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Weight Status and Associated Comorbidities in Children and Adults with Down Syndrome, Autism Spectrum Disorder, and Intellectual and Developmental Disabilities

LT Ptomey[a,*], **DL Walpitage**[b,*], **M Mohseni**[b], **ML Dreyer Gillette**[c,d], **AM Davis**[c,e], **B Forseth**[c,e], **EE Dean**[f], **LR Waitman**[b]

[a]Department of Internal Medicine, The University of Kansas Medical Center, 3901 Rainbow Boulevard, Kansas City, KS, 66160 USA.

[b]Center for Medical Informatics and Enterprise Analytics, The University of Kansas Medical Center, 3901 Rainbow Boulevard, Kansas City, KS, 66160 USA.

[c]Center for Children's Healthy Lifestyles & Nutrition, 610 E 22nd Street, Kansas City, MO64108 USA.

[d]Department of Pediatrics, Children's Mercy Kansas City, 2401 Gillham Rd., Kansas City, MO 64108 USA

[e]Department of Pediatrics, University of Kansas Medical Center, 3901 Rainbow Boulevard, Kansas City, KS, 66160 USA.

[f]Kansas University Center on Developmental Disabilities, University of Kansas, 1450 Jayhawk Blvd, Lawrence, KS 66045

Abstract

Background: Little is known about body weight status, and the association between body weight and common comorbidities in children and adults with Down syndrome (DS), autism spectrum disorder (ASD), and other intellectual and developmental disabilities (IDD).

Methods: Data were extracted from the University of Kansas Medical Center's Healthcare Enterprise Repository for Ontological Narration (HERON) clinical integrated data repository. Measures included demographics (sex, age, race), disability diagnosis, comorbid health conditions, height, weight, and body mass index percentiles (BMI%ile; <18 years of age) or BMI (≥18 years of age).

Results: 468 individuals with DS (122 children, 346 adults), 1659 individuals with ASD (1073 children, 585 adults), and 604 individuals with other-IDDs (152 children, 452 adults) were identified. 47.0% (DS), 41.9% (ASD) and 33.5% (IDD) of children had overweight/obese (OW/OB), respectively. Children with DS were more likely to have OW/OB compared to children with IDD or ASD (OR= 1.91, 95% C.I: (1.49, 2.46); OR=1.43, 95% C.I: (1.19, 1.72)), respectively.

Corresponding author: Lauren T Ptomey, PhD, RD, LD, University of Kansas Medical Center, Department of Internal Medicine, 3901 Rainbow Blvd, Mail Stop 1073, Kansas City, KS 66160, Phone: 913-588-7983, Fax: 913-945-8280, lptomey@ku.edu.

*Ptomey and Walpitage serve as Co-First Authors

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81.1% (DS), 62.1% (ASD), and 62.4% (IDD) of adults were OW/OB, respectively. Adults with DS were more likely to have OW/OB compared to those with IDD (OR=2.56, 95% C.I: (2.16, 3.02)). No significant differences were observed by race. In children with ASD, higher OW/OB was associated with significantly higher (compared to non OW/OB) occurrence of sleep apnea (OR = 2.94, 95% C.I: (2.22, 3.89), hypothyroidism (OR = 3.14, 95% C.I: (2.17, 4.25)) and hypertension (OR = 4.11, 95% C.I: (3.05, 5.54)). In adults with DS, OW/OB was significantly associated with higher risk of sleep apnea and type 2 diabetes (OR=2.93, 95% C.I: (2.10, 4.09); OR=1.76, 95% C.I: (1.11, 2.79) respectively). Similarly, in adults with ASD and IDD OW/OB was significantly associated with higher risk of sleep apnea (OR = 3.39, 95% C.I: (2.37, 4.85) and OR = 6.69, 95% C.I: (4.43, 10.10)), type 2 diabetes (OR = 2.25, 95 %C.I: (1.68, 3.01) and OR = 5.49, 95% C.I: (3.96, 7.61)), and hypertension (OR = 3.55, 95% C.I: (2.76, 4.57) and 3.97, 95% C.I: (3.17, 4.97)).

Conclusion: Findings suggest higher rates of OW/OB in individuals with DS compared to ASD and IDD. Given the increased risk of comorbidities associated with the increased risk of OW/OB, identification of effective interventions for this special population of individuals is critical.

Keywords

disabilities; down syndrome; autism; obesity; children; adults; weight

INTRODUCTION

Obesity is a major health crisis in the United States, affecting 32% of adults and 17% of children and costing an estimated $147 billion in medical care costs and over $3 billion in lost productivity annually(Ogden et al., 2018, Trogdon et al., 2008, Finkelstein et al., 2009, Flegal et al., 2016). Obesity is a risk factor for other disabling conditions, such as type 2 diabetes, high blood pressure, joint problems, and other conditions(Centers for Disease Control and Prevention, 2018). In people with intellectual and developmental disabilities (IDD), the rates of obesity are even higher. Several studies have reported that the prevalence of obesity among adults with IDD ranges from 27% to 59% in the United States (Hsieh et al., 2013, Rimmer and Yamaki, 2006, Yamaki, 2005). The prevalence of overweight and obesity (OW/OB; BMI ≥ the 85th%ile) in adolescents with IDD ranges from 19% to 60% (Maïano et al., 2014, Foley et al., 2014, Maiano, 2011), with the prevalence in children ranging from 10–45% (Maiano et al., 2016). Characteristics associated with having OW/OB are being female and having Down Syndrome (DS) (Hsieh et al., 2013).

Compounding the health consequences of IDD, adults and children with IDD have a higher prevalence of obesity-associated health conditions including cardiovascular disease, risk factors for cardiovascular disease, cardiovascular disease mortality (Draheim, 2006, Reichard et al., 2011, Lauer and Mccallion, 2015, Rimmer et al., 2010), and type 2 diabetes (Shireman et al., 2010, Balogh et al., 2015, Rimmer et al., 2010) compared with their non-IDD peers. Much like obesity rates, the type of disabilities is related to the prevalence of different health conditions. For example, individuals with DS have a higher prevalence of congenital heart disease, dementia, and obstructive sleep apnea compared with their non-DS peers (Alexander et al., 2016, Rimmer et al., 2004).

