I do is I can use my disability as a tool to get me out of the real world. Sometimes I describe it like, I live in my own head. I live in my own world separate from the real world, so whenever I'm uncomfortable in the real world I go into my world, and it's much different than the real world. And it helps me cope with the challenges I've been through in the past, and the challenges I'm still going through, like as a young adult and transitioning into adulthood, so it is a tool that I use. The harder thing is what I do. Sometimes, like when I'm at work, I try my best not to show it but when I get too stressed out, it just ends up showing physically and sometimes verbally. It's embarrassing to hear what I'm doing being described, being thrown back at me –like when I say thrown back, I don't mean in a negative way, just being told what I do. It can be a challenge in that way. Hiding can be a challenge. Like I said, if you leave me alone in a room for more than 30 seconds it starts coming, everything being sucked into my brain from the real world starts being joggled around in my brain and comes out differently, like physically and sometimes verbally. And it's hard because I have been caught doing stuff like that, and then I would have to make something up. And they'd be like, "What are you doing?" And I'd have to say, "Oh I just had a song in my head and I'm dancing." You know, and I would just... It would be like, "Pow!," a huge punch of embarrassment.

Caldwell: Have you met other people with ASD?

Barrows: Absolutely.

Caldwell: When did you first meet someone with your type of disability, do you remember?

Barrows: Recently, there was a person in our group, there's a woman who is 21 – me and her are becoming friends. She also has it but I think it is a different form than mine. I don't know that for a fact, but I know that she told that she has ASD or autism, and I think one time at a little meeting that we had. I believe that she was diagnosed with it, I don't remember it that well, but I think she did at one time say that she was diagnosed with it. I don't know her well enough to ask her the challenges she's been through as an individual with autism. That's one. But I have met individuals with autism. I do know somebody in another part of Vermont; and with this individual, he has it, and this individual does do things that are physical things with his body that are shown that have to do with his disability, and he has to use one of those machines to type in what he wants to say. I have met other individuals with autism. In comparison to my type and my challenges, I have no idea what they go through first hand. I think theirs is different, the autism that they have is shown differently outside than mine, but I have met other individuals with autism. But I am going to meet more, which makes me feel good.

Caldwell: There's more and more people writing books about what it's like, have you seen any of those?

Barrows: I can tell you that I have seen a book but I haven't actually read it, but I know that there are people writing books about autism, and what it is like to live with it and the ups and downs like a roller coaster that they ride one.

Caldwell: There's also a lot of internet groups popping up, like people keeping in touch using email and listservs, like autism communities –kind of like self advocacy, but with autism. Let me ask you about the self-advocacy movement. When did you first become involved in that?

Barrows: One time I think when I was in high school, I went to a gathering and it was in my special ed course that I took. It was here in Montpelier, and it was a gathering for those with developmental disabilities of all kinds. And there were only a few people in the group. But what it was about was about teaching us the *Seven Habits*, being proactive. Have you ever heard other *Seven Habits*? That's exactly what it was. It was about that. We were being taught the *Seven Habits*, and that was what the gathering was all about.

Caldwell: Was that with Tia Nelis?

Barrows: No, it was Karen Topper, but I do know Tia very well. I wasn't aware of the self-advocacy movement, but I did know at the time that there was... At that time I was wondering if there was or not. The real deal with being involved was when I was out of school when I was done with school. When I was done with school... *The Seven Habits*, I was probably 19

years of age when I started becoming really involved in the self-advocacy movement. It started in a post grad program that U32 runs, it's an apartment program, and teaches people with developmental disabilities how to live on their own. While I was in that, we would have meeting at certain times of the week or the month. Part of the program is also to get you involved in the community stuff and working full time or part time or volunteering, and that's part of what they teach in this apartment program. Through that more, is when I started getting involved in the self advocacy movement because the meetings that we had was talking about disabilities, and that was one of the things that the apartment program got me into, and I was attending these meetings because some of these meetings happened on the school days during the day during school. There were more meetings once a month that happened at a certain time of the week in the evening for those that already had day jobs and they can't make it for the day meeting that happens once a week. When I was in the program, I was attending those meetings once a week; that's how it started. Then we talked about disability rights and advocacy and speaking up for yourself; and that's when I think I started getting more involved with it. In high school I wasn't really aware of it, as much as I was when I was done with high school. I was in the post-grad program and the post-grad program introduced me and got me involved more. I was attending all the meetings but I wasn't running anything.

