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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 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 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 ID for a routine procedure. Three quarters of physicians report communicating primarily with persons other than the patient usually or always—an approach which in some instances may not align with best medical practice. The percentage of physicians who report sedating at least one individual with significant ID, and physician's volume of patients with significant ID. |

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 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 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 ID for a routine procedure. Three quarters of physicians report communicating primarily with persons other than the patient usually or always—an approach which in some instances may not align with best medical practice. The percentage of physicians who report sedating at least one individual with significant ID, and physician's volume of patients with significant ID.

Introduction

Between 1% and 2% of the U.S. population has an intellectual disability (ID). 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. ID is a spectrum and varies widely in its etiology and severity. Persons with ID constitute about 10.8% of Americans with a disability, and their numbers are growing due to increasing life expectancy.

However, adults with ID in the U.S. die approximately 9 years earlier than those without ID.⁵ 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.⁵ The leading causes of death in this population are heart disease, cancer, diabetes, and respiratory conditions.⁶ Adults with ID experience higher rates of multiple chronic physical and mental health comorbidities.^{7,8} Receipt of preventive health care, including long acting reversible contraception, colorectal, and cervical cancer screenings, are significantly lower in adults with ID.^{9–12} 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.¹³ While individuals with any disability often experience health care disparities, ^{14,15} people with ID additionally confront specific ID-related obstacles. ¹⁶ 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. ¹⁷

Guidelines for caring for individuals with ID recommend person-centeredness and effective communication, recognizing that patients' capacity to understand may be relational, contextual, and vary by cognitive factors.^{3,18} Communicating with patients with ID directly is often essential to providing patient centered care.¹⁹ 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.²⁰ As a result, patients with ID report feeling rushed, unheard and disrespected in healthcare encounters.^{21,22}

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.^{21,23,24}

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. 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. When such behavioral interventions are not effective or possible, consenting and sedating patients with ID is an ethically acceptable practice. Research

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, 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.¹⁷ 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.³⁰ 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 7 specialties: family medicine (primary care), general internal medicine (primary care), rheumatology, neurology, ophthalmology, orthopedic surgery, and obstetrics-gynecology (OB/GYN). We chose the first 6 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. 31,32

The survey was developed based on 20 interviews with physicians in Massachusetts^{33–36} and 3 online, focus groups with physicians in the selected specialties from 17 states.^{37,38} We pretested the survey using 8 cognitive interviews and a formal pilot test (n=50). The appendix includes the final questionnaire.

Survey Sample

Using IQVIA data, we identified all board-certified U.S. physicians in the 7 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 non-respondents 3 weeks after the initial mailing. A second mailing was sent to 552 non-respondents in January 2020; after again telephoning non-respondents, and a final mailing in March of 2020.

The survey contained screening question 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 U.S., or CSR 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 response rate #3, the overall response rate was 61.0%. ²⁶

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.

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 use 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. Since 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, lack of time as a barrier and perception of quality of care and did not include rural/urban 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% 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, while 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 ≥ 1 patient with significant ID monthly, 74.9% reported usually or always primarily communicating with someone other than the patient. In bivariate analyses

including only participants with ≥ 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 ≥ 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% :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, 8 eye exams and procedures, and 3 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 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. Future research should explore these and other potential explanations.

Notably, while 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 which research in Europe and Australia find that over the last 20-30 years there has been little progress in strengthening ID-specific training.^{39,40}

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. 41,42 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, ⁴³ prefer doctors speak to and gather information from them directly rather than from others attending the visit. 19,22

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.⁴⁴ 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 6 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 6 or more patients with ID per year, versus 5 or fewer, increased effective communication principles including information sharing and preparation for treatment. In general this finding requires additional study.⁴⁵

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 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 non-standard nomenclature for specialists in the field of ID. However, because we surveyed the general physician population in 7 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 which 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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LEGEND FOR FIGURES

Figure 1. Title: 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

On Figure 1., 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 <u>broader health care system</u>, how would you rate the <u>quality of care patients</u> 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/Non-binary 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

 $Medicine/Neurology/OB/GYN/Ophthamology/Orthopedics/Rheumatology/None\ of\ the\ above\ Recoded\ as:\ Primary\ care/Specialty\ care$

• 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/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

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.

