

Title Page

RACIAL AND ETHNIC DISPARITIES IN PERCEIVED BARRIERS TO HEALTH CARE  
AMONG US ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL  
DISABILITIES

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## **Abstract**

### **Background**

Barriers to health care access can greatly affect one's health status. Research shows that US adults with intellectual and developmental disabilities (IDD) have poor health and face barriers such as long waits for appointments. However, whether barriers differ by race and ethnicity has not been examined.

### **Methods**

We conducted a secondary data analysis using the 2002-11 Medical Expenditure Panel Survey dataset, and compared perceived barriers of community-living US adults with IDD in three racial and ethnic groups (White, Black, and Latino). Specifically, we examined the top reasons for not having usual source of care, delaying or foregoing medical care.

### **Results**

For Black and Latino adults with IDD, the most-mentioned reasons for not having usual source of care, delaying or foregoing medical care were “don't like/don't trust doctors”, “don't use doctors” and “don't know where to get care”. In comparison, the White group's biggest perceived barriers were location and insurance related. All groups cited being unable to afford care as a top reason for delaying or foregoing care.

### **Conclusions**

Policies/interventions to improve health care access in racial/ethnic minorities with IDD must first address the topic of developing trust between patients and the health professions.

Insurance and the rising costs of care are also key areas that need attention.

## **Background**

Access to health care is defined as the timely utilization of appropriate health services to attain the best health outcomes (Institute of Medicine, 1993). Barriers to health care access, such as lack of availability, high cost, lack of insurance coverage and language barriers, can greatly affect individual health status (US Department of Health and Human Services, 2015). Individuals with intellectual and developmental disabilities (IDD) face significant barriers to health care access such as not finding health providers trained in IDD (Ervin, Hennen, Merrick, & Morad, 2014; Kerins, Petrovic, Giancesini, Keility & Bruder, 2004; Reichard & Turnbull, 2004; Ward, Nichols, & Freedman, 2010), experiencing long waits for appointments (Ward, Nichols, & Freedman, 2010), and cost of receiving care (Morgan et al., 2010). Furthermore, those with more severe disabilities are likely to have even less access. For example, having high ADL (activities of daily living) needs was associated with less access to and receipt of mammograms among women with IDD (Wilkinson, Lauer, Freund & Rosen, 2011). These barriers prevent a group that is both socioeconomically disadvantaged and experiencing overall poorer health from achieving best possible health outcomes (Morin, Mélineau-Côté, Ouellette-Kuntz, Tassé, & Kerr, 2012).

Over the past decades, there has been a wealth of research demonstrating the persistence of racial and ethnic health disparities in the United States (Flores & Tomany-Korman, 2008; Krieger, Chen, Waterman, Rehkopf, & Subramanian, 2003). It is well-documented that Latinos and Black Americans have higher rates of chronic health diseases compared to Whites (Juckett, 2013; Smedley, Stith, & Nelson, 2003). Inadequate access to health care can deepen disparities in chronic health conditions by limiting health care utilization, and disparities exist in access to care and utilization as well (Shi, Lebrun, & Tsai, 2010; Smedley et al., 2003;). Racial and ethnic minorities face specific barriers to health care utilization. In the United States, members of racial minorities are less likely to have health insurance or have a usual source of care compared to Non-Latino White Americans (Richardson & Norris, 2010; Shi, Chen, Nie, Zhu & Hu, 2014; Smedley, Stith & Nelson, 2003).. African Americans are more likely to report cost as a barrier to health care utilization compared to whites (Blendon et al., 2007). While affordability and accessibility are important factors that relate to health care use, the fit between health care systems and providers and individuals in the health care system is also important (Pitkin Derose, Roan Gresenz, & Ringel, 2011). A key component of this is the relationship between individual and their healthcare providers. Some research suggests poor quality in the provider relationship among Black Americans and Latinos. For example, Black adults with chronic conditions were more likely to report their provider does not listen to them compared to White adults (Shi et al., 2014). Among Medicaid managed care clients, Spanish speaking Latino adults and were more likely to report negative provider communication, staff helpfulness and timeliness of care compared to English speaking White adults (Weech-Maldonado et al., 2003). In another study, researchers found the quality of the patient physician interaction was negatively related to dissatisfaction with health care among Latina, mostly Dominican, women (Abraído-Lanza, Céspedes, Daya, Flórez & White, 2011). Several studies have reported that cultural mistrust

