

Impact

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Micah Fialka-Feldman on his first day of living in the dorm at Oakland University in Rochester, Michigan. See story below.

What's a Parent to Do? Micah's College Dream

by Janice Fialka

My father proudly graduated from the University of Michigan in 1948, the first in his family of 11 children. Little did he know he established a generational pattern for the important men in my life. My two brothers, several cousins, and my husband all claim the same “maize-and-blue.” At the age of 5, our son, Micah, attended his first U of M football game and was immediately awestruck by the “Go Blue!” spirit. I sensed he felt destined to follow in the footsteps of his Papa, father, and uncles. He didn't have the words to express this dream – words did not come easily to him then – but his dream was deepened with every U of M game he attended.

We as parents wanted both our children, Micah and Emma, to have dreams. Dreams motivate our spirit, drive us forward, stretch us in new directions, and compel us to try new things. We wanted our children to gradually feel the pull of passion and purpose. But what if their dreams are met with words like “unrealistic,” “impossible,” “out of reach,” “can't do that,” “unheard of,” or simply “Why would he do THAT.....?” Those were some of the very words we heard when Micah talked about his college dream. “Look at the facts,” we were told, even by well-meaning people who cared about Micah. Fact # 1: Micah has a cognitive impairment with a low I.Q. score. Fact #2: Micah didn't read or write (though he could sign his name after years of practice.) Fact #3: There were no fully inclusive college programs in our community. Fact #4: Youth like Micah, with an IEP, go to community-based programs after high school, not college! What's a parent to do?

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From the Editors

Postsecondary education is a primary goal for the majority of high school students with transition plans, according to the National Longitudinal Transition Study–2. However, according to that same study, only about 3 in 10 young adults with disabilities have taken postsecondary education classes since high school. And among those with the lowest rates of participation are students with intellectual disabilities. This Impact issue explores what we know, and what we still need to know, about what works to support increased participation of students with disabilities, especially those with intellectual disabilities, in postsecondary education and why that participation is important. It includes stories about students with disabilities succeeding in higher education, strategies for families and school personnel to use in supporting planning for postsecondary education during high school, research findings and historical overviews on our national journey to support full participation in all areas of life – including education – for individuals with intellectual and other disabilities, and explanations of the education laws that can undergird that participation. It's our hope that readers of this issue will find new ways of thinking about the role of post-high-school education in the lives of young people with disabilities, and about the benefits to those young people as well as our communities and nation.

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Listening to the Dream

One of the first things we learned as Micah's parents was to listen to his dreams, even if they appeared "unusual." Our first experience with the "listening thing" occurred when Micah was in his first grade self-contained classroom. After four months he announced to us, "I want to go through the same door as all my friends." We were stunned, and later swayed by his insistence to move him into a general education classroom. Micah began to teach us "unusual" does not imply "impossible."

Getting Micah in a general education classrooms through 12th grade was a bit challenging. But "college" – that was something entirely different! We had no idea *how* we were going to help him get through that door. Nonetheless, Micah held steadfast. We were committed to listening to him and heard more than just "I wanna go to college." We began to hear his unspoken desires like, "Hey, I wanna be with my friends. I wanna talk about what they're talking about. I wanna tell everyone what college I'm going to. I wanna go to football games. I wanna keep learning." And maybe most importantly, "I wanna make my own choices."

As parents, we shifted our thinking (most of the time!) away from someone else's facts and words like "impossible" and turned toward "what's the next step?" This was often not easy, but always right, and eventually became a strategy for dealing with the so-called impossible: Keep taking the next step!

Building the Dream

During Micah's final two years of high school, a creative and dedicated group of college and public school professionals and parents from the metro Detroit area met to consider, and eventually create, an inclusive program through which young adults with intellectual disabilities could become college students. Now called the OPTIONS Program at Oakland University in Rochester, Michigan, it gave students with intellectual disabilities the opportunity to attend classes, participate in extra-curricular activities, and, in

Micah's case, live in the dorm. At age 19 Micah entered the program and through his six years in it grew academically, socially, morally, and politically in dramatic ways. He studied public speaking, created Power Point™ presentations on group dynamics, studied the difference between the ways males and females greeted each other in the Student Center for a sociology class, learned to use more hand gestures when speaking, studied social movements, took a hip-hop dance class, traveled to Israel, participated at the student leadership retreat, wrote papers (maybe not 20 pages long but two pages of facts he discovered with the support of a peer), and taught students how to use the voice-to-text software program critical to his communication. "Success" doesn't even begin to capture the extent of his growth, increased friendships and social networks, and enhanced skills to navigate the world. It wasn't a one-way street either. Based on the feedback from professors, staff, and students, he made important contributions to his campus and at several others across the nation.