Figure 2. Title: 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

On Figure 2., 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 <u>broader health care system</u>, how would you rate the <u>quality of care patients</u> 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/Non-binary 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/Ophthamology/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/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

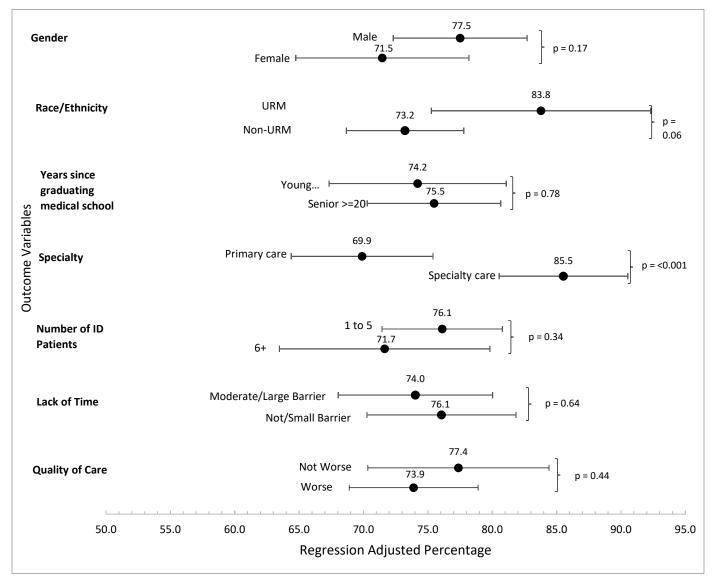
Recoded as: 1 to 5/6+

• 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.

Figure 1. Title: 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



On Figure 1., 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 <u>broader health care system</u>, how would you rate the <u>quality of care patients</u> 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/Non-binary 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/Ophthamology/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/Non-Underrepresented Minority)

• Number of Patients with Intellectual Disability: In an average month, about how many patients do you see with significant intellectual disability?

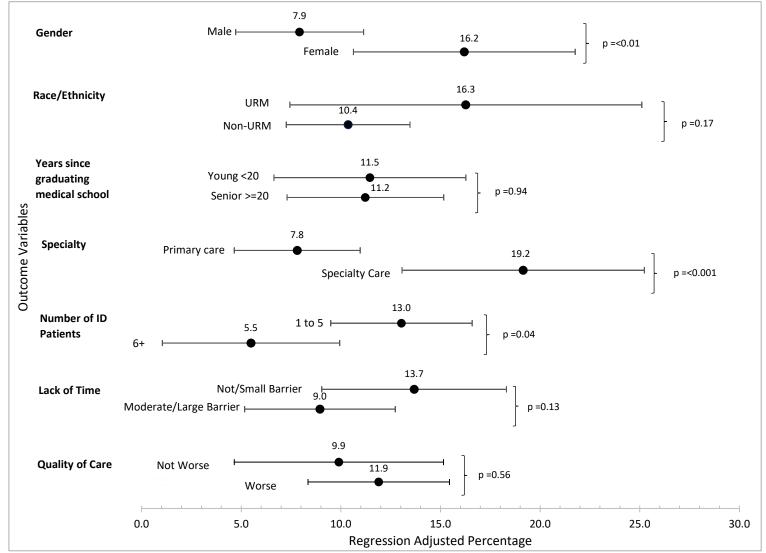
Response Option: write in Recoded as: 1 to 5/6+

• 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.

Figure 2. Title: 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



On Figure 2., 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 <u>broader health care system</u>, how would you rate the <u>quality of care patients</u> 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/Non-binary 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/Ophthamology/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/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

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.

TABLE 1. Respondent Characteristics By Frequency of Patients with Intellectual Disability Seen in

an Average Month

| | All | Number of ID patients seen in an average month | | | | | |
|--|--------------------------------|--|--------------------------------|--------------------------------|--|--|--|
| Characteristic | Respondents (N=714) | None (N=130) | 1-5 (N=422) | 6+ (N=141) | | | |
| | N*; Col% (SE [†]) | N*; Row% (SE [†]) | N*; Row% (SE [†]) | N*; Row% (SE [†]) | | | |
| Gender: | | p=(| 0.02 [‡] | | | | |
| 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§: | | p=0 | 0.35 [‡] | | | | |
| 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: | | p<0.001 [‡] | | | | | |
| < 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: | | p=0 | 0.08 [‡] | | | | |
| 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: | | p<0 | .001 [‡] | | | | |
| 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) | | | |

n's vary due to missing data

Standard Error

Based on Wald chi-square test of respondent characteristic by # of patients with significant ID seen in an average month