of providers results in reduced health care utilization and poorer satisfaction with care among Black and Latino adults (Benkert, Peters, Clark, & Keves-Foster, 2006; Lopez-Cevallos, Harvey, & Warren, 2014; Musa, Schulz, Harris, Silverman, & Thomas, 2009). However, reasons for cultural mistrust may be very distinct between these two racial/ethnic groups. Among African Americans, mistrust may be due to past discrimination (Shelton, Goldman, Emmons, Sorenson & Allen, 2001), injustices such as the Tuskegee Study of untreated syphilis (Devlin, Roberts, Okaya & Xiong, 2006; Hammond, Matthews, Mohottige, Agyemang, & Corbie-Smith, 2010), the perception that treatment is withheld in order for the medical industry to profit (Devlin et al., 2006), and the perception that doctors are not forthcoming with health information (Shelton et al., 2001). Latinos have reported “fear of being a guinea pig” and “lack of trust in medical people” (Davis, Bynum, Katz, Buchanan & Green, 2012), promised language translation services not being offered during medical visits (Devlin et al., 2006), and immigrant status (Shelton et al., 2001) as factors in mistrust and barriers to seeking various medical services.

For individuals with IDD, recent reports indicate there are racial and ethnic disparities in health outcomes among community-living adults (Magaña, Parish, Morales, Li, & Fujiura, 2016). These disparities persist after accounting for socioeconomic differences (Magaña et al., 2016), suggesting influence from other factors such as unequal health care access. However, the research on US adults with IDD does not include a single study of the intersections of race or ethnicity and barriers to health care access.

The few reports to date on barriers to health care for adults with IDD did not examine race and ethnicity (Drainoni et al., 2006; Hayden, Kim, DePaepe, & Taylor, 2005). Therefore, there is a tremendous gap in the literature on racial and ethnic differences in barriers to health care among persons with IDD. Understanding barriers to care is an important piece of developing interventions to reduce racial and ethnic disparities.

One of the goals of *Healthy People 2020* delineated in the Disability and Health section (DH-4), was to reduce barriers to care that specifically hinder adults with disabilities in receiving timely primary and preventive care (United States Department of Health and Human Services, 2015). Important to this goal is to ensure reduction in barriers to care is targeted to those most vulnerable. Therefore, in this study, we used nationally representative data to examine barriers to health care among community-dwelling US adults with IDD across three racial and ethnic groups: Non-Latino Whites, Non-Latino Blacks, and Latinos.

## **Methods**

### *Data and Sample*

The data used in this study were drawn from linked 2002-2011 Medical Expenditure Panel Survey (MEPS) and 2000-2010 National Health Interview Survey (NHIS) datasets. The MEPS is a national survey on medical conditions, health status, health care use and expenditures. The NHIS is an annual health survey that collects cross-sectional data from a nationally representative sample of the civilian non-institutionalized US population. Both NHIS and MEPS only collect information from non-institutionalized civilian households. Generally, one knowledgeable adult household member answers survey questions about all members of the household on their behalf.

Individuals with IDD were identified through a two-stage process. We used the NHIS variables in the Health Status and Limitation of Activity section of the Family Core to identify individuals with any activity limitations or needed assistance with activities of daily living (eating, bathing, dressing, and getting around inside the home) or instrumental activities of daily living (household chores, doing necessary business, and shopping or running errands). Next, we examined the conditions that were identified as the cause for these activity limitations. Reports of “intellectual disability” (year 2011), “mental retardation” (pre-2011) or “other developmental problem (e.g., cerebral palsy)” as the primary cause for their

limitation(s), were used as positive identification of IDD. Second, the MEPS Medical Conditions files (HC-069 to HC-146) were used. If the individual had at least one recorded medical condition with the ICD codes corresponding to “intellectual disability” or “developmental disabilities”, the individual was identified as having IDD (Table 1). The individual was excluded if their clinical diagnoses were “Delirium, dementia, and amnesic and other cognitive disorders”. Using these inclusion and exclusion criteria, we identified 1,185 individuals with IDD aged 18-65 years, of whom 539 were individuals with DD, 701 individuals with ID, and 55 individuals with both DD and ID.

*Insert Table 1 about here*

Race and ethnicity status was determined by using the NHIS race/ethnicity variable in the Household Composition sections of the person level files. The final analytic sample included a total of 1,131 adults with IDD with non-missing race/ethnicity information (615 White, 293 Black, 223 Latino; see *Table 2*). In *Table 2* we show the demographic characteristics by race and ethnicity within the samples with and without IDD.