In 2010, he received his certificate from the OPTIONS Program, celebrating his graduation. He now works in Detroit at the Michigan Roundtable for Diversity and Inclusion as a social justice educator for youth. He speaks nationally on disability and serves on the board of directors for TASH and the National Youth Leadership Network.

Guiding Principles

Looking back over the years, several principles guided our actions in supporting Micah's college dream:

- *Acknowledge the range of feelings.* For 12 years, Micah attended public schools. Although some days brought struggles to get him what he needed, the school experience was familiar and predictable. Near the end of his senior year, I had moments of sheer panic as I thought of Micah at college. Would he be safe? Would he be teased? Would he know how to get from one end of campus to another? He wasn't even comfortable crossing a small intersection by himself – how

was he going to take two public buses for one and a half hours to a campus? Feelings are part of all transitions. If we don't acknowledge them, share them with a trusted person, these emotions return, often hindering us from moving forward. It was very important for me to communicate with a couple of mothers whose children had disabilities and were older than Micah. They had lived through it, survived the transition, and knew what I was feeling and needed to hear. They understood and validated my fears, worries, and even sadness at times. They also celebrated and shared my excitement. My mantra, when I remember it, is, "Feel the feelings first, with someone you trust, then move on to the next step."

- *Support great expectations.* This is a common chorus often repeated in the world of disabilities, so much so that sometimes it loses its significance and meaning. What these three words meant to us as Micah's parents was that we had to believe Micah could learn more and do more than what was often expected of him. Finding the right supports was vital to achieving those high expectations. "He can do more" became a common chant in our family, not in a way that pressured him (we hoped), but in a way that allowed him to build on what he enjoyed and could do well, sprinkled with a little bit of nudging out of his comfort zone at times. When Micah said he wanted to go to college, believe me, we never expected that he would eventually share a film about disability history in his class on social movements. We did not know that at the beginning of each new semester, he would stand up in class and ask for a tutor to help him study (and would be thrilled that "so many pretty girls" came to his assistance). We did not know that his confidence would soar so high that he would be able to speak on his own in front of the University Board of Trustees to present his case to live in the dorm. We did not know that he would sign-up to travel to Israel (gulp), or that he would discover a strong desire to read and diligently work at it with friends, or that he would

find an interest in money, piqued by watching his friends use the on-campus bank. We did not know that he would understand the word “norm” and would inform us that it was *not* “the norm for college kids to wear boots in the winter!” He became more capable almost by the day. Even brain research supports what many parents have known for years: Students with intellectual disabilities do *not* stop becoming smarter and better problem solvers once they leave their senior year of high school. They continue to increase their problem-solving skills and academic performance *if* given authentic opportunities to learn, embedded in high expectations.

- *Be mindful of the changing parental roles.* A wise sociologist once told me there are two roles parents assume: one is the *protector* and the other is the *guide*. In the early years of raising children, the parent defends, cares for, looks after, and shields the child from harm and danger. It is easy to see how this role is often more deeply entrenched for parents of children with disabilities. We learn to be fierce advocates for our children. As they grow, we are challenged to move away from being the constant protector to being the emerging mentor or guide. We had to step back a bit and let Micah tell his story, hand in his un-perfect paper, sign his name at the doctor’s office, make his choices about what to wear. This re-arranging of roles is not a simple transition. When Micah ended up stuck at his bus stop for two hours 30 miles from home in an evening snow storm that shut down the entire county, I wanted to put on my Super-Mom cape, leap over tall snow mountains, and fly him to safety. I couldn’t. We literally became his guide (thank goodness for cell phones!). We created a plan whereby his father called him every 15 minutes as he stood in a bus shelter. (He did begin to think differently about the norm of not wearing boots after his feet almost froze that evening!!). After that experience his confidence increased, as did ours in him.

- *Build relationships with allies and his peers.* Beginning in 6th grade, Micah invited a few friends to help plan his IEP and attend part of every meeting. This involvement of friends continued into college. At his person-centered planning meetings, he always invited a few college peers to participate by bringing real-world solutions and insights into the discussions. They often came up with the most practical and astute ideas of how to support him. When Micah was in college, each year we invited him and a few of his friends to dinner. We kept the conversations light, fun, and we listened a lot. We learned so much. Eventually some of the peers felt comfortable sharing more ideas and questions. I recall one friend asking me how to handle Micah’s falling asleep in an early morning class. I asked her what she would do if another friend fell asleep. She quickly said, “I would elbow him and tell him to bring a cup of coffee to class.” She instantly “got it” as evidenced in her response to me, “Oh yeah, I get it. I guess I can do that with Micah too.” Folks need to know that it is okay to ask questions and share concerns. Micah learned to tell his tutors, “I’m okay with you asking about my disability. I’ll tell you about it and how I learn best.” Fundamental to Micah’s sense of self was his participation in organizations led by youth with disabilities, where he experienced disability pride and culture.

