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Commentary

Obesity in children with developmental and/or physical disabilities

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Abstract

Children with developmental or physical disabilities, many of whom face serious health-related conditions, also are affected by the current obesity crisis. Although evidence indicates that children with disabilities have a higher prevalence of obesity than do children without disabilities, little is known of the actual magnitude of the problem in this population. To address this concern, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) held a conference on obesity in children with intellectual, developmental, or physical disabilities, bringing together scientists and practitioners in the fields of obesity and disability to foster collaboration, identify barriers to healthy weight status in populations with disabilities, propose avenues to solutions through research and practice, and develop a research agenda to address the problem. This article describes current knowledge about prevalence of obesity in this population, discusses factors influencing obesity risk, and summarizes recommendations for research presented at the conference. Published by Elsevier Inc.

Keywords: Obesity; Children; Physical disability; Developmental disability; Intellectual disability

The rise of childhood obesity presents a significant public health challenge.[1] Children with disabilities, many of whom face serious health-related conditions related to their primary disability, also are affected by this health crisis. Although evidence indicates higher prevalence of obesity than children without disabilities, little is known of the problem's magnitude or how it varies across disability type.

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To address this concern, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) held a conference in 2010 on obesity in children with intellectual, developmental, or physical disabilities, bringing together scientists and practitioners in fields of obesity and disability to foster collaboration, identify barriers to healthy weight in populations with disabilities, and develop a research agenda. This paper summarizes not previously published discussions that occurred at this meeting, including obesity prevalence in children with disabilities, increased obesity risk in this population, gaps in knowledge, and recommendations for future research.

Obesity prevalence in children with disabilities

National survey data can assess prevalence of obesity among children and youth with disabilities, yielding representative samples that permit calculation of national prevalence estimates. Obesity prevalence in children is estimated based on body mass index (BMI) percentiles greater than or equal to the 95th percentile BMI relative to the CDC 2000 growth charts.[2]

Nationally representative data sources

Three nationally representative data sources provide information on prevalence of obesity among children and youth with disabilities.[3–5] The National Health and Nutrition Examination Survey (NHANES), continuously collected and released every two years, combines physical examinations with in-person or proxy interviews for dietary assessment. Disability categories include: limitations in mobility, vision impairment and hearing impairment. Because NHANES total sample of children ages 5–17 is about 1200 each year, data must be aggregated across multiple years to achieve adequate sample sizes for children with disabilities. NHANES is a reliable measurement of obesity among children with disabilities, but not for monitoring annual changes.

To better examine changes over time, the National Health Interview Survey (NHIS) can be used. NHIS collects parent-reported data through annual in-person household interviews. Since 2008, height and weight data for youth ages 12–17 are publicly available. Its disability classifications include limitations in vision, hearing, remembering, and mobility without special equipment. Though it has a larger sample size than NHANES, data must still be combined for multiple years to achieve a sufficiently robust sample for estimates of obesity prevalence among children with disabilities. NHANES provides direct measurements of heights and weights, while NHIS data are reported by parents, which tend to be less accurate.[6]

The telephone-based National Survey of Children's Health (NSCH), begun in 2003 and conducted every four years, collects information about children from their parents. Analyses of NSCH data reported herein have been done on the survey conducted in 2011. This survey provides data on more than 95,000 children and adolescents ages 0–17. NSCH allows identification of selected health conditions as well as special health care need status through five sets of questions relating to medication use, excessive medical care, ability limitations, receipt of speech/motor therapy, or receipt of behavioral/emotional treatment. The large sample size allows data to be disaggregated to the state level, but NSCH is not conducted annually, and is subject to biases associated with telephone surveys.[7]

Obesity prevalence in children and youth with disabilities

An analysis of 2005–2012 NHANES data covering ages 5–17, 2008–2013 NHIS data covering ages 12–17, and 2011 NSCH data covering ages 10–17 years indicates that children and youth with disabilities or special health care needs demonstrate higher rates of obesity than their peers without disabling conditions or special needs (Fig. 1). As assessed by NHANES, children and youth with disabilities were 35% more likely to be obese than peers without disabilities. NHIS data indicate that children with disabilities were 59% more likely to be obese than those without disabilities; NSCH data showed a 27% greater risk for children with special health care needs.