*Insert Table 2 about here*

### *Measures*

**Demographic variables.** Age, sex and race/ethnicity are self-reported. Race/ethnicity was structured in three categories: 1) Non-Latino White, 2) Non-Latino Black, and 3) Latino (regardless of race). Individuals in other (e.g. Non-Latino Asian) or unknown race/ethnicity categories were excluded (n=67 among those with IDD). Total household income was defined as having either less than, or equal to/greater than 125% federal poverty level. The MEPS Metropolitan Statistical Area (MSA) status variable was used to determine whether the household lived in a setting that was urban or rural. Marital status was also binary (married vs. unmarried). Education was categorized as less than high school vs. graduated high school. Insurance status was coded as insured all year or not insured all year. Living

arrangements were dichotomized into living by oneself and living with others. Smoking referred to “currently smoking”. Generally speaking, all of the demographic information was collected from one “knowledgeable adult household member” who served as a proxy reporter for all household members. However, participation from household members who were present and willing to participate was also “encouraged” (Agency for Healthcare Research and Quality, 2015). The demographic information was not verified through records or other means.

**Dependent variables.** We examined the following two outcome groups: 1) having a usual source of care, and reasons for not having a usual source of care, 2) delayed or foregone medical/dental care and prescription medications, and reasons for delaying or foregoing such care. Having a usual source of care refers to a particular doctor’s office, clinic, health center, or other place that the respondent usually goes to when they need care. The “reasons” variables were categorical, coded from verbatim text by MEPS staff post-data collection (Agency for Healthcare Research and Quality, 2013b).

#### *Data Analysis*

We calculated weighted percentages with balanced repeated replication (BRR) corrections, which accounted for the complex survey design and provided more accurate estimates than the conventional Taylor-series approach. Additionally, we compared weighted percentages for top reasons for 1) not having usual source of care, 2) delayed care and 3) foregone care, among the three groups. We used survey weights and variance adjustment parameters provided in the MEPS to accurately address survey design (Agency for Healthcare Research and Quality, 2013a). All analyses were conducted using Stata MP 14.2, including appropriate survey commands that address clustering and stratification and correct for standard errors. We used chi-square tests and t-tests to describe the extent of unadjusted racial and ethnic differences in demographic characteristics and health disparities (*Table 2*).

We then used chi-square tests to estimate to describe the extent of unadjusted racial and ethnic differences in having a usual source of care, delaying or foregoing care, and insurance coverage status (*Table 3*). Finally, we listed the top reasons (weighted percentage) by race/ethnicity for not having a usual source of care and delaying or foregoing care (*Table 4*).

### **Results**

In *Table 2*, we showed health care access in the forms of having a usual source of care, delayed or foregone care and insurance status in different racial/ethnic groups. Despite having statistically similar rates for having usual source of care, White adults with IDD had significantly higher percentage of private insurance coverage (35.5%) than the Latino group (22.1%) and the Black group (9.4%). In contrast, Black adults with IDD had the highest percentage of Medicaid coverage at 62.2%, compared to White adults at 28.4% and Latino adults at 52%. The Latino group had significantly lower percentage in being covered by both Medicaid and Medicare (10% vs ~19% in both White and Black groups). Black adults with IDD had the most delayed or foregone dental care, but the lowest delayed or foregone prescription medications. The three racial/ethnic groups were otherwise statistically similar in medical, dental and prescription medications.

*Insert Table 2 about here*

*Table 4* shows that each racial/ethnic group had different perceived barriers to health care. Both Black and Latino adults with IDD attributed not having a usual source of care to reasons such as “don’t like/don’t trust doctors”, “don’t use doctors/treat self”, which were not mentioned by their White counterparts. Notably, about 6% of Black adults and about 16% of Latino adults with IDD reported that they either did not like/did not trust doctors, or prefer treating themselves rather than using doctors. Both groups reported location-based barriers. In comparison, the White group’s top perceived barriers were primarily location-based or attributed to health insurance reasons. In reasons for foregoing and delaying care, all groups

cited being unable to afford care as a top reason for delaying or foregoing care. However, there were significant distinctions. For example, about 8% of White adults with IDD cited “problems getting to doctor’s office” as a reason for delaying medical care, whereas 25.6% of Black adults and 10.6% of Latino adults cited the same reason, but instead of delaying care they had to completely forego care.

*Insert Table 4 about here*

With some differences in the order of items, the Black and Latino groups had identical reasons for foregoing care, and very similar reasons for delaying care. On the other hand, only the White adults with IDD cited that their insurance “would not approve/cover/pay” as a reason to delay or forego their medical care.

