



Hi, it's Larry and welcome to Disability Nation - an audio magazine by and for people with disabilities. Disability Nation is your source for news and information affecting people with disabilities across North America and the world. Thanks for tuning in this week.

Disability is often an issue that has a significant impact on a family and specifically on the lives of parents raising the child with a disability. In fact, if you ask any parent, they will probably tell you that it's taken their life in a direction that they probably didn't plan on.

This time on Disability Nation, we'll talk with a family about the impact of disability on their lives and about how they seek to use this to educate their community about disability issues.

Also on the show this week I'll share some comments with you from Senator Tom Harkin of Iowa on the Community Choice Act of 2007.

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Micah Feldman: I like wanted to go to college because my dad went, my papa went, my cousins went and I just had a dream because that's just what kids do after they graduate high school; go to college and do, like, college things.

Janice Fialka: Micah's teacher Sharon Burke, who I refer to as the teacher I've waited my whole life for -- she went with Micah and Rich to a college night at a school that served kids with learning disabilities. So they had various universities' representatives there, talking about what their universities' program was. And

Sharon connected with someone from Oakland University and said, "We have a young man with a cognitive impairment which is different than a learning disability."

Sharon Berke:

I always knew that Micah was interested in post secondary education, specifically going to college. He would talk about that all the time. And he was talking about that since he was in elementary school. So everybody always knew that. You don't expect to hear that from students with cognitive impairments. Unfortunately, you don't expect to. And some people even when they hear it, question it, but he always made that very clear.

Sharon Howell:

I was just -- it never occurred to me that Micah would come to college because I thought about college as, this is what you do; you get an advanced degree of some kind. And then the more I read and the more I talked to Rick and Janice about things, they started talking about life choices and if -- and what's age-appropriate. And if most seventeen and eighteen year old people, that they knew, were able to go on to public colleges, why wasn't Micah able to do that? And that argument started to make a lot of sense to me.

Robert Wiggins:

Students with disabilities who reach a post high school age, but who aren't able to earn a high school diploma are still entitled to educational services through the public schools and through the Oakland Intermediate School District.

Larry Wanger:

That was an audio clip from a recent documentary entitled, "Through the Same Door: Inclusion Includes College," a documentary that features the journey of Micah Fialka-Feldman as he seeks to accomplish his dream of going to college.

Micah was born with a cognitive disability and this disability has had an impact of those around him as his family has been involved in disability advocacy and educating people about disability issues in their community. You can find a link to watch the full documentary online and get more information at the *Disability Nation* website. Here to tell us more is Ross Wine-Sky.

Ross Wine-Sky:

Hi. Today I'm here speaking with Micah Fialka-Feldman, Richard Feldman and Janice Fialka. Now all families are special, but can you tell me a little bit about your family and what you do?

Janice Fialka: Let's see. Micah, you want to talk a little bit and say who's in our family.

Micah Feldman: My mom, my dad, my sister, my aunt, my uncle, I don't know.

Janice Fialka: So, yeah. There's a mom, a dad. Micah's 22 years old and Emma is 18, and just left for her first year in college.

Richard Feldman: Micah is 22 years old, will be 23 years old September 20th, and has a cognitive impairment. And one of the things that Micah has always emphasized and brought to our family is his love of politics and his love of current events. We're very, very proud when it was the first time he had the opportunity to vote. We had a voting party. He's always talked about the -- and in practice, emphasized the importance of being with citizens and being an advocate for disability rights and young people with disabilities. Micah has inspired us to be working in a very committed way with folks who have disabilities and disability advocacy.

Janice Fialka: Perhaps, maybe one thing that we are fortunate, I think, both Rich and I were active in the 60's around peace and justice issues. And so even before we were parents, we were involved in the kind of issues that bring peaceful, sometimes to the street, and involves the idea that everybody -- that integration is something that we all need to work for. Little did we know that when we were involved in the 60's and 70's in the peace movement and the women's movement, that eventually we would learn about another movement that at that point we really didn't know much about and that is the disability movement.

