# Attitudes of Doctors Toward People with Disability, Including Intellectual Disability

Lisa I. Iezzoni, MD, MSc
Harvard Medical School, Department of Medicine
Health Policy Research Center, Mongan Institute,
Massachusetts General Hospital
December 8, 2021

# ADA enacted in 1990. Why in 2021 do people with disability still confront barriers and experience disparities in their health care?

**Many factors may cause these disparities according to surveys, focus groups, and in-depth interviews with people with disability.**

# POTENTIAL CAUSES OF DISPARITIES

- Complex underlying health conditions may require more attention than routine tests like mammograms
- People with disability are often poor, have low education, have problems with housing, getting food, transportation, etc.
- Inadequate training, knowledge about disabilities among doctors
- Inaccessible medical equipment, like exam tables
- Doctors make incorrect assumptions about people with disability
- Doctors have discriminatory attitudes about people with disability – as does much of society

**Some studies have examined attitudes of doctors, but within geographic regions or institutions.**

# NATIONAL SURVEY OF PRACTICING DOCTORS

- First national U.S. survey of practicing doctors about their experiences with and perceptions of caring for people with disability
- Funded by *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (Grant No. R01HD091211-01A1)
- Because it was first national survey, we covered many topics: went shallow, not deep
- Results here about physicians' perceptions

# PHYSICIAN SPECIALITIES

1. Internal medicine/general internal medicine
2. Family practice
3. Rheumatology
4. Neurology
5. Ophthalmology
6. Orthopedic surgery
7. Obstetrics/gynecology

# SURVEY DEVELOPMENT

- Conducted in-depth individual interviews with 20 practicing doctors in Massachusetts
- Conducted 3 focus groups with 22 practicing doctors total across 17 states
- Identified key topic areas for survey
- Conducted 8 cognitive interviews and 50 pilot tests of draft survey
- Final survey:  8 modules, 75 questions – again, broad but not deep

# CONDUCTING SURVEY

- Randomly sampled practicing doctors from national list; eliminated trainees, etc.
- 1,400 doctors in sample
- Center for Survey Research mailed paper survey in October 2019, with $50 bill inside
- Made follow-up phone calls and re-mailed survey
- Overall weighted response rate: 61%

**Many findings on various topics. Focus here on physicians' perceptions of caring for people with disability and several findings on ID.**

# MAIN FINDINGS: DISABILITY OVERALL

- 82% of doctors report that people with significant disability have overall worse quality of life than other people
- 41% of doctors are very confident in their ability to provide equal quality care to people with disability
- 56% strongly welcome people with disability into their practices

# HOW MANY PATIENTS WITH ID/MONTH?

- Doctors < 20 years since medical school
  - 0 patients with ID: 10%
  - 1-5 patients with ID: 68%
  - 6+ patients with ID: 22%
- Doctors ≥ 20 years since medical school
  - 0 patients with ID: 22%
  - 1-5 patients with ID: 59%
  - 6+ patients with ID: 19%
- $p = 0.001$

# QUALITY OF CARE

Thinking about the broader health care system, how would you rate the quality of care of patients with **intellectual disability** receive compared with patients without such limitations …?

- A lot better = 2%
- A little better = 6%
- The same = 24%
- A little worse = 47%
- A lot worse = 21%

**“I’ll talk to my patients, even the ones that aren’t able to interact at all, and I’ve had caregivers tell me ‘no they don’t understand you,’ but I’ll talk to them anyway.”**

# COMMUNICATION

- Always/usually communicates with someone other than patient with ID
  - 75% of all participants
  - Difference ($p < 0.0001$) by specialty
    - 85% of specialists
    - 70% of primary care doctors
  - Difference ($p = 0.05$) by race ethnicity of doctors
    - 73% of white doctors
    - 83% of doctors who identify as racial/ethnic minority

# SEDATION

- "When you see patients with significant intellectual disability, are these patients ever sedated in order to perform routine, office-based tests or treatments (e.g., blood draws, Pap smears, etc.)?"
  - 12% of all participants
  - Difference (p = 0.003) by gender
    - 8% of male doctors
    - 18% of female doctors (performing Pap tests??)
  - Difference (p = 0.003) by specialty
    - 8% of primary care doctors
    - 18% of specialists

# SEDATION, continued

- "When you see patients with significant intellectual disability, are these patients ever sedated in order to perform routine, office-based tests or treatments (e.g., blood draws, Pap smears, etc.)?"
  - 12% of all participants
  - Difference (p = 0.05) by urban/rural location
    - 10% of urban doctors
    - 22% of rural doctors
  - Difference (p = 0.001) by average # of ID patients monthly
    - 14% of doctors seeing 1-5 ID patients monthly
    - 5% of doctors seeing 6+ patient monthly

# LIMITATIONS

- Short survey – aimed for 15 minutes. Broad but shallow
- Did not include questions that explicitly link doctors' attitudes with their treatment decisions for patients with disability (e.g., sedation)
- Budgetary concerns limited survey size: could not compare across specialties; could not include other relevant specialties (e.g., pediatrics)

**“They are sexually active, and so contraception when they come to see me that is the real issue… People who cooperate, we put in IUDs … I medicate as best as I can…those who don’t cooperate. There is Depo- Provera and sterilization as needed.”**

# COMMENTS

- Social desirability bias not evident (survey gave doctors option to say people with disability have same – or better – quality of life)
- Response about worse quality of life suggests strong confidence in their answer (i.e., that no one would argue with their response)
- Raises questions about care for people with disability in times of scarce resources: COVID-19 pandemic
- Given potential bias of doctors, how do we ensure that people with disability get equal quality care?

**Why should patients with disability need to prove to their doctor that they value the quality of their life to get equal quality care?**