Caldwell: What was it like going to those groups? Had you ever heard that there was a disability rights movement, was a self-advocacy movement? What was it like going to those meetings?

Barrows: It was interesting. The issues that we talked about were good ones, so it actually felt pretty good. I wasn't really aware as much of a disability rights movement even though at the time –though I was sure that there was, to a certain extent –but I wasn't aware, everything that I am aware of today. I was definitely not aware of back then. So going to these meetings and being more introduced to it, and also given the opportunity to talk about issues that involved individuals with disabilities and disability rights really got me interested. Attending the meetings actually felt pretty good. So I was happy that I attended a lot of the gatherings and the meetings that they would have, because when I got more into it, I felt as thought I should be a part of this because I have a lot to say from my past and what needs to be done in the present.

Caldwell: Did you feel accepted there? In terms of your disability and the invisible disability? Was that an issue when you were going to those meetings?

Barrows: Not nearly as much as in high school. I think that people were more understanding that I had a disability. I think through the post-grad program that I was taking about, the apartment program, with the

description of it clearly in everyone's head, what it was, I think people understood that yeah, I did have a disability and it was invisible. Regardless of what, you do belong here; so, it was a lot better than in high school. I felt more included in those meetings than I would ever be in high school.

Caldwell: I wanted to get into the invisible disability and the self-advocacy movement. Do you have much experience on the national level with self advocacy?

Barrows: Well, we do have conferences both nationally and statewide. I believe there are also international conferences, but I don't know as much about that.

Caldwell: What I was trying to get at is people with invisible disabilities or autism, do you think that the self advocacy movement is accepting of all disabilities?

Barrows: Absolutely –all disabilities. To this day, I am trying to get more people involved with all kinds of disabilities, not just autism, but all kinds, every kind you can possible imagine. It really does. When we do that, it expands the movement. It really does. When we do that, it expands the movement, and gets things going, and continues things to go in the right direction. So I think that this movement that I was introduced to two and half years ago is doing a really good job of accepting all kinds of disabilities. If we continue to do that it will expand the movement to go forward, and we will get across everything we need to say and do. We will continue to move forward and continue to make progress, good progress. Because when I was introduced to the movement even more, I felt like they did a good job and they let me explain who I was and my disability and they understood.

Caldwell: So these meetings, the first ones you went to, were they just young people, or was it a mix of different ages?

Barrows: The majority of the people that would show up at these meetings were young adults, but it could be for all ages. Eighteen years –there is a cut off – it is for young adults. Some of the things we discuss at the meetings are adult, you know, has some content in it, more deeper into the movement. It is young adult and you do have to be eighteen years and older. Eighteen plus, you can be fifty, you can be sixty, you can be forty. So after you turn eighteen you are welcome to come.

Caldwell: What were the meetings like, what did you guys talk about?

Barrows: A typical meeting is that we would have an agenda. Somebody in our group would facilitate. We would take turns, every individual would take turns like every day or night meeting or whatever. We would talk about issues that involved politics, talk about issues that involved sports, like

Special Olympics, events, upcoming events and conferences; and when we did that, we would talk about things that we would do, what we could do to help, what the conference would be all about, come up with a theme for a conference, especially if it was a state conference. National conferences as well. I don't know if we would make up a theme or if we would be told the theme. Pretty much a typical meeting would be upcoming events, issues of political, socially, we would talk about disability issues in the country and in the world, and what we would need to come up with –when it came to conferences that were upcoming events were part of the meeting –what is expected of those conferences and where it would be held. We would also help out with the conferences. We would teach workshops to individuals with disabilities and it would be like teaching people like how to advocate for yourself, sometimes what we would talk about in our meetings we'd put into a workshop that we would put together so that we could teach it at a state or national conference.

Caldwell: So was this group a local chapter of the state Green Mountain self advocates?

Barrows: Absolutely.

Caldwell: Did you elect people? Did you have a president of the chapter?

Barrows: We did, actually. We would have... At our local, for our local advocacy group we would elect a president and a vice president. I'm not sure about a treasurer or secretary. For the national conferences... For the state conference there would be, there would also have it for statewide, president and a vice president for this state. Each and every individual state that had a self-advocacy group like the GMSA, and there's other groups like that and then nationally it would happen. Every group is different, depending on the level. I think there's more people elected at the national levels than the state level. That I'm not sure about.

Caldwell: Do you know how many local chapters there are in Vermont?

