

***Promoting Health for Persons with
Mental Retardation — A Critical Journey
Barely Begun***

Special Olympics, Inc.

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SUMMARY

As the largest organization in the world promoting acceptance through sport, Special Olympics has a 32 year track record of demonstrated success in providing year-round sports training and competition opportunities for children and adults with mental retardation. Founded in 1968 by Eunice Kennedy Shriver, Special Olympics, Inc. (SOI) is incorporated in the District of Columbia as a not-for-profit corporation focused on international sports.

Special Olympics flourishes in 150 nations and in each of the 50 states, the District of Columbia, Puerto Rico, Guam, the Virgin Islands, and American Samoa. One million people with mental retardation annually participate in Special Olympics training and competition programs globally. One million volunteers and 250,000 coaches around the world support these efforts, training athletes in 22 Olympic-type sports and organizing more than 20,000 local, regional, national and international sporting events annually. Through regular sports training programs, Special Olympics athletes enhance their athletic skills, improve their overall physical fitness, and develop increased self-confidence and self-esteem. In fact, published research indicates that for people with mental retardation, regular participation in Special Olympics sports training and competition activities yields all of these benefits and often leads to sustained improvement in overall physical fitness and emotional well-being (1).

Prevalence/Causes of Mental Retardation

The World Health Organization estimates that there are approximately 170 million people with mental retardation worldwide (2). In other words, nearly 3% of the world's population has some form of mental retardation. Accordingly, mental retardation is 50 times more prevalent than deafness; 28 times more prevalent than neural tube disorders like spina bifida; and 25 times more prevalent than blindness.

A person is diagnosed as having mental retardation based on three generally accepted criteria: intellectual functioning level (IQ) is below 70-75; significant limitations exist in two or more adaptive skills areas (e.g., communication, self-care, functional academics, home living); and the condition manifests before age 18. Mental retardation can be caused by any condition that

impairs development of the brain before birth, during birth, or in childhood years. Genetic abnormalities, malnutrition, premature birth, environmental health hazards, fetal alcohol syndrome, prenatal HIV infection, and physical abnormalities of the brain are just some of the known causes of mental retardation.

This report is the result of an analysis that was undertaken to identify and highlight the health status and needs of persons with mental retardation and to suggest approaches that could be implemented, given current knowledge and technology, to improve both the length and quality of their lives over the coming decade. Length and quality of life are central concerns of numerous high-level policy initiatives in many countries, including the United States. The recent launch of the Healthy People 2010 (3) initiative marks the third decade of a national commitment to improving the health and wellbeing of Americans. Major goals of the initiative include increasing the quantity and quality of life and reducing health disparities among various groups. However, if one focuses on the health status, needs and opportunities for persons with disabilities, the public policy record is much more Spartan. The previous Healthy People 2000 initiative (4), launched by the U.S. Department of Health and Human Services in 1990, included little direct focus on the health status and needs of persons with disabilities.

To its credit, the Healthy People 2010 report (3) dedicates a chapter and a number of objectives and “developmental objectives” to persons with disabilities. Yet, the chapter does not address specifically the health status, needs and access issues confronting millions of Americans with mental retardation or other specific disability groups. Further, there are notations of “no available data”, “inadequate data”, or “unanalyzed data” concerning persons with disabilities throughout the document. Similarly, several recent highly visible federal reports addressing oral health challenges and lack of access to oral health services for several special needs populations barely mentioned the population with disabilities, including individuals with mental retardation (5-7).

This is the central reason why Special Olympics is taking a leadership role with respect to the health status and needs of persons with mental retardation. While Special Olympics is not a health organization per se, it recognizes that individuals can not effectively or safely participate in sports training and competition at any level if they are constantly challenged by health liabilities and disparities.

Special Olympics is exerting leadership in the area of health for persons with mental retardation because, to date, adequate leadership has not emerged from the health care and public policy communities. Moreover, while there has been some welcome progress in terms of increased life expectancy and quality of life for persons with mental retardation over the past several decades, major health gaps remain and health improvement opportunities remain widely underaddressed.