- *Expect to live with uncertainty and risk.* I suspect that many parents raising a young adult with a disability have experienced a similar unsettling internal dialogue that goes something like this. “Do I let Micah try new things? If I do, what if something goes wrong? What if he gets hurt? Would I have this same fear if he didn’t have an intellectual disability? But he does, so what do I do?” I’m not sure this worried-parent script will ever cease, but after more than two decades I am somewhat better at expecting these periods of anxiety. I try to be mindful of them, maybe talk with a friend or family member,

create a plan, and eventually remember to not let fear dominate my decision-making and support of Micah. My husband and I try to minimize the risks, discuss pros and cons, and practice with Micah the best ways to handle awkward or uncertain situations. But, ultimately, we realize that overprotection will only hinder his ability to make safer decisions for himself. When this happened during Micah’s years at college, I tried to practice getting more information from Micah, gaining a sense of how *he* was doing, and if necessary reach out to others. My husband and I cannot shelter Micah from all risks, nor can we do that for our daughter, Emma. Risk-taking comes with the territory for all of us.

I recently read an article by Sunny Taylor (2004), an artist with a physical disability, in which she said that too often professionals (and I would add parents) equate independence as having “self-care skills” such as feeding, dressing, moving about the community, banking, etc. These skills can be important, but they are not the determining factor in one’s quality of life. In her words, people with disabilities define independence beyond self-care skills as the “...ability to be in control of and make decisions about one’s life, rather than doing things alone or without help.” Twenty years ago I don’t think I would have understood this definition. I think I do now. Micah has taught us that the quality of his life is primarily based on his ability to *know* he has choices and *can make choices* with support. And for Micah making his own choices has meant going to college (with or without his winter boots!) and it’s been worth the effort and risk for all of us.

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The Power of Inclusion: Personal Reflections on Creating Change

by Shea Howell

What then would be our reason for instituting a program for students whose goal is not degree completion? The participation of students with cognitive disabilities on our campus indicates that we have a broader view of our institution as a center for learning... The liberal arts tradition maintains that higher education is more than preparation for a specific career or profession. It is about the continual quest for deeper understanding, richer life experiences, and personal growth; in short, the overused term – life-long learning. If we accept this as the role of higher education, then we must believe that this is our mission toward all individuals.

– Virinder Moudgil, Senior Vice President for Academic Affairs and Provost, Oakland University, delivered at Options Graduation Ceremony, April 19, 2010

Micah Fialka-Feldman graduated from Oakland University in the spring of 2010, completing six years in a program designed to provide a fully inclusive university experience to young people with intellectual disabilities. With the support of Micah, his family, and visionary educational professionals, Oakland University opened its doors for full inclusion. In the course of this experience I was able to observe the power of inclusion to transform institutions and individuals.

I taught Micah in two classes during his final semester. He was in a public speaking class and I directed his capstone course. A year earlier Micah also took my class Persuasion and Social Movements. I was involved in his course selection throughout his academic career. I was able to watch Micah grow as an individual and to observe the impact he had on other students.

My first classroom experience with Micah was in Persuasion and Social Movements. This class fit his strengths. His family members are well-known activists and he has spent a lifetime surrounded by people engaged in move-

ments for change. Micah has a keen interest in politics; he was among the most-informed students in the class and participated fully in discussions. During the class he was the first to have seen *Milk*, a film about gay activist Harvey Milk of San Francisco. He encouraged classmates to see it and talked about how important it was for people to understand the struggles individuals faced. This kind of contribution was typical of Micah's participation, offering resources and insights to others.

Grades in that course depended on papers discussing some aspect of social movements. The only modification I made was to allow Micah to substitute video interviews for written papers. This did require giving him some clear direction in how to frame questions and approach issues. Generally, it was helpful for me to develop a few ideas and present them to Micah so that he could choose among them. He followed the same assignment schedule and handed in his interviews along with everyone else's papers. He worked with another student on their final presentation, analyzing his effort to overturn a university ruling preventing him from living in the dorm.