Barrows: I don't know the names of all of them, but there's one from Burlington; Saint Albans has one; ours is the Capital; there's Friends Helping Friends; Barre has one, the city next door; Burlington has one; Randolph has one; Brattleboro has one; Rutland has one; St. Johnsbury has one; Harwick has one; Newport has one. Was that eleven?

Caldwell: That's a bunch. That's pretty good. So have you served as an officer, elected position in the Capital Self Advocacy, any office?

Barrows: Bear with me when I say this, unfortunately I did not. I have not been president or vice president of my local group. Although some people think I should have been. I was not... At one point I didn't feel as though I should be because I've been told that if you're busy enough then you

shouldn't worry about it because then you'd have to keep track of all this stuff like a president would do. I'll tell you what, if I can just jump forward, they do elect at the state conference awards for allies and Self Advocate of the Year. So just like an election, there is a ballot that people fill out. Well, it's not really a ballot, but it's like you put names and someone gets chosen as Self Advocate of the Year and ally of the year of each and every local group in the state in Vermont. Twice I was chosen as Advocate of the Year. And I think we've had two different people that have been chosen as Ally of the Year. That would be like a support person in our group or someone who provides good support for us during the year, a person who lets us lead the way but gives us a lot of support as an Ally.

Caldwell: That's a pretty big accomplishment – so for two years you've gotten the award.

Barrows: Not two years in a row, but two years.

Caldwell: And you also work here at the Green Mountain Self Advocacy?

Barrows: I do.

Caldwell: What kind of stuff do you do?

Barrows: My position currently is an outreach worker. Karen Topper is my... I say that I am her anchor man, but I'm an outreach worker, that's the name of my position, and my job is to attend board meetings that we have. GMSA has a board meeting once every month. I also go out along with Karen and help her speak to local groups about advocacy and what it's all about. I also run the rolling workshops at state conferences and national conferences if needed to. Other things I do: the basic stuff, I check the email and answer the phone. What else? That's pretty much all I can remember, but there's more.

Caldwell: When did you start working here?

Barrows: I started working here about a month and a half ago, almost two months ago, now. I was introduced to the job. Well, before I worked here, I worked in the restaurant business. I worked in several restaurants. I've worked at Main Street Grill and Bar and Julio's on State Street. But for most of my time in the restaurant business, I was at Giosoli, which is on the River Street there. I worked there for two years. What happened was that an interactive TV type gathering and I think it was an election to elect GMSA officer. It was an interactive TV thing and I heard that the outreach job was open, and I figured that me being in the restaurant business for two years I'd kind of had enough. I thought about it for a bit and said to myself and of course to my parents, too, "I think its time for a change." I had been to one national conference, but three state conferences –two

before I got this job. So, all that said and done and put together, it added up. Since I was involved in this movement as a student for like two and a half years now, "Why can't I be involved in this movement even more and maybe become a leader?" It would be a way for me to meet people that I don't think I'm ever going to meet. So, it would give me an opportunity to meet people and I thought it through, and thought that I would like to be involved in the movement a little more by being a leader in a way or educator in a way. After hearing about the outreach worker position, after thinking it through, I wrote a note that recommended state conferences, attended a national conference, had experience working out with workshops. So, I put all that in a little note of recommendation which was one of the requirements for getting this job. I gave the note to the GMSA, and it wasn't just me but there were a couple of other people that were interested in the job.

I was called into the office for an interview, right here in this very office, and I got asked some questions about what advocacy means to me, what is it all about, what would you do in the future, stuff like that based on the disability rights movement, to help make it better. After that interview, I went to work at my restaurant business, came home after a long day at work in the evening. Just as I was chilling out, there was a phone message from the president of the GMSA. It was the president of the GMSA and he told me to call him back. I think it was the most exciting transition that I have had. Even thought I have to admit that I was comfortable in the restaurant business, it was time to take a role in helping this movement go in the right direction. So, when I got the job, I thought it through a little bit, and I really started. I gave my employer two weeks notice, my employer at the restaurant two weeks notice, and after that I started this job and from then on, its been going really well for me. So now here I am a former dishwasher; and I congratulate the GMSA on doing a great job in pulling me out of the restaurant business. Here I am as an outreach worker for this movement, working for the GMSA.

Caldwell: That's great. Let's talk about young people in the movement. What I'm trying to get at is some of the differences and similarities that young people with disabilities might be facing compared to the other older self advocates. From your experience and what you've seen in the state and in the movement, what are some of the differences that you see? Or do you see any for some of the young people now?

Barrows: I've seen.... Um...

