

# Caring for Adults With Significant Levels of Intellectual Disability in Outpatient Settings: Results of a National Survey of Physicians

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## Abstract

Between 1% and 2% of the U.S. population has an intellectual disability (ID) and often experience disparities in health care. Communication patterns and sedation use for routine medical procedures are important aspects of care for this population. We explored physicians' communication patterns and sedation use in caring for patients with significant levels of ID through a mailed survey of 1,400 physicians among seven specialties in outpatient settings (response rate = 61.0%). Among physicians who saw at least one patient with significant levels of ID in an average month, 74.8% reported usually/always communicating primarily with someone other than the patient. Among specialists, 85.5% (95% CI: 80.5%–90.5%) reported doing so, compared to 69.9% (95% CI: 64.4%–75.4%) for primary care physicians ( $p < 0.001$ ). Also, 11.4% reported sedating at least one patient with significant levels of ID for a routine procedure. Three quarters of physicians reported communicating primarily with persons other than the patient usually or always—an approach that, in some instances, may not align with best medical practice. The percentage of physicians who report sedating at least one individual is associated with significant ID and the physician's volume of patients with significant ID.

*Keywords:* disability, intellectual disability, survey, communication, sedation

## Introduction

Between 1% and 2% of the U.S. population has an intellectual disability (ID; Krahn & Fox, 2014). According to the *Diagnostic and Statistical Manual of Mental Disorders*, ID is defined by deficits in both intellectual function (e.g., reasoning, problem solving) and adaptive function (e.g., communication, social participation, practical living skills) with onset during childhood or adolescence (American Psychiatric Association, 2013). ID is a spectrum and varies widely in its etiology and severity (Sullivan et al., 2018). Persons with ID constitute about 10.8% of Americans with a disability, and their numbers are growing due to increasing life expectancy (Coppus, 2013).

However, adults with ID in the United States die approximately 9 years earlier than those without ID (Landes, McDonald et al., 2012). This gap has narrowed recently, suggesting ongoing opportunities for modifiability, but it is still greater than other age-at-death differences including by sex or race and ethnicity (Landes, McDonald et al., 2012). The leading causes of death in this population are heart disease, cancer, diabetes, and respiratory conditions (Landes, Stevens et al., 2021). Adults with ID experience higher rates of multiple chronic physical and mental health comorbidities (Cooper et al., 2015; Haverkamp & Scott, 2015). Receipt of preventive health care, including long-acting reversible contraception, colorectal, and cervical cancer screen-

ings, are significantly lower in adults with ID (Deroche et al., 2017; Parish et al., 2013; Wu et al., 2018; Xu et al., 2017). These disparities may be impacted by system, provider, and patient/caregiver factors.

People with ID typically obtain care in general outpatient settings, although specialized ID clinics do exist (Ervin et al., 2014). Although individuals with any disability often experience health care disparities (Iezzoni, 2011; Peacock et al., 2015), people with ID additionally confront specific ID-related obstacles (Hall & Kurth, 2019). A review of impediments to healthcare for individuals with ID identified common barriers including: inadequate provider training, knowledge, and awareness; communication problems; patients' loss of agency; patients' fear, stress, and embarrassment; and insufficient time (Doherty et al., 2020).

Guidelines for caring for people with ID recommend person-centeredness and effective communication, recognizing that patients' capacity to understand may be relational, contextual, and vary by cognitive factors (Bernal, 2006; Sullivan et al., 2018). Communicating with patients with ID directly is often essential to providing patient-centered care (Kripke, 2018). Yet, patients with ID are often excluded from health care decision making and, instead, the physician and the neurotypical person(s) accompanying the patient form the communication dyad (Keywood et al., 1999). As a result, patients with ID report feeling rushed, unheard, and disrespected in healthcare encounters (Potvin et al., 2019; Wullink et al., 2019).

Patients who perceive a lack of understanding of their needs may be less likely to report symptoms, comprehend and complete clinical recommendations, and attend appointments, which in turn may perpetuate health disparities. Strategies that promote rapport, comfort, respect for privacy, and understandability of information can improve health care experiences (Baumbusch et al., 2014; Potvin et al., 2019; Smith, 2016).