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 (Under Represented Minority) vs non-URM

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

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 ID patients |
|---|--|-------------------------|
| | Always/Usually | Yes |
| | N*; %, SE | N*; %, SE |
| All Respondents | 432; 74.9 (2.0) | 55; 11.5 (1.5) |
| Gender | p=0.11 [†] | p=0.003 [†] |
| Male | 279; 77.7 (2.5) | 26; 7.5 (1.5) |
| Female | 149; 70.9 (3.4) | 29; 17.7 (2.9) |
| Race/Ethnicity | p=0.05 [†] | p=0.21 [†] |
| 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 | p=0.30 [†] | p=0.53 [†] |
| 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 | p=<0.0001 [†] | p=0.003 [†] |
| 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 | p=0.08 [†] | p=0.05 [†] |
| 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 ID patients seen in a month [‡] | p=0.27 [†] | p=0.001 [†] |
| 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 | p=0.15 [†] | p=0.21 [†] |
| 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 | p=0.54 [†] | p=0.27 [†] |
| Not worse | 138; 76.8 (3.5) | 13; 8.9 (2.4) |
| Worse | 289; 74.2 (2.5) | 40; 12.3 (1.9) |

^{*} Some variables have missing values

[†] Based on Wald chi-square test of respondent characteristic by # of patients with significant ID seen in an average month

Excludes those who report seeing 0 patients with significant ID in an average month

Caring for Adults with Significant Intellectual Disability in the Outpatient Setting: Results of a National Survey of Physicians. Campbell EG, Rao SR, Ressalam JR, Bolcic-Jankovic D, Lawrence R, Moore JM, Iezzoni LI. 2021.

Appendix: Supplemental Materials

Caring for Patients with Functional Limitations: National Survey Funded by the NIH

2019



Principal Investigators:
Harvard Medical School
University of Colorado School of Medicine

Conducted by:
Center for Survey Research
University of Massachusetts-Boston

SURVEY INSTRUCTIONS

- Your responses are <u>completely confidential!</u>
- Your participation in this study is voluntary.
- If there is a question you would rather not answer, feel free to skip it and go on to the next question.
- Please return your completed survey in the enclosed postage-paid envelope to the Center for Survey Research.
- If you have any questions about this survey or do not wish to participate, please call Dragana Bolcic-Jankovic at the Center for Survey Research at 1-800-492-5845.

Completion and return of this survey confirms your consent to participate.

PLEASE COMPLETE THIS SECTION FIRST

| □₁Family p | ractico | | | | |
|---------------------|---|--|--|--|--|
| <u> </u> | | eral internal medicine | | | |
| □₃Neurolog | | oral internal medicine | | | |
| □ ₄ OB/GYN | ** | | | | |
| □₅Ophthalr | nology | | | | |
| □ 6 Orthoped | | | | | |
| □₁Rheuma | tology | | | | |
| □ 8 None of | the above → | IF NONE OF THE ABOVE, DO NOT CONTINUE. Please return the questionnaire in the envelope provided and we will remove your name from our list. This will ensure that you are not recontacted to participate in the survey. Thank you! | | | |
| 2. Do you curi | rently spend at | least 10 hours a week in direct patient care? | | | |
| □₁ Yes | | _ | | | |
| □ ₂ No → | □ 2 No → IF NO, DO NOT CONTINUE. Please return the questionnaire in the envelope provided and we will remove your name from our list. This will ensure that you are not re-contacted to participate in the survey. Thank you! | | | | |