Caldwell: For example, a lot of the movement, the history of the self advocacy movement came out of closing institutions, sheltered workshops, that sort of stuff, and maybe some of the younger people are dealing with those

issues, but also dealing with some different issues. That's what I'm trying to get at.

Barrows: Outside of the institutions and sheltered workshops, um... young adults, right? I've seen like, you know, struggles socially on their jobs. Maybe sometimes the individual's disability affects how they work, so it might affect how their boss treats them or how their co-worker treats them. I know that a secretary of our state group GMSA, I know that a newly elected secretary of the GMSA like a month ago, she said that, I think she's been told that she couldn't work because of her disability. I don't know the details but I think she fought that off and she might have stood up for herself, and she is either working there still or she is working some other place but doing the same job that she does. I haven't seen what has happened to her, but she described what happened to her because of her disability on the job.

Caldwell: Yeah, just some of the young people's issues that they are facing?

Barrows: She's not that young, she's like in her forties, and I don't know if you consider that young or not. But in a young adult, probably not getting enough services when it comes to employment? Maybe.... They... young adults... I gotta talk to some people. I gotta talk to some people. I don't think I've talked to enough people. I would say that services for individuals with disabilities are another issue, like the types of services that young people with disabilities need that are struggling outside of institutions and sheltered workshops, services in the community; and maybe trying to get out into the community, too. But somewhat because of the disability it's hard for them to? Maybe they have trouble finding a place to work that fits their needs and wants and accepting the disability that they have. I know there are issues outside of institutions and sheltered workshops, and I would have to talk to other people more about that, but what I just said is what I can think of so far. Does that help?

Caldwell: When you go to the state conferences, and see people around the state, do you see a lot of young people getting into the movement, like you? Some people I talked to in other states, they are really concerned; some people are concerned that they need to bring in more young people. So I'm wondering in Vermont, do you see young people coming into the movement?

Barrows: Well, I have seen that recently. There is a woman who came from Randolph, she moved from Montpelier to Randolph and she's now involved in the group. She's 21 and maybe I mentioned her from before, her's might be different than mine, but it is a developmental disabilities. According to the description that I got about this individual, in her past she wasn't involved in anything and she really wanted to be involved. She was very political; she has experience with writing letters to the editor and

talking to the governor and the senate and stuff like that. And even though she's a student, she has experience with that. And now she's relocating from Randolph to Montpelier. She's now involved in our local chapter of the GMSA. So that's what I've seen, and it makes me feel good that people are beginning to step up, and I want this to move in the right direction so I'm going to join to help with that the groups expanding really helps. And that's what I'm trying to get more of, trying to get the ground to expand more young adults as they translate from high school into young adulthood, as they get involved in this.

Caldwell: When do you think is the best time for them to get involved? Maybe groups should get involved even sooner, maybe earlier in high school or middle school?

Barrows: I think that would be a good idea to like introduce this to high school kids and middle school kids. I know that to join a group like mine you have to be eighteen or older. But I think we could start groups in schools. I know that some schools have alliances and clubs as part of their alumni. And maybe there could be a disability awareness club that could help them learn within the high school. As far as education, the *Seven Habits* we are definitely doing with high school kids; so that also in a way is helping them think about the movement and training them. *Seven Habits for Highly Effective Teens* is also helping them think about the movement and we have been introducing local groups and how we can start them if they are struggling. How we can help them out if they are struggling and how we can start new ones. And for those who are not eighteen, the *Seven Habits* for them; that also gives them a little bit of a perspective that there is a disability rights movement going on. The seven habits is part of it, of course.

Caldwell: Did you get a lot out of the *Seven Habits* when you went through the training?

Barrows: Absolutely. I met a lot of great people. I love teaching it to a lot of young teenagers. I love how like we get them to learn the basics of life and how these seven habits can help them move in the right direction in life and how they be more brave about how to advocate for their needs and wants, stuff like that. And also too, knowing that we are teaching them, but I'm also learning too. Both perspectives really help me. And it feels really good to teach the *Seven Habits* for teenagers. We just got finished with that a week ago and when I taught it I met a lot of great people. A lot of people look up to me after that, and it helps me to work on the seven habits and it teaches me more about the seven habits and things I missed when I was taught the *Seven Habits* when I was a teenager. So yeah, it helps out a lot and feels really good teaching it and feels really good learning about it.

Caldwell: Let me ask you a few questions about leadership. Would you consider yourself a leader?