While the previous literature has shown that obesity rates and prevalence of obesity-associated health conditions in individuals with IDD are high (Hsieh et al., 2013, Rimmer and Yamaki, 2006, Yamaki, 2005, Maïano et al., 2014, Foley et al., 2014, Maiano, 2011) there has been minimal research examining the demographic factors related to obesity in this population. For example, there are no studies or reviews that reported BMI status by race (Maiano, 2011). Additionally, most of the previous literature grouped all types of disabilities together, however, as previously demonstrated, there are different prevalence rates of obesity and obesity-associated health conditions based on type of disability. We are unaware of any literature showing the prevalence of obesity-associated health conditions stratified by diagnosis (DS, autism spectrum disorder (ASD), or other IDD) and BMI category. Finally, we are unaware of any previous reports that have reported the change in weight over time of individuals with IDD broken down by diagnosis.

To further advance our understanding of obesity prevalence in children and adults with IDD, this study utilized electronic medical records from individuals with IDD being treated at The University of Kansas Health Systems to answer the following questions: (1) What is the body weight status among children and adults with DS, ASD, and other IDDs by sex and race? (2) What is the mean weight change across time and annual weight change of children and adults with DS, ASD, and other IDDs? (3) What is the prevalence of common health conditions in children and adults with DS, ASD, and other IDDs by BMI status?

METHODS

Participant and Data Extraction and Management

Data for this retrospective study were extracted from the University of Kansas Medical Center's Healthcare Enterprise Repository for Ontological Narration (HERON), an i2b2-based clinical integrated data repository (Waitman et al., 2011, Murphy et al., 2010) that includes electronic health records (EHR), billing records, and clinical registries for patients seen by the University of Kansas clinics and hospital. HERON links patients across proprietary systems and data formats and transforms the records into an open source data model encoded using national terminologies. While billing records, specialty clinic EHRs, and laboratory results were used prior to 2008, the Epic EHR was implemented in November 2007 at which time vital signs started being recorded across the enterprise. HERON currently contains information from 36 million encounters for over 1 million patients. We identified the cohort of interest from the HERON system using the i2b2 query and analysis tool with specific diagnosis codes to select patients who had DS, ASD or other IDDs and had a visit during the period January 2008 to September 2019. Specific diagnosis codes are presented in Supplementary Table 1. Patients were excluded if they were <2 years of age, had a history of pregnancy, or were deceased.

The following de-identified data were collected for the patient sample: demographics (sex, age, race), disability diagnosis dates, comorbidities (Supplementary Table 2), height, weight, and BMI percentiles (<18 years of age) or BMI (≥18 years of age). Race categories in the EHRs were White, Black, Asian, American Indian, more than one race, declined, and missing. For the purpose of this analysis, we categorised race as White, Black, and Other, with Other comprising of Asian, American Indian, more than one race, declined, and

missing. Hispanic ethnicity is currently available from the EHR but was not consistently used during the early portion of our study period and was excluded from this analysis. Comorbidities were selected a priori to be those diagnoses most commonly associated with weight gain and seen in patients with intellectual disability. Data transformation, analytic files and statistical analyses were developed using Oracle SQL Developer, Oracle 12c database, and RStudio Server 1.1.463 software (R Core Team, 2013).

Measures

To examine BMI status and weight change across time we only included patients who had a minimum of two visits including height and weight at least 3 months apart to allow for sufficient variability of measures (e.g., height/weights from multiple days of an inpatient stay were excluded). For each patient we captured the first BMI record (weight/height) in the system and all other BMI records (weight/height) recorded after 3 months. Patients who only had one BMI or had their other BMIs recorded within 3 months of first BMI were excluded from the analysis. If BMI was not provided in the patient's record, we used height and weight data (measured in the same day) and calculated BMI.

As BMI categories are defined differently for children (BMI%ile) and adults (BMI), we further restricted our BMI analysis to patients having at least two encounters that allowed for BMI calculation as either a child or adult. There were some patients with two BMI data points as a child and as well as two BMI data points as an adult. These patients were categorised into one age category based on the maximum number of encounters they had in either of the age categories. Using first and last BMI%ile/BMI measures (in child/adult age category) additional measures were computed (as defined below) for analytical and reporting purposes.

BMI status was defined as average BMI%ile/BMI= (last BMI%ile/BMI+ first BMI %ile)/2. Then, weight status was further categorised into four weight category groups (underweight, normal weight, overweight (OW), or obese (OB)) by BMI/BMI%ile based on criteria from the CDC(Centers for Disease Control and Prevention, 2018) to define the weight category:

- *Child Weight Categories(BMI%ile)*: ≥ 95th%ile (OB), 85th to the 94th%ile (OW), 5th%ile to the 84th%ile (normal weight), and below the 5th%ile (underweight).
- *Adult Weight Categories (BMI)*: ≥ 30 kg/m^2 (OB), 25 to 29.9 kg/m^2 (OW) 18.5 to 24.9 kg/m^2 (normal weight), and < 18.5 kg/m^2 (underweight).

Data Analysis

Count based descriptive analysis was performed for each of the DS, ASD, and other IDD subpopulations. Analysis was performed separately for children and adults. BMI status and weight management status were calculated using frequencies. In addition, average BMI Percentile/BMI values and BMI measure times (intervals) were calculated. Furthermore, among each of the subpopulations, patients having selected comorbidities associated with weight status were identified: Congenital Heart Defect, Sleep Apnea, Type 2 Diabetes, Dementia, Hypothyroidism, and Hypertension were identified. For patients having a selected main diagnosis and a selected comorbidity condition, weight analysis was repeated using

the same approach as described above. For example, BMI status, weight management status, average BMI values, and BMI measure intervals were calculated for patients with both DS and CHD (child or adult). For comparison purposes, without restricting to the patients having two BMI measures (weight/height), comorbidity prevalence was calculated for each patient subgroup. Furthermore, chi-square analyses were performed to test associations between BMI status and sex, race and presence of comorbidities. Normal weight and underweight categories were combined to create a non-overweight or obese category, and initially, 3×2 tables were used to test the association with sex (Male and Female), 3×3 tables to test associations with race (White, Black, and Other Races), and 3×2 tables to test the associations with presence of given comorbidity (e.g. Sleep Apnea: Yes or No). Given the presence of significance associations, initial tables were further broken down to 2×2 tables (combining OB and OW categories) and odds ratios were calculated to quantify such associations.