### **Discussion**

Previously, access to health care have been studied with the assumption that US adults with IDD are a homogeneous group facing similar barriers (Drainoni et al., 2006; Hayden et al., 2005). However, the results of the present study suggested a different picture. While there were similarities across race and ethnicity groups, there were marked distinctions. Specifically, the distinctions included 1) a sense of distrust towards the health professions among Black and Latino adults with IDD, 2) differences in consequences from problems associated getting to the location of care, and 3) the unique difficulties with insurance to approve or cover needed care and provider visits among White adults with IDD.

To our knowledge, this is the first report of distrust towards the health professions among minority US individuals with IDD. Black and Latino adult respondents with IDD indicated that distrust toward health professionals was one of the top reasons for not having a primary care provider and for delaying and foregoing care. As stakeholders focused on physical access to facilities and physician attitudinal barriers, it is important to note that distrust can also be a key barrier that prevents Black and Latino adults with IDD from getting

timely access. Limited by the available data we were unable to further explore the source of the distrust. However, we postulated that distrust may stem from negative experiences associated with differential treatment, not only as related to IDD but also based on race and ethnicity. For the general population, van Ryn & Fu (2003) summarized evidence of race/ethnicity-based differential treatment in several areas: specialty care (minority patients less likely to be informed and involved in kidney transplant decisions and cardiac procedures), pain assessment and treatment (non-Whites not receiving adequate pain assessment or control), and mental health service (non-Whites more medicated and involuntarily hospitalized and secluded). Similar studies are urgently needed for the population with IDD. We suggest future research investigate whether certain demographic factors such as education and income/poverty could modify the relationship between race/ethnicity and health care access among people with IDD.

Problems getting to doctors' offices were not uncommon--in a recent report, about 54% of people with disabilities and their family members or caregivers indicated transportation to health care was very problematic in Massachusetts (Mitra et al., 2013). However, our study showed that such problems were more disruptive for Black and Latino adults with IDD as they appeared to be cut off from accessing needed care altogether, as opposed to accessing it in a delayed fashion like their White counterparts. Foregoing care due to transportation problems could result in multiple negative outcomes for Black and Latino adults with disabilities, such as the development of preventable secondary conditions (Simeonsson, McMillen, & Huntington, 2002), the consequences of untreated active diseases (Foster et al., 2007) and higher risks of physical and mental health problems (Ford, Bearman, & Moody, 1999). Understanding the racial and ethnic disparities in getting to health care providers is of critical significance for community-living adults with IDD. In the present study, we observed significant racial/ethnic differences in percentages living in urban areas

among . It is worth investigating in future research whether these differences (i.e. urban vs. rural) are related to the racial/ethnic gaps in health care access.

All three groups cited problems with health insurance and costs. Due to sample size limitations, we could not further investigate the matter. However, it is important to understand that even as the minority racial and ethnic groups “close the gap”, more work has to be done on two fronts—better coverage by insurance and more acceptance by health care providers.

This study has several limitations. Large surveys often severely under-represent people with IDD due to population-sampling strategies such as the exclusion of institution-living individuals (Havercamp & Scott, 2015). In the present study, we worked with a relatively small sample with IDD, which made up less than 0.4% of the entire study population. This suggested that underrepresentation might be a limitation. Large surveys also often rely on proxy reports, or produce skewed samples towards less severe disabilities because self-reports tend to be from those with mild impairments and exclude those who are deemed unable to give informed consent or to respond to survey questions (Emerson, Felce, & Stancliffe, 2013; Havercamp & Scott, 2015; Krahn, Fox, Campbell, Ramon, & Jesien, 2010). As such, we advise caution against over-generalizing the results to the entire population of people with IDD in the United States.

### **Conclusion**

To achieve better care for all, future policies/interventions must focus on barriers to care. A unique barrier for Latino and Black adults with IDD is a lack of trust of healthcare providers. Therefore, we must address the topic of eliminating institutional racism and developing trust between the racially and ethnically diverse disability community and the health professions.

