

**NIH Division of Nutrition Research Coordination
National Institutes of Health**

**NIH DNRC Research Conference on Developing a Research Agenda
on Improving the Health of Children with Disabilities**

June 5, 2010

Hilton Baltimore, Baltimore, MD

Note: The summary of the workshop is being presented in this manner to help disseminate the nature of the discussion that took place during the workshop. In doing so, various perspectives are presented about the complexity of the issues surrounding research applicable to individuals with disabilities, but yet emphasize the significant need to obtain additional knowledge to be able to make appropriate recommendations to achieve optimal health for such individuals. A list of all participants and their affiliation and the meeting agenda are provided as an appendix.

The National Institutes of Health (NIH) Division of Nutrition Research Coordination (DNRC) Research Conference on Developing a Research Agenda on Improving the Health of Children with Disabilities was convened on June 5, 2010, at the Hilton Baltimore Hotel in Baltimore, MD. The purpose of the meeting was to obtain information from invited participants about pressing research questions related to increased physical activity and nutritional practices in children with disabilities and the relationship of those factors to improved health status. The meeting was sponsored by the NIH DNRC in collaboration with the American College of Sports Medicine, Slippery Rock University, the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD); National Heart, Lung, and Blood Institute (NHLBI); National Institute for Arthritis and Musculoskeletal and Skin Diseases (NIAMS), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); National Center for Research Resources (NCRR); National Institute of Mental Health (NIMH); National Institute of Nursing Research (NINR); Office of Behavioral and Social Sciences Research (OBSSR); and the DNRC. and the Centers for Disease Control and Prevention (CDC). The meeting was held as part of the program of the Annual Meeting of the American College of Sports Medicine (ACSM).

I. Welcome and Introductory Remarks

Dr. James Whitehead, ACSM Executive Vice President, welcomed participants and expressed enthusiasm for ACSM's collaboration in the meeting. He explained that the ACSM has a significant portfolio of research on lifestyles and persons with disabilities that covers research, practice, and policy issues, and that the results from and deliberations during this meeting would help inform this work. The ACSM has partnered with a number of the organizations linked to this meeting, and looks forward to continuing these relationships and forming new ones. Dr.

Whitehead concluded his remarks by thanking the meeting's organizers for their leadership in convening this group of experts.

II. An Analysis of Evaluation Data From the National "I Can Do It, You Can Do It" Program: Implications for Physical Activity and Nutrition for Children With Disabilities

Dr. Robert Arnhold, National Project Director and Technical Advisor for the "I Can Do It, You Can Do It" (ICDI) Program, which was established in May 2004 by the Department of Health and Human Service's (HHS) Office on Disability, the President's Council on Physical Fitness and The NIH Division of Nutrition Research Coordination. The overarching goal of the ICDI Program is to provide children with disabilities with the knowledge, skills, and abilities to participate in physical activity in the communities in which they live with their parents, siblings, and friends. It establishes a mentoring program, matching healthy adults with children who have disabilities. ICDI increases physical activity, improves nutritional choices, and incorporates the Presidential Active Lifestyle Award. This multi-site, national project involves community-based recreation/fitness facilities, parks, and after-school programs. Current ICDI sites primarily serve children with high-incidence disabilities (e.g., autism, learning disabilities, and intellectual disabilities). There are some limitation to the ICDI Program which include the lack of control and comparison groups, heterogeneous disability groups, participant ages ranging from 6-25 years, the fact that it represents a convenience sample, etc. Strengths are the large size of the database (that continues to grow), 3-year longitudinal data, geographic diversity, etc.

In fall 2008, Slippery Rock University received a 3-year contract from the OS through support from DNRC to expand and evaluate the ICDI Program. Nine subcontracts to support this effort were funded in spring 2009. Technical assistance provided to the subcontractors includes training, annual site visits, and group meetings. As a result of this expansion, there are now nine national ICDI sites; each site conducts three, 8-week rounds of physical activity programs per year (sites are asked to recruit 60 mentors and 60 mentees for each round).

The ICDI mentor evaluation results were presented; mentors were three quarters female and ranged in age from 18-21 years to 46-55 years. Mentors reported that they engaged with their mentees in one-on-one physical activity (walks, biking, swimming, playing ball); talking to each other; playing organized sports together; discussing ways to be more physically active; and looking at nutritional information together.

With regard to the mentee evaluation, almost half of the mentees were in the 11-17 year age range. Roughly 42 percent had autism, 18 percent had mental retardation, and almost 16 percent had a developmental delay. Based on survey results pre- and post-participation in the ICDI Program, the mentees reported improved enjoyment of physical activity, increased number of days with 30 and 60 minutes of physical activity, and a decrease in the number of hours of television watched. The amount of fruit, salad, and other vegetables also increased following participation in the program

The findings were summarized within the context of three overarching group discussion research topics guiding the conference as follows:

- Topic 1 - Assessing the evidence base related to: (1) impact of physical activity; and (2) impact of nutritional biochemistry, physiology, metabolism, and behavior on the health of children with disabilities.
 - If we agree that BMI results are indicative of energy balance , an integration of physical activity and dietary intake , then the physical health of children with disabilities may be improved with increased physical activity.
 - Self-reported physical activity participation once per week for 1 hour is associated with increases in health indicators.
 - We believe that more sophisticated instruments should be designed/used to measure more precise levels of disability and dosage of physical activity.
 - The ICDI model is a holistic approach and does not isolate individual interventions.
 - ICDI is one of the few federally funded projects investigating both physical activity and nutrition behaviors of children with disabilities simultaneously. Preliminary results indicate promise for dual strategies to improve the health of children with disabilities.
 - ICDI provides a family-centered, individualized approach to physical activity and nutrition for children with disabilities and did not separate out strategies of either intervention.

- Topic 2 - The state of the science: Measurement and design issues for research on: (1) physical activity; and (2) nutritional biochemistry, physiology, metabolism, and behavior of children with disabilities.
 - It is obvious that there is a need for increased objective measures of physical activity to triangulate with self-report data already collected.
 - How do we determine the impact of physical activity on children with disabilities?
 - There is an increased need for objective measures of nutrition behaviors to triangulate with self-report of children with disabilities.

- Topic 3 - Evidence and efficacy of treatments and services to improve well-being and lifestyle behaviors among children with disabilities.
 - Based on ICDI observations alone, a strong correlation was observed between leveraging community resources, family behavior change, mentoring, and other incentives for lifestyle change that can improve the health status of children with disabilities.

III. 2008 Physical Activity Guidelines for Americans: Implications for a Research Agenda for Children With Disabilities

Dr. James Rimmer of the University of Illinois at Chicago described the report *2008 Physical Activity Guidelines for Americans*. Dr. Rimmer was a member of the report's Committee; his

role was to examine the evidence base to associate these guidelines with children and adults who have disabilities. In terms of the evidence for youth (age 6-17 years) without disabilities, there was strong evidence correlating physical activity with improvements in cardiorespiratory and muscular fitness, bone health, and cardiovascular and metabolic health biomarkers. There was also strong evidence tying physical activity with favorable body composition. Moderate evidence existed linking physical activity with a decrease in depression symptoms.

The recommended guidelines for youth include 60 minutes or more of physical activity daily. Moderate or vigorous intensity aerobic physical activity is highly recommended for youth. Dr. Rimmer explained that high intensity activities to lay a good foundation in musculoskeletal and cardiorespiratory health is critical at early ages when there is still a relatively low risk of adverse events and a high benefit from high-intensity activity. He presented examples of activities recommended in the guidelines for youth in the areas of aerobic activity (games such as tag, bicycle riding, jumping rope, martial arts); muscle-strengthening activity (games like tug-of-war, rope or tree climbing, sit ups, push ups); and bone-strengthening activity (games like hopscotch, hopping, jumping, sports like gymnastics and basketball). The question is, how do activities apply to youth with disabilities? This issue was not included in the 2008 report.