Weight change among 3 cohorts (DS, ASD, and Other IDD) were analyzed using basic descriptive summaries. For children, change in BMI%ile across the intervention was reported to reflect the weight change across time, along with the annualized change in BMI%ile. To calculate the annualized change in BMI%ile, average monthly change in BMI%ile was calculated by dividing a child's change in BMI%ile from first and last BMI measures by the time Interval (in months), and was then multiplied by 12. For adults, percentage (%) weight change across time (relative to measured first body weight) was reported, along with the annualized % weight change. To calculate the annualized % weight change for an adult, monthly % weight change rate was calculated, then extrapolated to get the annualized measure. Results were further broken down to sex and race subgroups.

RESULTS

Demographics

The initial patient sample included 14,278 patients and 13,098 patients met the inclusion and exclusion criteria. We elected to create 3 distinct patient groups. The first group were patients with DS diagnoses (n = 967). The next group had an Autism Spectrum Disorder (ASD) diagnosis (without DS; n = 9107). The final group were patients who had a diagnosis of IDD but were not included in either of the first two groups (n = 3018). These subgroups were further explored/filtered for weight analysis as described in the methods (Figure 1). Data management was performed for each of three subgroups, DS, ASD (without DS), IDD (without DS and ASD) separately using an identical approach. The final patient sample comprised 468 individuals with DS (122 children, 346 adults), 1658 individuals with ASD (1073 children, 585 adults), and 604 individuals with other-IDDs (152 children, 452 adults). Table 1 describes the demographics of the study sample.

BMI Status (Table 2)

DS.—In children with DS, 27.0% had OW, and 22.0% had OB. There were no significant differences in BMI status between males or females, or between races. In adults with DS, 27.3% had OW and 53.8% had OB. The risk of OW/OB was significantly higher in

females compared to males (OR=2.11; 95% CI:1.81, 2.47; p=0.02), there were no significant differences between races.

ASD.—In children with ASD, 17.5% had OW and 24.4% had OB There were no significant differences in BMI status between males or females, or between races. In adults with ASD, 24.3% had OW and 37.8% had OB. There were no significant differences in BMI status between males or females, or between races.

IDD.—In children with IDD 11.8% had OW and 21.7% had OB. The risk of OW/OB was significantly higher in females compared to males (OR= 1.87; 95% Cl:1.37, 2.55; p=0.05), there were no significant differences between races. In adults with IDD, 21.0% had OW and 41.4% had OB. The risk of OW/OB was significantly higher in females compared to males (OR= 1.61; 95% Cl:1.33, 1.96, p=0.03). There were no significant differences in BMI status between races.

When comparing the risk of OW/OB in children with different diagnoses, children with DS were more likely to have OW/OB compared to those with IDD (OR= 1.91; 95% Cl:1.49, 2.47; p<0.001) and those with ASD (OR=1.43; 95% CI:1.19,1.72; p=0.07). Adults with DS were more likely to have OW/OB compared to those with IDD (OR=2.56; 95% CI: 2.16,3.02; p<0.001) but not compared those with ASD (OR=0.99; 95% CI: 0.87,1.11; p=0.963).

Weight Change Across Time (Table 3)

DS.—In children with DS, the average period between weight observations was 41 ± 32 months with an average change in BMI %ile of 9.5 ± 23.1%. The annualized change in BMI %ile was 2.8 ±15.2%. In adults with DS, the average period between weight observations was 57 ± 34 months with an average weight change across time of 0.6 ± 24.6%. The annualized weight change was −0.2 ± 7.5%.

ASD.—In children with ASD, the average period between weight observations was 36 ± 29 months with an average change in BMI %ile of 1.5 ± 24.1%. The annualized change in BMI %ile was 2.1 ±22.8%. In adults with ASD, the average period between weight observations was 51 ± 35 months with an average weight change across time of 4.1 ± 14.1%. The annualized weight change was −1.55 ± 22.8%.

IDD.—In children with IDD, the average period between weight observations was 27 ± 24 months with an average change in BMI %ile of 1.5 ± 28.5%. The annualized change in BMI %ile was −0.1 ±33.4%. In adults with IDD, the average period between weight observations was 59 ± 37 months with an average weight change across time of 3.2 ± 61.1%. The annualized weight change was 2.2 ± 21.9%.

Presence of Comorbidities Associated with Weight Status (Table 4)

DS.—In children with DS the most common comorbidities were congenital heart disease (59.0%), hypothyroid (28.7%), and sleep apnea (25.4%). Twenty-three percent of our sample of children with DS were categorised as having no comorbidities, 38% had 1

comorbidity, 25% had 2 comorbidities, 10% had 3 comorbidities, 3% had 4 comorbidities, and 1% had 5 comorbidities. There were no significant associations between weight status and any of the 7 comorbidities. In adults with DS the most common commodities were hypothyroidism (56.1%), sleep apnea (37.6%), and congenital heart disease (24.6%). Seventeen percent of our DS sample were categorised as having no comorbidities, 31% had 1 comorbidity, 29% had 2 comorbidities, 14% had 3 comorbidities, 7% had 4 comorbidities, and 2% had 5 comorbidities. OW/OB was associated with an increased risk of sleep apnea (OR=2.93; 95% CI: 2.10, 4.08; p<0.001), and type 2 diabetes (OR=1.76; 95% CI: 1.11, 2.79; p=0.002).

