

Detours, not dead ends

Micah's dream to live in a dorm

Janice Fialka

Following an hour and a half bus ride, Micah arrived home late one evening after attending an evening college course at Oakland University. He was exhausted from the long ride, but enthusiastic over his newest realization.

"If I was living in the dorm now, I wouldn't have to take two buses home. After my class, I'd just walk across the campus to my dorm. I'd be home right away and there would be other kids to hang out with." He beamed as he realized more advantages awaited him. "Then in the morning, I could sleep in, eat breakfast in the cafeteria and walk to class." He paused and confidently concluded, "I like that idea, mom; that's what I want to do. I want to live in the dorm."

Thus began our next new adventure of opening more doors while politely changing the collegiate system. Micah, our 23-year-old son with cognitive impairments, is part of the new wave of adults with intellectual disabilities who are attending college courses and experiencing campus life as fully included students and citizens. His experience as a college student occurs at Oakland University in Rochester, Michigan with the support of the Options Program.

Being a college student over the past few years has expanded Micah's knowledge of what's possible and what options exist for him. During his first years as a commuting student, Micah felt little urge to live any place but home. He hardly knew what a dorm was and couldn't imagine not sleeping in his own bedroom. If asked, he would adamantly say, "One day I want to live with my friends, but not now!"

Learning About Choices

However, the more he hung out with his college friends, the more he learned about campus life. He watched them walk back to the dorms and listened to their stories of limitless ice cream every night in the cafeteria with no parents looking over their shoulders. He began to understand that if he lived in a dorm he'd be surrounded by young people his age...again, no parents. During a tour of the dorm and while visiting friends, he saw the layout of the rooms, the location of the beds, the computers on the desks, and how to get to the cafeteria and lounge.

His emerging discoveries reminded me that giving people choices (*Do you want to live at home or in the dorm?*) is not enough. Micah had to be exposed to the possibilities before he could make authentic choices. He needed time and real life experiences to imagine a different life for himself. By being a college student, new opportunities naturally emerge over time.

But, as any family who has a child with a disability knows, making a choice does not automatically make dreams come true. You have to proceed with confidence and expect the unexpected. A lot of hard work has gone into making Micah's dream to live with his college friends in a dorm match the policies of the university. Unfortunately, his happy-ending story of living on campus has not materialized yet, but his dream is moving forward.

His first hopes took shape when he received an email from the University Housing Department informing him that his dorm application was accepted. His moving date was set for January 6, 2008. He immediately asked a friend for help to complete the paperwork. He "borrowed" the \$100 deposit from us and then proudly delivered both items to the Housing Office. Later that night, he emailed his sister, Emma, using his voice-to-text technology. Emma already had one semester of dorm living under her belt. "I'm next, Emma," he wrote. "You have to buy me a new poster for my dorm room, like I bought you one."

We marked "Micah's Moving Date" on the calendar and prepared as best we could for this new and enormous change in our lives. His confidence and excitement grew with each packing box he collected.

The Detours

That date never arrived. An early morning email informed us of the university's new decision. Micah could not move into the dorm due to some overlooked university policy.

"I am going on a hunger strike on campus," Micah's dad responded immediately. We were all deeply disappointed. We knew how important it was for Micah to move in to the dorm. He had worked towards this dream for more than three years. It was in his bones and he was ready.

It just so happened that Micah had scheduled his annual Person-Centered Planning (PCP) meeting for the next day. This meeting is designed to help him identify his goals and supports for the upcoming year. Micah arranged the meeting to include about 15 people, including several college friends, the Associate Dean of Education, some professionals on his PCP team, and the Director of the Student Activities Center where Micah volunteers. They met in a small room in the University Center with five large pizzas. He welcomed everyone and used his prepared notes to guide him.

Micah shared his accomplishments during the year, which included raising the most money for St. Jude Hospital and joining Alpha Phi Omega, the service co-ed fraternity. He then asked each person to offer a quick story of what they see as his achievements and his strengths. As Micah's world gradually expands beyond ours, it helps to hear how he is perceived and what roles he takes in his community. We heard about the contributions he



making in his student organizations, how his friends value his great sense of humor, and how he responsibly shows up at his volunteer job ready to work. Those vignettes are critical in helping us, as parents “let go” a bit more each day. The observations from Micah’s community let us know if he is finding his place and how others relate with him. We can see what natural supports are in place and what gaps might be helpful, both now and down the road.

We were grateful when the director of the Student Activities Center shared that Micah needed more challenges at his volunteer job. Here was someone who had great expectations for him and wanted to see him enhance his skills. As parents, we felt less alone in our pursuit of high standards for Micah. The team was able to creatively problem solve and identify a few other tasks that Micah could learn. One student volunteered to coach Micah with these tasks.

You Gotta have Friends

As always, his friends—some of whom only knew Micah for a couple months—proved to be the most important resources and problem solvers. Over the years, we have learned that any planning meeting should not be dominated in numbers or ideas by well meaning professionals who often are removed from Micah’s everyday world and less likely to make authentic connections or identify real-life solutions.