Healthy People 2010 (3) makes a clear statement that is rationale enough for this report:

"...the principle - that regardless of age gender, race, ethnicity, income, education, geographic location, **disability** (emphasis added), and sexual orientation - every person in every community across the Nation deserves equal access to comprehensive, culturally competent, community-based health care systems that are committed to serving the needs of individuals and promoting community health” .

The major findings, conclusions and recommendations of this report are drawn from several sources, including: an independent, comprehensive review of the literature undertaken by scholars at Yale University (8); learned opinions from health and disability experts from various countries; administrative data derived from Special Olympics programs; and direct experiences of Special Olympics athletes, their families, program staff, and volunteers. Consistent with policies of Special Olympics, the findings, conclusions and recommendations in this report have been shared with a number of Special Olympics athletes.

Major Findings

1. Individuals with mental retardation suffer from a wide range of chronic and acute diseases and conditions. In many instances, they experience more frequent and severe symptoms than the general population. This is not solely a result of the primary disability of mental retardation, but reflects more fully the totality of risk factors and risk reduction opportunities made available to or denied to them. Importantly, their life and health experiences can not be adequately explained or rationalized solely by the fact that they have mental retardation, since they are impacted by secondary conditions and persisting environmental factors (social, economic, physical, etc.) that fail to ameliorate or actually exacerbate their risks.
2. Evaluating isolated categorical health deficits or conditions in persons with mental retardation through simple disease/condition comparisons with the general population is not, in itself, adequate for assessing health status or the need for health improvement. Even where there is evidence that the prevalence of a specific disease or condition may be similar between the general population and those with mental retardation, the adverse impacts can be greater on those with mental retardation. Health must be seen in overall functional terms, especially for populations with disabilities and including the aspect of meaningful social participation.

3. Numerous measures indicate that persons with mental retardation experience lower life expectancy and lower quality of life than the population in general. The magnitude of these gaps can not be explained solely by the existence of the mental retardation condition.
4. Notwithstanding the increasing focus on personal and population health promotion and disease prevention, both in the United States and elsewhere, persons with mental retardation have received little consideration in terms of health improvements that they may be able to realize. Consistent with this finding, the information concerning the health status and needs of persons with mental retardation is entirely inadequate. Further, there is a dearth of information as to specific disease prevention and health promotion interventions that could improve the quality and length of life for persons with mental retardation.
5. Even in situations where persons with mental retardation experience similar levels of disease to persons without mental retardation, access to timely and appropriate health care often is not adequate and generally poorer than for the overall population. This leads to unnecessary suffering, functional compromise, and costs to individuals, families and society.
6. Although persons with mental retardation need health and health financing programs that are responsive to their particular needs, too often they are forced into general programs that actually can compromise their health. The most recent example of this is the movement toward managed care in Medicaid.

Families have served as principal advocates for the health care of their children with mental retardation. While many families are fortunate to have private health insurance and/or personal resources to help cover health care expenses, too many families and individuals face substantial health care costs on their own. While a large percentage of the population with mental retardation is covered under state Medicaid programs, many of these programs are plagued by a variety of problems, including poor reimbursement rates to providers, excessive paperwork and delays, limitations and exclusions in benefits, and a generally poor reputation among providers.

As an example, while dental services for many children are covered under Medicaid, only one-in-five eligible children receive any dental services each year (9). In most states, there are limited dental care benefits for adults, so that children with mental retardation are no longer eligible for dental care

coverage under Medicaid, once they reach the age of maturity. Also, it should be noted that dental care is essentially unavailable under Medicare.