ASD.—In children with ASD the most common comorbidities were sleep apnea (5.6%), hypertension (5.6%) and congenital heart disease (5.3%). Eighty-two percent of our sample of children with ASD were categorised as having no comorbidities, 14% had 1 comorbidity, 3% had 2 comorbidities, and 1% had 3 comorbidities. Congenital Heart Disease was associated with an increased risk of OW/OB (OR=2.13;95%CI: 1.62, 2.81; p =0.02). OW/OB was associated with an increased risk of sleep apnea (OR=2.94; 95% CI: 2.22, 3.90; p<0.001), hypothyroidism (OR=3.14; 95% CI: 2.17, 4.55; p=0.002), and hypertension (OR=4.11; 95% CI: 3.01, 5.44; p<0.001,). In adults with ASD the most common commodities were hypertension (21.2%), hypothyroidism (15.7%), and type 2 diabetes (12.7%). Fifty-seven and one half of our ASD sample were categorised as having no comorbidities, 26% had 1 comorbidity, 11% had 2 comorbidities, 4% had 3 comorbidities, 1% had 4 comorbidities, and 0.5% had 5 comorbidities. OW/OB was associated with an increased risk of sleep apnea (OR=3.39; 95% CI: 2.37, 4.84; p<0.001,), type 2 diabetes (OR=2.25; 95% CI: 1.68, 3.00; p=0.003), hypothyroidism (OR=1.78; 95% CI: 1.29, 2.29; p=0.02), and hypertension (OR=3.46; 95% CI: 2.76, 4.58; p<0.001).

IDD.—In children with IDD the only prevalent comorbidity was congenital heart disease (10.5%). There was not enough data available to determine the association between weight and comorbidity risk. In adults with IDD, most common commodities were hypertension (39.4%), type 2 diabetes (21.0%), and hypothyroidism (18.1%). Thirty-nine percent of our IDD sample were categorised as having no comorbidities, 29% had 1 comorbidity, 18% had 2 comorbidities, 9% had 3 comorbidities, 4% had 4 comorbidities, 0.5% had 5 comorbidities, and 0.5% had 6 comorbidities. OW/OB was associated with an increased risk of sleep apnea (OR=6.69; 95% CI: 4.11, 10.11; p<0.001), type 2 diabetes (OR=5.49; 95% CI: 3.96, 7.61; p<0.001), and hypertension (OR=3.97; 95% CI: 3.17, 4.96; p<0.001).

DISCUSSION

The results of our study add to the existing literature that demonstrates both adults and adolescents with DS, ASD, and IDD have a high prevalence of OW/OB. The prevalence of OW/OB in our total sample of children with DS, ASD, and IDD (34–49%) are similar to the rates of OW/OB previously reported in adolescents with all IDDs 19% to 61% (Maïano et al., 2014, Foley et al., 2014, Maiano, 2011), and the rates of 10–45% reported for younger children with IDD (Maiano et al., 2016). The obesity rates of adults with DS, ASD, and IDD (38–54%) are similar to the 27–59% range found by previous studies in adults with all IDDs (Hsieh et al., 2013, Rimmer and Yamaki, 2006, Yamaki, 2005).

The current study found that both children and adults with DS had the highest rates of OW/OB compared those ASD or IDD. These results are similar to those by Krause et al (Krause et al., 2016) who reported that in adolescents with IDD, DS was associated with an increased risk of both being overweight (OR = 2.75; 95% CI 1.20, 6.30) and obese (OR = 3.21; 95% CI 1.41, 7.30). Similarly, Hsieh et al (Hsieh et al., 2013) reported that obesity rates were higher in adults with DS, with 53.4% of adults with DS classified as obese compared to 27.2% with ASD, and 36.3% with other IDDs.

Previous reports in adolescents and adults with IDD have found that females are more likely than males to be classified as obese (Hsieh et al., 2013, Krause et al., 2016, Stancliffe et al., 2011, Temple et al., 2014). The current study confirmed that adult females with DS and IDD had higher rates of obesity then males, however, in adults with ASD there was no significant sex difference. Interestingly, while previous studies have reported female adolescents (Krause et al., 2016) with IDD have an increased risk of OW/OB, we only found a significant sex difference between children with IDD, with no differences in children diagnosed with DS and ASD.

To our knowledge, no previous studies have examined the impact of race on obesity status in adolescents and adults with IDD. In typically developing children, obesity prevalence is higher in non-Hispanic black and Hispanic children compared to non-Hispanic whites (Ogden et al., 2018). In typically developing adults, there are no significant difference among non-Hispanic white and Hispanic males or females however, being non-Hispanic black is correlated with obesity status in women, but not men (Hales et al., 2020). The results of the current study found that there were no differences in obesity rates in across different races in adolescents or adults diagnosed with DS, ASD, or IDD.

Several reports from government agencies (2005) and professional organizations (Ptomey and Wittenbrook, 2015) have recommended efforts to reduce the prevalence of OW/OB and obesity-related chronic disease in individuals with IDD. However, there is limited data on change across time in this population. The current study is the first to look at weight change across time in a large sample of children and adults with IDD. Our data suggest the diagnosis with highest annual weight change are children with DS and adults with IDD. Additionally, our results suggest that non-white children with DS and black children with IDD and black adults with DS and ASD may have higher annual weight changes then their white counterparts. However, future research is needed to examine the impact of diagnosis, sex, and race on weight change across time.

Seven of the most prevalent comorbid conditions associated with weight status were selected a priori to be evaluated in conjunction with the primary IDD diagnoses (ASD/DS/IDD). Children in this study were found to have rates of medical comorbidities such as hypothyroidism and type 2 diabetes at rates consistent with prior literature (Krause et al., 2016, Rimmer et al., 2010). However, the prevalence rate of 25% for sleep apnea in children with DS included in this study was lower than previously reported in the literature which commonly observes rates between 45–66% (Marcus et al., 1991, Maris et al., 2016, De Miguel-Díez et al., 2003).

Children with IDD had fewer comorbidities than their peers with DS or ASD. These results suggest that not only are children with DS at the at highest risk for significant increases in weight across time, but they are also at the highest risk for developing obesity related comorbidities. In children with ASD, being overweight was associated with a four times greater risk for hypertension, and threefold greater risk for sleep apnea and hypothyroidism. Similarly, the presence of congenital heart disease in children with ASD was associated with a 2 times greater risk of OW/OB. The multitude of secondary health conditions associated with higher rates of obesity in children with DS and ASD should be addressed in future research.

