

## Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities

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### Abstract

**Background** To explore the prevalence of obesity and related secondary conditions associated with obesity in adolescents with intellectual/developmental disabilities (IDD).

**Methods** In total, 461 parents of adolescents with IDD ( $M = 14.9$  year,  $SD = 1.9$ ) across 49 US states completed a web-based survey containing questions related to their child's health status, including body weight and existing health conditions. Results were compared with published data for youth without disabilities.

**Results** Adolescents with autism and Down syndrome were two to three times more likely to be obese than adolescents in the general population. Secondary health conditions were higher in obese adolescents with IDD compared with healthy weight adolescents with IDD including high blood pressure, high blood cholesterol, diabetes, depression, fatigue, liver or gallbladder problems, low self-esteem, preoccupation with weight, early maturation and pressure sores.

**Conclusion** Obesity is as much of a health problem in youth with IDD as it is among youth without disabilities and, in certain disability groups, is a sig-

nificantly greater health problem. Obese youth with IDD have a high number of obesity-related secondary conditions predisposing them to greater health problems as they transition into adulthood. Federal and local initiatives to reduce obesity among youth in the general population must recognise the need for interventions that are also relevant (i.e. accessible and effective) for youth with IDD.

**Keywords** adolescents with disabilities, body mass index, obesity, overweight, secondary conditions

### Introduction

Youth with disabilities comprise 9.2% or 6 million school-age children in the United States (U.S. Department of Education *et al.* 2007). The epidemic of childhood obesity observed in youth without disabilities (Daniels *et al.* 2009) may also be a concern for youth with intellectual/developmental disabilities (IDD). Analysis of national school survey data, for example, suggested that one-third of 9th to 12th grade students with 'any physical or long-term health problems' were obese or overweight (Rimmer *et al.* 2007). Data from a population-based household survey found that obesity had a significantly higher prevalence among children with mobility limitations compared

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with those without mobility limitations (Bandini *et al.* 2005). Analyses of clinical data have also indicated a higher prevalence of obesity among children and adolescents with specific aetiologies such as spina bifida (Simeonsson *et al.* 2002), ambulatory youth with cerebral palsy (CP) (Hurvitz *et al.* 2008) and Down syndrome (Luke *et al.* 1996).

The social, physical and mental health issues that many youth with IDD are already exposed to could be further compromised by the additional health condition of obesity. While there is a need to establish greater clarity with respect to obesity prevalence among youths with IDD given that prevalence data and definitions used to classify youths with disabilities vary from study to study (Bandini *et al.* 1991, 2005; Rimmer *et al.* 2007; Stewart *et al.* 2009), there is also a strong need to determine the consequences of obesity among youths with IDD given the potentially harmful interaction with concurrent health conditions.

A few studies have shown that obesity presents a higher incidence of health problems including decreased social and physical functioning (Simeonsson *et al.* 2002), reduced quality of life (Hughes *et al.* 2006), difficulty forming peer relationships (Gortmaker *et al.* 1993; Koplan *et al.* 2005), increased likelihood of depression (Daniels 2006), and stigma and discrimination among youths with and without disabilities. Yet, there are significant gaps in the research literature related to the incidence of obesity and obesity-related secondary conditions among youths with IDD. Specifically, it is unknown what the incidence of secondary health conditions is among youths with IDD exposed to obesity, or if rates of obesity and health conditions are higher among youths with physical versus cognitive disabilities. Similarly, obesity status and obesity-related secondary conditions specific to youths with different aetiologies, which were not examined in previous research (Bandini *et al.* 2005; Rimmer *et al.* 2007; Stewart *et al.* 2009), can provide a better understanding of the potential health risks for certain population groups. Therefore, the purpose of this study was to examine the incidence of obesity and obesity-related health conditions in youths with IDD, utilising an Internet-based sampling frame that included data from across the United States. Results were compared with available data for youths without IDD to

determine if there were any health disparities between the two groups.