Barrows: Would I consider myself a leader? Um... Yeah, like a role model type of leader. Well, maybe I shouldn't say type. People have considered me a leader, helping this movement go the right direction. I don't know if I am the biggest leader ever, but I am a leader in a role model way.

Caldwell: My next question – and this is a tough question and there is no right answer. What would you say leadership means to you?

Barrows: Well there is many ways you can describe what leadership means, depending on the person you ask. But to me, what leadership means to me is having people advocating for what you need and what you want, but also making people understand what needs to be done in terms of your needs and your wants in life as an individual and also educating those about those needs and wants. A leader is someone to me, letting you lead the way when it comes to leading like a movement in the right direction but also having allies back you up, but having you lead the way every step of the way. And having you given the chance of standing up to the challenge when it comes to the issues such as civil rights, which is what we are fighting for when individuals with disabilities and yeah, it definitely counts on allies, definitely make people understand what direction the movement is going into, and educate people about the movement and why its happening. You lead the way in everything but definitely have back up. The center, you're the ones that are pushing to have a decision made based on your rights as an individual. You know yourself, so you know yourself better than everyone, so you stand up to the plate and advocate for what you need.

Caldwell: Yeah so part of it is advocating for yourself, but also taking direction, directing the movement?

Barrows: That's the best I can explain what leadership means to me. And role modeling counts in there too.

Caldwell: When you were coming up, did you have any role models that you can remember looking up to as a role model?

Barrows: Absolutely.

Caldwell: Think about who you looked up to, you know, maybe within the self-advocacy movement, but also beyond that who you looked up to and wanted to be like somebody you really respected, or somebody that was role model.

Barrows: I will start out in the self-advocacy movement, because I think that would be easiest to think of an individual that I can come up with. I would say a

good role model to start out with, the easiest person, is Chester Finn. He was one of the role models that I looked up to be cause I admired how he talked when he spoke to people about who he was and what needs to be done and just the way he speaks to people as a leader. I look to him as a role model for people like me, and also possibly for kids younger than me because he does such a good job at getting right to the point when it comes to talking to people with disabilities, and not only that but allies that support him and support people with disabilities.

Caldwell: Do you remember when you first met Chester?

Barrows: I first met him at the national conference in Atlanta in May 2006, around memorial weekend. And I heard of him a lot before that and I wanted to meet him. When I met him face-to-face, he asked me some questions about myself and wanted to know me a little bit. So I told him a little bit about me, and he told me a few things that he did when he was young. He thought of some of the things in common that we did and I did when we were young. When I was young, I used to play the clarinet. I told him that, and he also played the clarinet. That day when he spoke in front of everyone in the audience, he was so organized and out there, and professional at what he did. Since that day as I got to know him more at conferences after that, at state ones and other conferences as well. When he speaks I always comment on how well he speaks, and say, "Chester, you do such a really good job, how do you do that?" He would always give me good advice, and I think that would be another thing in leadership: giving good advice. I looked at him as a role model since I first met him.

Caldwell: Do you remember any advice he gave you?

Barrows: Yes I do, in fact, just a few days ago I was with Chester in Burlington. Forgot what that was, but it was a gathering in Burlington, I can't remember what it was, but he spoke in front of people who help out with organizations that help individuals with disabilities. I think it was... I don't remember at the moment. But I think afterward, after he spoke, he gave me good advice, after I asked him well, this is on my mind. But one thing I would like to do in the future is to be a national board member and travel from city to city and state to state, because I like traveling, of course, although I haven't been to as many places as I want to be or should be. And one of those positions that I could take in the advocacy group, is an officer not only at GMSA, but for the SABE – Self Advocates Being Empowered – which is the whole entire nation, and that's what Chester is. I think he's the chairman for SABE. But yeah, I've always discussed being a national board member, and one thing I do ask him for advice; and he says that it is coming along and he says I'm doing a good job in coming along but he says it does take practice, and to make a good understanding as to what needs to be done. He did tell me that, "You

know it does take practice. It does take courage. There are some challenges to the position." I don't remember one hundred percent of what he said but you gotta feel confident; confidence is another thing. There's a lot.

Caldwell: That's great. Any other role models or mentors that you've looked up to?