Implications of patient-provider communication and decision making also extend to potentially higher-risk scenarios where additional considerations for patient autonomy and dignity must be considered. For patients with ID who are unable to understand and/or cooperate with certain procedures, physicians must weigh the clinical need to perform medical interventions against the potential of emotionally traumatizing or physically harming the patient. For example,

safely performing Pap tests for individuals with ID can require prolonged preparation, creative communication approaches, and/or caregiver support (Broughton & Thomson, 2000; Wilkinson & Cerreto, 2008). Desensitization and contingency reinforcement strategies have been successfully implemented to achieve increased tolerability of physical exams, phlebotomy, imaging, dental procedures, and pill swallowing among individuals with ID (Kupzyk & Allen, 2019). When such behavioral interventions are not effective or possible, consenting and sedating patients with ID is an ethically acceptable practice (Brown et al., 1992; Zylstra & Prater, 2006). However, sedation should not be used to circumvent a lower-risk process of preparing the patient for a procedure. Furthermore, sedating without consent is unacceptable except in rare/life-threatening situations as a last resort.

A recent review of 63 studies found that, although many explored the healthcare experiences and perceptions of people with ID, few studies examined the views and experiences of physicians caring for this population (Doherty et al., 2020). We conducted the first national survey of which we are aware about the experiences and perspectives of U.S. practicing physicians caring for people across a range of disability types, including ID (Iezzoni et al., 2021). Better understanding physician practices and perspectives about adults with ID may elucidate key targets for intervention to improve quality health care and minimize inequities in this population.

## Methods

### Survey Development and Testing

We developed a new survey designed specifically for physicians serving adults with disabilities in seven specialties: family medicine (primary care), general internal medicine (primary care), rheumatology, neurology, ophthalmology, orthopedic surgery, and obstetrics-gynecology (OB/GYN). We chose the first six specialties because of the likely high prevalence of persons with disability in their patient panels. We included OB/GYN because many women see gynecologists for routine care and prior research has found high rates of physical access barriers in OB/GYN practices (Lagu et al., 2013; Mitra et al., 2017).

The survey was developed based on 20 interviews with physicians in Massachusetts (Agaronnik, Campbell et al., 2019a, 2019b, 2019c;

**Table 1**  
*Respondent Characteristics By Frequency of Patients With Intellectual Disability Seen in an Average Month*

Characteristic	All Respondents ( <i>N</i> = 714) <i>N</i> *; Col% ( <i>SE</i> <sup>†</sup> )	Number of Patients With Intellectual Disability Seen in an Average Month		
		None ( <i>N</i> = 130) <i>N</i> *; Row% ( <i>SE</i> <sup>†</sup> )	1–5 ( <i>N</i> = 422) <i>N</i> *; Row% ( <i>SE</i> <sup>†</sup> )	6+ ( <i>N</i> = 141) <i>N</i> *; Row% ( <i>SE</i> <sup>†</sup> )
Gender		<i>p</i> = <b>0.02</b> <sup>‡</sup>		
Male	451; 62.0 (2.0)	87; 20.3 (2.1)	251; 57.7 (2.5)	98; 22.0 (2.1)
Female	248; 38.0 (2.0)	37; 13.8 (2.4)	164; 69.2 (3.2)	42; 16.9 (2.6)
Race/Ethnicity <sup>§</sup>		<i>p</i> = <b>0.35</b> <sup>‡</sup>		
Non-URM	578; 81.8 (1.6)	101; 17.6 (1.7)	341; 61.4 (2.2)	122; 21.0 (1.8)
URM	118; 18.2 (1.6)	25; 21.3 (4.2)	69; 63.1 (4.9)	18; 15.6 (3.5)
Years Since Graduating Medical School		<i>p</i> < <b>0.001</b> <sup>‡</sup>		
<20 years	222; 33.5 (2.0)	26; 10.2 (2.1)	136; 67.8 (3.4)	50; 22.0 (3.0)
≥20 years	460; 66.5 (2.0)	97; 22.2 (2.1)	268; 59.1 (2.5)	86; 18.7 (1.9)
Primary Specialty		<i>p</i> = <b>0.08</b> <sup>‡</sup>		
Primary care	357; 64.1 (0.0)	57; 16.1 (2.0)	213; 63.0 (2.6)	73; 20.9 (2.2)
Specialty care	357; 35.9 (0.0)	73; 23.1 (2.6)	209; 59.5 (2.9)	68; 17.4 (2.0)
Practice Location <sup>  </sup>		<i>p</i> < <b>0.001</b> <sup>‡</sup>		
Rural	66; 10.9 (1.3)	3; 5.4 (3.1)	44; 71.4 (6.0)	15; 23.2 (5.6)
Urban	648; 89.1 (1.3)	127; 20.2 (1.7)	378; 60.6 (2.1)	126; 19.3 (1.6)

\**ns* vary due to missing data.

<sup>†</sup>Standard Error.