| A. CHARACTERISTICS OF YOUR MEDICAL PRACTICE | | | | | | |
|--|-------------|---------------|--|-------------|-----------------------------------|-------------------------|
| A1. In an average week, approximately outpatients do you see? # Patients per week → I | | thes | ncluding your e types of hea practice? | | | |
| TO SECTION H | | | #P #N | urse pract | (excluding itioners or assistants | residents) physician |
| A2. How would you describe your med practice site? (Check One - If you withan one practice, please answer about the practice of the practice o | vork in moi | e A4 . | Approximatel patients are p | | | |
| practice where you see the most pati | | | | | aid (Includ | |
| ☐ ¹Private practice in the community ☐ ²Teaching hospital | | | | % Medic | are | |
| ☐ 3 Community nonteaching hospital ☐ 4 Community health center ☐ 5 Other (Please Specify) > | | | | % Unins | ured/self-p | ay |
| | | | Are you the o | | co-owne | r of your |
| (please print) | | | □₁ Yes □₂ No | | | |
| B. PATIENTS WITH | SIGNIFICA | NT CHRO | NIC MOBILITY | LIMITAT | IONS | |
| By mobility limitations we mean significations standing, climbing stairs, and using arm | | | with movement | , including | difficulties | walking, |
| B1. <u>In an average month</u> , approximate mobility limitations? | tely how m | any patier | nts do you see | with sign | ificant ch | ronic |
| #Patients per month → | IF "0" SK | IP TO SEC | TION C | | | |
| B2. Do you or your staff routinely re limitations? | cord the w | eight of pa | atients with siç | gnificant o | chronic m | obility |
| ☐₁ Yes ☐₂ No → IF "NO" SKIP TO B3 ☐₁ Not applicable to my patients | → SKIP T | О В3 | | | | |
| B2a. When obtaining the weight of p standard scale, how often do you or | | | | | who canno | ot use a |
| | Always | Usually | Sometimes | Rarely | Never | N/A |
| B2a1. Use a wheelchair accessible weight scale (aka "roll-on scale") | □ 1 | □ 2 | □ 3 | □ 4 | □ 5 | 7 |
| B2a2. Use a weight scale within a lift device (e.g., Hoyer lift) | □ 1 | □ 2 | □ 3 | □ 4 | □ 5 | □ 7 |
| B2a3. Send patients outside your practice to measure their weight | □ 1 | ☐ 2 | □ 3 | □ 4 | □ 5 | 7 |
| B2a4. Use previous weight in patients' medical record | □ 1 | □ 2 | З | □ 4 | □ 5 | □ 7 |
| B2a5. Ask patients how much they weigh | □ 1 | □ 2 | □ 3 | □ 4 | □ 5 | □ 7 |

of

| B3. When patients with significant chronic mobility limitations cannot transfer independently onto an exam table or exam chair, do you or your staff…? | | | | | | | |
|---|----------------|-------------|----------------|---------------|-------------|---------------------|-----------|
| | Always | Usually | Som | etimes | Rarely | Never | N/A |
| B3a. Get help from a person(s) accompanying the patient | □ 1 | □ 2 | | □ 3 | □ 4 | □ 5 | □ 7 |
| B3b. Use a lift device | □ 1 | □ 2 | | П 3 | □ 4 | □ 5 | □ 7 |
| B3c. Use an automatic height adjustable examtable | l □ 1 | □ 2 | | П 3 | □ 4 | □ 5 | □ 7 |
| B4. When it is not possible to transfer a exam table or exam chair, is that due to | • | ith signifi | cant ch | ronic m | obility lir | nitations | onto an |
| | Majo reaso | | lerate ison | Mino reaso | | t at all a eason | N/A |
| B4a. Inadequate staffing | □ 1 | |] 2 | ☐ 3 | 3 | ☐ 4 | 7 |
| B4b. No height adjustable exam table/chair | □ 1 | |] 2 | ☐ 3 | | ☐ 4 | □ 7 |
| B4c. No lift device (e.g., Hoyer lift) | □ 1 | [|] 2 | ☐ 3 | 3 | ☐ 4 | □ 7 |
| B4d. Patient refuses to be transferred | □ 1 | Г |] 2 | □ 3 | 1 | ☐ 4 | □ 7 |
| B4e. Fear of injury to yourself or staff | □ 1 | | 2 | | 3 | □ 4 | 7 |
| B4f. Fear of injury to patient | □ 1 | 1 | □ 2 □ 3 | | 3 | □ 4 | |
| B4g. Fear of legal liability or exposure | □ ₁ | |] 2 | □ 3 | 3 | □ 4 | 7 |
| B4h. The amount of additional time it takes | □1 | |] 2 | □ 3 | 3 | □ 4 | □ 7 |
| B5. Have you or another employee in your practice ever been injured while transferring a patient with significant chronic mobility limitations? ☐ 1 Yes ☐ 2 No ☐ 7 Don't know/Not sure | | | | | | | |
| C: PATIENTS WI | TH SIGNIF | FICANT VI | SION L | IMITATI | ONS | | |
| By vision limitations we mean people who a other corrective lenses. | re blind or | have sign | ificant d | lifficulty s | seeing, et | ∕en with gl | asses or |
| C1. <u>In an average month</u> , how many pat | ients do y | ou see wi | th sign | ificant v | ision lim | itations? | |
| # Patients per month → IF "0" | " SKIP TO | SECTION | I D | | | | |
| C2. When seeing patients with significal | nt vision l | imitations | , how c | often do | you or a | staff mer | nber? |
| | Always | Usually | Some | times | Rarely | Never | N/A |
| C2a. Verbally describe the exam room | □1 | □ 2 | | 3 | □ 4 | □ 5 | □ 7 |
| C2b. Use printed materials in Braille (e.g., information sheets) | □ 1 | □ 2 | | 3 | □ 4 | □ 5 | □ 7 |
| C2c. Use printed materials in large fonts | □ 1 | □ 2 | | 3 | □ 4 | □ 5 | □ 7 |
| C2d. Allow patients to audio-record the visit | □ 1 | ☐ 2 | | 3 | □ 4 | □ 5 | □ 7 |