Barrows: Another great person, although I don't know her as well as I should, is Tia Nelis. She's another great person, role model. I've also asked her, too, like how you like, you know... I went to conference in New York; I taught an advocacy... Chester Finn is from New York, of course. He attends the state conferences, and a month before our state conference we were invited to New York for his conference in Albany. While I was there, Tia was there, and I remember asking Tia Nelis, "You know exactly what to say when you teach these workshops. How do you do it? How do you know all this stuff? How did you learn all this stuff? How are you so good at speaking in front of people? I'm just amazed at how you can go up there and know all that stuff and know exactly what to say and how to handle people." "Keep in mind, even though I'm up there I'm still learning. Your learning is never ever going to end." Just like Chester, she said, "It takes a lot of practice. It takes a lot of courage. One day you will be well known like that."

Caldwell: When you look back, you talked about the *Seven Habits*. Were there other things that you picked up leadership skills? In school or beyond that, in anything? Where do you think you picked up your leadership skills?

Barrows: Leadership skills....Through Karen...

Caldwell: This job has given you a lot of opportunities, too.

Barrows: Absolutely. Speaking of opportunities, I was actually offered to go with Chester Finn to Dallas, and I had to blow that off which I apologize for but I didn't feel as though I was ready quite yet. I feel like I don't know the airport systems that well, but I will admit that if I ever had everything down already when it comes to skills for a national board member, I would have done it. But I was offered an opportunity to go to Dallas with Chester Finn. He wanted someone to go with him to Dallas with him because part of his disability is that he needs someone to guide him. So, whenever he goes somewhere he needs someone to guide him. And I was offered to do that but there was so much going on in our schedule, too. I wasn't ready, but in the future, it will happen someday. Anyway, other places that I get role modeling and leadership skills, of course Karen, my job, my local group, that's another place where I get opportunities. Being known more, you get opportunities. Continue to do what I'm doing pretty much gives me

opportunities, when you speak, what they see in you, they want to have you.

Caldwell: There some questions here, and you may or may not know about some of this stuff, but you got some experience at the state... What do you think the self-advocacy movement needs in terms of support, funding, or advisors, or other support? What do you think it needs?

Barrows: I think it needs to expand, of course. More people should join it. Funding... It would be a lot easier to get more funding if this country wasn't at war. But I had to say that. But funding. Fundraising, if people would get more fundraising, it would help a little bit.

Caldwell: Do you think funding is important for the movement to grow?

Barrows: If we are moving to closing down the institutions and the sheltered workshops –yeah, funding for services, more services for people with disabilities to help them work in the community, more support, within the movement itself when it comes to people. More, increasing the number of officers would be a plus. There was one thing that I wanted to mention... What was it that GMSA needs? Think it has to do with more officers of some sort. I have to say the top things I can think of are definitely more funding, more funding for services, if we are moving in the directions of trying to get the institution closed for good, and sheltered workshops closed for good, definitely more funding and the funding should go to more services like health care, stuff similar to that any type of service that would help a person with a disability and good funding too. Like I said, if this country wasn't at war, funding would be easier.

Caldwell: What about Green Mountain Self Advocates? How would you like to see them grow, and what is your vision for them in the future?

Barrows: I've been told that we are kind of in away leading the national self-advocacy movement by being a role model to other states. Things that they are struggling with when it comes to moving in the right direction, GMSA? I would like to see I think this state movement, the amount of individuals we have in the movement expand, more allies, I would also like to see more parents of people with disabilities get more involved as well, in the state and nationally as well. Services –more funding. More support from the state government, just a little more support from the state government, for GMSA and for those who are participating in the movement.

Caldwell: What about your personal goals? Where do you see yourself going in the next five to ten years?

Barrows: Being a national board member, traveling, going to different schools, high schools, colleges, elementary schools, conferences, educating people,

getting them involved, teaching *Seven Habits*, speaking at the White House about this, doing what I'm doing on the national level, more advanced, which is what I want to do badly and I have to continue to work towards that.

Caldwell: Have you ever thought about college?

Barrows: I have on and off, I haven't, I haven't felt like I can afford college because it is so expensive. I have thought of taking some classes at the community college. I have taken one called intro to college studies, it just introduces you to some basics. A pre-college class, gives you a preview of college, and I did pretty good in that class even though it was only one class?

Caldwell: What was your favorite subject?

Barrows: A favorite subject at school? I had a few. I liked physical education, PE was great because you did a lot of activity in class and stuff. Bear with me when I say this: sex ed I think was one of my top three subjects. Sexual education.

Caldwell: If you ever think about going to college, what would you study?

Barrows: Human sociology, anything that has to do with the scientific study of human behavior. Another one is weather – meteorology.

