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A Comparison of Health Disparities among Americans with Intellectual Disability and/or Autism
Spectrum Disorders and Americans with Other Disabilities

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A Comparison of Health Disparities among Americans with Intellectual Disability and/or Autism
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Abstract

This paper uses recent survey data to compare and contrast American adults with intellectual disability (ID) and/or autism spectrum disorders (ASD) and those with other disabilities with regard to overall health, access to health care, and other aspects of community participation. Although people with ID and/or ASD and others with disabilities share many issues related to poorer health and access to care compared to the general population, adults with ID and/or ASD reported different experiences and outcomes than other people with disabilities. An examination of these differences provides insights into policy changes and targeted interventions that might improve overall health and community inclusion specifically for people with ID and/or ASD.

Keywords: intellectual disability, health care, Medicaid

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A Comparison of Health Disparities among Americans with Intellectual Disability and/or Autism Spectrum Disorders and Americans with Other Disabilities

Americans with disabilities are considered a health disparity population, which means as a whole they experience poorer health and less access to care than other Americans (Krahn & Fox, 2014; Iezzoni, 2011; Peacock, Iezzoni, & Harkin, 2015). For example, the Centers for Disease Control and Prevention (CDC) (2016) noted this population experiences much higher rates of chronic diseases associated with lack of physical activity and poor nutrition. Indeed, in 2016, Americans with disabilities were much more likely to have diabetes (16.3% vs 7.2%) or heart disease (11.5% vs 3.8%) and to be obese (38.2% vs 26.2%) (CDC, 2019a). Overall, people with disabilities were almost five times more likely to report being in fair or poor health (41.7% vs 8.7%) and four times more likely to report ever having depression (40.3% vs 10.1%). At the same time, Americans with disabilities were much more likely to report not seeing a doctor due to cost (25.7% vs 10%) and not having seen a dentist in the past year (46.0% vs 30.4%).

Based in part on these data, the CDC awarded funds to 19 states to develop and implement “Disability and Health Programs” (DHPs) that address health disparities among people with intellectual disability (ID) and/or mobility impairments. Reasons for these disparities are many, including discrimination, social determinants (e.g., income, education), and barriers to medical care (Iezzoni, 2011; Krahn & Fox, 2014; Krahn, Walker & Correa-DeAraujo, 2015). The DHPs across the 19 states have taken many varied approaches to addressing these underlying causes, while all of the programs recognize that poorer health for these populations can limit opportunities for full inclusion in community participation (CDC, 2019b).

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Although people with disabilities share many issues related to poorer health and access to care compared to the general population, people with ID and/or autism spectrum disorders (ASD) may have different experiences and outcomes than do other people with disabilities. The purpose of this paper is to examine the similarities and differences between Americans with ID and/or ASD and those with other disabilities with regard to overall health and access to health care. For example, do Americans with ID and/or ASD report better or worse health status, or do they encounter more or different barriers to care than do people with other disabilities? This examination provides insights into potential policy changes and targeted interventions that might improve overall health and community inclusion specifically for people with ID and/or ASD.

Method

We used data from the National Survey on Health Reform and Disability (NSHRD; Hall & Kurth, 2019) to compare the health and health care access experiences of American adults with ID and/or ASD and those with other disabilities.

National Survey on Health Reform and Disability

The NSHRD is a national, internet-based survey that includes questions from other national survey instruments such as the Behavioral Risk Factor Surveillance System (BRFSS), the National Health Interview Survey (NHIS), the Health Reform Monitoring Survey (HRMS), and questions previously used in health policy survey research by the authors. The survey was pilot-tested with people who have disabilities, including people with ID. Response formats range from yes/no responses, to Likert scales, to fill in the blank (such as self-reported disability). The items address numerous topical areas, including demographics, health status, insurance coverage, barriers to care and unmet need, and community inclusion. For most respondents, the survey takes about 20 minutes to complete. However, skip patterns can result in

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varying numbers of completed questions for respondents. For example, respondents with Medicaid and Medicare coverage are asked more questions than those with only Medicaid coverage.

Procedures

Participants were recruited through more than 50 national and state disability organizations, numerous national listserves/newsletters, national disability conferences, and social media. Participants were provided an online link to complete the survey. Data were collected for the 2018 NSHRD between February and June 2018 among adults ages 18 to 62. Participation was capped at age 62 because the survey will be administered longitudinally and the intent is to exclude participation after age 65, when individuals become eligible for Medicare due to age and also may no longer be employed. Participants had the option of taking the survey via telephone if they wanted to have the questions read to them, though only six chose this method. In addition, participants had the option of entering a drawing for one of five \$100 gift cards, and survey completion was not required to participate in the drawing. The NSHRD survey instrument and study protocol were approved by the University of Kansas Institutional Review Board.