Disability type and obesity prevalence

All three data sources indicate that children and youth with *mobility limitations* experience higher rates of obesity than children without these limitations. Obesity prevalence for children and youth limited in their ability to crawl,

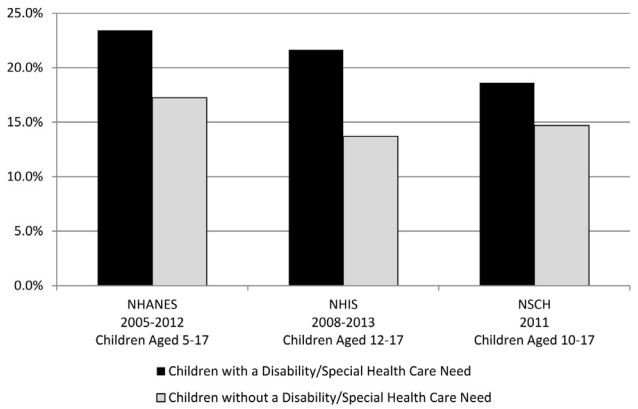

Fig. 1. Prevalence of obesity in children with and without a disability/special health care need using three U.S. national surveys. NHANES: National Health and Nutrition Examination Survey; NHIS: National Health Interview Survey; NSCH: National Survey of Children's Health.

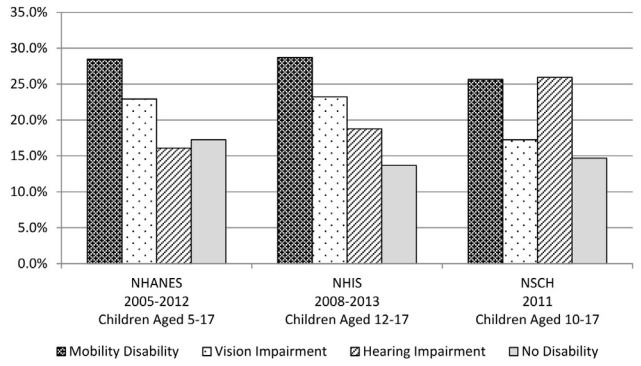

Fig. 2. Prevalence of obesity in children by disability type using three U.S. national surveys. NHANES: National Health and Nutrition Examination Survey; NHIS: National Health Interview Survey; NSCH: National Survey of Children's Health.

walk, run, or play is similar for NHANES and NHIS data (NHANES 28.5%, NHIS 28.7%, NSCH 25.7% using slightly different language). Children with *intellectual or developmental disabilities*[8] have much higher rates of obesity in the NSCH (26.7%) and NHIS (22.5%) than do children without these disabilities (15.2% and 14.4%, respectively), though intellectual and learning disabilities are not clearly identified in NHANES. Children with v*ision limitations* were identified by NHANES and NHIS, and had higher risk of obesity, but a significant association was not present in NSCH data. *Hearing limitations* were not significantly associated with obesity risk on the NHANES and NHIS, but were on the NCSH, perhaps because of NSCH's larger sample size combined with higher obesity rates of youth with hearing impairment[9] (Fig. 2).

Increased obesity risk in children with disabilities

Little is known about individual and environmental determinants of obesity and their relative contributions in children and youth with disabilities. Yet despite limited data and heterogeneity, it is possible to make assumptions about factors responsible for higher levels of obesity among children and youth with disabilities compared with peers without disabilities. One key factor is that children and youth with disabilities, many with limitations that influence access to physical activity and proper nutrition, live in the same obesogenic environment as other children.[10,11] Changes in food supply have resulted in an abundance of foods and beverages high in calories, fats, and added sugars available for consumption at all times of day and wherever children go, with many communities having limited access to affordable healthy food. These high-calorie products are heavily advertised, whereas advertisements for lower-calorie nutritious foods are almost nonexistent.[12] On the other side of the energy balance equation, barriers to physical activity exist within home, school, and community environments. In addition to replacing physical activity, electronic media use can contribute to obesity because it is often accompanied by snacking while exposing children to advertisements for high-calorie, low-nutrient foods and beverages.[12]

Conference participants identified three major areas in which children and youth with disabilities face additional challenges that make achieving and maintaining healthy weight difficult:

Biological, medical, and developmental

- **Feeding and difficulties in swallowing that may limit ability to breastfeed.** Breastfeeding may be especially difficult and not be adequately supported by professionals, negatively altering dietary intake in babies.[12]
- **Metabolic abnormalities disrupting appetite regulation.** In certain conditions, such as Prader–Willi syndrome and hypothalamic abnormalities, appetite regulation is disrupted, resulting in abnormally increased appetite, with dietary management approaches often not sufficient to curb intake.[13]
- **Medications affecting appetite.** Side effects of medications prescribed to address primary disabilities can increase appetite, decrease satiety, or alter metabolism.[14,15]
- **Sensory issues affecting preferences.** Sensory issues such as texture sensitivities can influence food acceptance or refusal and lead to imbalanced or obesogenic diets.[16]
- **Psychiatric or behavioral problems affecting intake.** Comorbidities are common in intellectual disabilities, such as attention deficit hyperactivity disorder and behavioral disorders.[17]
- **Physical limitations restricting physical activity.** Poor motor skills may prevent children with disabilities from moving fully, thereby limiting their ability to expend energy through play and physical activity.[18]