Caldwell: Have you ever heard about disability studies? It is similar to understanding disability, thinking about disabilities and the barriers people with disabilities face. There are not that many programs yet, but that might fit your interests. To go back to the question about young people, have you ever been to an institution or to a sheltered workshop?

Barrows: I have not seen institutions or sheltered workshops in real life. But maybe for educational purposes I wouldn't mind actually going in to see what one looks like. The thing with institutions and sheltered workshops, and institutions especially, with all the terrible things that I've heard of them and why they exist, my fear of going in to one is being really emotional, just feeling so bad for those who are in those types of environments. It was described to me as a jail cell. Just because you had a disability you're like, in there. And that's like, I think, one of the only reasons why. And with that said, and with the descriptions that I had, that I've been told, it would probably make me feel very, very sad, and put a little split in my heart. Knowing the fact that there's always opportunities for those individuals out in the community that could be increased or are just there but not really paid attention to, you know it would make me feel bad. But if it was an education reason, I would visit one to see what it was like. I'm so sensitive, and I care for people so much, it would put a knot in my feelings to see how they were treated in those institutions.

Caldwell: Did you learn from others, some of the history of the movement, or some of the history of how people with disabilities have been treated, histories about policy? Have you learned that along the way?

Barrows: I have, I believe. I've been told people with disabilities in the past have advocated for themselves. You probably remember this, but what happened in 1991, I've seen pictures of this, people in wheelchairs got out of their chairs and crawled up the stairs in Washington, DC. I think it had to do with the Americans with Disabilities Act, the ADA. Individuals with disabilities walked backward, or crawled up the stairs and when the government saw that, they changed to whole way they looked at the movement that was in progress at the time. But it was like actions that advocates took, yeah, I don't remember I was so young when that happened, plus I didn't get that much information about it, but I remember something like that happened.

Caldwell: How did you come across that? Did someone tell you or did you see it?

Barrows: I was first told about it and then I saw pictures of it, and I was just like, wow!

Caldwell: It seems like that's important for young people to know about things that happened, like history, to learn from history, especially about the history of the disability rights movement, and lot of people still don't know about it. Have you ever heard of Ed Roberts?

Barrows: Yeah, I've heard his name.

Caldwell: Yeah, I think that's important. And the history of the self-advocacy movement and how that started. Do you know anything about that, like when the self-advocacy movement started?

Barrows: I think it really went big in the '80s, at least from what I remember being told, but I think it always continued way back, 1920s or something. Just like the Jews were treated in the Nazi camps, people with disabilities got treated in the same way. I'm sure that the same went for slavery. It probably goes way back. I know during the civil rights movement with African Americans, that people with disabilities were involved in a way.

Caldwell: That brings me back to another question, about being a leader who is African American like Chester. I see a lot of leaders in the self-advocacy movement who are African Americans or Latino or other minorities, and it's interesting to see that and I don't know if you have any comments as to why that might be the case?

Barrows: I think that it's the understanding of what we as minorities have been through in the past and our history, and in our relation to what people with disabilities are facing and have faced in the past. I think our relationship to

that and the understanding between our history and the disability history is that we're all coming together and we're helping each other out. It's like the ally, I think. And also, too, I think it's the understanding. Let me give you an example. I think my boss Karen next door told me one time when civil unions were being legalized in Vermont, there was a woman in the same –I don't know if it was the same or different position than I'm in now, it was close to mine but she was an officer in the GMSA –and think at one meeting they were discussing it in a meeting and it was a hot topic –gay lesbian rights, and there was a huge debate, and some people were timid about it. She stood up and said if you don't agree with gay lesbian rights equal rights in marriage you might as well call me the "R" word because it's the same thing. It just changed the whole thing. Later they all punch slap in the face, "Oh maybe it is."

I do know that Chester Finn has a history of doing that too. He might say something similar to that, like if you don't respect people with disabilities or people who are different when it comes to diversity, it's the same as calling me the big "N" word. I think when you mentioned, if that's a good enough example that you're noticing a lot of minorities, I think it has to do with understanding we can try and relate to each other of what we've been through when it comes to experience with discrimination and hatred and bigotry. Kind of like when I take it back to when I was talking to you about the high school experience, when I came into a class where I had a disability that was more invisible than everyone else's, and at first they were like, "Oh, you know," but they got to know each other and became friends and united after talking about our differences. I think it's about the same thing, not about individuals but nation world wide, that's why individuals who are minorities like Chester Finn and I, we have an understanding. Our understanding of how we were treated in the past is relating to how people with disabilities are being treated today when it comes to hatred and discrimination. It's like civil rights, if you look at it, it's all one big civil rights movement. You just can't look at civil rights for African Americans, but for everybody. African Americans are being involved more, it's all one big movement and we know what needs to be done.