| D: PATIENTS WITH SIGNIFICANT HEARING LIMITATIONS | | | | | | |
|---|------------------------------|------------|--------------------|-------------|-------------|---------|
| By hearing limitations we mean people who aids. | are deaf or | have sign | ificant difficulty | / hearing, | even with I | hearing |
| D1. <u>In an average month</u> , how many pati | ents do yo | u see witl | n significant l | nearing lir | nitations? | • |
| # Patients per month → IF "0" | SKIP TO | SECTION | E | | | |
| D2. In your practice or health care system hearing limitations, how often do you ut | | | | ients with | significar | nt |
| | Always | Usually | Sometimes | Rarely | Never | N/A |
| D2a. In-person sign language interpreter hired by you or your practice setting (e.g., hospital) | □ 1 | □ 2 | ☐ 3 | □ 4 | □ 5 | □ 7 |
| D2b. In-person sign language interpreter brought by patients | □ 1 | □ 2 | □ 3 | □ 4 | □ 5 | □ 7 |
| D2c. Remote sign language interpreter accessible via computer | □ 1 | □ 2 | 3 | □ 4 | □ 5 | □ 7 |
| D2d. TTY/TDD device | □ 1 | □ 2 | □ 3 | □ 4 | □ 5 | □ 7 |
| D2e. Speak with someone who accompanies the patient | □ 1 | □ 2 | П 3 | □ 4 | □ 5 | □ 7 |
| D2f. Typed message through a mobile device or tablet | □ 1 | □ 2 | Пз | □ 4 | □ 5 | □ 7 |
| D2g. Notes written on paper | □ 1 | □ 2 | □ 3 | □ 4 | □ 5 | □ 7 |
| D2h. Speak louder/ slower | □ 1 | ☐ 2 | □ 3 | □ 4 | □ 5 | □ 7 |
| D2i. Lip reading by patients | □ 1 | □ 2 | □ 3 | □ 4 | □ 5 | □ 7 |
| | | | | | | |
| E: PATIENTS WITH | COMORBI | D SERIOU | IS MENTAL IL | LNESS | | |
| By serious mental illness we mean condition schizophrenia that seriously impair major life E1. In an average month, about how marillness? # Patients per month → IF "0" | e activities. ny patients | do you s | ee who have | | | nental |
| E2. Overall, how prepared are you and y illness? | our staff to | care for | patients with | comorbid | l serious r | nental |
| □ ¹ Very prepared □ ² Somewhat prepared □ ₃ Somewhat unprepared □ ⁴ Very unprepared | | | | | | |
| | 3 | } | | | | |

| F: PATIENTS WITH SIGNIFICANT INTELLECTUAL DISABILITY |
|---|
| By intellectual disability we mean people with significant limitations in intellectual ability and in adaptive behavior (e.g., social, conceptual, and practical skills) that were identified up to age 18. |
| F1. In an average month, about how many patients do you see with significant intellectual disability? |
| # Patients per month → IF "0" SKIP TO SECTION G |
| F2. When you see patients with significant intellectual disability, how often do you communicate primarily with a person other than the patient? |
| ☐ ₁ Always ☐ ₂ Usually ☐ ₃ Sometimes ☐ ₄ Rarely ☐ ₅ Never |
| F3. 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.)? |
| □ ¹Yes (please specify for which procedure) □ ²No |
| G: AMERICANS WITH DISABILITIES ACT |
| The Americans with Disabilities Act, signed in 1990, gives civil rights protections to persons with disability. |
| G1. Overall, how much do you know about your legal responsibilities or obligations as a physician under the ADA when caring for patients with disability? |
| □ 1 A lot □ 2 Some □ 3 A little □ 4 Nothing |
| G2. Who is responsible for <u>determining</u> what reasonable accommodation(s) patients with disability should receive while being cared for in your practice? (Check all that apply) |
| ☐ ¹ Physician(s) caring for the patient ☐ ² Patients/family ☐ ³ Practice staff/managers/administrators ☐ ⁴ Insurers/payors ☐ 5 Other (specify) |
| |