The second class, Public Speaking, also drew on Micah's strengths. During high school, he spoke to groups about people with disabilities. By the time he came to the university he had established a record of speaking events. Micah not only spoke on campus, but traveled locally and nationally to make presentations to gatherings large and small. Depending primarily on Power Point™ presentations to provide structure, Micah was comfortable as a speaker. In a class with mostly freshman and sophomores he was among the most natural, organized, and effective speakers. Micah's main challenge was to move beyond material that he had presented and to explore new ideas. Here, too, the primary strategy I

used was to develop some options for Micah so that he could select among ideas. While it was often difficult for him to generate new topic areas, once he grasped a direction he was able to move forward.

His final speech presentation in the course, on the use of the word "retarded," required research and organizational skills that challenged him. Working with his parents and another student, Micah crafted and delivered an excellent presentation, earning one of the highest grades in the class. More importantly, the speech touched off a discussion with

Adapting classes to meet the needs of students with cognitive disabilities took minimal effort. As a community we grew tremendously because of it.

students saying how much they appreciated Micah's perspective and how he made them think about things they had never considered. The experience of inviting people to think more deeply and to rethink old ideas are important gifts of inclusion to the campus community.

For the capstone course, Micah worked with Sarah Vore, a student doing a capstone in writing. Together, they produced a film about Micah's experiences at Oakland. Sarah and Micah met with Micah's family at their initiation and with Micah's permission. This proved to be an important support in developing the project. Micah's parents helped Sarah understand how to work with him to get his best ideas. They

encouraged Sarah to not only help him frame questions for interviews, but to be willing to challenge him. Having high expectations and not settling for less were important for their success in the project. Sarah wrote in her capstone paper about the experience:

Having never given much thought to higher education for this select group of individuals, my experiences with Micah have completely opened my eyes to the academic and social enrichment capabilities of those who are classified as “intellectually disabled.” (p. 3)

Earlier Sarah described her first meeting with Micah and how she was able to confront her own stereotypes:

I felt both a sense of intrigue and enthusiasm as we easily made conversation. It was during that moment that my prior myths associated with intellectual disabilities were dispelled. (p. 1)

Sarah’s reaction to Micah was not unusual. By his senior year he was among the most recognized students on the campus. In chronicling the highlights of the graduating class, the *Oakland Post*, the student newspaper, listed groundbreaking for new buildings, a 9% tuition hike, a faculty strike, and “After covering his story for over a year, Micah Fialka-Feldman won his personal battle to live on campus...” (“Return the favor,” 2010). This is perhaps my greatest lesson from this experience with Micah and efforts at inclusion. It is not only important for the growth of the individual, but it radically challenges and changes the stereotypes of others.

Even in the earliest days of the program, the potential for altering thinking was clear. In a book chapter co-written by Marshall Kitchens, the director of the Writing Center, and one of his students, Sandra Dukhie, about tutoring Micah on the use of assistive technologies, they noted the benefit to Micah’s increased confidence, but went on to say:

A primary benefit for Sandra was the sense of social awareness because of the project. Sandra describes working with Micah as “a wonderful experience.” Over the weeks that they worked together, she says, she acquired a greater appreciation for individuals with disabilities: “I now have a better understanding of some of the frustrations encountered by many individuals with cognitive impairments.” At the same time, Micah not only benefited from the experience in terms of communicative growth, but also from the social interaction, citing the social nature of the sessions as the most beneficial aspect. (p. 214)

Micah’s visible presence on campus resonated with other students with disabilities. In a moving article in the *Oakland Post*, Shawn Minnix (2010) wrote:

I thought I would take a minute to congratulate all of the seniors on their upcoming graduation. There is one person that I wish to acknowledge separately, and that would be Micah Fialka-Feldman, or as we just know him Micah. Micah has a cognitive disability, and is set to get his certificate at the end of this semester, finishing his odyssey and completing his education. I look at Micah and what he has accomplished and smile. He inspires us all to do greater things. I should know. In some ways, I used to BE Micah. I was placed in a school for the emotionally impaired when I was 6 years old, and I stayed there until I was 14 and it was hell from the start. I was told by my own principal that I would never finish high school.

The full inclusion of Micah and other students required professors who were willing to think creatively about what would enable students to contribute and learn in classes. The single most important source of these strategies emerged from meetings with Micah, with his administrative support team of professionals, and with his family. Out of these

meetings we were able to make adaptations that enriched the class experience for everyone. We recognized no one strategy fit all students or all classes, but through open communication and attention to the goal of full participation,

Through open communication and attention to the goal of full participation, we were able to find ways to meet the needs of all students.

we were able to find ways to meet the needs of all students. Adapting classes to meet the needs of students with cognitive disabilities took minimal effort. As a community we grew tremendously because of it.

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