<sup>‡</sup>Based on Wald chi-square test of respondent characteristic by # of patients with significant ID seen in an average month.  
<sup>§</sup>In subsequent analysis we grouped Asian and White (Non-Hispanic) respondents together, and Black, Hispanic and other ethnicities together into a dichotomous variable of URM (UnderRepresented Minority) vs. non-URM.

<sup>||</sup>Based on zip code of practice and computed using Rural Urban Continuum Codes as categorized by the U.S. Department of Agriculture.

Agaronnik, Pendo et al., 2019) and three online focus groups with physicians in the selected specialties from 17 states (Agaronnik et al., 2020; Agaronnik et al., 2021). We pretested the survey using eight cognitive interviews and a formal pilot test (*n* = 50). The final questionnaire can be found at <https://tinyurl.com/AppendixExhibit1A>.

### Survey Sample

Using IQVIA data, we identified all board-certified U.S. physicians in the seven specialties, excluding those practicing in military or Veterans Affairs hospitals, trainees, locum tenens physicians, hospitalists, and those without contact information. Within each specialty we drew simple random samples of physicians: 350 in family practice; 350 in general internal medicine; and 140 physicians in each of the other 5 specialties. The final sample included 1,400 physicians.

### Survey Administration

The Center for Survey Research (CSR) administered the surveys by mail in October 2019. All sampled physicians received a paper survey, cover letter, link to an online version, information sheet, postage-paid return envelope, and a \$50 cash honorarium. CSR began calling all nonrespondents 3 weeks after the initial mailing. A second mailing was sent to 552 nonrespondents in January 2020, after again telephoning nonrespondents, and a final mailing in March of 2020.

The survey contained screening questions to confirm specialty and that physicians spent ≥ 10 hours weekly in direct patient care. Of the 1,400 sampled physicians, 175 were ineligible because of screening question responses or because they were residents or fellows; retired; had an inactive medical license; too ill; deceased; away from practice for study duration; had left the United States; or CSR

**Table 2**

*Bivariate Analyses of Communication With Someone Other Than the Patient With Significant Intellectual Disability and Sedation of Patients With Significant Intellectual Disability for Routine Procedures*

Characteristics	Communicate primarily with person other than patient	Ever sedate patients with ID
	Always/Usually <i>N</i> *; %, <i>SE</i>	Yes <i>N</i> *; %, <i>SE</i>
All Respondents	432; 74.9 (2.0)	55; 11.5 (1.5)
Gender	<i>p</i> = <b>0.11</b> <sup>†</sup>	<i>p</i> = <b>0.003</b> <sup>†</sup>
Male	279; 77.7 (2.5)	26; 7.5 (1.5)
Female	149; 70.9 (3.4)	29; 17.7 (2.9)
Race/Ethnicity	<i>p</i> = <b>0.05</b> <sup>†</sup>	<i>p</i> = <b>0.21</b> <sup>†</sup>
Non-URM	350; 73.2 (2.3)	42; 10.4 (1.6)
URM	74; 83.0 (4.3)	12; 16.3 (4.4)
Years since graduating medical school	<i>p</i> = <b>0.30</b> <sup>†</sup>	<i>p</i> = <b>0.53</b> <sup>†</sup>
Young <20	141; 72.4 (3.6)	19; 13.0 (2.7)
Senior ≥20	278; 77.0 (2.4)	35; 10.9 (1.8)
Primary specialty based on sampled group	<i>p</i> = <b>&lt;0.0001</b> <sup>†</sup>	<i>p</i> = <b>0.003</b> <sup>†</sup>
Primary care	200; 69.7 (2.8)	23; 8.1 (1.7)
Specialty care	235; 85.0 (2.4)	32; 17.7 (2.8)
Rural/Urban	<i>p</i> = <b>0.08</b> <sup>†</sup>	<i>p</i> = <b>0.05</b> <sup>†</sup>
Rural	38; 64.1 (6.6)	11; 22.2 (5.9)
Urban	397; 76.5 (2.1)	44; 10.0 (1.4)
Average number of patients with ID seen in a month <sup>‡</sup>	<i>p</i> = <b>0.27</b> <sup>†</sup>	<i>p</i> = <b>0.001</b> <sup>†</sup>
1–5	328; 76.2 (2.3)	49; 13.6 (1.8)
6+	104; 70.8 (4.2)	6; 4.8 (2.0)
Lack of time: barrier for caring for patients with disability	<i>p</i> = <b>0.15</b> <sup>†</sup>	<i>p</i> = <b>0.21</b> <sup>†</sup>
Moderate/Large Barrier	204; 72.0 (3.0)	31; 13.4 (2.3)
Not/Small Barrier	228; 77.8 (2.6)	24; 9.6 (1.9)
Perception of quality of care received by patients with significant intellectual disability	<i>p</i> = <b>0.54</b> <sup>†</sup>	<i>p</i> = <b>0.27</b> <sup>†</sup>
Not worse	138; 76.8 (3.5)	13; 8.9 (2.4)
Worse	289; 74.2 (2.5)	40; 12.3 (1.9)

Note. ID = intellectual disability.