Participants

Potential survey participants were screened with the question “Do you have a physical or mental condition, impairment, or disability that affects your daily activities OR that requires you to use special equipment or devices, such as a wheelchair, walker, TDD or communication device?” Those who answered no to this initial question were excluded from the survey. Those who answered yes were invited to complete the survey, and were also asked the open-ended

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question, “What is your disability and/or health condition(s)? If you have more than one, please list your main one first.”

The total sample was 1,246 individuals who reported experiencing a wide array of disabilities and/or chronic health conditions. Using these self-reported disabilities, we divided the sample into six main disability categories: neurological, physical, chronic illness/disease, psychiatric, ID and/or ASD, and sensory. Table 1 gives examples of the types of self-reported conditions included in each category and shows the relative prevalence of each main disability type and the prevalence across disability categories.

We made the analytical choice to combine those that reported intellectual disability and/or autism spectrum disorders as their disability given the frequency of co-reporting both conditions as well as the known high rates at which ID and autism co-occur (e.g., Matson & Shoemaker, 2009; Srivastava & Schwartz, 2014). Further this decision generated a large enough sample size to analyze this group in comparison to Americans with other disabilities. A total of 109 individuals listed anywhere in their disability response, ID, ASD, or a condition associated with ID or ASD, including chromosome 12q duplication, Down syndrome, fragile X syndrome, intellectual disability, Noonan syndrome, and Rett syndrome. These respondents form our sample of individuals with ID and/or ASD. We compared this group to all survey respondents who did not report any ID and/or ASD, or associated conditions on numerous measures listed in Table 2.

The survey allowed participants to choose to use proxy responses if desired; 102 did so, including 48 people with ID and/or ASD. Among respondents with ID and/or ASD, the proxy responder was a relative living in the household for 33, a relative not living in the household for 11, and an assistant or other person for 4 respondents. Twenty-nine of the 48 proxy responders

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for participants with ID and/or ASD answered questions directly, while other proxy responders supported survey participation by reading the questions, clicking on chosen answers, or translating information.

Analyses

We used ANOVA for comparisons of continuous variables, such as age and mean days of poor mental or physical health, and chi-square analyses for comparisons of categorical variables, such as yes/no answers and satisfaction measures. All analyses were conducted using IBM SPSS Statistics software (version 25).

Results

Demographically, the group of individuals with ID and/or ASD differed from the group with other disabilities in several aspects (see Table 2). The group with ID and/or ASD was significantly more likely to be male, younger, and to have only a high school education or less; and was significantly less likely to be married. While rates of employment overall were similar to rates for the other disabilities sample, the group with ID and/or ASD was significantly less likely to be employed full-time and significantly more likely to report income below 138% of the federal poverty level.

From a health perspective, the two populations reported a similar overall health status, but the group with ID and/or ASD reported significantly fewer days with poor physical health while reporting significantly more days with poor mental health than the group with other disabilities (Table 2). The respondents with ID and/or ASD were also significantly more likely to report having additional co-occurring disabilities, including mental illness (38.1% of those with ID and/or ASD), chronic illness (30%), neurological condition (22.0%), physical disability (11.9%), and sensory disability (5.9%). The most commonly reported mental illnesses among

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this sample were depression, anxiety, bipolar disorder, post-traumatic stress disorder, and obsessive-compulsive disorder. Commonly co-occurring chronic illnesses for this population included diabetes, asthma, irritable bowel syndrome and obesity. Neurological conditions included ADHD/ADD, epilepsy/seizures, and cerebral palsy.

When looking at access to health care services, respondents with ID and/or ASD did not generally differ from the other respondents regarding rates and types of missed care due to cost or to the reported types and rates of unmet need (Table 2). More than a quarter of both groups reported not getting prescriptions, specialty care, tests, dental care, mental health counseling or durable medical equipment due to costs and almost a third reported problems with inadequate provider networks and insurance not covering needed services. Strikingly, however, people with ID and/or ASD who reported unmet need were more than three times more likely to report having been refused services by a health care provider than were people with other disabilities. At the same time, people with ID and/or ASD were somewhat more likely to have a usual source of care and to have lower out-of-pocket costs. Among those who needed it, people with ID and/or ASD were also more likely to have paid personal assistance services.