Dr. Rimmer discussed the dose-response pattern for youth without disabilities, noting that there is good evidence showing significantly improved cardiorespiratory fitness associated with a physical activity dose of 1-3 months of reaching more than 80 percent of maximum heart rate 3-4 times per week for 30-60 minutes at a time. Similarly, there is evidence showing significant improvements with strength (through resistance training) and bone health (through weight-loading activities). There are limited data, however, in health outcomes such as body composition, cardiometabolic health, and mental health. In the report, health outcomes were framed into six categories (cardiorespiratory health, musculoskeletal health, metabolic health, functional health, mental health, and healthy weight) with associated endpoints.

Secondary conditions and their associated endpoints (e.g., depression, pain, social isolation, fatigue) were not included in the report. There are limited data on the effects of physical activity on secondary conditions, but this issue needs to be addressed. Data from a 2004 survey show adults with disabilities have significantly increased rates of a number of conditions, such as chronic pain, sleep problems, extreme fatigue, weight or eating problems, periods of depression, etc than adults without disabilities .

Dr. Rimmer then presented a conceptual model he developed of low physical activity participation on health outcomes among youth with disabilities. The model is geared toward a systematic research center and starts with basic science and extends through public health science. The model starts with disability, and children with disability often have reduced cardiorespiratory health, reduced strength, and reduced balance. Published literature also suggests a dramatic reduction in psychological health (e.g., decreased self efficacy and increased loneliness, depression, and anxiety). Certain mediators also are addressed in the model, such as intrapersonal, interpersonal, and environmental barriers, which if changed, can affect physical and psychological health. The model also includes health outcomes, similar to those detailed in the *2008 Physical Activity Guidelines for Americans* (cardiorespiratory, musculoskeletal, metabolic, functional, mental, healthy weight), as well as secondary conditions (pain, fatigue,

depression, social isolation). As low physical activity increases in dimension, it increases physiological and psychological problems, changes the mediators, and leads to substantial problems with health outcomes and, theoretically, increases the rate, prevalence, and severity of secondary conditions. As participation in physical activities increases, one would expect to see reductions or mitigation of poor health outcomes and secondary outcomes.

There is a discrepancy in self-reported health status. In a 2003 study, 9.5 percent of children with disabilities reported fair/poor health compared with 1.6 percent of children without disabilities. Youth with disabilities have higher bed days and school absences due to illness compared with non-disabled youth. A 2009 study showed a high prevalence of cardiometabolic risk factors among adolescents with intellectual disabilities compared with non-disabled youth; another 2009 paper illustrated poor measures of functional health, mental health, and bodily pain in youth with cerebral palsy compared with non-disabled children. Additional studies have found a high prevalence of mental health symptoms (e.g., being withdrawn, experiencing somatic complaints, feeling anxious or depressed) among children with disabilities.

Through a grant from the U.S. Department of Education/National Institute on Disability and Rehabilitation Research, Dr. Rimmer and colleagues are studying the health and lifestyle of youth with disabilities. The researchers have enrolled 662 children aged 12-18 years; 212 with physical disabilities and 450 with cognitive disabilities. In the study population, the main causes of disability were autism, cerebral palsy, Down syndrome, and intellectual disability. There were higher proportions of disabled youth who were obese or overweight compared with youth who were not disabled (25% of youth with autism were obese, as were 31% of those with down syndrome, 12% with intellectual disability, 4% with cerebral palsy, and 19% with spina bifida—13% of youth in the study who were not disabled were obese). African-American and Hispanic youth with disabilities had a higher prevalence of obesity (25% and 23.3%, respectively) compared to non-disabled African-American and Hispanic youth (18.3% and 16.6%) and 16.7% of disabled Caucasian youth were obese, compared to 10.8% of non-disabled Caucasian youth.

In terms of meeting physical activity guidelines, 9.3 percent of obese/overweight youth with disabilities met the recommendations, 17.1 percent of healthy weight youth with disabilities met the recommendations, and 34.7 percent of youth without disabilities met the recommendations. Almost 60 percent of youths with a physical disability have difficulty finding programs to participate in, or parks where they can engage in physical activity near their home. It may not be possible, or even desirable in some cases, to have 60 minutes of rigorous physical activity for all children with disabilities. Disability groups are understudied with regard to physical activity. For example, in the areas of cardiorespiratory and musculoskeletal health, there are only three randomized controlled trials among children with cerebral palsy, one non-randomized trial among children with intellectual disability, and one pre-post study among children with down syndrome.

Dr. Rimmer and colleagues conducted six systematic reviews on youth with cerebral palsy and one on youth with developmental disabilities. They found that for youth with cerebral palsy, strength and aerobic training could improve cardiorespiratory fitness, muscle strength, walking performance, and general gross motor skills. The methodological quality of the studies reviewed was limited (e.g., small study populations, no control group, no randomization) and most

exercise trials were short term (less than 26 weeks) and did not examine carryover effects. There was little information on outcomes such as metabolic health, mental health, functional health, healthy weight, and secondary conditions.

In terms of federal funding strategies, Dr. Rimmer suggested starting with basic science (e.g., efficacy, safety, dose-response, which mainly falls under the purview of NIH); moving to applied science (e.g., effectiveness, specific disability groups, mostly through the National Institute on Disability and Rehabilitation Research [NIDRR]); and then public health (community-based approaches, cross-disability groups, mostly through CDC). Dr. Rimmer noted that greater synergies could be forged with CDC's Division of Nutrition, Physical Activity, and Obesity (DNPAO), which currently funds 25 states to address problems associated with obesity and other chronic diseases through state-wide efforts. Dr. Rimmer concluded his remarks by commenting that from a broad science perspective, there are two ways to overcome the barriers to physical activity that make it more difficult for youth with disabilities to exercise: enabling the environment and empowering the child and family.

IV. Diet, Nutrition, and Developmental Disabilities: Making the Case

Dr. Starke-Reed presented this talk in place of Dr. Daniel Raiten, NICHD, who was unable to attend the conference.

The working premise or core principle is that nutrition is intimately and inextricably involved in all aspects of human biology. The working definition is: optimal nutritional status (as an endpoint for health) may be defined as the sum total of the processes involved in the taking in and utilization of food substances by which growth, repair, and maintenance of activities of the body as a whole or in any of its parts are accomplished. The processes of nutrition include ingestion, digestion, absorption, metabolism, functional utilization, and nutrient/gene interactions. A bi-directional interaction may exist by which nutritional status can affect or be affected by any or all of these processes. Thus, each needs to be considered in determining the role of diet/nutrition in health and/or disease.

The conceptual framework illustrates the interplay between diet/nutrition, health outcomes, and the environment. In 1977, the National Academy of Sciences identified five areas of functionality affected by nutrition: (1) immuno-competence, (2) reproductive health/function, (3) physical activity/work performance, (4) social/behavioral performance, and (5) cognition. Genetic programming has been proposed as an additional area of functionality affected by nutrition.

In making the case for an intervention in children at a population level, there is historical knowledge on the role of nutrition/nutrients in health development as well as regarding the interaction between nutrition/nutrients and health outcomes (e.g., iron and cognition). There also are conditions of use to be expected (e.g., the normal exposure) and specific questions that might be considered regarding potential interactions between diet/nutrition and potential concomitants (e.g., gender, critical periods, role of environmental exposures, etc.). Two core questions were identified relative to diet versus standard treatment to ameliorate clinical concern: Where do

normal nutrient requirements end and specific condition-related needs begin? What is the role of diet/nutrition in a given developmental disability that would require special consideration above and beyond provision of a well-balanced diet that provides all essential nutrients needed for growth, development, and health?