## References

- Abraído-Lanza, A. F., Céspedes, A., Daya, S., Flórez, K. R., & White, K. (2011). Satisfaction with health care among Latinas. *Journal of health care for the poor and underserved*, 22(2), 491.
- Agency for Healthcare Research and Quality. (2013a). MEPS HC 036: 1996–2011 Pooled Linkage Variance Estimation File. Rockville, MD Retrieved from [http://meps.ahrq.gov/mepsweb/data\\_stats/download\\_data/pufs/h36/h36u11doc.shtml](http://meps.ahrq.gov/mepsweb/data_stats/download_data/pufs/h36/h36u11doc.shtml).
- Agency for Healthcare Research and Quality. (2013b). MEPS HC-147: 2011 Full Year Consolidated Data File. Rockville, MD Retrieved from [https://meps.ahrq.gov/data\\_stats/download\\_data/pufs/h147/h147doc.shtml#2588Reco ding](https://meps.ahrq.gov/data_stats/download_data/pufs/h147/h147doc.shtml#2588Reco ding).
- Agency for Healthcare Research and Quality. (2015). Frequently asked questions. Retrieved from [https://meps.ahrq.gov/mepsweb/communication/household\\_participant\\_faqs.jsp#HCF AQ](https://meps.ahrq.gov/mepsweb/communication/household_participant_faqs.jsp#HCF AQ)
- Benkert, R., Peters, R.M., & Keves-Foster, K. (2006). Effects of perceived racism, cultural mistrust and trust in providers on satisfaction with care. *Journal of the National Medical Association*, 98, 1532-40.
- Blendon, R. J., Buhr, T., Cassidy, E. F., Perez, D. J., Hunt, K. A., Fleischfresser, C., Benson, J. B., Herrmann, M. J. (2007). Disparities in health: Perspectives of a multi-racial, multi-ethnic America. *Health Affairs*, 5, 1437-1447. doi: 10.3777/ hlthaff.26.5.1437
- Buseh, A., Kelber, S., Millon-Underwood, S., Stevens, P., & Townsend, L. (2014). Knowledge, group-based medical mistrust, future expectations, and perceived disadvantages of medical genetic testing: perspectives of Black African immigrants/refugees. *Public Health Genomics*, 17(1), 33-42.

Davis, J. L., Bynum, S. A., Katz, R. V., Buchanan, K., & Green, B. L. (2012).

Sociodemographic differences in fears and mistrust contributing to unwillingness to participate in cancer screenings. *Journal of Health Care for the Poor and Underserved, 23*(40), 67.

Devlin, H., Roberts, M., Okaya, A., & Xiong, Y. M. (2006). Our lives were healthier before:

focus groups with African American, American Indian, Hispanic/Latino, and Hmong people with diabetes. *Health Promotion Practice, 7*(1), 47-55.

Drainoni, M.-L., Lee-Hood, E., Tobias, C., Bachman, S. S., Andrew, J., & Maisels, L. (2006).

Cross-disability experiences of barriers to health-care access consumer perspectives. *Journal of Disability Policy Studies, 17*(2), 101-115.

Emerson, E., Felce, D., & Stancliffe, R. J. (2013). Issues concerning self-report data and

population-based data sets involving people with intellectual disabilities. *Intellectual and Developmental Disabilities, 51*(5), 333-348.

Ervin, D. A., Hennen, B., Merrick, J. & Morad, M. (2014). Healthcare for persons with

intellectual and developmental disability in the community. *Frontiers in in Public Health, 2*(83), 1-8. doi: 10.3389/fpubh.2014.00083

Flores, G., & Tomany-Korman, S. C. (2008). Racial and Ethnic Disparities in Medical and

Dental Health, Access to Care, and Use of Services in US Children. *Pediatrics, 121*(2), e286-e298. doi:10.1542/peds.2007-1243

Ford, C. A., Bearman, P. S., & Moody, J. (1999). Foregone health care among adolescents.

*JAMA, 282*(23), 2227-2234. doi:10.1001/jama.282.23.2227

Foster, H. E., Eltringham, M. S., Kay, L. J., Friswell, M., Abinun, M., & Myers, A. (2007).

Delay in access to appropriate care for children presenting with musculoskeletal symptoms and ultimately diagnosed with juvenile idiopathic arthritis. *Arthritis Care & Research, 57*(6), 921-927.