When we discussed the dorm issue, it was easy to see everyone’s frustration. Rather than sink into doom and despair, several students (some hired by Micah as personal assistants and some buddies from campus) asked what they could do to convince the university that their decision was dead-wrong. One student decided to write a letter to the University President, asking him to immediately reverse the decision. The other students joined the chorus. Inspired, Micah said he would collect the letters and recruit other students to join in the writing campaign. The sparks of hope were igniting and unifying the group.

During the meeting, I asked Micah if he’d be interested in staying overnight once a week with a friend who lived in student housing. I didn’t know if Micah would want to do this or if a friend would come forward, but I felt compelled to find alternate ways to help Micah achieve his dream. I knew that one-night-a-week wasn’t the same as living in the dorm full-time, but it might be a

small step—a detour toward his dream. Micah said “absolutely yes” which was immediately followed by one of his fraternity friends offering the place. “Micah, you can stay with me. You’ve been at our apartment before so you know the scene. What’s the best night?”

As if remembering his first realization about the benefits of dorm living, Micah said, “Tuesday night I have a late class so I can just walk over to your apartment in student housing. Tuesday’s the night!”

“No, you don’t have to walk home, Micah,” his friend offered. “It’ll be dark. I can pick you up after your class.” Now I knew why this student’s nickname was “Buddha.”

In less than 30 minutes, several interim strategies were identified — all by Micah and his friends. Once again, I witnessed the “village” working.

Lessons We are Learning as Micah Enters Adulthood

In some ways, they are many of the same lessons that we’ve been practicing and re-learning, and practicing and re-learning throughout the first two decades of his life.

- **Our primary goal, especially as he moves into adulthood is to support and strengthen his interdependence.** Let’s face it. No one is truly independent, and in fact that is not what I desire for myself, my children, my neighborhood, or my world. Our success as a people depends on our ability to build community and connections.
- **To have dreams you must have real-life experiences.** Micah had to be a college student attending classes and navigating the campus before he could dream of dorm living.
- **Circles of support must invite, value, and engage peers.** The professionals and parents have to learn to “sit on their mouths” (Roman, 2003) and allow Micah’s real community to find solutions and offer supports. This may require some expert facilitation and nudging to keep the conversation going, but it doesn’t imply dominating the discussion.
- **Remember that a person’s confidence is strengthened when their abilities are publicly recognized and expectations start high, and then reach higher.** When Micah heard that



his friends were going to write letters to the university president, he was inspired to self-advocate and seek out other students to write letters. He is actively joining in the campaign for equal housing! And he was taking on leadership skills he hadn't tried before.

- **Never stop inviting and asking for help and ideas from a wide variety of perspectives.** I had no idea if anyone would come forth with an invitation to have Micah stay overnight on a weekly basis, but by taking the risk and asking, the door opened and stayed open! Buddha came forth and now Micah stays every Tuesday with him. He loves his Tuesday nights with his college friends.
- Paid supports can make **genuine connections that expand the circle of support.** There's a perception in the disability field that paid supports are "bad" and natural supports are "good." In reality, all supports can be instrumental in creating and nurturing authentic experiences and connections. Micah had many of his college buddies at the Person Centered Planning Meeting in part because one student he hired, an active student leader, introduced Micah to many people and organizations.
- **Relationships must be intentional and strategic.** Many people without disabilities have the ability to make connections wherever they go with very little effort. But for many people with disabilities, relationships must be fostered over time and may have to start with very intentional, almost artificial, mechanisms: Best Buddies, lunch groups, peer tutoring. But rich and authentic relationships can develop out of these intentional relationship-building strategies. Micah has seen experienced this over and over—just look at his calendar!
- **Parents can move from the role of caregiver to that of coach or mentor when others in the community provide practical support, encouragement, and resources.** Until others show up, parents can't sit down.
- **Our children really do learn by example.** Over the years, Micah has watched us regularly ask for help from others (though it wasn't easy to do!). We learned to reach out to others, invite them into Micah's circle, and provide them with concrete, practical suggestions to support Micah and his dreams. Micah seems to have watched and learned about self-advocacy from his family and from many other mentors. He now sends emails, makes phone calls, and invites others to hang out with him.
- **Serve food at all settings!** This needs no explanation...

The Journey Continues

At this moment, there is no happily-ever-after ending of eating ice cream and living in the dorm. Micah, his family, and circle are working to change the recent decision not allowing Micah to live in the dorm. Meetings are planned and strategies are being devised. Through it all, Micah knows that he is not alone. He is a genuine part of a community who cares about him and supports him. Nor is it a one way deal. Micah too gets involved with his friends' dreams as well. Currently he is campaigning vigorously for one of his friends who is running for president of student government.

Micah has learned a lot from this experience—both disappointments and validation. He has learned what discrimination feels like, but he has also learned how to advocate and engage others to support his dream, and to never give up. His efforts took him on a path to Buddha, even if for only one night a week. Maybe that's true enlightenment!

Janice Fialka is Micah's mother. She is also a social worker, national speaker, author and advocate. To read more of her publications and learn about her speaking, visit: www.danceofpartnership.com or email her at ruaw@aol.com. She wishes to thank Beth Sweeden and Karen Hildebrandt for their wise assistance with this article.

Reference

Roman, C.P. (2003). "It's not always easy to sit on your mouth." *Social Work with Groups*, 25 (1/2), 61-64.

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