With regard to a conceptual framework for endpoints, data needs, and generalizability, there are four primary approaches available to determine the impact of nutrition on a given condition: (1) measurement of dietary intake, (2) anthropometry, (3) assessment of biochemical indices/biomarkers of nutrient status, and (4) direct nutritional intervention. It is difficult to draw conclusions or generalize results to the larger population about a given diet/disease relationship based on only one of these approaches in the absence of any other corroborating nutritional data, because:

- In the absence of biochemical indices/biomarkers, intake data alone is insufficient to determine the functional status or effect of nutrients on an individual's health.
- When obesity and malnutrition often occur together, one can no longer rely on anthropometry alone to make a judgment about nutrition and health.
- It is difficult to make any inferences about biochemical indices without knowing an individual's intake.
- Aberrant circulating levels of a particular nutrient may be due to inadequate intake or an inherent biochemical problem associated directly or indirectly with a given condition.
- Without knowing the pre-intervention status of an individual, it is difficult to distinguish between the elimination of a dietary deficiency or the correction of a nutritional anomaly associated with either the disease or an intervention (e.g., the drug used to treat the condition).
- The ability to determine optimal doses for interventions or the potential of indigenous food sources is contingent on an appreciation of the dietary intake, physiological need, nutritional status, and the impact of the condition on the processes of nutrition.

Randomized controlled clinical trials may not necessarily be the gold standard for understanding the role of diet/nutrition in health. There are several limitations associated with intervention-driven clinical trials. For example, it is difficult to generalize results in the absence of controls for various environmental background factors, including the nutritional context. Furthermore, nutrients are not drugs, and subjects are not "naïve" to the treatment; therefore there is the need to obtain some baseline idea of exposure and control. In addition, there is difficulty associated with determining the effective intervention dose, vehicle, timing, or duration in the absence of critical baseline data. A number of questions to be considered when defining a nutrient-disease relationship were presented:

- Does the condition interfere with the child's ability to obtain an adequate/nutritious diet?

- If yes, is it possible that some of the symptoms are in fact secondary to the dietary insufficiency rather than directly related to the primary disorder?
- Does the disorder have metabolic consequences that might directly impact nutritional status?
- Are the stresses associated with normal growth and development greater in those with this condition, and if so, does that put a greater demand on nutritional needs?
- Is there the potential for iatrogenic nutritional problems (e.g., drug/nutrient interactions) associated with this disorder?
- What is the relationship between genetics and nutrient dependency (e.g., vitamin B₆-dependent seizures, inborn errors of metabolism, hemoglobinopathies, etc.)?

Issues to consider when assessing the customary dietary intake of indigenous study populations include: (1) methodologies (e.g., food frequency questionnaires, etc.); (2) seasonal variations in intake; (3) regional differences in food supplies (within and between communities); (4) the availability of food composition data for indigenous foods; and (5) dietary supplement use. Other considerations for research include nutrient-nutrient interactions, nutrient-drug interactions including nutrient interactions with traditional therapies such as herbal/botanical remedies, and physiological state/developmental factors.

The goal is to develop evidence-based programs to address the impact of nutrition. For population-based efforts in this regard, surveillance data are needed to document the presence of single or multiple nutritional problems (e.g., single or multiple micronutrient deficiency or dual burden of over- and under-nutrition) in a given setting. Sensitive and specific biomarkers of both nutrient status and functional changes associated with nutritional status also are needed. Additionally, there is a need to assess dietary intake, including use of the full range of possible dietary supplements with specific reference to the ability to provide adequate amounts of the micronutrients via the normal food supply, fortification, changes in dietary pattern, etc. Finally, there is the need to assess social/behavioral factors that impact on people's decisions about food and the use of interventions including complementary and alternative medicine as well as dietary supplements.

Developing evidence-based micronutrient interventions likely will require partnerships that reflect: (1) good will and a willingness to collaborate; (2) multidisciplinary collaborations involving nutritional, behavioral, psychiatric, and clinical/neurophysiological scientists; (3) training and support for building the capacity for sustainable evidence-based research practices; and (4) standardized protocols and methodologies.

V. Overview of NIH IC Interest in Research on Improving the Health of Children With Disabilities

National Institute of Arthritis and Musculoskeletal and Skin Diseases

Dr. Amanda Boyce discussed that NIAMS supports research into the causes, treatments, and prevention of arthritis and musculoskeletal and skin diseases. Childhood diseases and conditions within the NIAMS mission include osteogenesis imperfecta, muscular dystrophy, cachexia, juvenile rheumatic diseases (e.g., juvenile idiopathic arthritis, juvenile lupus, and scleroderma), genodermatoses, and chronic pain.

NIAMS, on behalf of the NIH, leads the Patient Reported Outcomes Measurement Information System (PROMIS) Initiative. This large, trans-NIH initiative will: (1) develop and test a large item bank measuring patient-reported outcomes; (2) create a computerized adaptive testing system that will allow for efficient, psychometrically robust assessment of patient reported outcomes for a wide range of chronic disease outcome research; and (3) create a publicly available system that can be added to and modified periodically and that will allow clinical researchers access to a common item repository. A series of pediatric pain scales are being developed as part of this project. The Institute has a few active grants examining exercise in pediatric populations with rheumatic diseases.

Eunice Kennedy Shriver National Institute of Child Health and Human Development

Dr. Nitkin stated the mission of the NICHD is to assure that every individual us born healthy and wanted, that women suffer no adverse consequences from the reproductive process, and that all children have the opportunity to fulfill their potential for a healthy and productive life unhampered by disease or disability. In pursuit of this mission, the Institute conducts and supports laboratory, clinical, and epidemiological research on the reproductive, neurobiologic, developmental, and behavioral processes that determine and maintain the health of children, adults, families, and populations. He listed a number of NICHD mission areas of emphasis, including nutrition and development. Three NICHD Branches/Centers are particularly relevant to the subject of this conference:

- Intellectual and Developmental Disabilities (IDD) Branch. The IDD Branch sponsors research and research training aimed at preventing and ameliorating intellectual and related developmental disabilities. The program supports biomedical, biobehavioral, behavioral, and translational research in etiology, pathophysiology, screening, prevention, treatment, and epidemiology.
- Endocrinology Nutrition and Growth (ENG) Branch. The ENG Branch provides the NICHD with a focus for research and research training in nutritional science, childhood antecedents of adult disease, developmental endocrinology, developmental neuroendocrinology, and physical growth and body composition, including bone health and obesity.
- National Center for Medical Rehabilitation Research (NCMRR). The NCMRR aims to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of people with disabilities. A primary goal of Center-supported research is to bring the health-related problems of people with disabilities to the attention of the best scientists in order to capitalize on the myriad advances occurring in the biological, behavioral, and engineering sciences.

In response to a question about whether the NCMRR has any activities related to more of a public health perspective rather than a basic science perspective, the NCMRR does have work on the public health side of the spectrum. Its research portfolio meshes well with that of other agencies, including the NIDRR, particularly in areas such as health services research, disability research, and functionality research. The NCMRR funds studies on family issues and barriers to support.

National Heart, Lung, and Blood Institute

Dr. Ershow presented a slide showing the Institute's organization chart and described NHLBI interests in improving the health of children with disabilities, noting that one common aspect of disabilities is limitations in oxygen transport or exercise adaptation. Relevant NHLBI program offices include the Division of Cardiovascular Sciences, Division of Blood Diseases and Resources, Division of Lung Diseases, National Center for Sleep Disorders and Research, and Division for the Application of Research Discoveries. She referred participants to the WeCan Program for Children, which includes a physical activity and nutrition program applicable for children with disabilities (similar to the ICDI Program). For more information, visit <http://www.nhlbi.nih.gov/health/public/heart/obesity/wecan/>.