## Methods

### Participants

A convenience sample of adult family members of adolescents with IDD, ages 12 to 18 years, was recruited from state and local disability and health advocacy organisations, the subscriber list of a parent magazine, and a disability-related independent website from September 2008 to March 2009. Recruitment methods included blast emails, web banner advertisements and flyers. Recruitment materials directed eligible family members to visit a survey web site and respond to questions regarding the health of their child. Parents who visited the web site were screened to determine if they met the following three eligibility criteria: (1) living with a child between the ages of 12 and 18 years; (2) responsible for providing care to child; and (3) child has a physical or cognitive disability and receives special education services. Exclusion criteria included parents who were unable to complete the survey online and youths who did not have an IDD. Respondents residing outside the USA were also excluded from the analyses. The research protocol was reviewed and approved by the local institutional ethics panel.

### Data collection

Parents who met the inclusion criteria were invited to participate in an online survey. The following measures were used to collect data pertaining to demographics, disability status and health conditions.

#### *Demographics*

Basic demographic information included age, sex and race/ethnicity.

#### *Disability aetiology*

Family members were asked to select their child's primary disability from a list of the following conditions: autism spectrum disorder; attention deficit/hyperactivity disorder; blindness or vision

problems; CP; deafness and hearing problems; Down syndrome; epilepsy or seizures; head injury; impairment or deformity of foot or leg; impairment or deformity of hand, arm or finger; learning disability; mental retardation [this term was used during the time of data collection but has since been replaced with the new term, intellectual disability (ID)]; mental or emotional problem/disorder; missing legs, feet, comma, hands, arm or fingers; paralysis of any kind; spina bifida; spinal cord injury; and 'other'. Families who selected one of the following five conditions (autism, ID, Down syndrome, spina bifida, CP) were included in the data analysis.

#### *Body weight status*

Parents self-reported their child's height and weight which were used to compute body mass index [BMI, weight (kg)/height<sup>2</sup> (m)]. A percentile ranking of each adolescent's raw BMI score relative to age- and sex-specific national norms was obtained using the criteria established by the 2000 Centers for Disease Control and Prevention Growth Charts for the United States (Kuczmarski *et al.*, 2000). Based on the obtained percentile ranking, BMI status was classified into the following four categories: obese (BMI  $\geq$  95th percentile), overweight (BMI  $\geq$  85th percentile), healthy weight (BMI < 85th percentile and  $\geq$  5th percentile) and underweight (BMI < 5th percentile).

#### *Obesity-related health conditions*

After reviewing the current literature on health conditions associated with obesity reported in youths without IDD (Daniels, 2006; U.S. Department of Health and Human Services 2001) and adding one secondary condition specific to youths and adults with IDD (i.e. pressure sores), the following 15 conditions were included in the survey: asthma, high blood pressure, high blood cholesterol, diabetes, depression, fatigue, gastrointestinal problems, joint or bone pain, sleep apnea, liver or gallbladder problems, low self-esteem, preoccupation with weight, Blount's disease, early maturation and pressure sores. Family members were asked if they have ever been told by a health professional that their child had any of these conditions.

#### Statistical analyses

Data for youths with IDD were statistically weighted using the demographic characteristics (i.e. age, sex and race) of youths without IDD obtained from the 2007 Youth Risk Behavior Survey (YRBS), a national school-based survey of high school youth between 9th and 12th grades (Centers for Disease Control and Prevention 2008), so that the total sample of youths with IDD agreed with the demographic characteristics of youths in the general population. Obesity status of youths with IDD was calculated using the weighted data and then compared with youths from the YRBS using the odds ratio, which was calculated by dividing the odds in youths with IDD by the odds in youths in the general population. The difference between youths with and without IDD was tested using the 95% confidence interval associated with the odds ratio.