The overall prevalence rates of comorbidities among adults with DS, ASD, and IDD were similar to those previously reported in the literature in adults with all IDDs (Hsieh et al., 2013, Draheim, 2006, Alexander et al., 2016, Shireman et al., 2010, Balogh et al., 2015). Among the three groups, adults with DS had the highest rates of congenital heart disease, sleep apnea, dementia, and hypothyroid disease. These results are similar to previous findings that have found that individuals with DS have a higher prevalence of congenital heart disease, dementia, and obstructive sleep apnea compared with their non-DS peers (Alexander et al., 2016, Rimmer et al., 2004). Interestingly, adults with DS had the lowest rates of hypertension. Among adults with DS, OW/OB (BMI $\geq 25 kg/m^2$) was associated with an almost 3 times greater risk of sleep apnea and 2 times greater risk for type 2 diabetes. Adults with IDD had the highest rate of type 2 diabetes and hypertension. In adults with IDD, those with OW/OB were almost 7 times more likely to have sleep apnea, 5.5 times more likely to have type 2 diabetes, and 4 times more likely to have hypertension than their healthy weight counterparts. Among adults with ASD, obesity was associated with a 3.5 times greater chance of hypertension, 3 times greater risk for sleep apnea, and 2 times greater risk for type 2 diabetes. In general, among many of the comorbidities such as type 2 diabetes, sleep apnea, and hypertension which require daily medications and treatments, and limit long-term survival, adults with DS, ASD, and IDD were at a 2–5 times greater risk of being diagnosed. Given the very high burden of these diseases in terms of health care costs and long-term risk, it is critical to identify strategies to improve or maintain healthy weight status in adults with IDD.

Study Limitations

The present sample was identified utilizing retrospective database analysis of a clinical integrated data repository, and thus, data were limited to those available at the time of entry for the patient encounter. Therefore, our methodology differs from that of previously published research in terms of sample selection (e.g., Special Olympics participants, small intervention/clinical studies), and to some degree, amount of available data. The breadth of the ages of participants and diversity of presenting diagnoses may make it challenging to compare to previously published research. We limited our focus to selected highly prevalent comorbidities, and thus the data should be interpreted with caution, as it is only reflective of these specific diseases that were coded within the medical record as well as those for which patients sought medical care. Another limitation was that while we reported the weight change across time by gender and race, statistical comparisons among these sub-groups were not preformed due to differences in measurement time intervals, age,

and also small sample sizes when broken into sub-groups. Finally, the current project was conducted in a single academic medical center that provides regional referral for autism spectrum disorders and may not be representative of children and adults from other parts of the US. A strength of this study was our ability to differentiate DS and ASD from other IDD diagnoses and our sample size. Future analysis will seek to generalise and expand these analyses across institutions sharing common data representations such as the Greater Plains Collaborative(Waitman et al., 2014) and other PCORnet (Fleurence et al., 2014) participants. Additionally, future analysis will include a valid and reliable standardized weight change measure to capture the non-linear weight change trend for performing statistical comparisons among sub-groups, and adjusting for the effect of confounders, such as age.

CONCLUSIONS

While all individuals with DS, ASD, and other IDDs have high rates of OW/OB, children and adults with DS have higher rates of OW/OB than those with ASD or IDD. Adult females with DS and IDD have higher rates of obesity then their male counterparts. Additionally, children with DS had the highest annual BMI percentile change and obesity related comorbidities, and adults with DS had higher frequencies of being diagnosed with one or more comorbidities compared to adults with ASD or IDD. Future research should focus on developing weight management interventions for individuals with all IDDs, however special emphasis should be given to interventions targeting weight loss or prevention of excess weight gain in children with DS, since adolescence appears to be a time of excessive weight gain in this population. It is plausible that if obesity rates were lowered among children, rates of OW/OB in adults may decrease along with weight related comorbidity rates and future health care costs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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REFERENCES

Healthy People2020. Washington, DC: U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion,.

Alexander M, Petri H, Ding Y, Wandel C, Khwaja O & Foskett N 2016. Morbidity and medication in a large population of individuals with Down syndrome compared to the general population. Developmental Medicine & Child Neurology, 58, 246–254. [PubMed: 26282180]

Balogh RS, Lake JK, Lin E, Wilton A & Lunsky Y 2015. Disparities in diabetes prevalence and preventable hospitalizations in people with intellectual and developmental disability: a population-based study. Diabet Med, 32, 235–42. [PubMed: 25185567]

Centers for Disease Control and Prevention2018. Overweight and Obesity.

De Miguel-Díez J, Villa-Asensi JR & Álvarez-Sala JL 2003. Prevalence of sleep-disordered breathing in children with Down syndrome: polygraphic findings in 108 children. Sleep, 26, 1006–1009. [PubMed: 14746382]

Draheim CC2006. Cardiovascular disease prevalence and risk factors of persons with mental retardation. Ment Retard Dev Disabil Res Rev, 12, 3–12. [PubMed: 16435328]

Finkelstein EA, Trogdon JG, Cohen JW & Dietz W 2009. Annual Medical Spending Attributable To Obesity: Payer-And Service-Specific Estimates: Amid calls for health reform, real cost savings are more likely to be achieved through reducing obesity and related risk factors. Health affairs, 28, w822–w831. [PubMed: 19635784]

Flegal KM, Kruszon-Moran D, Carroll MD, Fryar CD & Ogden CL 2016. Trends in obesity among adults in the United States, 2005 to 2014. Jama, 315, 2284–2291. [PubMed: 27272580]

Fleurence RL, Curtis LH, Califf RM, Platt R, Selby JV & Brown JS 2014. Launching PCORnet, a national patient-centered clinical research network. J Am Med Inform Assoc, 21, 578–82. [PubMed: 24821743]

Foley JT, Lloyd M, Vogl D & Temple VA 2014. Obesity trends of 8–18 year old Special Olympians: 2005–2010. Research in developmental disabilities, 35, 705–710. [PubMed: 24397890]

Hales CM, Carroll MD, Fryar CD & Ogden CL 2020. Prevalence of obesity and severe obesity among adults: United States, 2017–2018.

Hsieh K, Rimmer JH & Heller T 2013. Obesity and associated factors in adults with intellectual disability. J Intellect Disabil Res.

Krause S, Ware R, Mcpherson L, Lennox N & O'callaghan M 2016. Obesity in adolescents with intellectual disability: Prevalence and associated characteristics. Obesity research & clinical practice, 10, 520–530. [PubMed: 26559898]

Lauer E & Mccallion P 2015. Mortality of People with Intellectual and Developmental Disabilities from Select US State Disability Service Systems and Medical Claims Data. J Appl Res Intellect Disabil.