NHLBI's Division of Cardiovascular Science has a large portfolio of basic, clinical, and population science research. Program interests relative to etiology, prevention, and treatment include the mechanistic roles of diet, nutritional status, metabolism, and exercise as well as behavioral strategies and environmental changes to abate cardiovascular disease risk. Congenital heart defects is another area of interest, with children surviving longer and now reaching adulthood (and facing cardiovascular disease risk) and consideration of maternal risk factors. NHLBI has a Working Group on Obesity and Other Cardiovascular Risk Factors in Children With Congenital Heart Disease.

The Institute's Division of Lung Diseases focuses on asthma, cystic fibrosis, pulmonary fibrosis, and pediatric pulmonary disease. The National Center for Sleep Disorders and Research addresses issues related to sleep disordered breathing in overweight and obese individuals, the role of lifestyle factors in normal and disordered sleep, and research needed on sleep disordered breathing in handicapping conditions. The NHLBI Division of Blood Diseases and Resources works on genetic anemias, transplantation biology, and research needed on nutrient needs, exercise physiology, dietary supplements, and pain management.

Dr. Pratt, also of NHLBI, noted that the Institute has some childhood obesity-related programs, including some associated with the National Collaborative on Childhood Obesity Research, a joint effort of four of the nation's leading research funders – the **Centers for Disease Control and Prevention**, (CDC), the **National Institutes of Health** (NIH), the **Robert Wood Johnson Foundation** (RWJF) and the **United States Department of Agriculture** (USDA) – to address the problem of childhood obesity in America.. She noted that although the Institute does not have one program dedicated to disability, many of its ongoing activities incorporate children with disabilities. The impetus is on researchers to design studies and work with NIH Program

Officers to find appropriate and available funding mechanisms (about 70% of NIH-supported research is investigator initiated)
National Center for Research Resources

Dr. Rosemary Filart of the NCRR noted that the Center's goal is accelerating research from basic discovery to improved patient care. From her 2009 portfolio review of NCRR awards, she identified research programs that are generating opportunities for disability and health research. These programs include the Clinical and Translational Science Awards (CTSA) Consortium, General Clinical Research Centers (GCRC), Science Education Partnership Award (SEPA), and Small Business Innovation Research/Small Business Technology Transfer. Other programs that do not currently have anything specific on children with disabilities but could be resources for future work include the Human Tissue and Organ Resource (HTOR) for Research, Institutional Development Award (IdEA), and the Research Centers in Minority Institutions (RCMI).

Office of Behavioral and Social Sciences Research

Dr. Nilsen explained that the OBSSR is housed within the NIH Office of the Director. Unlike NIH Institutes, the OBSSR does not fund grants, although it does co-support them. OBSSR is a Congressionally mandated Office; its mission is to: (1) increase the scope of and support for behavioral and social sciences research, (2) inform NIH leadership and the community about behavioral and social sciences research, (3) represent the NIH to the behavioral and social sciences research community, and (4) disseminate behavioral and social sciences research information to the NIH and the public.

OBSSR's vision is to mobilize the biomedical, behavioral, and social science research communities as partners to solve the most pressing health challenges faced by society, including improving the health of children with disabilities. Dr. Nilsen explained that OBSSR programmatic directions to achieve this vision include:

- Promoting the next generation of basic science. OBSSR will support and facilitate the next generation of basic behavioral and social science research informed by breakthroughs in complementary areas such as genetics, informatics, and multilevel analyses.
- Fostering interdisciplinary research. The Office will facilitate collaborative research across the full range of disciplines and stakeholders necessary to fully elucidate the complex determinants of health and health systems challenges. Such collaborations will yield new conceptual frameworks, methods, measures, and technologies that will speed the improvement of population health.
- Focusing on systems-thinking approaches to health. OBSSR will stimulate research that integrates multiple levels of analysis—from cells to behavior to society—required to understand the ways in which individual and contextual factors interact to determine health status.
- Facilitating problem-based research. The OBSSR will work with its NIH partners to identify problems in population health where behavioral and social scientists, biomedical researchers,

practitioners, and health services decision makers can work together to develop prevention, treatment, and policy interventions and to accelerate their translation and adoption.

In concluding her remarks, Dr. Nilsen explained that almost 10 percent of NIH's budget (\$3.06 billion in 2007) goes to behavioral and social sciences research.

National Institute of Mental Health

Dr. Avenilla noted that NIMH's mission is to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery, and cure. The Institute's strategic plan focuses on: (1) promoting discovery in the brain and behavioral sciences to fuel research on the causes of mental disorders; (2) charting mental illness trajectories to determine when, where, and how to intervene; (3) developing new and better interventions that incorporate the diverse needs and circumstances of people with mental illnesses; and (4) strengthening the public health impact of NIMH-supported research. He noted that issues related to obesity and nutrition can be a cause or consequence of mental disorders.

Dr. Avenilla explained that NIMH's Division of Developmental Translation Research supports programs of research and research training with the ultimate goal of preventing and curing mental disorders that originate in childhood and adolescence. This Division's mission is to translate knowledge from basic science to discover the developmental origins of mental disorders and effect their prevention and cure, including:

- Neurobehavioral mechanisms responsible for the development of psychopathology
- Trajectories of risk/illness based on the combined and interactive influences of genetics, brain development, environment, and experience
- Design and testing of innovative and personalized preventive and treatment interventions.

NIMH supports training and career development grants (K awards). Dr. Avenilla emphasized the importance of collaboration among investigators interested in obesity or nutrition research.

Integrated discussion on NIH interests

NIH ICs stand ready to help researchers with proposal-related questions and can answer questions about the study section process and how to frame research questions. Many researchers are losing out by not contacting and taking advantage of NIH Program Officers who are valuable resources and serve as advocates at the NIH for this research

Dr. Gloria Krahn of CDC suggested that future Requests for Applications (RFAs) include specific language on children with disabilities. Dr. Librett added that children with disabilities are arguably the most vulnerable population when it comes to obesity. Many RFAs are for trials of pharmacological or device interventions; physical activity as an intervention does not fit into either category.

Dr. Ershow echoed earlier comments on the importance of working with NIH Program Officers to promote research on physical activity/nutrition in children with disabilities. She suggested that researchers could send Program Officers a short outline of research concepts to get feedback on the most appropriate funding mechanism. If the project is not appropriate or timely for NIH funding, Program Officers can refer researchers to other funding agencies such as CDC or the National Science Foundation (NSF).

Dr. Roberta Carlin of the American Association on Health and Disability agreed that there is validity in integrating the term “disability” into future RFAs. The State of New York has begun to include disability in every RFA released by the state health department. Not only does this improve the chances for funding this type of research, it also serves to educate the reviewers. Dr. Rimmer emphasized the need to educate reviewers, commenting that study sections generally do not understand the science of disability. Dr. Starke-Reed reminded participants that study sections are always looking for members, and those who are experts in disability would provide valuable expertise to the process.

Dr. Ershow noted that the NIH has a program at every IC for noncompeting supplements to existing grants for the purpose of bringing in a greater diversity of experts being trained in science and research. Traditionally, the bulk of these supplements have been awarded to minority candidates; however, young investigators with potential and an interest in science who have disabilities but who show promise to become researchers in the long term can also be eligible for these supplements. Different funding mechanisms exist for previously funded researchers who have experienced an accident or ailment and are disabled but can continue their research in some manner.

VI. Group Discussion Topic 1: Assessing the Evidence Base

The rest of the conference was dedicated to addressing three overarching topics and associated guiding questions through group discussion.