- Hammond, W. P., Matthews, D., Mohottige, D., Agyemang, A., & Corbie-Smith, G. (2010). Masculinity, medical mistrust, and preventive health services delays among community-dwelling African-American men. *Journal of General Internal Medicine*, 25(12), 1300-1308.
- Havercamp, S. M., & Scott, H. M. (2015). National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disability and Health Journal*, 8(2), 165-172.  
doi:http://dx.doi.org/10.1016/j.dhjo.2014.11.002
- Hayden, M. F., Kim, S. H., DePaepe, P., & Taylor, S. J. (2005). Health status, utilization patterns, and outcomes of persons with intellectual disabilities: review of the literature. *Mental Retardation*, 43(3), 175-195.
- Institute of Medicine. (1993). *Access to Health Care in America*. Washington, DC: The National Academies Press.
- Juckett, G. (2013). Caring for Latino patients. *American Family Physician*, 87(1).
- Kerins, G., Petrovic, K., Gianesini, J., Keilty, B., & Bruder, M. B. (2004). Physician attitudes and practices on providing care to individuals with intellectual disabilities: an exploratory study. *Connecticut Medicine*, 68(8), 485-490.
- Krahn, G., Fox, M. H., Campbell, V. A., Ramon, I., & Jesien, G. (2010). Developing a Health Surveillance System for People With Intellectual Disabilities in the United States. *Journal of Policy & Practice in Intellectual Disabilities*, 7(3), 155-166.  
doi:10.1111/j.1741-1130.2010.00260.x
- Krieger, N., Chen, J. T., Waterman, P. D., Rehkopf, D. H., & Subramanian, S. (2003). Race/ethnicity, gender, and monitoring socioeconomic gradients in health: a comparison of area-based socioeconomic measures—the public health disparities geocoding project. *American Journal of Public Health*, 93(10), 1655-1671.

- López-Cevallos DF, Harvey SM & Warren JT (2014). Medical Mistrust, Perceived Discrimination, and Satisfaction with Health Care Among Young-Adult Rural Latinos. *The Journal of Rural Health, 30*(4): 344–351.
- Magaña, S., Parish, S., Morales, M. A., Li, H., & Fujiura, G. (2016). Racial and Ethnic Health Disparities Among People With Intellectual and Developmental Disabilities. *Intellectual and Developmental Disabilities, 54*(3), 161-172. doi:10.1352/1934-9556-54.3.161
- Mitra, M., Lifford, C. J., Smith, L. D., Landers, B., Tanenhaus, R., & May, G. S. (2013). *Health Needs Assessment of People with Disabilities in Massachusetts*, 2013. Retrieved from Worcester, MA: <http://www.mass.gov/eohhs/docs/dph/health-equity/needs-assessment-report-for-health-and-disability.pdf>
- Morgan, J. P., Minihan, P. M., Stark, P. C., Finkelman, M. D., Yantsides, K. E., Park, A., ... & Must, A. (2012). The oral health status of 4,732 adults with intellectual and developmental disabilities. *The Journal of the American Dental Association, 143*(8), 838-846.
- Morin, D., Méryneau-Côté, J., Ouellette-Kuntz, H., Tassé, M., & Kerr, M. (2012). A comparison of the prevalence of chronic disease among people with and without intellectual disability. *American Journal On Intellectual And Developmental Disabilities, 117*(6), 455-463. doi:10.1352/1944-7558-117.6.455
- Musa, D., Schulz, R., Harris, R., Silverman, M., & Thomas, S. B. (2009). Trust in the health care system and the use of preventive health services by older black and white adults. *American Journal of Public Health, 99*(7), 1293-1299.
- Pitkin Derose, K., Roan Gresenz, C., Ringel, J.S. (2011). Understanding disparities in health care access—and reducing them—through a focus on public health. *Health Affairs, 30*, 1844-1851.

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- Reichard, A., & Turnbull III, H. R. (2004). Perspectives of physicians, families, and case managers concerning access to health care by individuals with developmental disabilities. *Mental Retardation*, 42(3), 181-194.
- Richardson, L. D., & Norris, M. (2010). Access to health and health care: how race and ethnicity matter. *Mount Sinai Journal of Medicine: A Journal of Translational and Personalized Medicine*, 77(2), 166-177.
- Shelton, R. C., Goldman, R. E., Emmons, K. M., Sorensen, G., & Allen, J. D. (2011). An investigation into the social context of low-income, urban Black and Latina women: implications for adherence to recommended health behaviors. *Health Education & Behavior*, 38(5), 471-481.
- Shepard, V. B., Wang, J., Yi, B., Harrison, T. M., Feng, S., Huerta, E. E., ... & Latin American Cancer Research Coalition. (2008). Are health-care relationships important for mammography adherence in Latinas? *Journal of General Internal Medicine*, 23(12), 2024.
- Shi, L., Chen, C. C., Nie, X., Zhu, J., & Hu, R. (2014). Racial and socioeconomic disparities in access to primary care among people with chronic conditions. *The Journal of the American Board of Family Medicine*, 27(2), 189-198.
- Shi, L., Lebrun, L. A., & Tsai, J. (2010). Access to medical care, dental care, and prescription drugs: the roles of race/ethnicity, health insurance, and income. *Southern Medical Journal*, 103(6), 509.
- Simeonsson, R. J., McMillen, J. S., & Huntington, G. S. (2002). Secondary conditions in children with disabilities: spina bifida as a case example. *Mental Retardation and Developmental Disabilities Research Reviews*, 8(3), 198-205.
- Smedley, BD., Stith, AY., & Nelson, AR (2003). *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Washington DC: National Academies Press.