Prevalence of secondary conditions across different disability groups of youths with IDD was compared by body weight status (i.e. overweight vs. healthy weight) using Fisher's exact test. All statistical analyses were performed using SPSS version 16 and SAS version 9 for the weighting procedure and subsequent analyses. Level of significance was set at 0.05.

#### Results

Table 1 summarises age, weight, height and BMI of youths with IDD by disability aetiology and demographics. Results from the one-way ANOVA revealed that there was a significant difference in weight [ $F(4, 456) = 27.37, P < 0.000$ ], height [ $F(4, 456) = 34.43, P < 0.000$ ] and BMI [ $F(4, 456) = 19.82, P < 0.000$ ] across gender and disability groups. *Post hoc* comparisons using a Tukey HSD test revealed that youths with autism were significantly heavier and taller than the other disability groups. Youths with CP were significantly lighter than the other groups with the exception of youths with spina bifida, and the mean BMI was lower than any other group.

Table 2 compares the prevalence of obesity and overweight in youths with and without disabilities. Data for youths with IDD were weight-adjusted by age, sex and race/ethnicity to allow for comparisons

**Table 1** Sample characteristics of youth with IDD by weight, height and BMI ( $n = 461$ )

Characteristics	<i>n</i> (%)	Age (years)	Weight (lb)	Height (inches)	BMI*
Disability					
Autism	159 (34.5)	14.7 ± 1.9	144.7 ± 45.9	64.3 ± 5.0	23.6 ± 5.8
Cerebral palsy	117 (25.4)	14.9 ± 2.0	95.4 ± 29.9	59.1 ± 5.2	19.0 ± 4.8
Down syndrome	81 (17.6)	15.4 ± 2.0	129.3 ± 34.8	59.6 ± 3.3	25.4 ± 5.9
Intellectual disability	82 (17.8)	15.0 ± 2.0	117.8 ± 39.6	61.6 ± 6.0	21.4 ± 5.4
Spina bifida	22 (4.8)	15.0 ± 1.8	120.1 ± 46.2	58.1 ± 6.2	24.4 ± 6.9
<i>F</i> -test			$P < 0.000$	$P < 0.000$	$P < 0.000$
Sex					
Male	311 (67.5)	14.8 ± 1.9	129.1 ± 45.8	63.1 ± 5.7	22.4 ± 6.1
Female	150 (32.5)	15.2 ± 2.0	111.9 ± 36.2	58.8 ± 4.7	22.4 ± 5.8
<i>t</i> -test		$P = 0.019$	$P < 0.000$	$P < 0.000$	
Total	461 (100)	14.9 ± 1.9	123.5 ± 43.6	61.7 ± 5.7	22.4 ± 6.0

Values are mean ± standard deviation.

\*BMI = [weight (kg)/height<sup>2</sup> (m)].

BMI, body mass index; IDD, intellectual/developmental disabilities.

**Table 2** Comparison of obesity between youth with IDD and youth without disability by type of disability

Disability type	Youth with disability ( $n = 461$ )	Youth w/o disability <sup>†</sup> ( $n = 12\ 973$ )	Odds ratio	95% CI
Autism				
% obese (>95th percentile)	24.6	13.0	2.19	1.44–3.31
% overweight (>85th percentile)	42.5	28.8	1.84	1.28–2.64
Down syndrome				
% obese (>95th percentile)	31.2	13.0	3.00	1.86–4.81
% overweight (>85th percentile)	55.0	28.8	3.01	1.95–4.66
Intellectual disability				
% obese (>95th percentile)	12.4	13.0	0.96	0.51–1.81
% overweight (>85th percentile)	27.2	28.8	0.93	0.58–1.49
Cerebral palsy				
% obese (>95th percentile)	4.0	13.0	0.30	0.13–0.68
% overweight (>85th percentile)	18.8	28.8	0.57	0.37–0.87
Spina bifida				
% obese (>95th percentile)	18.6	13.0	1.61	0.66–3.93
% overweight (>85th percentile)	64.5	28.8	4.50	2.16–9.41

Data were weight-adjusted by age, gender and race using sample raking so that proportionate segments of age, gender and race were matched between our sample and YRBS data.

