Special Olympics Health

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Special Olympics Inclusive Health (US) – Healthy Weight Goals

In the United States (US), the estimated prevalence of intellectual disability (ID) ranges from 1-3%, and cuts across the boundaries of age, race, sex, and socioeconomic status. While people with ID are a demographically diverse population, one critical feature they often share is poorer health. People with ID have a higher prevalence of adverse health conditions, less access to health promotion programs, inadequate attention to care needs, and inadequate access to quality health care services. Systemic challenges exacerbate these disparities, including limited training of, and inadequate reimbursement for, providers. As a result, people with ID are often excluded from existing health care systems, and have inequitable opportunities for health.

For the past 20 years, Special Olympics International (SOI) has endeavored to identify and address the unmet health needs of people with ID through its Healthy Athletes screenings and local year-round health promotion programming. As part of Special Olympics' new health strategy in the US, Special Olympics will complement this work with an expanded emphasis on strengthening the nation's capacity to support the health of people with ID. This new strategy aims to normalize the inclusion of those with ID in mainstream health systems, including policies, programming and services, training programs, research, and funding streams. The ultimate goal of this work is to eliminate disparities in health outcomes for people with ID, which means equitable access to health care, education, and services throughout communities.

Over the next five years, Special Olympics, in collaboration with the Association of University Centers on Disabilities (AUCD) and other partners, will work towards this goal with a particular focus on healthy weight. The ability to create large-scale, sustainable change is dependent on broad cross-sector coordination and collaboration. The attainment of inclusive health in the area of healthy weight will not be the result of individual actions, but rather the collective effort of committed leaders and organizations, united around a vision that is just, viable and inspired. This document explains the healthy weight goals and outcomes needed to create a world where people with and without ID have the same opportunities to be healthy.

Health Education, Services, and Delivery

Rationale: Health care professionals and students receive inadequate training on treating and communicating effectively with patients with ID, as well as on their particular health needs, including the myriad and complex factors that contribute to overweight and obesity in this population.

Key Health influencers: Health care and allied professionals, health care provider organizations, clinical training programs, continuing education providers, professional associations/accrediting bodies, elected officials and government policy makers.

Goals:

1. Medical schools, residency, and fellowship programs, as well as nursing, nutrition, and allied health training programs, will integrate content on ID into their curricula. Content will include evidence-based communication strategies, inclusive health resources on obesity prevention and treatment, and nutrition and physical activity education and community resources.
2. Existing continuing education programs targeting healthy weight professionals will similarly integrate content aligned with these inclusive health resources.
3. Health care delivery sites that accept federally funded insurance (Medicare, Medicaid, Child Health Insurance (CHIP), Supplemental Security Income (SSI), and Affordable Care Act (ACA)) will provide information and offer services that are appropriate for and accessible by people with ID . These health care delivery sites include: Federal Qualified Health Centers (FQHCs),

Indian Health Service sites, state and local public health departments, home health agencies, private providers, and NGO health care delivery sites

4. Health care delivery sites described above will refer patients with ID for preventive health care identified within the US Preventive Health Services Recommendations for Primary Care Practice http://www.uspreventiveservicestaskforce.org/BrowseRec/Index.
5. Legislation and policies will provide equitable access to quality, accessible, and affordable health care, education, and services for people with ID. These policies include people with ID being formally designated by the US Government as a medically underserved population (MUP).

Public Health and Community Population-Based Preventive Health Services

Rationale: Federal, State, tribal and local public health healthy weight education, prevention and treatment services and programs are rarely accessible and inclusive of people with ID. It is critical to create a sustainable and enabling environment to promote healthy weight in the communities in which people with ID live.

