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# Total energy expenditure and body composition of children with developmental disabilities

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#### ABSTRACT

Background: Obesity prevalence is increased in children with developmental disabilities, specifically in children with spina bifida and Down syndrome. Energy expenditure, a critical aspect of weight management, has been extensively studied in the typically developing population, but not adequately studied in children with developmental disabilities.

Objective: Determine energy expenditure, fat-free mass and body fat percentile and the impact of these findings on recommended caloric intake in children with spina bifida and Down syndrome.

Methods/Measures: This pilot study included 36 children, 18 with spina bifida, 9 with Down syndrome and 9 typically developing children. Half of the children with spina bifida were non-ambulatory. Doubly labeled water was used to measure energy expenditure and body composition. Descriptive statistics described the sample and MANOVA and ANOVA methods were used to evaluate differences between

Results: Energy expenditure was significantly less for children with spina bifida who primarily used a wheelchair (p = .001) and children with Down syndrome (p = .041) when compared to children without a disability when adjusted for fat-free mass. However, no significant difference was detected in children with spina bifida who ambulated without assistance (p = .072).

Conclusions: Children with spina bifida and Down syndrome have a significantly decreased energy expenditure which directly impacts recommended caloric intake. No significant difference was detected for children with spina bifida who ambulated, although the small sample size of this pilot study may have limited these findings. Validating these results in a larger study is integral to supporting successful weight management of these children.

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#### Introduction

The prevalence of overweight or obesity in children with the developmental disabilities (DD) of spina bifida (SB) and Down syndrome (DS) has been reported as two to four times higher than

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their typically developing (TD) peers. Large national surveys are not available for these populations. Reported estimates of overweight and obesity prevalence are based on convenience samples and may vary based on the measurement methodology performed. Currently, Body Mass Index (BMI) using standing height is commonly employed in clinical environments due to ease of use and cost-effectiveness. However, estimates of overweight or obesity based on BMI in children with certain disabilities are inaccurate.<sup>2</sup> It has been suggested that BMI criteria for obesity be modified for those with SB,<sup>3,4</sup> but population-based studies are

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needed to confirm this approach. One study in youth with DS suggests that BMI accurately identifies excess body fatness in youth  $\geq$ 95th percentile, but less accurately in those between the 85th and 95th percentile.<sup>5</sup>

Excess body weight in children with DD creates the same risk for obesity-related co-morbidities such as cardiovascular disorders and type 2 diabetes as in TD children. Additional obesity-related concerns include decreased mobility and independence with self-care and increased risk of skin breakdown, social isolation, surgical complications and barriers to caregiver's providing daily care. A primary goal for children with DD is to facilitate independence and autonomy as they transition into adulthood. Related risks of obesity create unnecessary barriers to transition and can lead to negative self-management behaviors and poor outcomes.

The basis for the increased prevalence of obesity in children with DS and SB is multifaceted. As in the general population, understanding the balance of energy in (nutrition) and energy out (physical activity and basal metabolism) in children with DS and SB is essential. If energy intake is higher than energy expenditure, weight gain ensues. Confounding these primary issues are multiple factors inherent to the child's underlying condition that diminishes energy expenditure. Children with SB have: a) decreased lean body mass and basal metabolic rate, b) altered or reduced mobility dependent on the level of spinal lesion, and c) overall decreased energy needs, due in part to lower extremity paralysis, when compared with their TD peers. 7,11–13 Children with DS often have reduced levels of physical activity, a lower basal metabolic rate secondary to less lean mass, increased incidence of hypothyroidism, and abnormal response to certain hormones (i.e. prepubertal children with DS have increased leptin that should increase the individual's satiety)<sup>9,14,15</sup> These factors contribute to a lower energy expenditure which results in a reduced caloric need, increasing the risk for excess caloric intake and subsequent weight gain.<sup>11,16</sup> In addition, parents and caregivers often overestimate the amount of energy expended through physical activity contributing to overestimation of energy needs. 17–19 Although not evaluated in parents of children with DD, it is feasible to consider that this may occur in this population also.

Currently, total energy expenditure has been extensively studied in TD children<sup>20–25</sup> but few studies have been reported in children with SB or DS.<sup>11,14,26,27</sup> The knowledge of the child's energy expenditure, and subsequently recommended caloric intake, is an integral component of weight-related research, intervention development and provision of clinical care. The four groups in this study are children with: 1) SB who use wheelchairs (SB-WC), 2) SB who ambulate independently (SB-AMB) 3) DS (DS), or 4) no chronic illness (CON). The aims of this pilot feasibility study were to 1) compare total energy expenditure (TEE), body fat percentiles (BF%) and fat-free mass (FFM) by group, and 2) based on FFM, examine the impact of TEE on the child's energy needs in a sample of 36 children 4–18 years of age.

#### Methods

This study was part of a larger feasibility study that examined the use of various measures to assess energy expenditure in children with SB and DS. Internal Review Board approval was obtained through a Midwestern Children's Hospital.

#### Design/Setting

This cross-sectional pilot study was conducted within the Pediatric Translational Research Unit, a partner of the National Institutes of Health funded Clinical and Translational Science Institute

of Southeast Wisconsin located within a Midwest Children's Hospital.

#### **Participants**

Study participants were recruited through mailings to patients of a local clinic, study advertisements posted in the clinic, social media sites, or SB and DS newsletters. Inclusion criteria were children with a diagnosis of SB, DS or no chronic illness; between 4 and 18 years of age and English speaking. Children who lived or were traveling >200 miles during the test period were excluded as differences in water across geographic regions could potentially impact doubly labeled water (DLW) analysis.<sup>28</sup> The sample was stratified by group, age, and mobility status (Table 1). Prior to participation, consent and assent were obtained.

#### Measures

#### Demographic questionnaire

Child's diagnosis, gender, race, ethnicity, age, method of mobility, family income, and marital status were collected from parent report.

#### Anthropometric assessments

Arm span was measured on all participants and a standing height (cm) was obtained if the child could stand independently. Arm span was obtained by two clinicians using a tape measure with the child sitting in a chair holding arms perpendicular to the floor. The measure was taken across the child's back from the tip of the longest finger to the tip of the opposite longest finger. For height, participants stood erect with their back against the calibrated wall-mounted stadiometer and the headpiece lowered to the crown of their head. Each measure was performed three times and the average used. Body weight (kg) was obtained either by 1) a calibrated digital scale for children who could stand or 2) a wheelchair scale for those who used a wheelchair. In the latter, the child was weighed sitting in the wheelchair which was subsequently weighed alone and subtracted from the original combined participant and wheelchair weight.

#### Body Mass Index

The child's height(s) and weight were used in the BMI calculation (kg/m²). The BMI was plotted on age and gender appropriate Centers for Disease Control (CDC) graphs to determine the BMI percentile and weight status classification. For children able to stand, BMI based on standing height and arm span were calculated. For children unable to stand independently, only arm span was used. Overweight status was identified as BMI  $\geq$  the 85th percentile on the CDC growth charts.  $^{29}$ 

Total energy expenditure, body fat% and fat-free mass

Total energy expenditure is the amount of calories an individual

**Table 1**Recruitment sample.

Age of Child	Spina Bifida who Primarily use Wheelchair	Spina Bifida who Ambulate Without Assistance	Down Syndrome	No Chronic Illness
4-7 years of age	3	3	3	3
8-12 years of age	3	3	3	3
13-18 years of age	3	3	3	3

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