<sup>†</sup> 2007 YRBS data.

IDD, intellectual/developmental disabilities; YRBS, Youth Risk Behavior Survey.

with non-disabled youths. Youths with autism were more likely to be obese (BMI ≥ 95th percentile) and overweight (BMI ≥ 85th percentile) compared with youths without IDD (obese – 24.6% vs. 13.0%, OR = 2.19, 95% CI = 1.44–3.31; overweight

– 42.5% vs. 28.8%, OR = 1.84, 95% CI = 1.28–2.64). Similarly, youths with Down syndrome were also more likely to be obese (31.2%) and overweight (55.0%) compared with youths without IDD (obese – OR = 3.00, 95% CI = 1.86–4.81; overweight –

**Table 3** Prevalence of secondary conditions by body weight status and disability group

Secondary health condition*	Cognitive disabilities ( <i>n</i> = 322) <sup>†</sup> (autism, intellectual disability, Down syndrome)			Physical disabilities ( <i>n</i> = 139) <sup>†</sup> (cerebral palsy and spina bifida)		
	Overweight ( <i>n</i> = 130) (%)	Healthy weight ( <i>n</i> = 166) (%)	<i>P</i> -value <sup>‡</sup>	Overweight ( <i>n</i> = 28) (%)	Healthy weight ( <i>n</i> = 72) (%)	<i>P</i> -value <sup>‡</sup>
Asthma	24.3	15.5	0.082	28.0	23.5	0.787
High blood pressure	1.9	0.7	0.575	19.0	1.5	0.012 <sup>§</sup>
High blood cholesterol	7.7	0.7	0.005 <sup>§</sup>	9.5	0.0	0.057
Diabetes	6.5	1.4	0.041 <sup>§</sup>	0.0	1.5	1.000
Depression	21.9	15.1	0.184	28.0	14.5	0.219
Fatigue	13.2	8.3	0.216	23.1	9.4	0.097
Gastrointestinal Problems	32.1	33.8	0.792	37.5	35.4	1.000
Joint or bone pain	12.4	12.5	1.000	34.8	34.3	1.000
Sleep apnea	24.3	29.1	0.403	4.0	15.9	0.172
Liver or gallbladder problems	2.8	2.0	0.696	12.5	4.3	0.171
Low self-esteem	17.6	14.5	0.496	12.0	8.8	0.698
Preoccupation with weight	10.1	2.6	0.015 <sup>§</sup>	12.0	1.4	0.055
Early maturation	12.4	4.6	0.036 <sup>§</sup>	21.7	11.4	0.297
Pressure sore	1.8	0.7	0.574	30.8	14.3	0.081

\* No subjects reported having Blount's disease.

<sup>†</sup> Includes adolescents who are underweight.

<sup>‡</sup> *P*-value derived from Fisher's exact test (two-sided).

<sup>§</sup> Significance at  $P \leq 0.05$ .

OR = 3.01, 95% CI = 1.86–4.66). Youths with spina bifida were more likely to be overweight than non-disabled (OR = 4.50, 95% CI = 2.16–9.41).

Table 3 highlights the prevalence of obesity-related health conditions in youths with IDD by body weight status and type of impairment (cognitive vs. physical). Overweight youths with cognitive disability (autism, Down syndrome, ID) reported a significantly higher prevalence of secondary health conditions compared with their healthy weight counterparts on high blood cholesterol (7.7% vs. 0.7%,  $P = 0.005$ ), diabetes (6.5% vs. 1.4%,  $P = 0.041$ ), preoccupation with weight (10.1% vs. 2.6%,  $P = 0.015$ ) and early maturation (12.4% vs. 4.6%,  $P = 0.036$ ). In the physical disability group (CP, spina bifida), overweight youths with IDD had a significantly higher prevalence of high blood pressure compared with their physically disabled counterparts who fell into the healthy weight category (19.0% vs. 1.5%,  $P = 0.012$ ). Across the two physical disability groups, overweight youths tended to show a higher trend for each secondary condition.