Maiano C2011. Prevalence and risk factors of overweight and obesity among children and adolescents with intellectual disabilities. Obesity Reviews, 12, 189–197. [PubMed: 20406413]

Maiano C, Hue O, Morin AJ & Moullec G 2016. Prevalence of overweight and obesity among children and adolescents with intellectual disabilities: a systematic review and meta-analysis. Obesity Reviews, 17, 599–611. [PubMed: 27171466]

Maïano C, Normand CL, Aimé A & Bégarie J 2014. Lifestyle interventions targeting changes in body weight and composition among youth with an intellectual disability: A systematic review. Research in developmental disabilities, 35, 1914–1926. [PubMed: 24830882]

Marcus CL, Keens TG, Bautista DB, Von Pechmann WS & Ward SLD 1991. Obstructive sleep apnea in children with Down syndrome. Pediatrics, 88, 132–139. [PubMed: 1829151]

Maris M, Verhulst S, Wojciechowski M, Van De Heyning P & Boudewyns A 2016. Prevalence of obstructive sleep apnea in children with Down syndrome. Sleep, 39, 699–704. [PubMed: 26612391]

Murphy SN, Weber G, Mendis M, Gainer V, Chueh HC, Churchill S, et al. 2010. Serving the enterprise and beyond with informatics for integrating biology and the bedside (i2b2). Journal of the American Medical Informatics Association, 17, 124–130. [PubMed: 20190053]

Ogden CL, Fryar CD, Hales CM, Carroll MD, Aoki Y & Freedman DS 2018. Differences in obesity prevalence by demographics and urbanization in US children and adolescents, 2013–2016. Jama, 319, 2410–2418. [PubMed: 29922826]

Ptomey LT & Wittenbrook W 2015. Position of the academy of nutrition and dietetics: nutrition services for individuals with intellectual and developmental disabilities and special health care needs. J Acad Nutr Diet, 115, 593–608. [PubMed: 25819518]

R Core Team2013. R: A language and environment for statistical computing.

Reichard A, Stolzle H & Fox MH 2011. Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. Disabil Health J, 4, 59–67. [PubMed: 21419369]

Rimmer JH, Heller T, Wang E & Valerio I 2004. Improvements in physical fitness in adults with Down syndrome. Am J Ment Retard, 109, 165–74. [PubMed: 15000673]

Rimmer JH & Yamaki K 2006. Obesity and intellectual disability. Ment Retard Dev Disabil Res Rev, 12, 22–7. [PubMed: 16435329]

Rimmer JH, Yamaki K, Davis-Lowry BM, Wang E & Vogel LC 2010. Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities. Journal of Intellectual Disability Research, 54, 787–794. [PubMed: 20630017]

Shireman TI, Reichard A, Nazir N, Backes JM & Greiner KA 2010. Quality of diabetes care for adults with developmental disabilities. Disabil Health J, 3, 179–85. [PubMed: 21122783]

Stancliffe RJ, Lakin KC, Larson S, Engler J, Bershadsky J, Taub S, et al. 2011. Overweight and obesity among adults with intellectual disabilities who use intellectual disability/developmental disability services in 20 U.S. States. Am J Intellect Dev Disabil, 116, 401–18. [PubMed: 22126656]

Temple V, Foley J & Lloyd M 2014. Body mass index of adults with intellectual disability participating in S pecial O lympics by world region. Journal of Intellectual Disability Research, 58, 277–284. [PubMed: 23331860]

Trogdon J, Finkelstein EA, Hylands T, Dellea P & Kamal-Bahl S 2008. Indirect costs of obesity: a review of the current literature. Obesity Reviews, 9, 489–500. [PubMed: 18331420]

United States Department of Health and Human Services2002. Closing the gap: A national blueprint for improving the health of individuals with mental retardation. Report of the Sureon Generals's conference on health disaprities and mental retardation. Rockville, MD: Office of the Surgeon General.

Us Department of Health and Human Services2005. The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. Washington, DC: US Department of Health and Human Services.

Waitman LR, Aaronson LS, Nadkarni PM, Connolly DW & Campbell JR 2014. The Greater Plains Collaborative: a PCORnet Clinical Research Data Network. J Am Med Inform Assoc, 21, 637–41. [PubMed: 24778202]

Waitman LR, Warren JJ, Manos EL & Connolly DW Expressing observations from electronic medical record flowsheets in an i2b2 based clinical data repository to support research and quality improvement. AMIA Annual Symposium Proceedings, 2011. American Medical Informatics Association, 1454.

Yamaki K2005. Body weight status among adults with intellectual disability in the community. Ment Retard, 43, 1–10. [PubMed: 15628929]