When Micah was born almost 23 years ago, and was given a label, we were tossed into this new world; and were very fortunate to have met people who help us know that as a family and as citizens, we need to take both stands, so that all people have the right to dream and to move forward in their dreams. So, I think that's a few things. Is there anything you want to say, Micah, about our family in terms of what is special or what we're involved in?

Micah Feldman: Yeah. To like, take family trips and have fun.

Ross Wine-Sky: Micah, I know you're also a disability advocate and an activist.

Micah Feldman: Yes. I'm on the KASA Board and I'm on conference calls and then I'm on the NYLN and the Mentorship Committee with

NYLN. It's the National Youth Leadership Group; KASA is Kids As Self Advocates. And I've been there since 2003. And then I'm on the other group called NYLN, and it's [www.nyln.com](http://www.nyln.com), too.

Ross Wine-Sky: I met your mom and your dad while we were both doing some speaking at an event. I understand you do some public speaking, too?

Micah Feldman: Yeah. I speak about my life and about what I do and stuff, and college and school.

Ross Wine-Sky: Janice, I've been to your website. Can you tell me a little bit about what your website is?

Janice Fialka: Sure. Well, I think, just a brief background, sort of -- or information about my background. I was a social worker, or Cell M social worker, and so I sort of bring that insight and experience. And also being a mother of a child with a disability, I have different roles, or different experiences. So many years ago I started doing talking and training and some writing on the relationship between parents and professionals. Because one of the things that I noticed very early, is that sometimes you can get very well meaning people together to plan and support a child with a disability, but things often, the communication sometimes isn't as easy as anyone wants to be.

So I developed this training and have done some writing around ways to strengthen the relationship between parents and professionals; ways, to understand why, as I say, well-meaning people come together and sometimes aren't always understanding of what the different partners bring. So my website is really a resource to parents and professionals. There's a lot of articles written from the parent and the professional perspective. They're all positive. There's practical suggestions about ways to really strengthen the communication. There's a lot of links to other important educational or informational sources as well.

That's a little bit about the website. You can also actually see we just recently just finished a documentary about Micah. Micah has been fully included in regular education pretty much his whole life, since he was in 1st grade and he said he wanted to go in the same door as all the other kids. So, as we say, we've always been following him through the same door. So we did a documentary that talks a little bit about his inclusion, not only in high school, but also now on a college campus. Then there's

also information about the various books and book clubs that I've been writing. Maybe Rich has something to add to that, too?

Richard Feldman:

Well, I think you were asking Micah about some of his involvements and one of the things he's been doing recently is going around with this film that we've completed, that the filmmakers spent 33 hours with Micah and turned it into a film of 24 minutes called, *Through the Same Door: Inclusion Includes College*. And one of the things that's amazing and as a family has been so inspiring is the number of people that call on a regular basis and say, "I can now dream of about what my kid can be doing again." Or a teacher will call, and say, "I have to apologize to a parent who, because I didn't -- I wasn't respecting their dreams for their dreams for their children, or with their children."

And as active, committed individuals, we see the inclusion movement as an extension of all the other movements, because it's saying that our society has to change and create a place where everybody has the respect and the ability to be involved and to work.

Janice Fialka:

There's another part of the website, too, that will speak for Emma, since she's not here, but Emma, who is Micah's sister, has also written some pieces about being the sibling and what that experience has been like. And she's very honest and very proud. She and Micah have presented. She talks about the range of emotions that she's gone through as well, and her whole interdiction to the disability right movement as well. Those are some of the things. There's a lot to go through, but we are just delighted that we could support the work of people. And you know the nice surprises that we get, wonderful e-mails and phone calls from parents and teachers and other students who then share their story about moving forward or working on their dream.

Ross Wine-Sky:

Micah, what would you say your dream is?

Micah Feldman:

To have a good college year and have a good job and have fun. I'm right now this term taking a public speaking class and a class on people that became presidents.

Ross Wine-Sky:

What do you find, Micah, about the disability movement as you speak in different places in the country?