\*Some variables have missing values.

<sup>†</sup>Based on Wald chi-square test of respondent characteristic by # of patients with significant ID seen in an average month.

<sup>‡</sup>Excludes those who report seeing 0 patients with significant ID in an average month.

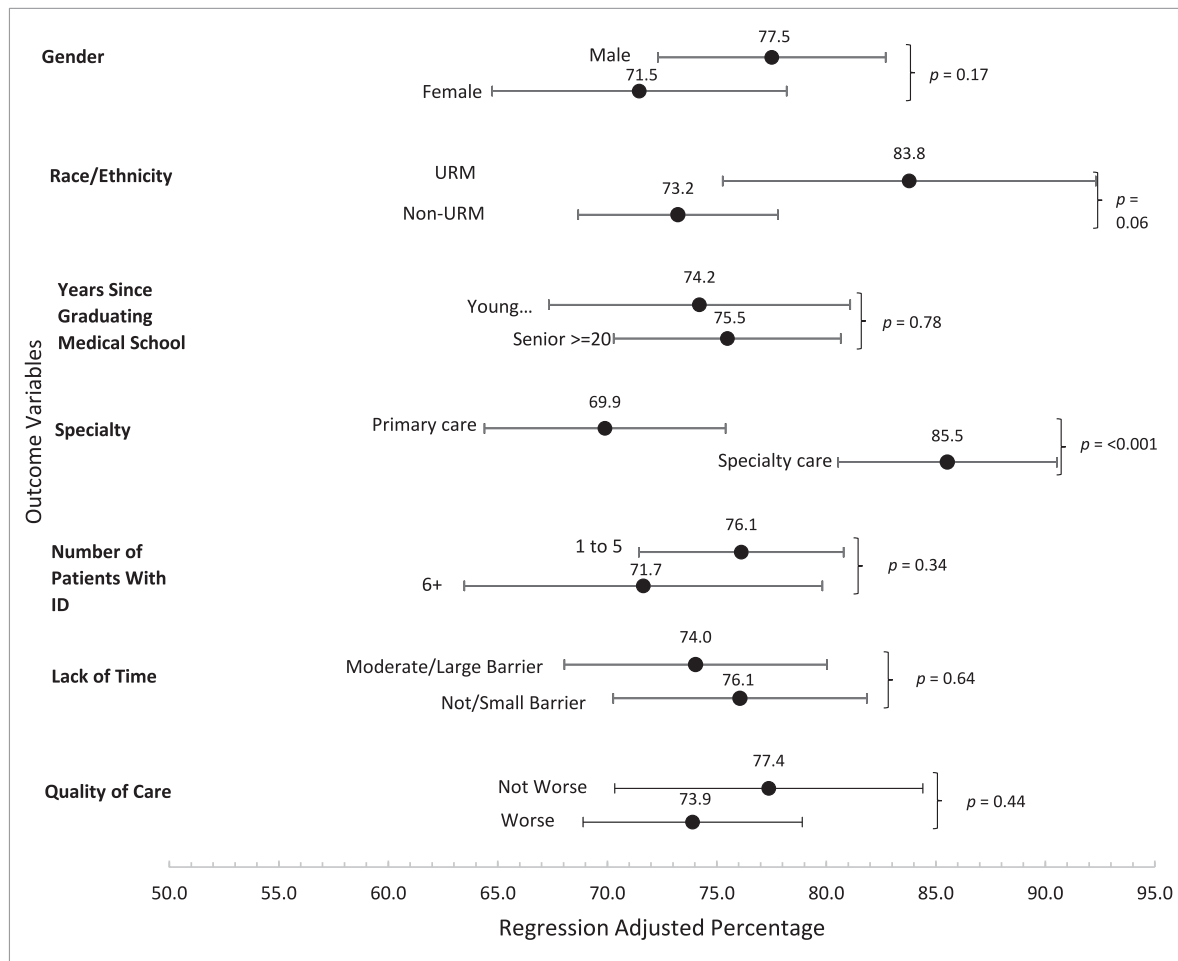
could not reach them via mail, phone, or internet. Of the 1,225 eligible physicians, 714 completed the survey. Using the American Association of Public Opinion Research (2016) response rate #3, the overall response rate was 61.0%.