Key Health Influencers: Health Resources and Services Administration, Public Health Accreditation Board, federal health promotion agencies, state and local public health departments, NGOs, Disabled People's Organizations (DPOs), fitness organizations, fitness and nutrition professional organizations

Goals:

6. Accreditation Standards for State, Local, and Tribal Health Departments will adopt inclusive principles, measures and recommendations.
7. Tax funded[1] public health programs for healthy weight education, prevention and treatment will adopt inclusive practices and strategies so people with ID have equal opportunities and access to existing mainstream services and programming promoting healthy weight.
8. National and local public services, including recreational facilities, hospitals/clinics, group homes, and schools, will adopt inclusive practices and strategies to promote healthy weight in the community.
9. National and local organizations promoting healthy eating and physical activity (e.g., public health departments, YMCAs, fitness centers, Weight Watchers, Cooking Matters, etc.) will enhance and modify programs and services to become inclusive of people with ID, and will increase availability of healthier food and beverages for people with ID in the community.
10. Health and wellness apps will be accessible for people with ID. This digital inclusion means taking into account accessibility needs of people with ID to include adapted or modified user interfaces, language and guidance. Examples include, adapted nutrition and fitness trackers, modified or adapted workout apps that are accessible for people with ID, nutrition/cooking app that provides step by step guide to preparing healthy meals that are accessible for people with ID.

Funding for Research and Programming

Rationale: The vast majority of research funding and Institutional Review Board protocols exclude (or make it difficult to include) people with ID due to their diagnosis or medications. Furthermore, most foundations and programmatic funders do not include people with ID (in the way they do for women and girls or other groups that experience health disparities) as a preferred population for targeted or inclusive projects. As a result, there are limited evidence-based effective obesity prevention and treatment strategies suitable for people with ID and very few dollars supporting any kind of implementation. The majority of funding that does exist goes into special needs programming rather than supporting inclusive approaches that might ultimately be more sustainable.

[1] Funding from CDC, USDA, HHS, HIS, DOE, HUD, Federal, State or municipal tax support

Key Health Influencers: Universities, research organizations, journals, national and institutional research entities, foundations, donor agencies, state and local governments

Goals:

11. National and institutional research entities will remove people with ID from research and clinical trial exclusion criteria
12. National and institutional research entities will ensure people with ID are included in research by allocating funding opportunities and resources for research on healthy weight, obesity prevention and treatment inclusive of and/or with a focus on people with ID.
13. National health professional journals that focus on topics of healthy weight, obesity prevention and treatment, will include content inclusive of people with ID, and/or publish supplemental content focused on research and evidence-based practice specifically targeting the ID population.
14. Foundations and other funding entities will build inclusion of those with ID into grant opportunity announcements as a population of interest.

Health Care Financing

Rationale: In the US, people with ID heavily rely on publicly financed healthcare – Medicaid and Medicare. Existing barriers to access and quality care faced by other recipients of these public insurance programs are aggravated for people with ID who may require longer appointments, who have difficulty finding doctors who are trained in communicating and working effectively with them, and who, because they have limited access to preventive programming and care, are more likely to have chronic health concerns. Below-market reimbursements for Medicaid and Medicare to healthcare providers have resulted in limited access to quality primary care, obesity prevention and treatment services, referrals, as well as poorer health outcomes. One of the reasons for this is that currently, reimbursement opportunities for prevention and treatment around healthy weight are complex and often, the allied health professionals qualified to provide these services, such as registered dietitians, may not be aware of how to bill for these services. As a result, people with ID are more likely to visit emergency rooms, more likely to be hospitalized when they do so, and more likely to be misdiagnosed, resulting in inappropriate medication prescriptions and higher care costs, compared to the general population.

Key Health Influencers: Payers and regulators of health care, including public and private health insurance providers and state and federal regulatory agencies.

Goals:

15. Clinicians and allied health care providers (e.g. dietitians) will understand the managed care organization and Centers for Medicare, Medicaid Services reimbursement processes for individual behavioral and group counseling, medical nutrition therapy, and intensive behavioral therapy for obesity and co-morbidities.
16. Healthcare insurers will increase allowances for preventive services and treatment which address healthy weight for people with ID. This will include reimbursement for and/or fewer restrictions or impediments on nutrition services, behavior analysis services, physical therapy services, as well as care coordination and case management services that may help reduce obesity-related chronic health conditions and increase diagnosis and treatment of those conditions in the primary care setting.