- Micah Feldman: I kind of think it's cool when I meet someone cool like people and stuff. And it makes me strong and stuff.
- Ross Wine-Sky: How often do any of you go out and speak? Because I know I've seen all of you that do speaking engagements.
- Micah Feldman: I try to speak only twice every month or something.
- Janice Fialka: Well, I would say that on an average, I'm probably speaking at least once a week someplace. I do a lot of training here in Michigan where we live. Recently, really in the last, I would say 6 or 7 months, we would often be traveling as a family. So Rich is able to give the father's perspective. I talk a little bit about the mother, and Micah talks about his dreams and he's the funniest of them all. He's always making people laugh as well. And then when Emma was with us, too, she would talk a bit about the sibling issues. So, that's a little bit about some of the places that we've traveled as well. I think one thing is, that we just try to be very honest about our experiences.
- Richard Feldman: And I think the other thing is, is that when we are speaking, sometimes in places where it's around education or it's around disabilities, and inclusion. Other times I work, for example, doing a lot of community work in Detroit with, for example, the Detroit City of Hope program. Part of my responsibility is to make sure that other community-involved people are aware of the inclusive education movement and disability rights and Disability Pride. We'll make sure that other youth organizations around Detroit and around Michigan are aware of Kids As Self-Advocates, are aware of Micah's film; are aware of the Disability Pride parade in Chicago.
- And that's part of the work we are committed to. Because we fundamentally believe that Micah's security and the security of all people, whether they have disability or don't, is about the kind of society we create, the kind of values that underlie the community in which we create. And that's not a society that we have right now, and it's not a community that we have right now. It's one that we all have to work for.
- Ross Wine-Sky: What kind of changes have you seen in the last 15 or 20 years?
- Janice Fialka: I think since his birth 22 years ago, one of the biggest changes is that there are so many resources out. I mean, when we started, there was maybe, if you go to the local bookstore, maybe 5 books on issues related to disability. Now there's

shelves and shelves and shelves, and many of them are written by people with disabilities.

That's an enormous change. I think that because of the work of so many people, including people like yourself, we moved or are beginning to move away from position of disability as something to be ashamed of, something to hide, something not to be discussed to disability is a natural part of human nature. And it's not, and we've learned from other people who have taught us important lessons, that it's not about overcoming your disability, but learning to see that it's a part of you and learning what the gifts are.

So I think there is -- it's small, but there's a creeping cultural change in how we even view differences. And the other one that strikes me immediately is that there's been a real shift in full inclusion. When Micah was born, I didn't even know the word inclusion. But he let us know that he wanted to be with his peers, and for whatever reason, we trusted him, so there was -- we learned how important it is for all kids to learn together. There's no special ed kid; they're all kids and some need support. I mean, no one would have ever thought that Micah would be going to college.

Kids with what we used to call mental retardation, now we call it either cognitive or intellectual disability. No one ever expected them to be on a college campus. And here we have young people like Micah all over the country, not millions, but scores and scores, who are in the college classroom, sitting next to people, learning together, getting support. So there's been huge strides. Yes, you're right with what you said earlier. We do have a long way to go, but we've gone miles and miles. So that's kind of my thoughts. Micah, is there anything you've noticed?

Micah Feldman: There's more youth groups and stuff.

Ross Wine-Sky: When you go to a youth group, does it take people a while to get to know you?

Micah Feldman: Oh, no.

Ross Wine-Sky: No?

Micah Feldman: They say, "Hi," and, "Oh, yeah; you're the famous guy." And they know me already.

**Janice Fialka:** One of the things that I know that I've learned as a parent is that we as human beings need to see that asking for help and connecting with people is a strength. In order for Micah to be where he is today, and for all of our whole family, we've had to reach out to the community; and that's in some ways not the American way. And I think what we've learned is that by bringing in people, supporting Micah through a circle of friends and engaging people in a very intentional way, that we've allowed people to grow and experience. And we've not kept ourselves isolated. So I guess if you're looking -- if I was to share advice that would be one of the things; to really define asking for help as a strength. So that's an idea I have.