### Outcome Variables and Measures

The survey asked, “In an average month, about how many patients do you see with significant

intellectual disability?” Based on the overall distribution of the responses, we created three categories for participants’ monthly volume of patients with significant ID: none, 1–5, and 6+. We intentionally employed the term “significant intellectual disability” to focus respondents on the subpopulation of persons with ID whose care would most likely require accommodations, such as proxy reporters and sedation.

**Figure 1**  
*Adjusted Percentages and 95% Confidence Intervals From Multivariable Logistic Regression Models Associating Variables to Communication With Someone Other Than the Patient With Significant Intellectual Disability*



Note. The dots represent point estimates and the bars represent confidence intervals.

The outcome variable as written on the survey is:

- When you see patients with significant intellectual disability, how often do you communicate primarily with a person other than the patient?  
 Response Options: Always/Usually/Sometimes/Rarely/Never  
 Recoded as: Always and Usually/Sometimes and Rarely and Never

The predictor variables as written in the survey and their coding in the regression:

- Quality of Care: Thinking about the broader health care system, how would you rate the quality of care patients with [intellectual disability] receive compared to patients without such limitations...?  
 Response categories: Much better/A little better/The same/A little worse/Much worse  
 Recoded as: Worse/Not Worse
- Gender: What is your gender?  
 Response Options: A woman/A man/Transgender/Nonbinary or genderqueer/Prefer not to say  
 Recoded as: Male/Female)
- Years Since Graduating Medical School: In what year did you graduate from medical school?  
 Response Option: Four spaces to enter Year  
 Recoded as: Young <20/Senior >=20
- Specialty: What is your primary specialty?  
 Response Options: Family Practice/Internal Medicine/Neurology/OB/GYN/Ophthalmology/Orthopedics/Rheumatology/None of the above  
 Recoded as: Primary care/Specialty care

We measured the frequency with which physicians reported communicating primarily with someone other than the patient during a clinical encounter. The survey asked, “When you see patients with significant intellectual disability, how often do you communicate primarily with a person other than the patient?” Response categories were “never,” “rarely,” “sometimes,” “usually,” and “always.” We grouped “usually” and “always” coded as 1 and all other responses coded as 0.

We also examined use of sedation. The survey asked, “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.)?” Response categories were “yes” or “no.” The survey asked physicians who responded “yes” to specify the procedure(s) for which patients received sedation. We grouped these open-ended responses into clinically related categories.

### Data Analyses

All data analyses used SAS 9.4 (SAS Institute, Cary, NC, USA) and SUDAAN 11.0.3 (RTI International, Research Triangle Park, NC, USA) and weighted all analyses adjusting for the inverse probability of sampling and response rate differences across specialties. Because all variables are dichotomous, we used two-sided Wald chi-square tests for the bivariate analysis assessing the significance of the independent relationships between each characteristic and the number of patients with ID (Table 1), and the relationship of all characteristics including the number of patients with ID with the outcomes. Further, to assess the relationship of the characteristics with the outcomes of interest, we included them simultaneously in a multivariable logistic regression model, and produced adjusted percentages and

95% confidence intervals (CI). Variables were included in the regression if they made sense conceptually and had a sufficient sample size. The final models included gender, race/ethnicity, years since graduating from medical school, primary specialty, number of patients with ID, and lack of time as a barrier and perception of quality of care; rural/urban was not included in the models. For the analyses of characteristics with the outcomes, we included 563 respondents in our analysis excluding those who did not see any outpatients ( $n = 14$ ), did not see any patients with ID ( $n = 130$ ), or were missing data on the number of patients with ID ( $n = 7$ ).

### Results

Overall, 62.0% of participants were male, 18.2% were underrepresented minorities (URM) (Hispanic, African American, and other), 64.1% were primary care physicians, and 35.9% were other specialists (Table 1). Also, 75.0% had graduated from medical school more than 20 years ago, and 89.1% practiced in urban settings.