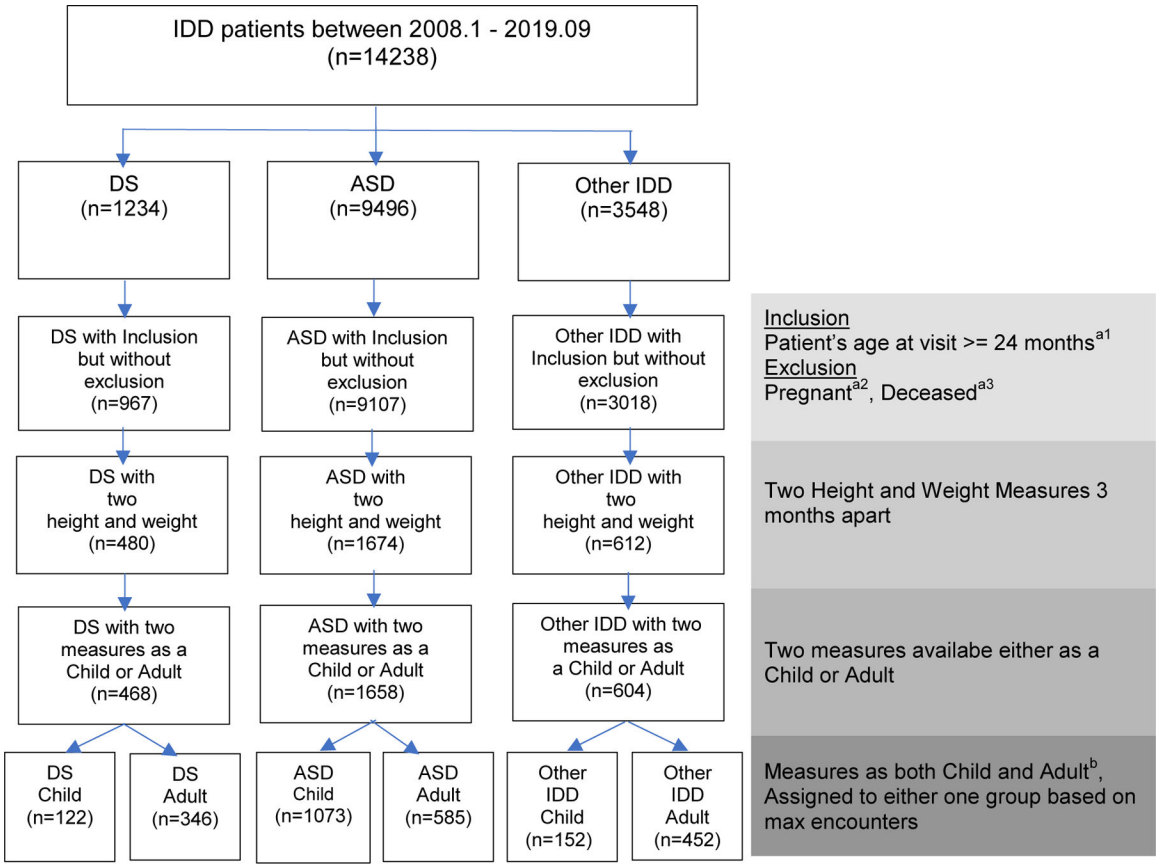

Figure 1. *CONSORT* Diagram

From the IDD patents DS patients were first selected as patients having Down Syndrome diagnosis, ASD patients are patient who have Autism Spectrum Disorder but without DS, Other Intellectual and Development Disability patients are other patients without DS or ASD. For patient subgroup, *DS (a1=1148, a2=79, a3=107, b=37)*; ASD *(a1=9445, a2=31, a3=121, b=206);* Other IDD *(a1= 3483, a2=72, a3=325, b=45)*

Table 1.

Sex, Race, and IDD Diagnosis of the Study Sample.

Age Group	Diagnosis	Sex				Race					
		Female		Male		White		Black		Other	
Children	DS	58	47.5%	64	52.5%	76	62.3%	9	7.4%	37	30.3%
	ASD	206	19.2%	867	80.8%	777	72.4%	110	10.3%	186	17.3%
	IDD	58	38.2%	94	61.8%	97	63.8%	25	16.4%	30	19.7%
Adults	DS	164	47.4%	182	52.6%	293	84.7%	259	7.2%	28	8.1%
	ASD	166	28.4%	419	71.6%	469	80.2%	63	10.8%	53	9.0%
	IDD	225	49.8%	227	50.2%	316	69.9%	86	19.0%	50	11.1%

Table 2.

BMI Statistics in Children and Adults with DS, ASD, and other IDDs.

Age Group	Diagnosis	Demographic Characteristics	Total	BMI							
				Underweight		Normal		Overweight		Obese	
Children	DS										
		Sex									
		Female	58	0	0.0%	28	48.3%	14	24.1%	16	27.6%
		Male	64	0	0.0%	34	53.1%	19	29.7%	11	17.2%
		Race									
		White	76	0	0.0%	38	50.0%	18	23.7%	20	26.3%
		Black	9	0	0.0%	5	55.6%	2	22.2%	2	22.2%
		Other	37	0	0.0%	19	51.4%	13	35.1%	5	13.5%
	ASD										
		Sex									
		Female	206	2	1.0%	112	54.4%	44	21.4%	48	23.3%
		Male	867	17	2.0%	492	56.7%	144	16.6%	214	24.7%
		Race									
		White	777	12	1.5%	437	56.2%	142	18.3%	186	23.9%
		Black	110	2	1.8%	58	52.7%	22	20.0%	28	25.5%
		Other	186	5	2.7%	109	58.6%	24	12.9%	48	25.8%
	IDD										
		Sex									
		Female	58	1	1.7%	31	53.4%	9	15.5%	17	29.3%
		Male	94	3	3.2%	66	70.2%	9	9.6%	16	17.0%
		Race									
		White	97	1	1.0%	65	67.0%	11	11.3%	20	20.6%
		Black	25	1	4.0%	14	56.0%	3	12.0%	7	28.0%
		Other	30	2	6.7%	18	60.0%	4	13.3%	6	20.0%
Adults	DS										
		Sex									
		Female	164	2	1.2%	32	19.5%	33	20.1%	97	59.1%
		Male	182	4	2.2%	28	15.4%	61	33.5%	89	48.9%
		Race									
		White	293	5	1.7%	52	17.7%	84	28.7%	152	51.9%
		Black	25	1	4.0%	3	12.0%	5	20.0%	16	64.0
		Other	28	0	0.0%	5	17.9%	5	17.9%	18	64.3%
	ASD										
		Sex									
		Female	166	6	3.6%	56	33.7%	39	23.5%	65	39.2%
		Male	419	21	5.0%	139	33.2%	103	24.6%	156	37.2%
		Race									
		White	469	25	5.3%	144	30.7%	118	25.2%	182	38.8%

Age Group	Diagnosis	Demographic Characteristics	Total	BMI							
				Underweight		Normal		Overweight		Obese	
		Black	63	1	1.6%	24	38.1%	13	20.6%	25	39.7%
		Other	53	1	1.9%	27	50.9%	11	20.8%	14	26.4%
	IDD										
		Sex									
		Female	225	17	7.6%	55	24.4%	47	20.9%	106	47.1%
		Male	227	15	6.6%	83	36.6%	48	21.1%	81	35.7%
		Race									
		White	316	26	8.2%	93	29.4%	68	21.5%	129	40.8%
		Black	86	4	4.7%	24	27.9%	17	19.8%	41	47.7%
		Other	50	2	4.0%	21	42.0%	10	20.0%	17	34.0%

Table 3.