7. The majority of health professionals who are otherwise qualified to treat persons with mental retardation fail to do so. This is largely the result of a lack of appropriate, specific training, inadequate reimbursement policies, fear, and prejudice.
8. Existing federal, state and voluntary programs to meet the health needs of persons with mental retardation are inadequate. Enhanced and new efforts with supplemented and targeted resources will be required. Coordinated and integrated rather than piecemeal efforts must be a priority.
9. Significant additional targeted research is needed to more fully characterize and understand the health status and needs of persons with mental retardation and to test models for improving health. Still, existing data are adequate to conclude that persons with mental retardation are woefully under addressed in terms of national (virtually every nation's) health priorities. The Special Olympics Strategic Research Plan (10) can serve as a blueprint for many research efforts. However, strong research partners, including funders, will be necessary.

Recommendations

1. **All public and private programs, initiatives and reports that address the health needs of the public should explicitly examine the unique needs of persons with mental retardation.** Because of the complex constellation of physical, mental, and social variables that combine to challenge the health and wellbeing of this population, general conclusions based on individual demographic or risk factors are inadequate for designing effective policies and programs to help persons with mental retardation. “One size fits all” solutions to the financing and delivery of services will assure that persons with mental retardation will continue to be underserved and/or receive inappropriate services.
2. **An expert working group should be convened by the Secretary, U.S. Department of Health and Human Services to address equity gaps and opportunities that exist to better characterize the health needs of persons with mental retardation. If necessary, to stimulate action, public hearings should be convened by Congress to garner necessary focus and priority.**

The goals of the Healthy People initiative only can be achieved when the health status and needs of specific populations are well documented, effective community and clinical education programs exist, prevention and treatment programs are designed, and adequate resources are made available.

3. **Specific health objectives for persons with mental retardation should be established, consistent with the overall goals of Healthy People 2010 (3) - namely, to increase quality life years and to reduce the gaps in health status.** Leadership should come from the U.S. Department of Health and Human Services through the Administration on Developmental Disabilities, Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), in conjunction with the Department of Education.
4. **The CDC should conduct a comprehensive review of the degree to which data collection and analysis regarding the health and wellbeing of persons with mental retardation have positively or negatively impacted the lives of persons with mental retardation and what opportunities exist to redress past shortcomings.**

Substantially enhanced documentation of the health status and needs of persons with mental retardation is needed. Currently, too many surveillance processes fail to collect adequate information on this population and fail to perform relevant data analyses in a timely fashion, which then could inform policy development and program design.

5. **A diverse expert working group should be convened to examine the health and wellbeing for persons with mental retardation from the perspective of what could be achieved to enhance health opportunities, if existing disparities and conflicts in policies and organizational priorities could be resolved. This will directly impact the health of persons with mental retardation and the costs to society.**

Too often, efforts to describe the scope of health and social challenges for persons with mental retardation have focused on the magnitude of disability and the cost of long-term and respite care. Policy makers and health organizations need to frame appropriately the opportunities that exist to facilitate skill development and independence for persons with mental retardation. They need to identify, in qualitative and in quantitative terms, the benefits to society for investing in the potential of persons with mental retardation.

- 6. Special Olympics should convene a blue ribbon corporate health advisory group for persons with mental retardation to develop a strategic and integrated corporate strategy for maximizing the impact of corporate contributions (intellectual, technical assistance, in-kind, cash) for the betterment of persons with mental retardation.**

Given the inadequate resources and attention to the health needs and possibilities for persons with mental retardation, it is time for leading health organizations, including pharmaceutical companies, health equipment and supply companies, health insurers, and government and philanthropic organizations to commit resources to promoting health and preventing disease in this population, so that by 2010, clear health gains and realistic health promotion opportunities are created for persons with mental retardation.

Likewise, leading philanthropic organizations need to undertake a critical self-examination of the degree to which they have addressed the health needs of persons with mental retardation. Organizations with weak records of support in this area should make concrete commitments to funding programs and projects to improve the health of persons with mental retardation.

- 7. A focused effort to create health literacy enhancement opportunities for persons with mental retardation needs to be undertaken.** Closing the gap in health literacy has been identified in the Healthy People initiative (3) as a principal strategy for reducing health disparities. Persons with mental retardation also need to have health information presented to them in ways that may empower and motivate them toward seeking higher levels of health. While this will not be possible universally, there are tens of millions of persons with mental retardation globally who can not simply be categorized as unable of taking an active role in their own healthcare. Further, caretakers will be more motivated to act in the best health interests of persons with mental retardation if they are aware of what appropriate standards are.