- Assessing the evidence base related to: (1) impact of physical activity; and (2) impact of nutritional biochemistry, physiology, metabolism, and behavior on the health of children with disabilities. Implications for different types of disabling conditions, examine strength of evidence, and identify research gaps.

Dr. Pratt chaired this discussion.

Question 1: Does increased physical activity improve the physical and mental health of children with disabilities?

Dr. Pratt asked to revisit one of the topics in Dr. Rimmer’s presentation, specifically his comments on gaps in the literature. Dr. Rimmer explained that a cursory review of the literature over the last 12 years broke out identified studies by health outcomes recommended by the *2008 Physical Activity Guidelines for Americans* report, focusing on intellectual disability, down syndrome, and cerebral palsy. Dr. Pratt noted the lack of studies in these categories and asked

the group what the impact of additional work in these areas would have on the activity and nutrition fields.

Dr. Librett asked about identifying categories or disabilities in which it is possible to extrapolate using existing evidence. If one knows that the evidence is unequivocal for improved cardiorespiratory health associated with physical activity in the general population, what does it mean for the disabled population? He noted that there are some health outcomes that likely cannot be extrapolated to disabilities. In fact, in some cases, physical activity may be a contraindication. Dr. Pitetti asked about the current recommendation for children to receive 60 minutes of moderate to vigorous daily physical activity and whether the group agrees with this recommendation—if so, does it apply to children to all types of disabilities? Dr. Pratt noted that this topic will be covered later in the session.

Dr. Giannini explained that in the past, physical activity recommendations for children with cerebral palsy would have been the same for those who have traumatic brain injury or stroke. This may not be the case anymore; additional data are needed from large trials. Affecting change at the national level requires data; it cannot be done based on an assumption. It was noted that a qualifying criterion of the ICDI Program was that individuals participate in 60 minutes of daily physical activity to qualify for the Presidential Active Lifestyle Award.

When asked about a working definition of the term “disability,” Dr. Pratt explained that a person has a disability if she or he has a chronic physical or mental impairment that substantially limits a major life activity. Dr. Frey noted that there are some published limited intervention studies on children with disabilities indicating that they can benefit from physical activity, even among muscular dystrophy populations.

Dr. Pratt summarized discussion on Question 1 by noting that there is some evidence that physical activity has a positive effect on children with disabilities, but these data are limited and are not specific for different types of disabilities. Furthermore, there are little or no data on secondary conditions.

Question 2: What dose of increased physical activity is required for improving the physical and mental health of children with disability? Do dosages differ by type and severity of disability?

Dr. Rimmer noted that in children, the pattern of physical activity typically occurs throughout the day—how does this pattern translate into a child who has a physical or cognitive disability? There is a need to have children with disabilities involved and playing with their peers, and sustaining physical activity to the point where it becomes a behavior is important. Dr. Rimmer suggested that access, participation, and sustainability be a significant focus in addition to the health aspects. Dr. Nitkin agreed, adding that physical activity also has a much broader effect on children in addition to the short-term, immediate health effects. Physical activity enables children and improves their psyche. He emphasized the need to recognize that physical activity is being delivered to this population with a broader context than just the benefit of the immediate exercise.

Dr. Krahn noted that recent findings suggest that physical activity among pre-pubertal children improves their chances of not becoming obese later in life. Dr. Arnhold commented that the President's Council on Physical Fitness has recognized that not all children with disabilities have the same functional levels. For some disabilities, the Council recommends 30 minutes of physical activity rather than 60 minutes, depending on the needs of the individual child. Dr. Pratt noted that the 60 minute per day recommendation does not imply that all 60 minutes of physical activity need to take place at one time; physical activity can be broken up into smaller periods spread throughout the day.

Dr. Pitetti asked about measuring the dose of physical activity, noting that a reliable, valid, and feasible method of measuring physical activity in children. Three existing options include heart rate monitors, accelerometers, and pedometers. The least inexpensive, most feasible, and most reliable method is the pedometer. Dr. Turk noted that there are no data on whether the dose of physical activity should be the same or depend on the severity of impairment. Most of the data on physical activity among children with disabilities have been on those with mild impairment; there is a gap in the literature on the affects of physical activity among severely disabled children. Dr. Marge commented that too much physical activity may be dangerous in some of these populations.

Dr. Pratt summarized the discussion on Question 2 by explaining that with respect to the 60-minute recommendation, more research is needed in terms of application to children with disabilities.

Question 3: Do specific nutritional factors of biochemistry, physiology, metabolism, and behavior improve the physical and mental health of children with disabilities?

When asked what was meant by "specific nutritional factors," Dr. Pratt explained that these may include caloric intake and similar measures. Dr. Turk asked about how one would implement this type of approach among children, and likely their families. Is there an understanding of which of these implementation strategies is effective?

Dr. Frey commented that anecdotally, she has seen that food is used a great deal as a reward, both by families and by the education system, in the population of disabled children. Many times, the attitude that "they get little joy out of life, let them eat what they want" is taken, and children are placated with poor nutrition despite educating parents and educators. Dr. Librett suggested that it would be interesting to study the interaction between medications and the diet among children with disabilities. Similarly, an interesting study would be one that assumes that good nutritional practice is fundamental regardless of whether a child is disabled, and examining the additional effect of physical activity.

Dr. Rimmer suggested that this question could be rephrased as "do the current nutritional factors observed in children with disabilities affect their biochemistry, physiology, metabolism, and behavior?" Do the current practices of families (e.g., feeding behaviors) affect the health of children with disabilities from a biochemical standpoint? Do the medications that are used in significant populations of children with disabilities affect the biochemistry or physiology? The large majority of children with disabilities are taking at least one medication regularly. Dr. Pratt

suggested that if one were to pursue these questions, one of the first tasks would be to assess the current practices of children with disabilities in terms of their eating behaviors.

Dr. Cooper commented that if a child has a disability, current thinking is that he or she is affected more by a lack of physical activity than a non-disabled child. He noted the need to communicate differently with children who have different levels of mental disability. He asked whether the barriers to physical activity in the non-disabled population are exacerbated in the disabled population. Dr. Marge said that a certain metabolic problem has been identified in children with down syndrome, and asked whether factors such as this could explain obesity or other outcomes in children with disabilities. Dr. Layla Esposito, NICHD, commented that these types of questions will be addressed at a future NICHD meeting on obesity and children with disabilities and offered to share the findings from this meeting with the group.

Dr. Krahn suggested re-examining Question 3 in terms of the core issues underlying it and indicated that it may be helpful to reverse Question 3 in a sense to try to understand the current nutritional practices and physical activity practices by disability. How does this information, via biochemistry, physiology, or metabolism, feed into a series of core health outcomes? This approach may help identify gaps in populations and identify increased vulnerabilities (e.g., family issues, environmental access to participation issues, etc.). Dr. Pratt added that age categories, in addition to disability categories, would need to be considered.

Question 4: What is the evidence for the need to increase physical activity and good nutrition practice strategies simultaneously in order to improve the health of children with disabilities?

Dr. Frey reminded participants that there are baseline studies showing that children with disabilities are less physically active across a variety of disabilities. In general, these children need to increase their amount of physical activity and are not meeting current recommendations for non-disabled children; however, the population of disabled children needs guidelines that are appropriate for them. Dr. Pratt agreed, citing Dr. Rimmer's earlier comments indicating that more research is needed in this area. Dr. Rimmer noted that the gold standard of physical activity measurement is the Youth Risk Behavior Survey (YRBS), which does not report data on youth with disabilities. It is difficult to obtain prevalence information without including children with disabilities in the YRBS (the State of North Carolina has developed a module to the YRBS that includes children with disabilities). Dr. Rimmer also pointed out that the definition of the term disability is not consistent across disciplines and across the published literature; this is particularly problematic with regard to surveillance data (both the need for additional surveillance data and the need for additional clarity and consistency in existing surveillance data).

