
How Are Medical and Dental Schools Teaching Students About Intellectual and Developmental Disabilities?



Full Article:
[APA citation]



<https://withfoundation.org>



<https://www.aucd.org/>



<https://uc-lend.med.ucla.edu/>

Problem

Many medical and dental students **do not** learn about intellectual and developmental disabilities (IDD) in school.



Many individuals with disabilities have health problems during their life.

They need to get better health care to live well and be healthy.

Doctors and dentists need to learn more about giving good health care to their patients with IDD.

One self-advocate said, "I have had negative, non-inclusive experiences with med students."

Questions

A study was done to learn how medical and dental schools are teaching their students about **intellectual and developmental disabilities (IDD)**.

- What things do medical and dental students learn about IDD?
- What are things that they do not learn about caring for patients with disabilities?



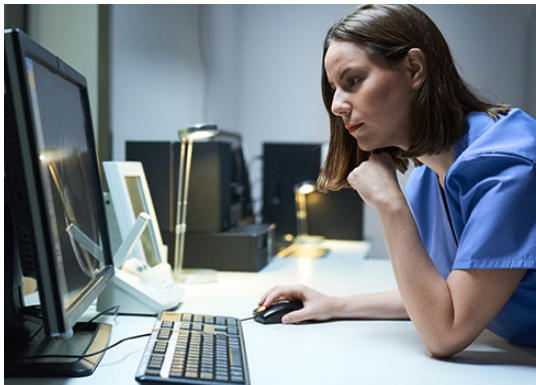
- What are things that would be good for them to learn to make health care better for individuals with IDD?
- How do medical and dental schools include self-advocates, or individuals with disabilities, in training their students?

Study

A research team asked people from 24 medical and dental schools to answer questions in an **online survey** and in **online group discussions**.

Online Survey

- 38 people answered most of the survey questions.
- 18 of the 38 people (about 50%) were medical or dental students.
- Other people included school leaders, teachers, and self-advocates.



Online Group Discussions

- Zoom meetings with self-advocates who did the online survey:
 - One group had 5 self-advocates;
 - The other group had 8 self-advocates.
- The research team asked each group the same questions.
- The self-advocates took turns sharing their thoughts and feelings.

Answers

The study team made a report to share **key things they saw in the survey and heard in the discussions.**

What Did They Learn From the Online Survey?

People from all 24 schools said that they taught students about IDD.



- 23 out of 24 schools included self-advocates, who helped them:
 - Set goals for what things students should learn about IDD;
 - Make things to teach medical and dental students about IDD;
 - Teach students about disabilities and individuals with IDD;
 - Find out what the students did *or* did not learn about IDD *and* how the class could be better.
- Self-advocates mostly helped schools **make things about IDD** and **teach medical and dental students** about IDD.

✓ What Do Students Learn About IDD?

Common things that medical and dental students learn about IDD include:

- How different things change a person's health, like:
 - how long they went to school;
 - if they have a job or not;
 - how much money they make or have;
 - if they can go to a doctor or dentist;
 - how they spend time at home or in the community.
- How support teams work together to help individuals make decisions about their health and health care.

Most people who took the survey said that **medical and dental students want to learn more** about intellectual and developmental disabilities (IDD).

✗ What Do Students Not Learn About IDD?

Things that medical and dental students **do not** learn include:

- Different ways people talk about disability; for example:
 - Disability is a strength and a part of who a person is (*social model*).
 - Disability is a problem that needs to be fixed (*medical model*).
- Sex health, like relationships, having a baby, and gender (he, she, they)
- How doctors or other health and disability professionals:
 - Test individuals for a disability;
 - Tell individuals the name of their disability;
 - Help individuals get services or things they need to be healthy.

What Did They Learn From the Online Group Discussions?

Self-advocates talked about 6 things:

- 1. Why they helped** medical and dental schools teach students about intellectual and developmental disabilities (IDD):
 - They had bad things happen to them in health care settings;
 - They wanted to improve health care for others;
 - They thought it was important for doctors and dentists to understand how people with different disabilities live their life.



“I feel it's very important that dental students learn from people with IDD with lived experience about what it's like to be in a dental chair,” said one self-advocate.

2. How they helped schools teach students about IDD:

- They set goals for what students should learn about IDD;
- They made new things for students to read or hear about IDD;
- They told teachers how to make their classes better;
- They talked to students about IDD as a teacher.