With regard to public benefits and insurance coverage, respondents with ID and/or ASD were significantly more likely to report Medicaid coverage and eligibility for Supplemental Security Income (SSI), as well as use of other public benefits (e.g., food stamps, Temporary Assistance to Needy Families [TANF]), than were other respondents (Table 2). Similarly, respondents with ID and/or ASD were significantly less likely to report eligibility for Social Security Disability Insurance (SSDI) payments and, relatedly, were less likely to have Medicare coverage than other respondents. Just below half of both groups reported having health insurance through an employer. Among those who reported having health insurance through an

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employer, though, respondents with ID and/or ASD were significantly more likely to have such coverage through a parent or spouse and people with other disabilities were significantly more likely to have this coverage through their own employment.

Finally, the survey asked participants a series of questions about their community participation (Table 2). On questions about levels of satisfaction with their community, leisure and social activities, people with ID and/or ASD generally reported more satisfaction than respondents with other disabilities, and significantly more satisfaction with time spent on leisure activities. Notably, however, respondents with ID and/or ASD were significantly more likely than were respondents with other disabilities to report feeling socially isolated from other people and their communities.

Discussion

Other research demonstrates the existence of health disparities for Americans with disabilities and for Americans with intellectual disability and or autism spectrum disorders. This study contributes to the literature by comparing health and access to care for these two populations. The results from analyses of our survey data not only confirm that people with ID and/or ASD are a health disparity population, they demonstrate how this group differs in some important ways from people with other disabilities. Demographically, the ID and/or ASD sample is less likely to be employed full time, less likely to have education beyond high school, and less likely to be married; these factors may explain why they are more likely to have lower incomes, often below 138% of federal poverty level, or about \$17,236 per year for an individual. These characteristics also constitute social determinants of health that put people with ID and/or ASD at greater risk for poor health outcomes (Anderson et al., 2013; Healthy People 2020, 2019; Krahn & Drum, 2007; Krahn, Hammond, & Turner, 2006; Wood, Avellar, & Goesling, 2009).

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Indeed, the findings show that people with ID and/or ASD are more likely to report co-morbid health conditions, including numerous mental health conditions. In addition, people with ID and/or ASD are significantly more likely to report higher numbers of poor mental health days compared to those with other disabilities, highlighting a need for better mental health interventions for this population. These findings affirm other work noting high rates of mental health issues for people with ID (e.g., Havercamp & Scott, 2015; Lauer, Nicola, Warsett, & Monterrey, 2019) and also demonstrate that, even compared to other disability groups, people with ID and/or ASD have a greater burden of mental health conditions and poorer mental health outcomes.

Access to adequate health care is critical in addressing health disparities, yet all of the people with disabilities in this study report having high levels of forgone care due to costs and high levels of unmet health care needs. Other research documented these concerns for people with disabilities and suggested possible solutions (Hall, Kurth, Gimm, & Smith, 2019; Kennedy, Wood, & Frieden, 2017). A particularly disquieting finding from the health care access section of this survey, however, is the large discrepancy in the number of people with ID and/or ASD who report being refused services by a health care provider compared to those with other disabilities. That any person is discriminated against by a medical provider is troubling, but this finding suggests that people with ID and/or ASD are facing overt discrimination beyond that experienced by others with disabilities when they seek medical services (Ali et al., 2013; Ervin et al., 2014). As others have suggested, education is essential in changing provider attitudes and improving outcomes (Ervin & Merrick, 2014; Iezzoni & Long-Bellil, 2012). Such training needs to occur not only in medical school curricula, but in continuing education programs for physicians, nurses, and other frontline providers. Moreover, these providers need to receive

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training to understand the co-morbid physical and mental health conditions that are common among people with ID and/or ASD in order to address all aspects of needed care.