In response to a question about what constitutes physical activity and how it is measured, Dr. Pitetti responded that physical activity, if measured by heart rate, is the heart rate level when the child is active. If measured by accelerometer, it is the number of counts per minute that falls within the threshold for being active. If measured by pedometer, it is the duration that the number of steps per minute falls within the threshold of moderate to rigorous activity. In these types of studies, researchers are trying to introduce the best environment that will provide children with disabilities the opportunity to engage in moderate to vigorous physical activity. He

reminded attendees that children like to have fun, not necessarily to exercise. Based on pedometer readings, it is possible to select programs that lead to children being more physically active. Dr. Cooper commented that the approaches used for healthy children and adults may not work for the disabled population—this is an area ripe for future research endeavors. For example, the relationship between heart rate and physical activity may not be the same in the disabled population as it is in the non-disabled population.

Dr. Turk pointed to the need to reliably collect data and focus equally on nutrition and physical activity, determine the intervention and the dose, and be clear about what is being measured. Dr. David Gray, Washington University School of Medicine, emphasized the need to consider the importance of environmental factors. In his experience, when the costs associated with transporting people to a gym are covered, it is more effective than nutrition or medication-type interventions. Dr. Pratt agreed, noting that previous work she was involved in identified transportation to be a significant barrier to having children go to a community recreation center to participate in physical activities.

Dr. Gray suggested that children with disabilities should be grouped by function. He commented that it is desirable to know how to achieve healthy behaviors and increased participation in activities that are important to this population as opposed to focusing on secondary conditions. A different type of study design is required for this type of research. He also noted that this effort would require multi-institute funding and collaboration in a community setting (a basic science component would be needed as well). Dr. Pratt agreed with the need for multi-institute participation in addressing these research needs. Dr. Gray commented that a multi-institute funded effort and a study section specific to children with disabilities may be beneficial to get these types of studies funded and carried out.

Question 5: What is the evidence that both approaches (physical activity and nutrition) are needed to reduce overweight and obesity in children with disabilities?

Dr. Frey noted that this is a complicated question, and this issue is still a challenge in the non-disabled population. She suggested rephrasing the question to reflect the need to determine the relative contribution of physical activity versus nutrition (or vice-versa). This question also assumes that all children with disabilities are overweight or obese—a more appropriate term may be “unhealthy weight.”

Dr. Krahn noted that CDC is funding a small group to address this issue, trying to look at different disability types by risk for overweight/obesity. The groups most at risk appear to be those with intellectual disabilities or who have mobility limitations (or a combination of both). Dr. White commented that often, the majority of measures are collected in the clinical setting and that more work is needed in the area of community-based trials. If people gain physical health, what does it do in terms of their level of participation in the community? Dr. Cooper cautioned against focusing solely on obesity and emphasized that both nutrition and physical activity approaches are needed to determine optimal body composition. Dr. Pratt added that in addition to environmental factors, policy changes need to be included in the discussion.

Dr. Rimmer discussed the differences between clinically defined physical activity and nutrition compared with community-based definitions of physical activity and nutrition. There are important questions to answer among the population of children with disabilities from both the clinical and community perspectives.

VII. Group Discussion Topic 2: State of the Science

This session was chaired by Drs. Filart, Boyce, and Quatrano.

- The state of the science: Measurement and design issues for research on: (1) physical activity; and (2) nutritional biochemistry, physiology, metabolism, and behavior of children with disabilities. Identify the strength of evidence and research gaps.

Dr. Filart asked the group if discussions can be framed around “physical activity” rather than just “exercise” in order to encompass a broader range of physical activities among children with disabilities. The group was in agreement.

Question 1: What are the best measures for determining the impact of increased physical activity in children with disabilities?

Dr. Quatrano suggested that to help frame this question, it is important to consider the model perspective and outcomes. He asked if any participant had a perspective on models and/or longitudinal or cross-sectional research. Dr. Gray commented that randomized trials might not be feasible for this type of work, because it is difficult to disguise what is being done to the study population. Randomized trials are possible in these populations, but should not be the gold standard. Longitudinal repeated design studies over several years are missing in this field, and there is a need to give consideration to funding longer-term studies. A “science of replication” is needed, so that researchers take a new approach to interventions and replicate what is done in the clinical setting in the classroom, playground, and other areas.

Dr. Turk also voiced support for longitudinal studies. In cerebral palsy in particular, this research is severely lacking to help researchers gain a better sense of the natural history of these disorders. Dr. Dallas Jackson, Slippery Rock University, asked how feasible it would be to have a multiple baseline research design compete successfully through scientific review. Dr. Cooper commented that study section members reviewing research on a physical activity intervention likely would want to see evidence of change in some of the data (e.g., a change in some physiologic variable such as muscle mass or strength). In attempting to determine the impact of increased physical activity, any study should have some clear measures. Dr. Filart expounded, noting the need to determine the different physical activities for different persons with impairments of different levels of participation and degrees of community integration. For example, studies would need to be stratified to ask questions involving children with cerebral palsy to participate in school-based exercise, to compete in organized sports, or to require modified activities of daily living intervention?

Dr. Ershow commented that overseas, some countries have organized health care systems with long-term followup registries that might be able to deliver data that are much more difficult to obtain in the United States.

Dr. Heidi Stanish, University of Massachusetts, noted that the child's age and the nature/severity of the disability guide the answers to the questions being discussed at this conference. For a pre-school aged child, physiological markers may not be as important as developing the motor skills so that child can play with his or her friends. Consideration must be given to the population being studied, and the intervention should be designed around this population.

Dr. Gray explained that one limiting factor associated with measuring physiological factors in the community setting is that many participants will not agree to provide blood or saliva samples. Dr. Cooper agreed that it can be difficult to obtain these physiological measures, but added that it can be done. He and his colleagues conducted a study in low socioeconomic schools—the researchers received permission to draw blood in sixth and eighth grade students. If one finds an effect on quality of life and determines that a child is more engaged because he or she can do more, and this is backed up by physiological data, that message translates into policy more readily than a program that simply notes that a child is happier due to some intervention. Dr. Ershow explained that issues associated with effective implementation at the personal and community level are different; community-based research requires a different research model, one that considers barriers, economic factors, motivational factors, etc.

Dr. Frey commented that it would be helpful to identify and suggest ways to overcome the challenges associated with conducting community-based studies on people with disabilities. One challenge is enrolling a high enough study population so that the research is sufficiently powered. In large part, the problems encountered in carrying out community-based research are not faced by clinical research. Dr. White reminded participants that the end user of the intervention must be considered—if a procedure becomes too complicated, it will negatively affect recruitment, participation, and retention in the study.

Question 2: What are the best measures for determining the impact of nutritional practices on improving the health of children with disabilities?

Dr. Krahn noted the need to begin agreeing on common measures (e.g., 24-hour diaries, etc.); without common measures, it is difficult to build a knowledge base. Dr. Cooper agreed, adding that there is a need to be as minimally invasive as possible. Part of the research agenda could include supporting or developing technologies that are minimally invasive to provide data without risking the loss of participation. He added that biomedical engineers should be represented at the table; many biomedical engineers are involved in rehabilitation methodologies that could benefit this field. Dr. Rimmer emphasized the need to build off existing technologies and pointed out that there are a number of effective nutritional measures available. Including an expert with knowledge of these measures who is in a position to ask questions about their use in disabled populations would be beneficial.

Dr. Turk commented that multicenter study designs are needed to address the low recruitment rates seen in many community-based studies and studies of children with disabilities. Dr.