### Volume of Patients With ID

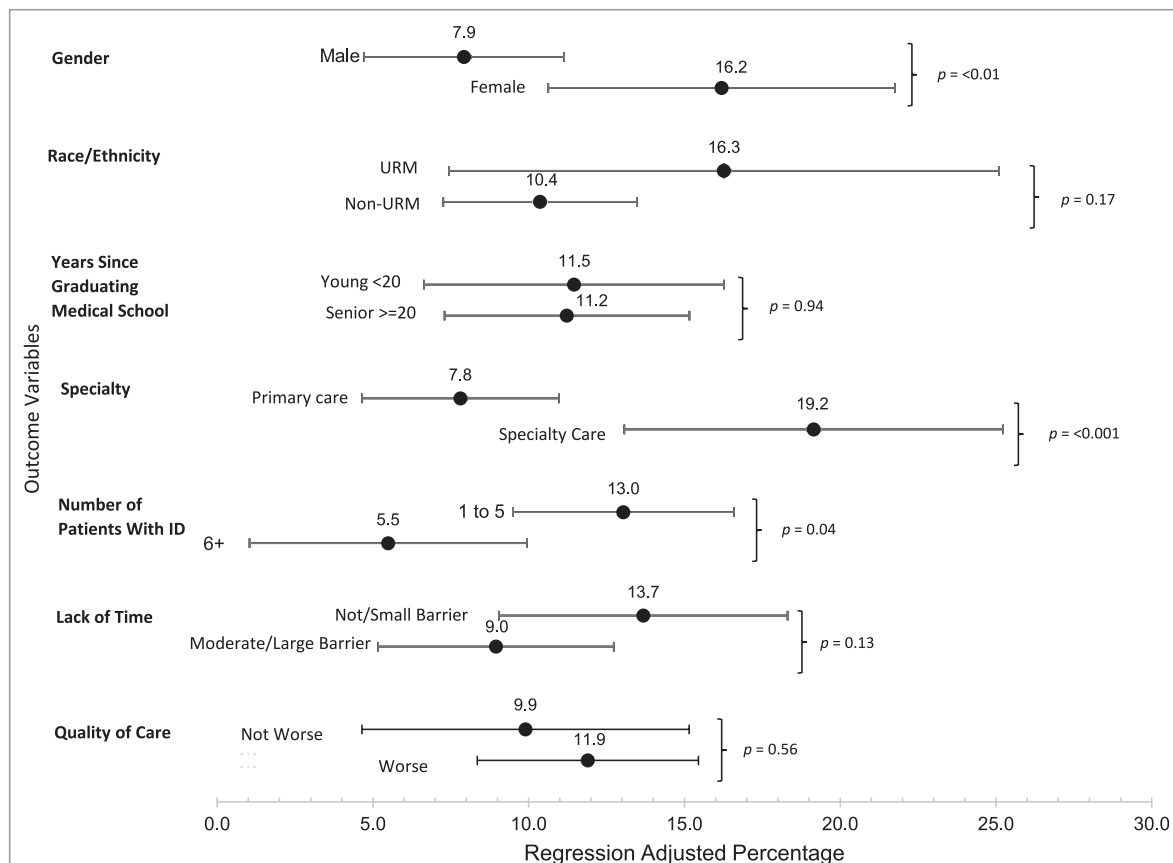
Overall, 18.6% reported seeing zero patients with significant ID in an average month, 61.7% saw between 1–5, and 19.7% saw 6 or more such patients (Table 1). Among physicians seeing at least one patient with significant ID, the mean number of such patients monthly was 6.2. Women, younger physicians, primary care, and rural physicians were more likely to see patients with ID than their counterparts (Table 1).

### Communicating Practices

Among those who saw  $\geq 1$  patient with significant ID monthly, 74.9% reported usually or always primarily communicating with someone other

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- Race/Ethnicity: Please describe your race/ethnicity.  
African American (non-Hispanic)/Asian/Native American/Pacific Islander/Hispanic/White (non-Hispanic)/Other or combination (Please Specify)  
Recorded as: (Underrepresented Minority [URM]/Non-Underrepresented Minority)
  - Number of Patients With Intellectual Disability: In an average month, about how many patients do you see with significant intellectual disability?  
Response Option: write in  
Recorded as: 1 to 5/6+
  - Lack of Time: Please tell us how much [lack of time] is a barrier for you in caring for patients with disability...?  
Response Options: Not at all a barrier/Small barrier/Moderate barrier/Large barrier  
Recorded as: Not a barrier or a small barrier/Moderate barrier or a large barrier
  - Rural/Urban was not included due to insufficient sample sizes.

**Figure 2**  
*Adjusted Percentages and 95% Confidence Intervals From Multivariable Logistic Regression Models Associating Variables to Sedation of Patients With Significant Intellectual Disability for Routine Tests/Treatments*



Note. The dots represent point estimates, and the bars represent confidence intervals.