In summary, there was a clear tendency towards youths with excess weight exhibiting a higher prevalence of secondary health conditions compared with their counterparts who fell into a healthy weight range.

## Discussion

The results of this study demonstrated that there is a higher prevalence of obesity and obesity-related secondary conditions among youths with IDD, which underscore the substantial health disparities that are present in this population. The findings on higher rates of obesity among youths with IDD are consistent with previous research by Stewart *et al.* (2009), who reported the prevalence of obesity in Scottish youths with ID to be significantly higher for both boys and girls than in the general pediatric population (37% vs. 20% and 36% vs. 15%, respectively). Similarly, Curtin *et al.* (2005) found higher obesity rates among adolescents with autism

spectrum disorders and attention deficit hyperactivity disorder (ADHD).

Our findings on obesity prevalence among youths with IDD cannot be compared with existing data because the sample and sample selection process were markedly different from previously published research in terms of age, gender, definition and type of disability, racial/ethnic background, country, socio-economic status, actual vs. self-report height and weight, and living arrangement. For example, in research conducted by Stewart *et al.* (2009) on 206 Scottish youths with mild to moderate IDD, obesity prevalence was higher than what we reported but the sample selection consisted of youths with autism spectrum disorder, ADHD, developmental delay and mild to moderate learning disabilities (which in the USA is referred to as ID). In one of the most comprehensive secondary data analyses to date on obesity prevalence among youths with disabilities, Bandini *et al.* (2005) reported data on 1128 children with developmental disorders, which included four disability categories: physical limitations, attention deficit disorder, learning disability and those receiving special education or early intervention services. Physical limitations were defined as limited in the ability to crawl, walk, play or run but specific disability groups were not mentioned. Data on overweight/obesity prevalence varied substantially by age and gender. Curtin *et al.* (2005) also examined obesity prevalence among youths with autism spectrum disorder and found that within a small sample of youths who had a similar age as our cohort (12–17 years), the obesity rate was 80%. However, the small sample size ( $n = 42$ ) spread across three age groups (2–5, 6–11, 12–19) limits this finding to a very small number of youths, which is likely the reason why there were no statistically significant differences (in any of the age groups) when the data were compared with a national data set of youths without disability.

Given the substantial differences in methods and population demographics among existing studies examining obesity prevalence in youths with disabilities, we chose to compare our finding to a U. S. national data set on a large cohort of youths without disability (YRBS). Our findings demonstrated a substantially higher rate of overweight and obesity among youths with autism, Down syndrome

and spina bifida. This was particularly troublesome given how much higher these numbers were compared with non-disabled youths. The rate of obesity or overweight in these three disability groups was two to four times higher than non-disabled youths matched on age and gender. Potential explanations may include the possibility that these youths may be less conscious of the health risks associated with their health behaviours and body weight, or may be related to their difficulty with self-monitoring techniques (Susman *et al.* 1987). Certain conditions such as autism are also characterised by altered eating habits or patterns that may make healthy eating behaviours more challenging for this group (Schreck *et al.* 2004).

Obese or overweight youths with IDD have a substantially greater number of obesity-related secondary conditions compared with youths with IDD who fall into a healthy weight category. Among the 14 secondary conditions tracked in our population, youths who were obese or overweight had substantially higher rates in 11 of the 14 conditions. Substantial differences in secondary conditions between obese/overweight youths and healthy weight youths included asthma, high blood pressure, high blood cholesterol, diabetes, depression, fatigue, preoccupation with weight and pressure sores. The multitude of secondary health conditions associated with higher rates of obesity in youths with IDD must be addressed in future research given their severity and potential risk for compromising health in adulthood. It is plausible that if obesity rates were lowered among youths with IDD, secondary conditions and future health care costs would also be lowered.