Rimmer agreed and emphasized the need for federal representatives to consider how best to establish multicenter-funded studies across the NIH and across other federal agencies.

Dr. Rimmer asked if there was a way for the NIH to build some infrastructure under newly identified areas of research need, within the context of the discussions held during this conference and where the field of research on nutrition and physical activity in children with disabilities is moving. Dr. Nitkin explained that researchers need to take an opportunistic attitude. For example, if there is a change in the local school district's policy related to physical education or integrating children with disabilities, it presents the opportunity to ask questions and frame issues.

Question 3: Who will conduct the research? What are the implications for training additional researchers to address these health-related issues for children with disabilities?

Dr. Librett asked about the possibility of creating a study section on a particular disability. Dr. Nitkin explained that there are already nutrition study sections in existence; the topic of nutrition and disability is likely too narrow to warrant an individual study section. Dr. Ershow agreed, adding that there needs to be enough research in an area for there to be at least about 100 applications per review cycle to warrant a specific study section (study sections do have the option of bringing in outside expertise in certain circumstances).

Dr. Pratt noted that the NIH can issue a Program Announcement with Review (PAR) on specific topics; in these cases, special emphasis panels comprised of experts in this subject area are convened to review the PAR applications. In response to questions about whether the NIH should have a study section focused on disability or rehabilitation, Dr. Nitkin explained that the NIH tends to focus on the intervention rather than the disability in these cases. There is a need to explain that children with disabilities have special needs and there are special research opportunities. Dr. Rimmer added that proposals are judged against each other, and those with the greatest impact on society get funded. This makes it particularly challenging in this field, because studies on children with disabilities generally are viewed as having less of an overall impact than studies on non-disabled children.

Dr. Ershow commented that it may be that investigators in this area need to learn more about how to conduct robust research with complex social models. This issue could be a suitable topic for a conference grant application or a T15 proposal, which includes training.

Dr. Stanish asked whether those who study special populations in this field are seen as physical activity researchers or researchers on children with disabilities. In a sense, it may be the case that researchers in this area are trying to do too much and "wear too many hats." Study section reviewers need to understand disability, and training on disabled populations needs to take place in specialties outside of physical activity and nutrition.

Question 4: What are the preferred research designs for testing hypotheses about expected health and quality of life outcomes? What are some examples?

Dr. Filart reviewed topics which arose from earlier discussions during the conference such as consideration of trial design, outcomes research, stratifying by age and disability type, and challenges associated with small samples sizes in rare diseases research.

Dr. Cooper asked if a new funding agency focused on comparative effectiveness research would be created. Dr. Filart explained that a great deal of American Recovery and Reinvestment Act funding has been allocated to comparative effectiveness research in 2009-10. There will be additional information on the new Patient Centered Outcome Research Institute which will address CER further.

Dr. Krahn reminded participants to be mindful with regard to quality of life and to what extent some of the current measures assess function. Similarly, Dr. Pratt reminded participants of the need to include psychosocial measures, including mediators and moderators, when considering outcomes.

VIII. Group Discussion Topic 3: Evidence and Efficacy

Drs. Avenilla and Nilsen chaired this session.

- Evidence and efficacy of treatments and services to improve well-being and lifestyle behaviors among children with disabilities. Explore the strength of evidence and research gaps.

Question 1: What are the key factors for effectively changing lifestyle for better health status in children with disabilities?

Dr. Avenilla noted that some of the earlier presentations in the day featured examples of services and treatment studies. More of these efforts are needed, whether they are new randomized trials or replications of existing studies. He asked participants whether the nature and strength of the evidence from the work featured earlier in the meeting was enough to justify pursuing verification studies in larger populations.

Dr. Pitetti reported work by his group in which the investigators found that 60 percent of waking hour activities in children with intellectual disability took place outside of school (e.g., around the home, daycare facilities, etc.). The diet for these children was completely regulated and controlled by that environment, which is something to consider for future research. Dr. Pitetti and colleagues also found that time spent with family is a key indicator of a child's activities. Among children who are not disabled and have one or two parents who are physically active, there is a 3.5 times greater chance of that child being physically active. Dr. Pitetti commented that this likely holds true for children with disabilities as well. In addition, parents' dietary behavior and food availability have effects on the diets of children with disabilities. These types of family and socio-environmental issues play key factors in the diet and physical activity level of children with disabilities.

Dr. Tymeson echoed Dr. Pitetti's comments, noting the need for a multifaceted approach in communicating the goals of physical activity and diet programs to parents/siblings and educators, with the hope that this information carries over to the greater community. Dr. Nitkin asked about the degree to which parents and schools understand the disabled child's condition. If a school or parent is overly cautious or overly concerned and goes too far in protecting, supporting, or shielding the child, it could do harm. This is particularly true in the case of cerebral palsy. Dr. Tymeson added that the extent to which parents are educated is critical. Parents of disabled children need to be informed as to what constitutes appropriate physical activity given the nature and severity of their child's condition. Dr. Frey agreed that parent support is an extremely robust determinant of a child's physical activity level. In many cases, parents want their child to participate in specialized programs, but access to these programs is poor in many areas/circumstances.

Dr. Elissa Jelalian of Brown University explained that there is movement across the United States to change policy with regard to physical education in schools. This may present opportunities to examine the effectiveness of different policies/physical activity curricula.

Dr. Librett commented that there is some measure of apprehension among parents of children with disabilities who are entering special programs. However, this apprehension quickly dissipates once the child is in the program and demonstrates potential and improvement. One way to potentially move the field forward would be to take the evidence used in generating the national recommendations for physical activity in the general population and identify differences in research results in the population of children with disabilities.

Dr. Pitetti noted that the family characteristics of those who have a child with a disability are significantly different than those of families who do not have a disabled child. For example, families of children with disabilities tend to participate in fewer community activities because they have a greater demand on them due to the child's physical, social, and education needs. Oftentimes, these demands detracts from other family members' needs (e.g., physical activity). Another difference is that children with disabilities tend to come from families of a lower socioeconomic status.

Question 2: What are the barriers for changing lifestyle for better health status in children with disabilities?

Dr. Avenilla summarized the barriers to changing lifestyle for better health status that had been discussed thus far, including a lack of resources (both community based and school based) available to families and children as well as time constraints. Dr. Kemeny added transportation needs to the list of barriers, commenting that transporting children to programs can be especially difficult in rural areas. Dr. Tymeson suggested that training professionals who are in community-based programs is another barrier. He noted that not every YMCA, park, recreation center, etc., has a person trained to know how to manage children with disabilities. Dr. Nitkin reminded participants that a lack of transportation and resources negatively impacts nutrition as well, particularly in rural areas. Cultural and language differences also were suggested as possible barriers.

Dr. Carlin explained that transportation is a key issue, and remains so even once the child is delivered to the facility/program. For example, many facilities are not easily accessible for children with disabilities (e.g., entry door location, lack of elevators, bathroom location). YMCAs and local community centers are often staffed by high school or college-aged youth and there generally is a fair amount of turnover.

Dr. Stanish noted that NIH money will not be allocated for addressing barriers such as physical accessibility issues and suggested that the group focus on barriers, constraints, and facilitators that can be changed. Improving transportation to a special needs program for a few years through a grant does not foster sustainable change. With regard to transportation, however, Dr. Kemeny commented that it is much easier to transport a mentor to a child with a disability rather than vice versa. Dr. Filart noted that partnering with groups that have developed and implemented solutions to transportation challenges might benefit future research endeavors. Depending on the town and city, these established groups with accessible transportation include private and publically funded outpatient rehabilitation centers, therapeutic recreational rehabilitation programs, and accessible community center programs.