The outcome variable as written on the survey is:

- 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.)?  
 Response Options: Yes (please specify for which procedure)/No

The predictor variables as written in the survey and their coding in the regression:

- Quality of Care: Thinking about the broader health care system, how would you rate the quality of care patients with [intellectual disability] receive compared to patients without such limitations...?  
 Response categories: Much better/A little better/The same/A little worse/Much worse  
 Recoded as: Worse/Not Worse
- Gender: What is your gender?  
 Response Options: A woman/A man/Transgender/Nonbinary or genderqueer/Prefer not to say  
 Recoded as: Male/Female)
- Years Since Graduating Medical School: In what year did you graduate from medical school?  
 Response Option: Four spaces to enter Year  
 Recoded as: Young <20/Senior >=20
- Specialty: What is your primary specialty?  
 Response Options: Family Practice/Internal Medicine/Neurology/OB/GYN/Ophthalmology/Orthopedics/Rheumatology/None of the above  
 Recoded as: Primary care/Specialty care
- Race/Ethnicity: Please describe your race/ethnicity.  
 African American (non-Hispanic)/Asian/Native American/Pacific Islander/Hispanic/White (non-Hispanic)/Other or combination (Please Specify)  
 Recoded as: (Underrepresented Minority [URM])/Non-Underrepresented Minority)

than the patient. In bivariate analyses including only participants with  $\geq 1$  patient with significant ID monthly, only primary care versus other specialty showed statistically significant associations (85% specialists versus 69.7% primary care,  $p < 0.001$ , Table 2). Also, URM respondents were more likely to communicate with someone other than the patient (83.4% v 73.2%,  $p = 0.05$ ).

Figure 1 shows results of a multivariable logistic regression evaluating who usually or always communicated primarily with a person other than the patient. Among specialists 85.5% (95% CI: 80.5%–90.5%) usually or always reported communicating with a person other than the patient compared to 69.9% (95% CI: 64.4%–75.4%) for primary care physicians ( $p < 0.001$ ).

### Sedation of Patients

Among participants who saw  $\geq 1$  patient with significant ID monthly, 11.4% reported they had ever sedated at least one such patient for a routine procedure. As shown in Table 2, 17.7% of females reported ever sedating a patient with ID compared to 7.5% of males ( $p = 0.003$ ). Similar results were found for specialty (17.7% specialists versus 8.1% primary care,  $p = 0.003$ ), location of practice (22.2% rural versus 10.0% urban,  $p = 0.05$ ), and volume of patients with ID (13.6% for those seeing 1–5 patients with ID versus 4.8% of those seeing 6+ such patients,  $p = 0.001$ ).

Figure 2 shows the results of the logistic regression related to sedation. After adjusting for all independent variables, 16.2% (95% CI: 10.6%–21.8%) of females reported having sedated at least one patient with significant ID compared to 7.9% (95% CI: 4.7%–11.1%) of male physicians ( $p = 0.01$ ). Similarly, 19.2% (95% CI: 13.1%–25.2%) of specialists reported sedating a patient with significant ID compared to 7.8% (95% CI: 4.7%–11.0%) of primary care physicians ( $p < 0.001$ ). In terms of the number of patients with significant ID seen per month, 13.0% (95% CI: 9.5%–16.6%) of physicians who saw between 1–5 patients with

significant ID per month reported sedation, compared to 5.5% (95% CI :1.0%–9.9%) of those who saw 6+ such patients monthly ( $p = 0.04$ ).

### Procedures for Which Patients Are Ever Sedated

The survey asked physicians who reported sedating patients with ID to list the procedures for which patients with ID were sedated. Of the 37 relevant entries, the most common involved reproductive tract procedures including Pap tests ( $n = 23$ ) and pelvic exams ( $n = 10$ ). Nine participants listed phlebotomy, eight eye exams and procedures, and three imaging procedures. Single participants listed various other procedures (e.g., dental care, breast exam, joint injection).

### Discussion

Our study provides the first national data regarding U.S. physicians' attitudes and experiences with caring for adults with significant levels of ID. Given the population prevalence of ID, discovering that 18.6% of physicians reported seeing no patients with significant ID in an average month was surprising. Physicians' patient panels vary in size, and those with smaller panels might be less likely to see patients with significant ID. Although it would contradict the Americans With Disabilities Act, some physicians could also refuse to accept patients with significant ID, as shown in previous research (Iezzoni et al., 2021; Lagu et al., 2013). Future research should explore these and other potential explanations.

