

How Much Do Clinicians Know About Intellectual and Developmental Disabilities?

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Context

- ▶  1/6 children is diagnosed with a developmental disability
- ▶ **6.5 million** Americans have an intellectual disability
- ▶ Out of 700+ physicians, **59.7%** said they were **not confident** in giving the same level of care to a disabled patient as they would a nondisabled patient
- ▶ People with intellectual and/or developmental disabilities (IDD) are more likely to not return for wellness and prevention visits, and are more likely to be denied healthcare compared to nondisabled people

Research & Action Plan

Research Questions:

- What do family medicine physicians currently know about IDD patients and how to treat them?
- Where do medical residents gain most of their knowledge of IDD from?
- How comfortable are residents with IDD patients and families?

Step 1.) Quality Improvement Project

The data was collected from a Quality Improvement (QI) project on KUMC's Family Medicine Department* that created a RedCAP survey instrument that targeted healthcare provider knowledge and comfort in working with IDD patients and families.

Inclusion Criteria: Any healthcare provider in KUMC's Family Medicine Department, including residents.

*Developed by KUMC's Chapter of the American Association of Developmental Medicine and Dentistry

Step 2.) Resident Interviews

After the QI data collection, semi-structured interviews were conducted with current family medicine residents about their medical education surrounding IDD and their comfort in working with IDD patients.

Data Analysis: All interviews were transcribed, and then coded and analyzed with qualitative software, Dedoose.

Step 3.) IDD Curriculum Development

based on the data that was collected and analyzed from the QI Project and the Resident interviews, an IDD special interests group within KUMC's family medicine department will develop a curriculum to educate future family medicine residents on IDD healthcare.

IDD Special Interests Group: This group included family medicine residents, IDD community members, and members from the Kansas Leadership Education on Neurodevelopmental and related Disabilities (LEND) Program

Key Findings

Step 1.) Quality Improvement Project

Family Medicine Provider comfort working with IDD Patients

Comfort Levels (0 = not confident; 100 = very confident)

How confident are you in providing evidence-based preventive and medically necessary care to individuals with developmental disabilities? n = 33

Minimum	Maximum	Mean	Median	Standard Deviation
0	78	48.52	50	22.89

Rate the extent of your comfort utilizing accessible communication when providing care to individuals with developmental disabilities (i.e. AAC devices, interpretation) n = 32

Minimum	Maximum	Mean	Median	Standard Deviation
6	100	53.22	56	26.93

How confident do you feel treating individuals with developmental disabilities with various gender identities? n = 33

Minimum	Maximum	Mean	Median	Standard Deviation
8	100	54.06	62	24.47

How comfortable are you with discussing sexual health with patients with developmental disabilities in your practice? n = 33

Minimum	Maximum	Mean	Median	Standard Deviation
1	100	58.27	66	25.84

How comfortable are you working with other disciplines that may be caring for people with IDD (i.e. Occupational Therapy, Pharmacy)? n = 33

Minimum	Maximum	Mean	Median	Standard Deviation
12	100	70.61	74	22.69

*Pay attention to the Mean comfort ratings for each question. Notice how "providing medically necessary care" is the lowest mean rating

Step 2.) Resident Interviews

Key Quotes

"We have very little [IDD] education in medical school. I think we got one session over the course of a half day, but I don't recall that we had anything specific [about IDD] during medical school."

How do you think your IDD education, or lack thereof, has shaped your residency? "Probably more fearful that I don't feel comfortable working with [IDD patients]; that I don't know enough to provide them adequate care, to be honest."

"One of the big struggles we encounter is we get [IDD] patients who see maybe somebody who's a specialist... and then they come to the adult world, and we [family medicine providers] have no formal training. We don't know what the resources are. Frankly, there aren't resources."

Do you feel that your IDD education or lack thereof has prepared you well enough to work with patients with IDD?

"No, absolutely not. I feel like whenever we initially got this email [to interview for this project], I was like, oh my gosh. I don't even know what I'll talk about because I feel like I'm lacking so much in that area and I just feel so under-prepared."

Discussion

- How and what we educate our healthcare providers on is a public health concern. The disability community should not hold the onus to educate their healthcare providers on their conditions and disabilities.
- Currently, there is mass discomfort and lack of knowledge on IDD from healthcare providers. This could be largely due to having no required IDD education in most medical schools.
- Despite the mass prevalence of IDD in the US, IDD individuals and families struggle to find healthcare providers that are comfortable and competent in caring for them, in addition to taking on new patients.
- More conversation about provider education needs to happen in the public health sphere.

Step 3.) IDD Curriculum Development

4 part lecture series for resident didactic sessions with each session teaching to the competencies:

1	Legal concerns, ADA information	Session given by Medical Legal attorney
2	Resources available to individuals/families with IDD	Session led by IDD family member and a social worker
3	Clinical assessment and care across the life span	Session led by family medicine residency director
4	Case presentations of patients with IDD	Session developed by residents, facilitated by a physician
5*	IDD Q&A panel	Still being discussed and depends on residency program's schedule