Parent, family, and caregiver

- **Lacking knowledge.** Those caring for children with disabilities may lack knowledge about nutrition, physical activity, and weight and do not provide a nutritious, calorie-balanced diet or opportunities for physical activity. Overfeeding may occur because of a lack of awareness of child's satiety, use of food as a reward or because other health issues faced by a child with disabilities may make weight seem less important.
- **Exhibiting overprotective instincts.** Parents and caregivers may be reluctant to allow a child to be physically active out of concern for injury or social exclusion by peers.[19]

- **Lacking anticipatory guidance from health care professionals.** Providers caring for children with disabilities may regard weight as less important than other health and psychosocial issues, and therefore may not provide proper guidance to parents and the child.[20]

School and community

- **Lack of tailored services.** Services, including adaptations, may not be tailored to the unique needs of a child with a disability, and not be adequately integrated into physical education classes or alternative activities, such as adapted sports.[21]
- **Limiting opportunities for physical activity in school and community settings.** In addition to stigma, children with disabilities experience access barriers such as lack of transportation, inability to use traditional playground and sports equipment, and poorly understood skills supervision and specialized instruction.[22–24]
- **Lacking support systems during transition.** Resources provided through school and family may no longer be available or must be accessed differently. Transitioning to more independent residential settings can alter food-related activities and impact health. For example, transitioning into independent living can increase participation in grocery shopping, meal planning, and cooking[25,26] but more food options can also lead to newly increased personal responsibility to choose independently.[26]

Transition can be successful if nutrition plans are in place before the move, with support and follow up available.[26] When dietetic inputs were not continued through transition, follow-up measures one year after discharge into community found significant numbers of individuals experiencing unintentional weight changes.[27] Adults who moved into more independent settings within the previous year experienced more ''hours of limitation'' due to weight problems than those who had not changed living arrangements.[28]

Gaps in knowledge and recommendations for research

Understanding the scope of the problem

Although obesity can be a symptom associated with genetic conditions, its etiology is less clear in children with disabilities. Increasing knowledge about dietary intake and energy expenditure could help us understand why children with disabilities are disproportionately obese and to inform prevention and treatment interventions.

Dietary intakes. Little work has been done investigating dietary intake of children and youth with disabilities, due in part to challenges in acquiring valid dietary intake data. Children with intellectual or developmental disabilities are typically less able to assist in recalling portion size than are children without disabilities, while children with oral motor problems may be challenged to account for food actually consumed. In addition, the full burden of reporting falls to care providers, and children with disabilities who often have multiple care providers, including parents, teachers, therapists, and health care providers, making collecting accurate dietary data difficult. Limited data suggest that guidelines for energy intake for typically developing children may not be appropriate for children with developmental disabilities. However, data are not yet sufficient to determine recommended energy intakes for children and youth with different types of disabilities.

Dietary research needs

1. Describe factors that influence children's dietary intake, and whether they are the same and of similar magnitude in children with and without disabilities.
2. Determine how food's sensory characteristics influence food preferences of children with disabilities.
3. Identify successful approaches to healthy eating among families of children with disabilities.
4. Calculate recommended levels of energy intake and other nutrients for children and youth with disabilities.

Energy expenditure. Few studies measure daily total energy expenditure or components of daily energy expenditure in children with disabilities. A review of literature on energy expenditure in children and adolescents with disabilities published before 2010 identified only two studies of children with Down syndrome,[29,30] one study of children with spina bifida,[31] and four studies of children with cerebral palsy.[31–34] Even fewer studies examine energy intake and expenditure or include body composition measurements. Other gaps in knowledge exist about how changes in body composition, alterations in growth, and physical disabilities may affect energy and nutrient needs.

A limited number of studies are published on physical activity habits and its influence on overweight and obesity of children with intellectual and developmental disabilities. Available evidence consistently shows children with disabilities have low levels of health-related fitness, which is generally associated with a low level of physical activity.[35–39] Studies on physical activity of children with disabilities suggest low levels among children with autism spectrum disorders,[40,41] cerebral palsy[42,43]; intellectual disabilities[44] including those with Down syndrome,[45] and other disabilities.

Yet studies indicate that children and youth with disabilities can engage in physical activity at a level that produces improvements in motor skills and physical fitness. Exercise programs carried out in community settings have been successful in improving fitness for children with severe autism,[46] intellectual disabilities,[47] cerebral palsy,[48] and

developmental disabilities[49] as well as in after school settings for adolescents with visual impairments.[50]

Energy expenditure research needs

1. Identify unique determinants of physical activity for youth with disabilities through longitudinal studies.
2. Determine validity and reliability of instruments to assess physical activity in children with disabilities.
3. Determine physical activity patterns of specific disability groups through large-scale observational studies that include a comparison/control group.
4. Develop, implement, and test physical activity interventions for specific disability groups through long-term controlled trials that include a significant maintenance phase.
5. Determine dose of physical activity needed to increase energy expenditure sufficiently to prevent and/or treat obesity in specific disability groups.