Δ

receive while being cared for in your practice? (Check one)

☐ ¹ Owners of practice ☐ ² Patients/family ☐ ³ Insurers/payors

| | | _ | t at all a arrier | Small barrier | Moderate barrier | e Large barrier |
|---|--------------------|----------------------------------|----------------------|------------------|---------------------|--------------------|
| G4a. Lack of time | | | □ 1 | ☐ 2 | ☐ 3 | □ 4 |
| G4b. Lack of reimbursement for care for patients with disability | additional time it | takes to | □ 1 | □ 2 | □ 3 | □ 4 |
| G4c. Lack of formal education/to | raining | | □ 1 | □ 2 | □ 3 | □ 4 |
| G4d. Lack of funds to purchase | special equipme | nt | □ 1 | ☐ 2 | □ 3 | □ 4 |
| G4e. Lack of physical space in gaccommodate patients with disa | | | □ 1 | □ 2 | ☐ 3 | □ 4 |
| G4f. Lack of appropriate facilitie | s for service dog | s | □ 1 | □ 2 | □ 3 | □ 4 |
| G6. Overall how confident a disability as you provide to □ 1 Very confident □ 2 Somewhat confident □ 3 Not very confident □ 4 Not at all confident G7. In general, compared to persons with significant dispersons with signific | o patients without | out disability. \ | Vould yo | u say? | | |
| G8. Thinking about the bro | | | | | | |
| with different significant lir آ | Much better | ve compareα τ A little better | | T | tle worse | Much wors |
| OO - Markilla | | | | 7.110 | | |
| G8a. Mobility | | | □ 3 | | □ 4 | <u> </u> |
| G8b. Hearing | <u> </u> | □ 2 | □ 3 | | □ 4 | 5 |
| G8c. Vision | □ ₁ | <u> </u> | 3 | | _ 4 | <u> </u> |
| G8d. Serious mental illness | □ 1 | □ 2 | □ 3 | | □ 4 | □ 5 |
| | | | | | | |

| | Strongly disagree | Somewhat disagree | Somewhat agree | Strongly agree |
|---|------------------------------------|---|--|--------------------------------|
| G9a. Understanding my patients with disability is valuable to me as a physician. | □ 1 | ☐ 2 | □ 4 | □ 5 |
| G9b. The treatment of patients with disability is too time consuming. | □ 1 | □ 2 | □ 4 | □ 5 |
| G9c. People with disability are often treated unfairly in the health care system. | □ 1 | □ 2 | □ 4 | □ 5 |
| G9d. I welcome patients with disability into my practice. | □ 1 | □ 2 | □ 4 | □ 5 |
| G9e. Nonadherence is an issue with patients with disability because they lack adequate support. | □ 1 | □ 2 | □ 4 | □ 5 |
| H. PERSONA | AL DEMOGRA | APHICS | | |
| H1. What is your gender? Do you identify as: MARK ONE □ 1 A woman □ 2 A man □ 3 Transgender □ 4 Non-binary or genderqueer □ 5 Prefer not to say H2. Please describe your race/ethnicity. MARK ONE □ 1 African-American (non-Hispanic) □ 2 Asian | praction # H5. Do that re your jo | you have an equire accompob as a physical No leave and you or an imany significants | ny significant modation(s) i cian? Specify) nmediate fam | limitation(s) n order to do |
| ☐₃ Native American ☐₄ Pacific Islander | H6a. N | Mobility | Yes | |
| ☐ ₅ Hispanic ☐ ₅ White (non-Hispanic) | H6b. H | • | □ ₁ | |
| □ 7 Other or combination (Please Specify) | H6c. V | ision / | 1 | |
| H3. In what year did you graduate from | H6d. S | Serious mental il | Iness 🔲 1 | |
| medical school? | H6e. Intellectual disability | | | |
| Year | Than | k you for tal this im | king the time | • |
| Comments: In the space below please provide patients with disability that you feel it is import | | | regarding ca | ring for |
| | | | | |
| RETUR | N INSTRUCTIONS | | | |