Dr. Avenilla asked about the level of lifestyle change that should be sought for children with disabilities. Lifestyle is much larger than teaching a child with autism how to ride a bicycle. However, although this will not change that child's lifestyle, it will provide him or her with the opportunity to engage in an activity he or she has not done before, it may increase confidence and social engagement, etc. Dr. Nitkin added that there should be different goals for different children (and different disabilities/severities). Parents of a child with autism are not going to focus on physical activity as much as they are on engaging their child. He also reminded participants that biological, physical, and psychosocial factors are interrelated. Dr. Frey cautioned participants not to confuse improved with social interaction with becoming socially included.

Dr. Nilsen summarized that identified barriers include a lack of resources for both schools and community centers, family time demands, professional training, transportation, access to programs, and cultural and language differences.

Question 3: Should children with disabilities who have a propensity toward overweight and obesity be treated differently in research endeavors?

Dr. Rimmer suggested that this represents a sedentary model—an activity that creates psychological and physiological adverse health consequences. He indicated his belief that every funded research project should include a disability component, noting that for years, disability has been an exclusion criterion for a large proportion of federally funded research.

Dr. Avenilla suggested that children with disabilities who have a propensity toward overweight and obesity be treated differently in research endeavors, but the question is, how should they be treated? It is important that the research community be sensitive to this population's particular needs and abilities in designing these studies.

Dr. Pratt explained that all children have the propensity to become overweight or obese if their caloric intake supersedes output. Perhaps the question is not whether children with disabilities

have a propensity to become overweight, but rather whether different types of disabilities have some impact on controlling weight.

IX. Adjourn

Before closing the meeting, Dr. Starke-Reed thanked participants for their input and analysis. She emphasized that there is a interest in pursuing research in this area.

ATTACHMENT 1 – CONFERENCE AGENDA

NIH DIVISION OF NUTRITION RESEARCH COORDINATION NATIONAL INSTITUTES OF HEALTH in Partnership with

National Heart, Lung, and Blood Institute, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Center for Medical Rehabilitation Research/NICHD, National Institute of Diabetes and Digestive and Kidney Diseases, National Institute of Mental Health, National Institute of Nursing Research, National Center for Research Resources, Office of Behavioral and Social Sciences Research/NIH Office of the Director, and Division of Human Development and Disability/National Center for Birth Defects and Developmental Disabilities/CDC.

NIH DNRC Research Conference on Improving the Health of Children with Disabilities

**in collaboration with the
American College of Sports Medicine**

Saturday, June 5, 2010

**Key 8 Ballroom, Hilton Baltimore, Convention Center
Baltimore, MD**

AGENDA

7:30 – 8:30 a.m. Registration of participants

8:30 - 10:00 a.m. Opening Session:

Welcoming remarks, introductions and overview of the Conference, today's objectives, and expected outcomes: Chair,

Dr. Pamela Starke-Reed (10 minutes): Issues to be reviewed by Dr. Starke include definition of terms, format of meeting, plans for future meetings, advisability of addressing children with physical disabilities separately from children with mental health problems.

Comments by James Whitehead, Executive Vice President, American College of Sports Medicine (5 minutes)

Review of the I Can Do It, You Can Do It Program and its Evaluation Component utilizing two strategies of Increased

Physical Activity and Good Nutritional Practices in nine demonstration sites throughout the U.S. Also, an assessment of the Evidence about physical fitness of children with disabilities: Dr. Robert Arnhold, Slippery Rock University (20 minutes)

2008 Physical Activity Guidelines for Americans: Implications for a Research Agenda for Children with Disabilities: Dr. James Rimmer, University of Illinois at Chicago (25 minutes)

Considerations for how to develop evidence based nutritional guidelines for developmentally disabled children: Dr. Daniel Raiten, National Center for Child Health and Human Development (15 minutes)

(5 minute question and answer periods after each presentation by Drs. Arnhold, Rimmer and Raiten)

10 – 10:15 a.m. Refreshment Break

10:15 – 10:45 a.m. Overview of Institute or Center interest in research on improving the health of children with disabilities (Each partner institute, center and office will present a 3 minute overview with reference to a slide depicting their interests and objectives. Copies of the slides will be included in the packets of materials given to each participant before the Conference (10 presentations = 30 minutes)

10:45 – Noon Group discussion Topic #1: Discussion Chair: Dr. Charlotte Pratt, “Assessing the evidence base of the impact of physical activity and nutrition for children with disabilities”: Implications for different types of disabling conditions; examine strength of evidence and identify research gaps:

1. Does increased physical activity improve the physical and mental health of children with disabilities?
2. What dose of increased physical activity is required for improving the physical and mental health of children with disability? Do dosages differ by type and severity of disability?
3. Do specific nutritional practices improve the physical and mental health of children with disabilities?
4. Evidence for the need to apply both strategies simultaneously—increased physical activity and good nutritional practices in improving the health of children with disabilities?
5. Evidence that both approaches are needed to reduce overweight and obesity in children with disabilities?
6. Other questions?

Noon – 1:00 p.m.	Working luncheon
12:30 – 2:00 p.m.	<p>Group discussion Topic #2: Discussion Co-Chairs: Dr. Rosemarie Filart, Dr. Amanda Boyce, and Dr. Louis Quatrano: “The state of the science: Measurement and design issues for research on physical activity and nutrition for children with disabilities”: Identify strength of evidence and research gaps.</p> <ol style="list-style-type: none"> 1. Best measures for determining impact of increased physical activity in children with disabilities? 2. Best measures for determining impact of nutritional practices on improving the health of children with disabilities? 3. Preferred research designs for testing hypotheses about expected health and quality of life outcomes? Examples? 4. Who will conduct the research? Implications for training additional researchers to address these health-related issues for children with disabilities. 5. Other questions.
2:00 – 2:15 p.m.	Refreshment break.
2:15 – 3:15 p.m.	<p>Group discussion Topic #3: Discussion Co-Chairs: Dr. Frank Avenilla and Dr. Wendy Nilsen: “Evidence and efficacy of treatments and services to improve well-being and lifestyle behaviors among children with disabilities:” Explore strength of evidence and research gaps.</p> <ol style="list-style-type: none"> 1. What are the key factors for effectively changing lifestyle for better health status in children with disabilities? 2. What are the barriers for changing lifestyle for better health status in children with disabilities? 3. Should children with disabilities who have a propensity toward overweight and obesity be treated differently in research endeavors? 4. Other questions?
3:15 – 3:45 p.m.	Summary of discussion by each of Group Leaders re the three Topics: 10 minutes for each summary report.
3:45 – 4:00 p.m.	Conclusions and next steps: Chair Dr. Starke-Reed
4:00 p.m.	Adjournment

Glossary:

Disability: A person has a “disability” if she or he has a (1) chronic physical or mental impairment that (2) substantially limits (3) a major life activity.

Different types of disabling conditions: children with neurological disorders that result in cognitive and/or motor impairments and functional limitations in activities of daily living; children with serious sensory disorders resulting in blindness or deafness; children with intellectual disorders; children with mental health problems that adversely impact learning and personal and social behavior; children with cardiovascular or pulmonary disease that result in functional limitations; children with bone and joint disease (juvenile rheumatoid arthritis); and children with multiple chronic health conditions or disabilities.

Strength of evidence: refers to the quality of research and strength of recommendations from reported research that is used to substantiate a finding about a hypothesis or intervention. (double-blind studies, randomized controlled clinical trials, observational studies with repeated measures, multiple case studies, single case reports).

ATTACHMENT 2– LIST OF PARTICIPANTS

NIH DNRC Research Conference on Developing a Research Agenda for Improving the Health of Children with Disabilities

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**NIH DNRC Research Conference on Developing a Research Agenda for
Improving the Health of Children with Disabilities**

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