Developing appropriate obesity measurement

An accurate obesity definition for youth with disabilities is needed in order to evaluate and manage it in clinical settings. This obesity definition should account for race-specific risk thresholds as well as disorder-specific characteristics to the extent that they affect bone mass, muscle mass, and body fat distribution, and take into account consequences of obesity, such as increased risk of cardiovascular conditions, metabolic syndrome, diabetes, and functional problems. Equally important is the need for acceptable validity and reliability, as well as feasibility for both clinical and epidemiologic purposes.

Methodological concerns about the appropriateness of measuring obesity using BMI in children and youth with disabilities include difficulty in accurately measuring height and weight of wheelchair users and others who cannot stand, differences in body composition resulting from certain disabling conditions (e.g., Down syndrome), and the inappropriateness of BMI as a measure of obesity in children with limb loss. In addition, using BMI to assess obesity does not distinguish fat from muscle mass. This limitation may be especially problematic in children who have altered muscle tone or disorders characterized by muscle wasting, such as spinal cord injuries. Inaccuracies in measuring height and weight may be more common in children with disabilities because of anatomical differences, such as scoliosis or contractures, suggesting that standard assessments of BMI, compared to DEXA, hydrodensitometry, and bioelectrical impedance analysis, may not accurately estimate obesity in these children. BMI is also subject to misclassification errors, especially at overweight levels and during puberty, because of rapidly changing height and weight.[51]

CDC growth charts (http://www.cdc.gov/growthcharts/cdc_charts.htm) are currently the only tool available for use in this population. Some specialty growth charts exist, but they are typically based on small sample sizes for certain populations.,[52–56] and not available for other childhood disabilities.

Obesity measurement research needs

1. Assess validity of BMI as a measurement of body fatness in children with physical disabilities or altered body composition.
2. Develop tools that measure adherence with recommended healthy lifestyle behaviors by children and their parents.
3. Conduct observational studies to identify unique risk factors for obesity and evidence-based interventions in children with disabilities to inform potential interventions.
4. Explore clinical utility of measuring resting metabolic rate.

Current knowledge of obesity interventions for school-age children with disabilities

No studies specifically targeting obesity prevention and treatment interventions in children with disabilities have yet been published and children with disabilities are typically not included in research involving children without disabilities. Before developing successful obesity interventions for children with disabilities, an understanding of obesity intervention for children without disabilities is needed that precludes the recommendation of one specific strategy or combination of strategies.[57,58] Reviews of youth obesity intervention offer different conclusions according to population of interest, type of intervention, and review methods.[58–64] Despite diverse findings, a consistent theme is that family-based, lifestyle interventions including behavioral programs targeting diet and physical activity lead to clinically and statistically significant reductions in youth obesity.[58]

Children with disabilities can adhere to short-term, structured exercise and fitness programs, but sustainability of these programs and long-term weight loss are unknown. Although determinants of obesity in children with disabilities are yet to be established, it is reasonable to assume that family-centered lifestyle obesity interventions are also appropriate for youth with disabilities. Several expert groups have provided models or practice guidelines for youth obesity interventions that emphasize health care provider referral to specialists.[65–69] Involvement of family to successful treatment of youth treatment was identified as important across groups.

Recommendations for obesity interventions and children with disabilities research

1. Interventions should center on stakeholder collaboration, including individual, community, family, school, and recreation and medical.

2. Interventions should be designed using CONSORT statement criteria with sufficient statistical power to support findings.[58,70]
3. Interventions should be designed across disabilities using both functional and medical classification as directed by the International Classification of Function.
4. Assessment of unique needs of children with disabilities is necessary to develop interventions that include necessary supports to facilitate success.
5. Obesity determinants and their relative contributions in children with disabilities should be used to guide development of effective interventions.
6. Obesity interventions designed for those without disabilities need to be systematically evaluated, replicated and adapted as needed for children with disabilities. Multidisciplinary and multi-site consortia studying obesity interventions in children with disabilities across geographic and cultural areas should be formed to alleviate the problem of small sample sizes.
7. Community-based participatory research is needed to understand impact of obesity interventions on other life outcomes for children with disabilities such as accessibility, socialization, and play.
8. Interventions must be based on accepted behavior change theories.[58]
9. Outcomes should be based on age and development, while process indicators must be included in study reports to clarify treatment fidelity and adherence.[58]
10. Use of mixed methods research should be promoted.[58]

Conclusion

There is a pressing need for increased collaboration among researchers and clinicians addressing obesity in the general population and those with expertise in populations with disabilities in order to study antecedents that lead to obesity and develop empirically-driven interventions for weight management in this population.

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