RUNNING TITLE: Perceived Barriers to Care

United States Department of Health and Human Services. (2015). Healthy People 2020 topics & objectives 2013 - disability and health. Retrieved from

<http://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health>

US Department of Health and Human Services. (2015). *Healthy People 2020 - Determinants of Health*. Retrieved from <https://www.healthypeople.gov/2020/about/foundation-health-measures/Determinants-of-Health>

van Ryn, M., & Fu, S. S. (2003). Paved With Good Intentions: Do Public Health and Human Service Providers Contribute to Racial/Ethnic Disparities in Health? *American Journal of Public Health, 93*(2), 248-255. doi:10.2105/AJPH.93.2.248

Ward, R. L., Nichols, A. D., & Freedman, R. I. (2010). Uncovering health care inequalities among adults with intellectual and developmental disabilities. *Health & Social Work, 35*(4), 280-290.

Weech Maldonado, R., Morales, L. S., Elliott, M., Spritzer, K., Marshall, G., & Hays, R. D. (2003). Race/ethnicity, language, and patients' assessments of care in Medicaid managed care. *Health Services Research, 38*(3), 789-808.

Wilkinson, J. E., Lauer, E., Freund, K. M., & Rosen, A. K. (2011). Determinants of mammography in women with intellectual disabilities. *The Journal of the American Board of Family Medicine, 24*(6), 693-703.

Table 1  
*Inclusion and Exclusion Criteria*

Inclusion Criteria	
Types of Disability	ICD-9 Codes and Conditions
Developmental disabilities	299: Autism Spectrum Disorders, Asperger’s Syndrome, Rett’s Syndrome, Childhood Disintegrative Disorder 315: Developmental delays and disorders
Intellectual disabilities	317: Mild intellectual disabilities 318: Other specified intellectual disabilities 319: Unspecified intellectual disabilities
Exclusion Criteria	
Diagnoses	Clinical Classification Software codes
Delirium, dementia, and amnesic and other cognitive disorders	653: Delirium, dementia, and amnesic and other cognitive disorders

Table 2  
*Demographic Characteristics of Adults with and without IDD in the Analytic Sample*

Variables	IDD				Non-IDD			
	White N=615	Black N=293	Latino N=223	F	White N=148,807	Black N=54,250	Latino N=83,091	F
<b>Demographics</b>								
Mean age (SE)	35.3 (0.93)	36.9 (1.18)	32.0 (1.04)	3.4*	41.4 (0.10)	38.5 (0.15)	36.5 (0.12)	382.4***
Less than HS	166 (39.3)	115 (50.8)	91 (59.0)	2.6*	10,754 (11.8)	7,021 (21.5)	18,692 (41.2)	1018.9***
<125% FPL	227 (28.5)	152 (45.7)	97 (37.1)	4.3**	24,325 (12.2)	21,052 (30.8)	32,598 (30.6)	534.7***
Male	339 (55.4)	158 (60.6)	133 (69.1)	2.0	71,480 (48.9)	23,401 (45.9)	40,046 (51.1)	49.5***
Urban	429 (74.5)	234 (84.4)	207 (95.8)	5.4**	113,322 (79.5)	46,239 (89.0)	74,838 (92.4)	34.0***
Married	72 (11.7)	14 (5.1)	19 (9.5)	2.2 <sup>+</sup>	69,471 (47.1)	12,613 (25.2)	29,544 (35.8)	770.0***
Insured all year	567 (91.9)	274 (93.3)	193 (88.5)	0.9	71,179 (87.9)	21,546 (79.8)	26,518 (62.2)	876.5***
Live By Oneself	180 (28.8)	58 (23.1)	14 (8.8)	5.4**	22,979 (17.0)	8,060 (17.3)	5,111 (9.4)	172.1***
Smoking	113 (17.7)	51 (21.5)	15 (11.5)	2.9 <sup>+</sup>	24,770 (21.3)	7,754 (22.4)	6,338 (13.7)	220.8***
<b>Health status</b>								
Fair/poor health	175 (23.6)	124 (37.3)	95 (40.9)	4.6**	14,719 (8.3)	7,766 (12.4)	8,486 (9.2)	61.5***
Fair/poor mental health	161 (24.4)	119 (36.7)	93 (41.1)	5.4***	9,046 (5.5)	3,859 (6.5)	3,999 (4.7)	21.8***
BMI >= 30	216 (33.1)	121 (40.6)	91 (40.3)	1.0	31,037 (20.5)	14,092 (26.8)	15,943 (20.1)	198.9***
Diabetes	39 (5.8)	33 (8.2)	22 (12.2)	1.8	9,663 (6.9)	4,761 (9.6)	4,883 (7.0)	37.5***