Our findings that youth with CP had lower BMIs and rates of obesity and overweight compared with non-disabled youths must be interpreted cautiously. Data from two studies show the potential inaccuracy of using BMI with this population. In an earlier study by Bandini *et al.* (1991), BMI levels for youths with CP ( $n = 13$ ) ages 15 to 20 years were lower than what was typically reported for non-disabled youths. Only one subject had a body weight greater than the 50th percentile using height and weight criteria. However, half the subjects had a percent body fat that exceeded the 95th percentile for age, which is a significantly higher rate of obesity compared to classifying youths with CP using BMI. Hurvitz *et al.* (2008) also reported that

ambulatory youths with CP had a high prevalence of obesity (33%) but that in non-ambulatory youths with CP, obesity levels were much lower. Future research should focus on alternative strategies for collecting body composition data on select populations of youths with paralysis/paresis as BMI may not be an accurate indicator of weight-related health status.

### Study limitations

The overrepresentation of families of youths with IDD from a more educated, higher socioeconomic background limits our findings to a predominantly white population with higher educational levels. However, in the small number of minority youths with IDD in our study, obesity rates were higher for this cohort. These data are consistent in minority adult populations where researchers have reported a disproportionately higher rate of obesity among non-Hispanic Blacks and Hispanics with disabilities (Jones & Sinclair 2008). More research is needed on minority youths with disabilities to determine the higher incidence of obesity in this subgroup.

Given the length of the survey, we elected to target only 15 major secondary conditions identified from the literature (U.S. Department of Health and Human Services, 2001; Daniels *et al.* 2005). It is plausible that other secondary conditions (e.g. deconditioning, relationship problems, loneliness, etc.) may have been present in our cohort but were not identified.

While BMI is closely associated with measures of adiposity derived from more sophisticated testing instruments (i.e. Dual X-ray Absorptiometry), among youths with some form of paralysis (i.e. spina bifida) or paresis (i.e. CP), BMI may not be as accurate an estimate of adiposity (Warner *et al.* 1997). Therefore, there is a pressing need to establish cost-effective *alternative* methods to BMI to assess adiposity in youths with physical disabilities.

Use of self-report height and weight data to calculate BMI, as well as using proxy reports of health status, may actually underestimate obesity prevalence. Self-report data often lead to underreporting, and the true prevalence of obesity and related health conditions is likely to be even higher than that reported in this research (Rimmer & Wang

2005). Level of severity was not measured and health conditions experienced by our sample could potentially vary by level of severity.

### Conclusion

The results of this study found substantially higher rates of obesity and obesity-related secondary conditions in certain groups of youths with IDD. Chronic and secondary conditions associated with obesity in youths with IDD have the potential to undermine physical independence and community participation. As youths transition into adulthood may incur substantial health care costs to treat and manage these conditions. Although much attention has focused in recent years on the epidemic of childhood obesity among youths without disabilities (Daniels *et al.* 2009), greater attention must be directed at effective treatment strategies for overweight youths with disabilities (Rimmer *et al.* 2007). Future research must establish a common set of disability definitions and level of severity so that prevalence data can be compared across different studies to better understand the prevalence, antecedents and consequences of obesity among youths with various physical and cognitive disabilities. Similarly, there is a strong need to develop and test interventions that are effective for reducing or managing obesity among youths with disabilities. The *Surgeon General's Report on the Health and Wellness of People with Disabilities* (U.S. Department of Health and Human Services, 2005) emphasises the need to decrease the incidence of obesity and other secondary conditions and improve lifestyle health behaviours among youths with disabilities.

### Acknowledgements

Funding for this study was supported by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research, Grant No. H133A0600066. There are no conflicts of interest by any of the authors on this manuscript.

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Accepted 17 June 2010