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The Healthy Weight Research Network: a research agenda to promote healthy weight among youth with autism spectrum disorder and other developmental disabilities

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Abstract

The Healthy Weight Research Network (HWRN) for children with autism and developmental disabilities (ASD/DD) is an interdisciplinary network with national representation. This paper discusses the modified Delphi procedure that was used to develop the HWRN's research agenda to address the problem of obesity in children with ASD/DD. The five research areas identified for priority included: 1) Family practices around food/mealtimes; 2) Physical activity and sedentary behaviors in relation to weight; 3) Relationship between food patterns, behavior, and weight gain; 4) Program-adaption and delivery; and 5) Influence of school and community-based organizations on food intake and physical activity. The goals and agenda of the HWRN hold promise for making progress toward the prevention and successful treatment of obesity in this population.

Keywords

Autism; Developmental Disabilities; Obesity; Research Network; Prevention

Introduction

A growing body of research suggests that children with developmental disabilities (DD), including those with autism spectrum disorder (ASD), have a prevalence of obesity at least as high, if not higher, than their typically developing peers (1–8). While many of the risk factors for children with ASD/DD are likely the same as for typically developing (TD) children, especially within the context of an obesogenic environment, this population's unique needs and challenges may also render them more susceptible to the adverse effects of typical risk factors, and they may also be vulnerable to additional risk factors not shared by children in the general population. Research on obesity prevention and intervention specific

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to these populations is in its infancy, and we know fairly little about the unique obesity risk factors in this population or their impact on quality of life. As such, obesity in children with ASD/DD is a topic that deserves national attention and, importantly, a focused research agenda. In response, the Healthy Weight Research Network for Children with Autism Spectrum Disorders and Developmental Disabilities (HWRN) was established in 2013 with funding from HRSA's Maternal and Child Health Bureau. The HWRN is a national interdisciplinary network comprising researchers in adaptive physical education, epidemiology, exercise science, psychology, medicine, nutrition, and social work.

Research networks assemble researchers and practitioners from a range of related disciplines to conduct, promote, and disseminate research on complex topics that require an interdisciplinary approach to ensure forward progress (9, 10). Research networks can leverage and use resources in efficient and innovative ways, and can devote resources to projects that are deemed important by a consensus of well-informed constituents. The purpose of this paper is to describe the HWRN and the development of its research agenda.

Methods

The overarching goal of the HWRN is to bring together a national network of researchers to address a consensus-driven research agenda to carry out and support research that will move the field forward in innovative and transformational ways. The HWRN comprises three co-directors, twelve members who represent diverse fields of expertise, and five advisors including family members, self-advocates, and policy leaders. Members span the United States geographically, from Massachusetts to California, and represent most regions of the country including New England (2), southern, (3) mid-Atlantic (3), mid-western (2) and far-western (2) states. Members were selected for their expertise in the field of pediatric obesity and/or autism and developmental disabilities, based on the extant literature, recommendations from contacts, and knowledge on the part of the Network leadership. The HWRN also has an internal working group with a statistician, data analyst, and administrative support personnel.

The three main goals of the HWRN are to: 1) develop and maintain a national interdisciplinary research network that focuses on promoting healthy weight among children with ASD/DD; 2) develop and implement research protocols that fulfill the aims of the network's research agenda; and 3) disseminate network research findings to diverse audiences. Specifically, in order to accelerate research on the problem of obesity in children with ASD/DD, the HWRN conducts secondary data analyses of existing datasets to shed light on the epidemiology of obesity in the population of children with ASD/DD, and also provides funds to support the conduct of pilot research that aligns with the HWRN's mission and research agenda. The HWRN also disseminates information about obesity in youth with ASD/DD through peer-reviewed publications, research briefs, and conference/meeting presentations which are designed to increase awareness of the problem, risk factors, and promising practices for a variety of stakeholders, including researchers, professionals, policy makers, and the community at large. By engaging a national network of interdisciplinary researchers, there is an increased opportunity for the development of collaborative projects that capitalize on the members' shared interests and complementary skills and expertise.

The first major undertaking of the HWRN was to set its research agenda to serve as the foundation for its activities. We used a modified Delphi procedure, an iterative process that gathers data from individuals within their realms of expertise and includes problem definition, discussion, feedback, and revision (11–13). The Delphi procedure was conducted in three rounds: an initial survey of Network members and advisors, a group meeting and brainstorming session, and a final survey where Network members were asked to rank order final themes. The end goal was to identify 3 to 5 priority areas that would frame the HWRN's research agenda.