Weight Change Across Time in Children and Adults with DS, ASD, and other IDDs.

Age Group	Diagnosis	Demographic	N	Months Between Weight Measurements		Total Weight Change Across Time[1]			Annualized Weight Change[1]
				Mean (SD)	*Max*	*Mean (SD)*	*Max Loss*	*Max Gain*	*Mean (SD)*
Children	DS	Total	122	40.8 (32.0)	137	9.5 (23.1)	47	80	2.8 (15.2)
		Sex							
		Female	58	39.7 (33.7)	137	8.7 (23.0)	47	65	3.6 (14.0)
		Male	64	41.7 (30.6)	126	10.2 (23.4)	40	80	2.1 (16.3)
		Race							
		White	76	38.3 (31.1)	133	4.1 (20.8)	47	70	−0.1 (14.9)
		Black	9	49.7 (35.8)	126	30.3 (29.2)	7	80	6.3 (10.6)
		Other	37	43.6 (33.0)	137	15.5 (22.3)	25	65	7.8 (15.5)
	ASD	Total	1073	36.2 (29.5)	134	1.5 (24.1)	94	90	2.1 (22.8)
		Sex							
		Female	206	36.4 (29.8)	124	1.5 (22.7)	87	90	1.5 (20.0)
		Male	867	36.1 (29.4)	134	1.5 (24.4)	94	72	2.3 (23.4)
		Race							
		White	777	35.2 (28.7)	134	2.8 (23.7)	94	82	2.7 (23.2)
		Black	110	41.7 (31.2)	128	−1.3 (22.5)	72	90	0.6 (19.2)
		Other	186	37.2 (31.3)	132	−2.0 (26.0)	94	72	0.6 (22.9)
	IDD	Total	152	26.9 (24.9)	93	1.5 (28.5)	70	94	−0.1 (33.3)
		Sex							
		Female	58	26.5 (24.5)	91	0.9 (26.8)	70	72	4.3 (35.9)
		Male	94	27.2 (24.5)	93	1.8 (29.7)	65	94	−2.9 (31.6)
		Race							
		White	97	23.9 (22.4)	88	3.1 (29.3)	65	94	0.8 (38.6)
		Black	25	31.7 (25.1)	91	7.0 (20.5)	22	60	3.7 (12.9)
		Other	30	32.9 (28.8)	93	−8.6 (30.1)	70	72	−6.1 (26.6)
Adults	DS	Total	346	56.8 (33.9)	134	0.6 (24.6)	40	49	−0.2 (7.5)
		Sex							
		Female	164	58.4 (35.5)	134	−0.2 (33.0)	40	47	−0.2 (9.1)
		Male	182	55.5 (32.4)	134	1.3 (13.0)	39	49	−0.2 (5.7)
		Race							
		White	293	57.0 (33.6)	134	0.8 (14.4)	40	49	−0.3 (7.3)
		Black	25	65.4 (36.2)	34	−2.2 (76.6)	40	24	2.2 (11.4)
		Other	28	48.8 (33.7)	121	0.6 (10.6)	24	23	−0.4 (4.8)
	ASD	Total	585	50.8 (35.4)	141	4.1 (14.1)	39	69	1.6 (22.8)
		Sex							

Age Group	Diagnosis	Demographic	N	Months Between Weight Measurements		Total Weight Change Across Time[1]			Annualized Weight Change[1]
				Mean (SD)	*Max*	*Mean (SD)*	*Max Loss*	*Max Gain*	*Mean (SD)*
		Female	166	55.6 (36.5)	139	3.8 (17.8)	39	69	1.9 (12.1)
		Male	419	48.9 (34.8)	141	4.3 (12.4)	28	63	1.4 (25.9)
		Race							
		White	469	51.5 (35.9)	141	4.1 (13.8)	39	63	1.2 (6.9)
		Black	63	52.0 (33.2)	120	4.7 (17.0)	33	69	8.9 (54.8)
		Other	53	43.2 (32.6)	123	3.7 (13.8)	21	46	−3.8 (41.8)
	IDD	Total	452	59.4 (37.0)	140	3.2 (61.1)	45	269	2.2 (21.9)
		Sex							
		Female	225	60.7 (38.7)	140	3.1 (60.1)	47	46	2.7 (28.1)
		Male	227	58.3 (35.3)	137	3.2 (62.3)	45	269	1.5 (13.3)
		Race							
		White	316	58.7 (37.9)	140	2.8 (70.9)	45	48	2.7 (25.8)
		Black	86	62.7 (36.4)	126	3.9 (32.7)	44	269	0.4 (8.2)
		Other	50	58.7 (32.1)	136	4.1 (12.7)	28	41	1.1 (3.9)

[1] Values in children are reported as change in BMI %ile, values in adults are reported as % weight change.

Table 4.

Number and Percentage of Individuals with DS, ASD, and IDD Diagnosed with Different Comorbidities

Diagnosis		Congenital heart disease		Sleep Apnea		Type 2 Diabetes		Dementia		Hypothyroidism		Hypertension	
		Ct.	Pct.	Ct.	Pct.	Ct.	Pct.	Ct.	Pct.	Ct.	Pct.	Ct.	Pct.
DS	Total	157	32.3%	161	34.4%	>48	>10.3%	>81	>17.3%	229	48.9%	64	13.7%
	Children	72	59.0%	31	25.4%	<11	-	<11	-	35	28.7%	14	11.5%
	Adults	85	24.6%	130	37.6%	48	13.9%	81	23.4%	194	56.1%	50	14.5%
ASD	Total	84	5.1%	120	7.2%	93	5.6%	>17	>1.0%	128	7.7%	184	11.1%
	Children	57	5.3%	60	5.6%	19	1.8%	<11	-	36	3.4%	60	5.6%
	Adults	27	4.6%	60	10.3%	74	12.7%	17	2.9%	92	15.7%	124	21.2%
IDD	Total	57	9.4%	>70	>11.5%	>95	>15.7	>47	7.8%	>82	>13.6%	>178	>29.5%
	Children	16	10.53%	<11	-	<11	-	<11	-	<11	-	<11	-
	Adults	41	9.07%	70	15.5%	95	21.0%	47	10.40%	82	18.1%	178	39.4%