**Richard Feldman:** One of the things that's so fundamental as an inspiration about what inclusion and understanding some of the values that underlies the importance of disability rights and pride movement, is our society the way it is right now, judges people by how much they can consume, how much money they can make. So it's how you much you make at work or how much you can buy from the store. And that is a pretty, pretty destructive way to evaluate and judge human beings. But that's the culture we've all been raised in.

And what we all know from being activists and citizens, is we have to get to the place where we're evaluating people based on the kind of human being they are, and the kind of relationships that we create with each other, and the kind of values that lead to a cooperative kind of society and the creation of new kinds of communities. And until we do that, we're just going to be this individualistic society that prevents people of disabilities from being both included and from changing our society.

**Ross Wine-Sky:** Can you tell me your website if people listening right now want to go there?

**Janice Fialka:** Sure, and we hope they do. It's [www.danceofpartnership.com](http://www.danceofpartnership.com). And people can actually view the video right on the home page. The second website is [www.throughthesamedoor.com](http://www.throughthesamedoor.com).

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At the end of last month, the Senate Finance committee held its first hearing on the Community Choice Act of 2007. This important legislation which is sponsored by a number of senators, including Tom Harkin of Iowa, will dramatically change how Medicaid dollars are spent in this country, and provide alternatives for people with disabilities who are in nursing homes or institutions in order to get the cares that they

need. The following is a portion of some comments made by Senator Harkin at the hearing.

It's been about seventeen years ago; seventeen years ago this summer that the Americans with Disabilities Act was signed into law by President Bush. There were 4 goals set out in that bill; equal opportunity, full participation, independent living, and economic self-sufficiency. But the time when this passed the senate, and the President signed it, and later into law in 1990. I said it at the time on the floor, since I was the chief sponsor of that bill - I said at the time that this opens the door, but the next most important thing we have to do is provide personal attendant services to people.

So it's been 17 years since ADA and since we've started this push. It's been over 10 years ago since MiCasa was first introduced. Now, MiCasa was a precursor of this bill, the Medicaid Attendant Supported Services Act. It's about giving people choice, about where they want their Medicaid dollars to be spent. That's really all it's about. Let us decide where that money should be spent. Now, I just close with a story about my nephew Kelly, to give you an idea about the differences.

My nephew Kelly was injured 27 years ago 27 yeas ago. He was a young man of 19. He got injured, became a quadriplegic. Well, he wanted to go to college, so he went and he got good service. He went to college, he got his degree. He then became independent, he's lived in his own home ever since. He got the use of his arms back and he can actually drive his van with a lift. He gets the van, goes to work every day. He has a nurse comes in every morning, check -- every morning a nurse comes in get him out of bed, does his exercises, does his other things he needs, drains him, all that kind of stuff, get him ready to go to work. Kelly gets in his van, goes to work. He comes home, he makes his own meals, invites friends over to his house. Then he has some one comes in, helps him get ready for bed.

Next morning, gets up, nurse comes in, gets him ready to go and he goes to work, he pays taxes. Contributing member of society -- now how does he afford to do all this? Is his family rich? No. His mother, my sister, died many years ago. Family very modest means. His dad is now 88 years old. They don't have any money. How does Kelly afford to do all this?

He got injured in the military.

He got injured in the military. The VA picks it up. The VA picks up everything. Gives him the opportunity to go to school, to live independently, to have his own life, to get a job and pay taxes. If Kelly at age 19, I say to my friends, if he'd gotten injured in a car wreck, he would have never been able to live the life that he has lived. He wouldn't have those services available to him. That's the difference. He had his choices simply because he was injured in the military.

I say it's now time to gives every disabled person in this country the things Kelly had. The kind of choices to make, the freedom to live their own lives, not where housed in a

nursing home. That's why this is so timely. This is so timely. We've been waiting a long time, as I've said, 17 years. 10 years since it was first introduced, 8 years since the Supreme Court said in the *Olmstead* decision, that the state had to provide the least restrictive environment under the Americans with Disabilities Act.

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