Notably, although junior physicians were more likely to see patients with ID, they were just as likely as their senior colleagues to primarily communicate with a person other than the patient and equally likely to use sedation. This may reflect ongoing gaps in medical education, as research in Europe and Australia found there has been little progress in strengthening ID-specific training over

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- Number of Patients With Intellectual Disability: In an average month, about how many patients do you see with significant intellectual disability?  
Response Option: write in  
Recoded as: 1 to 5/6+
  - Lack of Time: Please tell us how much [lack of time] is a barrier for you in caring for patients with disability...?  
Response Options: Not at all a barrier/Small barrier/Moderate barrier/Large barrier  
Recoded as: Not a barrier or A small barrier/Moderate barrier or a large barrier
  - Rural/Urban was not included due to insufficient sample sizes.



the last 20–30 years (Salvador-Carulla et al., 2015; Trollor et al., 2020).

As noted above, patient-centered communication is essential to caring for patients with ID. Directly communicating with individuals with ID at a developmentally appropriate level is always important, regardless of strict definitions of capacity and competence. In healthcare decision making, a legal guardian or power of attorney for healthcare may make final medical decisions, but this authority should be exercised with maximum patient input. Research from Australia shows that carefully defining consent around specific outcomes and leveraging tailored assistive communication strategies can maximize the ability for many adults with ID to fulfill systematically applied capacity criteria. Additionally, shared decision aids have been successfully piloted among adults with ID and can facilitate shared/supported decision making (Sheehan et al., 2019; Vrijmoeth et al., 2018). The fact that 74.9% of physicians report they usually or always communicate primarily with someone other than the patient raises some concern. This practice could impinge on patient autonomy and contribute to patient-reported dissatisfaction or disenfranchisement related to diminished involvement in their care. Adults with ID express wanting caregivers/supports to facilitate, not replace, their communication with their medical providers (Wilkinson et al., 2013) and prefer doctors speak to and gather information from them directly rather than from others attending the visit (Kripke, 2018; Wullink et al., 2019).

This finding also highlights the importance of understanding the goals and perspectives of individuals who accompany patients with ID. These might be family members, hired caregivers, friends, clergy, legally appointed guardians, etc. These individuals likely vary in how well they understand or support the patient's healthcare preferences, and their opinions may differ from the patient's own characterization of unmet needs and quality of life (Koch et al., 2015). Thus, it is critical for physicians to carefully assess the extent to which someone accompanying an individual with ID is trusted by the patient and to ask permission for their involvement.

The findings related to sedation raise several issues that require further study. For example, we found, even after accounting for specialty, female physicians are more likely to report having sedated a patient with significant ID compared to male

physicians. Perhaps female physicians see more women with significant ID who need reproductive tract procedures requiring sedation. This explanation is consistent with our findings that the most common procedures reported as involving sedation related to the female reproductive tract.

We found that physicians who see six or more patients with ID monthly were significantly less likely to sedate these patients compared to other physicians. Perhaps physicians who see more patients with significant ID have more ID experience and have adopted alternative approaches to sedation or have different sedation thresholds. Alternatively, physicians with less ID experience may either skip procedures or perform the procedures with sedation after weighing potential risks and benefits. An Israeli study found that seeing just six or more patients with ID per year, versus five or fewer, increased effective communication principles including information sharing and preparation for treatment. In general, this finding requires additional study (Werner et al., 2017).

Building on the present study, more research is needed to better understand the characteristics of providers who see patients with ID at high versus low volume, factors that influence the use of sedation, and how these relate to patient experience and health outcomes. Downstream implications for future policy and practice may include targeted enhancements of medical provider training and the formal adoption of evidence-based standards to improve patient participation, with goals of optimizing patient and provider satisfaction, and reducing health and healthcare inequities.

### Limitations

Because this was the first national survey of U.S. physicians about caring for patients with several types of disability, our survey was broad but not deep (i.e., we addressed many topics, but none in great depth). We make no judgments about the appropriateness of sedation among patients with significant levels of ID. Our findings do not generalize to physicians outside of the specialties we studied. Our survey asked about patients with “significant intellectual disability.” We recognize this is nonstandard nomenclature for specialists in the field of ID. However, because we surveyed the general physician population in seven specialties, we felt the use of this term was necessary to focus respondents on the subpopulation of patients with

ID whose care may require accommodations such as sedation. Finally, these results are susceptible to social desirability bias and, thus, the point estimates related to communicating primarily with persons other than the patient and ever having sedated a patient with significant ID may be lower-bound estimates.

## Conclusion

Three quarters of physicians report they usually or always primarily communicate with someone other than patients with significant ID. This suggests that communicating primarily with patients is the exception rather than the rule—a finding that is contrary to what is considered best medical practice and may be related to decreased access to high-quality healthcare in this population. However, only slightly more than one-tenth of physicians have ever sedated a patient with significant ID for a routine procedure. Physician-level factors meaningfully associated with having done so include female gender, being a specialist, and seeing a low volume with significant ID in an average month.

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