Public programs, particularly Medicaid, are especially important to health care for people with ID and/or ASD compared to other people with disabilities. Their Medicaid coverage may explain the lower out-of-pocket costs for care and higher rates of having a usual source of care reported by respondents with ID (Rudowitz, Garfield & Hinton, 2019). Even with the prevalence of Medicaid coverage, cost is still a barrier to care for a large number of respondents with ID and/or ASD. Similarly, Medicaid is vitally important in providing paid personal assistance services (PAS) for many individuals with ID. Less than half of people with ID and/or ASD who report needing PAS, however, indicate that this service was paid for by insurance. Given the high rates of Medicaid coverage for people with ID, Medicaid systems and providers should be mindful of the barriers to care for this population and undertake efforts to assure access to preventive and wellness services, including mental health and oral health care (Ervin et al., 2014; Ervin & Merrick, 2014). In addition, more attention should be paid to the fact that people with ID and/or ASD are more likely to report having multiple disabling conditions. Multiple conditions signal their potential need for improved access to specialty care, which many reported they had foregone.

Finally, participation in one's community as well as leisure and social activities are important to supporting good mental and physical health (Emerson, 2011; Marks & Sisirak, 2016). People with ID and/or ASD report better satisfaction with community and leisure participation measures than do people with other disabilities. However, 86.1% of the sample of people with ID and/or ASD feel some level of isolation, compared to 73.9% of people with other disabilities. This finding, in combination with the high rates of co-morbid depression and anxiety

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for respondents with ID and/or ASD, strongly suggests that interventions are needed to better support programs that encourage social engagement in one's community for this population.

Limitations. This study has several apparent limitations. First, people with ID and/or ASD may have had less opportunity to complete our online survey than other respondents, particularly those who did not have access to a computer or other internet-connected device. Second, the recruitment methods for survey participants may have resulted in a sample that is more likely to use disability services in their communities or online, perhaps excluding some individuals who are less connected to such services. Third, we had to combine the sample of individuals with ID and ASD, largely because these disabilities were often reported as co-occurring. However, there are potential differences in the experiences of these populations that should be further explored in future research. Finally, 44% (48/109) of survey participants with ID and/or ASD used a proxy responder. Among these, 60% (29/48) of the proxy responders answered questions on behalf of the individual with ID. Thus, 27% (29/109) of the overall ID and/or ASD sample responses were from proxy responders. In most cases, proxy responders were family members living with the individual who likely had knowledge of the individual's experiences. Nevertheless, this higher rate of proxy responders for those with ID and/or ASD is important to note and consider when examining results of the study (Fujiura & RRTC Expert Panel on Health Measures, 2012), particularly as research has noted discrepancies between self and proxy respondents.

Conclusion

Overall, findings from this study reinforce the importance of continued efforts to address health disparities for all Americans with disabilities. Findings also reinforce the fact that many Americans with ID and/or ASD live in poverty and are much less likely to be employed full time

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than are other people with disabilities, likely contributing to poorer health outcomes for this population. Given the high rates of foregone care due to costs, more must be done to make comprehensive health care services available and affordable to all people with disabilities. In addition to better models of health insurance and access to health care for people with disabilities, future research should focus on several areas, including programs to address social isolation while also promoting better health among people with ID and/or ASD, much as the CDC suggested in its call for Disability and Health Programs; and improved education for medical providers on how to engage patients with ID and/or ASD and address their multiple health needs. Ultimately, improved health will provide a foundation for more authentic and meaningful inclusion of people with ID and/or ASD in all aspects of their communities.

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Table 1

Frequencies of Self-Reported Primary Disability Types of Survey Respondents and All Self-Reported Disability Types

Responses	<i>n</i>	% of Total
Primary Disability Type ^{a,b}		
Neurological	324	26.0
Physical	268	21.5
Chronic illness or disease	238	19.1
Psychiatric	193	15.5
ID or ASD	87	7.0
Sensory	74	5.9
Prefer not to answer	62	5.0
Reports more than one disability type	609	48.9
Disability Prevalence by Type (not mutually exclusive)		
Chronic disease or illness	493	39.6
Physical	417	33.5
Psychiatric	398	31.9
Neurological	382	30.7
ID or ASD	109	8.7
Sensory	107	8.6

^a Disability type categorized based on responses to open-ended survey item: “What is your disability or chronic health condition? If you have more than one list your main one first.”

^bChronic illness/disease category includes conditions such as diabetes, COPD, Ehlers-Danlos syndrome, heart disease, HIV/AIDS, cancers; Physical includes muscular dystrophy, achondroplasia, osteoporosis, arthritis; Psychiatric includes bi-polar, schizophrenia, major depression, disassociate identity disorder, anxiety; Neurological includes multiple sclerosis,

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cerebral palsy, spinal cord injury, Parkinson's, ADHD, traumatic brain injury, paraplegia, quadriplegia, epilepsy, stroke; ID or ASD includes Down syndrome, autism spectrum disorders, Fragile X syndrome; Sensory includes deafness/hard of hearing, blindness/low vision and/or partial blindness.

