

# Quest

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## IN GOOD HANDS

Finding child care you can trust

students

*Speak up*

Taking on accessibility challenges in higher education



**MOVING FORWARD**  
Celebrating FDA approval of Spinraza  
pg 13

*I wrote the cover story for the 2017 winter issue of MDA's Quest magazine. It's also available online: <https://www.mda.org/quest/article/advocate-u>. My client was GLC, a marketing communications agency. The text is below:*

## **Advocate U**

### **Taking on accessibility challenges in higher education**

For many young adults, the college experience is a rite of passage and an exciting time for growth. This time comes with additional challenges and opportunities for the 9 percent of college students with disabilities in the United States. For some, it's not just about the lessons that come from living away from their parents and families, making decisions about their future or navigating the world on their own. It's also a chance to learn to advocate for themselves and others.

While the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 require higher education institutions to provide academic adjustments and accessible housing, equal access goes beyond classes and dormitories.

"I think the accessibility of social settings is especially important for students," says [Alexandra McArthur](#), MDA's national director of young adult and community engagement. "How do they fully participate in college life if they're not able to get in the front door of the party or gathering?"

### **Becoming an advocate**

Some problems with accessibility stem from geography — think sprawling campuses or lots of hills — or the age of the buildings. "A lot of higher education institutions are older, and some of them have done a better job of retrofitting than others," McArthur says.

[Sarah Bellish](#), who has [spinal muscular atrophy \(SMA\)](#), discovered this during her freshman year at Baldwin Wallace University (BWU), founded in 1845 in Berea, Ohio. "Our buildings are very old," says the sophomore, who uses a power wheelchair. Bellish is dedicated to advocating for improved accessibility at BWU. She's come up against inaccessible dining halls, malfunctioning elevators and a lack of accessible bathrooms.

"I was at a musical — we have a really great theater department — and needed to go to the restroom. But there was not a single accessible restroom in the entire building. That was crazy."

Bellish submitted an online work order drawing attention to this particular problem, but she didn't stop there. "I was contacted immediately saying that they were going to fix it. Then I talked to our [university] president, who I've spoken to quite a few times about issues. After I talked to him, that was when the initiative to check every single building came into play."

### **Know yourself**

Understanding your needs is a critical first step to becoming a successful advocate. "The challenges that I faced weren't just on campus," says Jean-Marie Lawrence, a graduate of the University of

Tennessee at Chattanooga who has [limb-girdle muscular dystrophy \(LGMD\)](#). Though she worked with the school's vocational rehabilitation counselor, "I was struggling to get the personal assistance services I knew I needed," she says.

This experience fueled Lawrence's passion to change the system. Since graduating in May 2010, she has been pursuing her second master's degree while working as a transition and academic coach at the nonprofit Journey Educational Services.

"I saw a lot of issues, and I knew that I couldn't change it on the outside; I needed to get to the inside," says Lawrence. "My passion became working on disability policy as well as working with people with disabilities to help them learn early on what they need in terms of university services, personal knowledge and advocacy skills to be able to navigate the new terrain as an adult with a disability."

Lawrence recommends starting early by speaking with disability services at universities you're considering to "get a really good feel for how committed they are to their students and advocating for their students, or helping their students learn how to do that for themselves."

### **Know your rights**

"Your college or university has to make certain accommodations, and if they're making that very difficult, then you need to know how to bring in different support systems or even legal action, if needed," McArthur explains.

Bellish says she sometimes struggles with feeling like she's always asking people for things, but she reminds herself that her requests are reasonable. "You're allowed to push a little bit until you actually see the changes that you need. It's not like you're asking for anything crazy. You're just asking for something that's going to make your life a little bit better."

McArthur cautions that self-advocacy isn't just about making demands. "It's asking questions like, How do you think we can work on this together? How would you propose we make this accessible? It's really about being as clear as possible about the challenge, and then working together to find a solution."

### **Speak up**

Letting others know about your rights and needs often elicits a surprisingly positive response. "A lot of times, people want to help. It's just that they have absolutely no idea what you're going through or what to expect," says Bellish.

Dimpal Patel, a senior at the University of North Carolina at Charlotte who has a form of muscular dystrophy, kept quiet her freshman year when the desk and toilet in her dorm were too low to use comfortably. "But when I was talking to my disability services coordinator at the end of the year, I asked them to fix it for next year, and he said they could have fixed it this year if I'd told them earlier," she says. "I didn't know [the university] would be that accommodating."

This experience helped Patel find her voice. "I used to be nervous talking on the phone or talking to people I didn't know," she says. "Advocating for myself has allowed me to break away from my

comfortable, shy self and speak out. I have learned how to stick up for myself.”

### **The greater good**

Whether it’s asking for changes to your dorm room or advocating for accessible bathrooms all across campus, speaking up for yourself helps others, too.

Owen Kent, a 24-year-old filmmaker with SMA in his senior year at the University of California, Berkeley, is grateful for the efforts that came before him, which have made it easier for him to be an active leader in campus organizations. “I’m fortunate that when I started in a lot of positions, they were already somewhat accessible,” he says. “That’s not to say they were set up for it. I definitely had to do a lot of self-advocacy, saying, ‘Hey, that’s not going to work for me. Let’s do it this way, and here’s why’.”

For example, as president of his campus housing co-op, one of his duties was to lead the meetings while taking notes. “I wasn’t going to be able to type fast enough to take notes, so I suggested that we have someone else do that,” he says. “It worked really well, and even now that I’m not president, that’s how it’s done.”

Although not all accessibility problems will be fixed so easily, in Kent’s and many others’ experiences, by being clear about your needs, knowing your rights and finding the right person to talk to, change is possible.

“Maybe you’re the first person in a wheelchair to be living on campus,” says McArthur. “What an opportunity for the institution to learn how to accommodate successfully, right? And what an opportunity for you to learn how to coordinate your care and to figure out how to request help. I think all of this can be in the spirit of learning, and that’s what college is all about.”

*Charmaine Dymond is a freelance writer in Halifax, Canada.*

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### **Transitioning to Higher Education**

MDA is dedicated to improving the lives of kids and adults living with neuromuscular diseases. Supporting individuals as they pursue their educational goals and learn to be self-advocates is one way we can help.

“We take our role in advocacy seriously,” says Alex McArthur, MDA’s national director of young adult and community engagement. “Ultimately, we want to support our young adults in achieving whatever their dreams are, whether that includes living on campus at the university, going to community college right next door or not going to college. We are here to help and provide resources and referrals to make those dreams a reality.”

To find out what resources are available to help you with your transition to higher education, contact your local MDA office or the MDA National Resource Center at [ResourceCenter@mdausa.org](mailto:ResourceCenter@mdausa.org) or **800-572-1717**.