One self-advocate said, "I was involved in reviewing the materials that were created with other Autistics.

Looking at the use of language, the flow, ensuring that it was totally rid of any medical model terms.

And offering suggestions for replacement words, adding more to concepts that did not have enough information, or other sensory challenges that I saw."

3. How it felt to be included in helping medical and dental schools:

- Many self-advocates felt that their ideas were important and used to make things for students to learn about IDD;
- Some self-advocates felt that their ideas were not important and not used to teach students about IDD;
- One person felt bad because the classroom was not accessible.



*“One of the things that happened that made me feel not important was that the classroom where the lecture was held was not accessible for my mobility scooter,”
said one self-advocate.*

4. Why inclusion is important in helping medical and dental schools:

- Individuals with disabilities have different strengths and needs;
- One person said, *“We are all unique, although we have similarities.”*



“I think it is so important for advocates to share their lived experience with anyone and everything that is going to support us. We need to step out and make ourselves available,” said one self-advocate.

5. What things medical and dental students should learn about IDD:

- Mental health, like adults with IDD may feel sad or worried a lot;
 - Physical health, like adults with IDD may have more issues with their memory or weight than adults without IDD;
 - Sexual health, like adults with IDD should learn about safe sex;
-

“I was surprised to learn that others did not think we needed to cover how to educate patients with disabilities about women’s health issues and family planning,” said one self-advocate.



- Sensory issues, like a person who does not like loud sounds or bright lights.
-

Another self-advocate said, “I think that sensory issues are [...] an important topic for people. I think that's one of the main reasons why some of the people that I know don't go to the dentist, that it's painful and they have sensory issues.”

6. What things school leaders should do to make their program better:

- More self-advocates and teachers with IDD should be included to help schools teach students about IDD;
- More schools should help their students get real-life practice in giving good health care to patients with IDD.



“One of the things that I recommend for medical and dental schools is to actually hire knowledgeable people who are trained, people with IDD, and people with disabilities to teach medical and dental students,”
said one self-advocate.

Wrap-Up

The study found that all 24 medical and dental schools taught students some things about intellectual and developmental disabilities (IDD).

Most of the schools (96%) had self-advocates with disabilities help them.



Medical and dental schools should do more to include self-advocates in:

- setting goals for what things students should learn about IDD;
- checking what students did *and* did not learn about IDD to make classes better for other students.

Including the voices of individuals with IDD is key to teaching medical and dental students about patients with IDD.

The study also found that medical and dental students want to learn more about caring for their patients with disabilities.



Leaders at medical and dental schools should make sure that they:

- teach their students more things about intellectual and developmental disabilities (IDD);
- ask self-advocates, teachers, and leaders with disabilities for help in making IDD classes and programs better for students;
- help students get real-life practice caring for patients with IDD;
- keep up-to-date with the most recent ways to help people with IDD.

Schools need to work directly with members of the disability community to make health care better for individuals with disabilities.

“It's important for the doctors and medical professionals, as well as dentists, to know what we deal with on a daily basis when we go to medical appointments or dentist appointments,” said one self-advocate.

Thank You

Funding for this study was provided by a grant from the WITH Foundation. The mission of WITH Foundation is to promote the establishment of comprehensive healthcare for adults with developmental disabilities that is designed to address their unique and fundamental needs.



The Association of University Centers on Disabilities (AUCD) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. These programs serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change. This report is provided in partial fulfillment of tasks outlined in a cooperative agreement (#2 UA5MC11068-15-00) between AUCD and the Maternal and Child Health Bureau (MCHB). The contents of this report do not necessarily reflect the views or policies of MCHB, the Health Resources Services Administration (HRSA), U.S. Department of Health and Human Services, or the U.S. Government.



The UC-Leadership Education in Neurodiversity (UC-LEND) program is a federally-funded training grant awarded by the Maternal and Child Health Bureau at the Health Resources (MCHB) and Services Administration (HRSA) under award T73MC30114. The information, content, and/or conclusions are those of the author and should not be construed as the official position of, nor should any endorsements be inferred by MCHB, HRSA, or the US Government.



Author RP would like to acknowledge NIH NIGMS training grant GM008042.



For more information, contact us at:

krosenau@mednet.ucla.edu