Note: Those in other (e.g. Non-Latino Asian) or unknown race/ethnicity categories (n=67) were excluded from this analysis. The F statistic is based on survey-design-corrected Pearson chi-squares tests. Weighted percentages appear in parentheses following unweighted counts unless otherwise specified. IDD = adults with intellectual and developmental disabilities; Non-IDD=adults without intellectual and developmental disabilities; N = unweighted count; SD = standard deviation; HS = high school; FPL = federal poverty level; BMI = body mass index.

<sup>+</sup>  $p < .10$ , \*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ . Weighted percentages appear in parentheses following unweighted counts unless otherwise specified.

Table 3  
*Health Care Access of Adults with IDD in the Analytic Sample*

Health Care Access (Count, %)	White N=615	Weighted %	Black N=293	Weighted %	Latino N=223	Weighted %	F
Have usual source of care	511	83.3%	241	84.5%	166	76.8%	2.0
Insurance Status							
Any private	174	35.5%	22	9.4%	33	22.1%	16.6***
Medicaid only	205	28.4%	175	62.2%	120	52.0%	21.2***
Medicare only	54	9.2%	11	2.7%	10	4.4%	4.0*
Medicaid and Medicaid	128	18.7%	161	18.9%	28	10.0%	4.2*
Uninsured	48	8.2%	19	6.9%	30	11.5%	1.6
Delayed or foregone care							
Medical	49	7.9%	13	3.9%	10	5.8%	2.3
Dental	64	10.5%	35	12.9%	15	6.0%	5.3*
Prescription meds	39	6.3%	6	2.1%	5	4.1%	7.0**

Note: The F statistic is based on survey-design-corrected Pearson chi-squares test. The p values were adjusted using balanced repeated replication (BRR) for survey design and Bonferroni method for multiple testing. <sup>+</sup>  $p < .10$ , \*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ .

Table 4  
*Barriers to Health Care Access among Adults with IDD in the Analytic Sample*

<b>Top 5 Reasons for Not Having Usual Source of Care (n=199)</b>						
<b>White</b>		<b>Black</b>		<b>Latino</b>		
1	Recently moved to area	10.2%	Usual source of care in area not available	4.1%	Don't use docs/treat self	9.7%
2	No health insurance	8.9%	Don't like/ Don't trust doctors	3.6%	Cost of medical care	7.9%
3	Usual source of care in area not available	6.5%	No health insurance	3.2%	Goes to different places for care	7.2%
4	Cost of medical care	5.5%	Don't use docs/treat self	2.4%	Recently moved to area	7.0%
5	Goes different places for care	3.2%	Don't know where to go	2.1%	Don't like/Don't trust doctors	5.7%
<b>Top 3 Reasons for Foregoing Medical Care (n=44)</b>						
<b>White</b>		<b>Black</b>		<b>Latino</b>		
1	Could not afford care	35.5%	Could not afford care	44.6%	Could not afford care	48.9%
2	Insurance would not approve/cover/pay	14.0%	Problems getting to doctor's office	25.6%	Don't know where to get care	25.1%
3	Doctor refused family's insurance plan	9.7%	Don't know where to get care	18.0%	Problems getting to doctor's office	10.6%
<b>Top 3 Reasons for Delaying Medical Care (n=47)</b>						
<b>White</b>		<b>Black</b>		<b>Latino</b>		
1	Could not afford care	28.5%	Problems getting to doctor's office	37.5%	Did not have time or took too long	62.4%
2	Insurance would not approve/cover/pay	8.3%	Could not afford care	13.7%	Could not afford care	22.5%
3	Problems getting to doctor's office	7.9%	Did not have time or took too long	11.8%	Don't know where to get care	15.1%

Note: "seldom/never sick" / "other reasons" excluded.