Results

The first round of the Delphi process was conducted in the fall of 2013 by querying the Network members and advisors via an online survey about their perceptions of research gaps in the field of obesity in youth with developmental disabilities. Respondents were asked to provide text-based written answers to the open-ended question, *What do you see as the research gaps in the effort to prevent or treat obesity in youth with autism and other developmental disabilities? Please list up to five (5) research gaps.* Eighteen participants provided responses which were reviewed by the four members of the Administrative Core, with the goal of identifying common ideas/themes. The types of responses given varied, ranging from general conceptual ideas to specific research questions. Compound responses were split into separate entries and repeated ideas were retained. Initially, responses were divided into 18 themes or categories, which were then reviewed and aggregated into slightly broader themes.

Following the collection and compilation of the initial set of research gaps, an in-person kick-off meeting for the HWRN was convened in Boston, Massachusetts in November 2013. The meeting was designed to establish collaborative relationships among Network members and to continue the process of refining the research agenda. A 90-minute session was devoted to reviewing the themes identified during the first round of the Delphi and further expansion of ideas. Network members were randomly assigned into small groups for each of two 20-minute discussions. Half of the themes were reviewed in Round 1 and the other half were reviewed in Round 2. The entire group then reconvened and suggestions by the groups for new content were offered. The group as a whole participated in discussions which generated new ideas that were incorporated into the existing themes. HWRN members and advisors unable to attend the meeting were contacted via email for their ideas which were incorporated for the next round in the process.

Following the meeting the 3 Network co-directors met face-to-face to consolidate the information gathered. The goal was to retain all of the ideas generated but to condense them into a manageable number and to state them in a consistent manner, i.e., as research questions. Examples of the research questions that corresponded to themes included: *How do children's behavioral responses influence parental behavior around feeding practices? To what extent do school wellness policies address the needs of children with ASD/DD? Do children with ASD/DD have different dietary patterns and eating behaviors than typically developing children that contribute to weight gain (e.g. food selectivity)? What cost-effective*

and sustainable models exist or can be developed to promote healthy weight in children with ASD/DD?

Network members were presented the following nine themes for a final vote via an online survey: 1) Family practices around food/mealtimes; 2) Influence of school and community-based organizations on food intake and physical activity; 3) Relationship between food patterns, behavior, and weight gain; 4) Perceptions and priorities of parents and health professionals around weight status; 5) Determinants of growth and development; 6) Prevalence of obesity and obesity-related comorbidities; 7) Physical activity and sedentary behaviors in relation to weight; 8) Program-adaption and delivery; and 9) Medications and weight status. HWRN Members and Advisors (n=20) ranked what they believed to be the four most important of these themes. Respondents were also provided an open-ended comment field to indicate any themes they felt should be represented but were not listed. Fifteen participants (75%) responded to the survey. Five top themes based on the rankings emerged, which are themes 1, 7, 3, 8, and 2 described above. Themes 3 and 8 received the same number of votes, which constituted a tie, and thus a total of five themes were identified as the final set for the research agenda. These themes were then presented to the HWRN membership for a vote which were unanimously accepted as the official HWRN research agenda.

Discussion

The HWRN research agenda identifies a series of research themes to address the problem of obesity in children with ASD/DD, an issue that has received little attention in the literature to date. The five research themes represent key areas where current research is lacking. For example, further research is needed to determine the association of specific eating patterns and obesity in children with ASD/DD and whether these associations persist throughout adolescence and adulthood. Additionally, ways in which youth can be supported to engage in sufficient amounts of physical activity to prevent or treat obesity warrant further investigation. The dearth of adapted and tailored curricula for youth with ASD/DD may prevent their full participation (14) and may also place burdens on school personnel to adapt and implement programs where time and specific training are lacking (15, 16).

The opportunity to identify and promote a research agenda has the potential to move the field forward to both understand obesity in youth with ASD/DD and inform the development of evidence-based prevention and intervention strategies. The interdisciplinary nature of the Network, its national representation, and the members' expertise enable the HWRN to address an important but as yet understudied problem in an under-served population. As a vibrant, growing Network, we anticipate that the research agenda will be reviewed, reevaluated, and refined as the Network evolves and matures. This will include reaching out to the broader community of researchers, clinicians, professionals, family members, and self-advocates to obtain their input on the relevance of the research agenda and the identification of new topics areas worthy of inclusion. The work of the HWRN holds promise for shedding light on the multifactorial problem of obesity in children with ASD/DD and in making progress toward its prevention and successful treatment.

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Table 1

Final HWRN Research Themes

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1. Family practices around food/mealtimes
 2. Physical activity and sedentary behaviors in relation to weight
 3. Relationship between food patterns, behavior, and weight gain
 4. Program-adaption and delivery
 5. Influence of school and community-based organizations on food intake and physical activity
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