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Table 2

Group Comparisons of People with Self-Reported Intellectual Disability and/or ASD and People with Other Self-Reported Disability

Characteristic	% of ID and/or	% of Other	p-value
	ASD Group (n = 109)	Disability Group (n = 1,075)	
Demographics			
Sex, female	41.3	71.3	< .00001 ^a ***
Race, non-white	22.9	24.0	.725 ^a
Marital status, married	6.5	35.4	< .00001 ^a ***
Highest education level high school or less	46.9	11.4	< .00001 ^a ***
Mean age	32.8 years [CI: 30.6, 35.1]	45.3 years [CI: 44.6, 46.0]	< .0001 ^b ***
Employed or self-employed	50.5	59.4	.198 ^a
Full time	36.4	48.0	.026 ^a *
More than one disability type	65.1	44.3	< .00001 ^a ***
Household income level below 138% Federal Poverty Level	51.4	31.3	< .00001 ^a ***
Received Supplemental Security Income (SSI)	43.0	14.1	< .0001 ^a ***
Received Social Security Disability Insurance (SSDI)	18.9	33.7	.002 ^a **

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Characteristic	% of ID and/or	% of Other	<i>p</i> -value
	ASD Group (<i>n</i> = 109)	Disability Group (<i>n</i> = 1,075)	
Received other public benefits (e.g., food stamps, childcare, TANF)	35.5	23.2	.004 ^{a**}
Has a usual source of medical care	90.8	87.1	.013 ^{a*}
Had less than \$1,000 in medical out-of-pocket costs in the last year	72.8	54.3	.012 ^{a*}
	Health Status		
Overall health status, fair or poor	28.4	40.8	.046 ^{a*}
Mean physical health days not good in last 30	6.4 days [CI: 4.6, 8.2]	9.5 days [CI: 9.8, 11.1]	< .0001 ^{b****}
Mean mental health days not good in last 30	12.3 days [CI: 10.2, 14.3]	9.5 days [CI: 8.9, 10.1]	.006 ^{b*}
Smokes/uses tobacco	11.9	14.1	.113 ^a
	Insurance Coverage Type		
Has Medicaid coverage	60.4	29.8	< .0001 ^{a****}
Has Medicare coverage	23.4	33.0	.111 ^a
Has employer-sponsored health insurance	42.5	49.3	.177 ^a

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Characteristic	% of ID and/or	% of Other	<i>p</i> -value
	ASD Group (<i>n</i> = 109)	Disability Group (<i>n</i> = 1,075)	
Through own employment	31.8	66.0	< .00001 ^a ****
Through a family member	65.9	29.6	< .00001 ^a ****
Barriers to Care & Unmet Need			
Inadequate provider network	30.2	30.2	.993 ^a
Did not get prescription due to cost	27.2	35.1	.106 ^a
Did not see doctor due to cost	19.6	18.6	.802 ^a
Did not see specialist due to cost	31.3	34.5	.518 ^a
Did not get medical test or treatments due to cost	27.1	35.7	.089 ^a
Did not get dental care due to cost	40.6	50.2	.066 ^a
Did not get mental health treatment due to cost	36.9	39.1	.694 ^a
Did not get substance use treatment due to cost	3.2	6.3	.497 ^a
Did not get Durable Medical Equipment (DME) due to cost	29.4	45.4	.026 ^{a*}
Has paid Personal Assistance Services (PAS) (among those needing PAS)	45.9	34.2	.046 ^{a*}

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Characteristic	% of ID and/or	% of Other	<i>p</i> -value
	ASD Group (<i>n</i> = 109)	Disability Group (<i>n</i> = 1,075)	
Refused services by a medical provider	9.2	3.0	.001 ^{a**}
Community Participation			
Not satisfied with time spent on leisure activities	18.7	26.0	.027 ^{a*}
Not satisfied with current level of social activities	24.8	30.0	.499 ^a
Not satisfied with activities in the community	22.2	30.6	.383 ^a
Feel socially isolated from others and community	86.1	73.9	.040 ^{a*}

Note: DME = durable medical equipment; PAS = personal assistance services; TANF = Temporary Assistance For Needy Families program; CI = confidence interval.

^a Uses a chi-square test. ^b Uses an ANOVA with 95% CI.

p*< .05. *p*< .01. ****p*< .001.