Caldwell: Does GMSA work with the independent living movement?

Barrows: That I'm not sure about. I might, but I'm not sure about. I have heard them mentioned a couple of times.

Caldwell: Have you met anyone from the Independent living centers?

Barrows: Absolutely. I know a person who works there. But we have been connecting to them. I know we do.

Caldwell: So just to go back and see if we covered everything. I think we covered most everything. Just to ask you again when you look back and in your life now, who are the people who are closest to you?

Barrows: Family or friends or both?

Caldwell: Both.

Barrows: My parents, my boss, my former boss. My former boss wanted a shirt, so he's feeling a little bit of where I'm going. A couple of allies in our group. Other self advocates. Our national board officers, our president, there's quite a lot of people.

Caldwell: Do you have certain beliefs that guide your life? Certain ways of looking at life that guide you?

Barrows: Don't change, no matter what people say or think. That's a huge belief that I have. Does it have to be religious or not religious?

Caldwell: No, it doesn't have to be religious. Just certain kinds of beliefs that guide your life. Like what you just mentioned.

Barrows: Just believe in myself.

Caldwell: Do you have religious beliefs? Is religion important?

Barrows: I did go to church at one point. I would consider myself to be more spiritual. But there is a little thing that I have towards Buddhism. I was looking at Buddhism at one point. But I don't know if I want to go that far yet, but I'd like to explore it more. Buddhism helps you deal with grief, the loss of family members. Their belief is that you die physically but your spirit still lives always, so that's a good way to actually deal with some of the toughest grief that you go through in life, when it comes to a close friend or family member that has passed away. Overall I'm a very spiritual person. I wouldn't consider myself to be religious, but I'm very spiritual.

Caldwell: Are there any kind of lessons that you've learned in life?

Barrows: Yes, I learned to look at all the tough times in my childhood since growing up in Vermont as motivation to continue to move in the right direction –to continue to be me and succeed in being me and continue to do better in life. And academically learn more. Just to do better in life. Use it as motivation socially to meet more friends, so even though my childhood was a rollercoaster, it's all now a motivation to do better in life.

Caldwell: When you say it was a rollercoaster, was it mainly in school?

Barrows: Absolutely.

Caldwell: I wanted to ask you about... In terms of your confidence and pride, you seem to have a lot of that now. Were there times when you didn't feel good about yourself, and what helped you to get where you are at now?

Barrows: When I was being bullied in high school and a lot of teachers didn't understand me, physically. Like I said earlier, that period of my childhood when I didn't feel good about myself, and I'd think, maybe I am dumb, maybe I am stupid. But I think the thing that helped me was, as I look back on it, at least I didn't quit. I didn't give up and I needed to learn. I didn't give up, and when I began to advocate for my needs, I didn't quit doing that. Even though I faced challenges like everyone else does... If you don't give up you can look at the mirror and be proud of yourself, that at least it didn't stop you from being you. You didn't stop you from continuing to move in the right direction. Even though sometimes you had to push things out of the way that are tough to push out of the way.

Caldwell: Did you think it was also... You talked a lot about coming together with other people with disabilities, and saw that you weren't the only one, you think that was real important?

Barrows: Absolutely, that also helped me a lot, now that I know there are a lot of people I can connect with, I can take that as a learning experience. And just having that knowledge, that I'm not the only one with a disability out there and different out there, it makes me feel, helps me feel good about myself. Even though it is a tough world and stuff happens and some of that stuff can be rough, there's always opportunities out there and don't give up looking for those.

Caldwell: I think we covered that everything I wanted to ask, is there anything you can think of that you wanted to cover that we didn't get into?

Barrows: I just happy of who I am, just happy that I'm involved in this movement. I hope that this movement goes the right direction. I am looking forward to continue to meet people that I want to have a connection to, continue to move the right direction with my life, continue to use the past as motivation for the future. Continue to make great decisions in my life, continue to help people that have the same struggles as me, continue to talk to people. Continue to be me. Continue to have pride in myself and never look down on myself and look in the mirror and smile at an individual that is succeeding. And if you keep that confidence in you and if you don't give up in what you want to do, and if you don't give up period, you will feel pretty damn good about your life.