- 8. The Inspector General, of the U.S. Department of Health and Human Services, as well as the Association of State Attorneys General, should evaluate whether the provisions of publicly funded and private health programs are providing equal or equitable protection to persons with disabilities, including those with mental retardation.**

- 9. A broad public health assessment of mental retardation needs to be undertaken by leading public health and professional organizations that can lead to formulations of effective organizational policies and programs. The new National Center on Birth Defects and Developmental Disabilities at CDC should have an explicit program focus and adequate resources to fund research, surveillance, and assessments on the prevention of secondary disabilities among persons with mental retardation.**

The public health community needs to reassess and reprioritize mental retardation as an important public health challenge that goes beyond simply primary prevention of diseases and conditions that result in mental retardation.

- 10. The NIH and other federal agencies with a health research mission should allocate increased levels of research funds to issues critical to understanding all dimensions of mental retardation and where research opportunities exist to pursue the prevention and rectification of the primary and secondary effects of mental retardation. Special Olympics should formally transmit its strategic research agenda to these agencies as a basis for consensus development around the strategic role of federal agencies in such research.**

Additional Perspectives

The findings and recommendations in this report have as their principal basis the comprehensive literature review conducted by Horwitz et. al. at Yale University (8), data and perspectives from Special Olympics program offerings and services delivery, and responses from key informants from a number of countries who are knowledgeable of and work in areas related to mental retardation.

Dr. Stephen Corbin and Dr. Donald Lollar asked professional colleagues in several countries to respond to a survey instrument (available from Special Olympics upon request) containing items addressing the existence of data, policies, laws, and programs for individuals with mental retardation, and their health status and needs. The key informant responses were solicited after completion of the other portions of the report so that they might serve a validation function. Responses came from individuals in Kenya, India, Australia, and the Czech Republic. As it turned out, these responses validated the findings and recommendations that had been articulated.

To date, health data collection and analysis for the population with mental retardation has not been a priority in these countries. Representative country data were not available to characterize in any comprehensive way the health status and needs of persons with mental retardation. Data that are available are not collected on an ongoing or periodic, scheduled basis. The tendency is for official data collection sources to seek data on disability in general or to rely on general population data which are of limited utility for understanding the health needs of persons with mental retardation.

Some institutional data are available (Czech Republic), but the depth of information varies significantly. It was noted that in Australia, de-institutionalization of persons with mental retardation has interrupted not only the availability of health services to these persons, but also negatively impacted the collection of information about the health needs and health service access for much of this population.

All respondents indicated that access to necessary health care services for individuals with mental retardation is a problem. Even in countries where medical care is made available by law to all citizens, persons with mental retardation have difficulty receiving needed care from qualified providers. Children with mental retardation tend to fare better than do adults with mental retardation. Those living in cities generally receive inadequate care and those in villages are even worse off. NGOs provide some assistance (Kenya), but this is not sufficient. It was pointed out that in Australia, many conditions could be ameliorated and or prevented by early intervention, but periodic screening is not a well-established part of the system. Disease prevention and health promotion services for persons with mental retardation do not appear in any systematic way through government or private sources and are not a public priority.

Further, bias against persons with mental retardation is reported to exist still, even among health care providers, and most persons with mental retardation are not in a strong position to communicate their health needs and desires. Several respondents indicated that individuals with mental retardation may be eligible for a level of services similar to those provided to individuals with other disabilities, but, in actuality, they usually end up with poorer access to care. For example, in India individuals with visual impairments and individuals who are orthopedically challenged have better access to health services than do individuals with mental retardation. Lack of adequate resources to pay for needed care is a consistent problem and, in the case of institutions (Czech Republic), adequate resources to provide appropriate staffing levels is a challenge.

The greatest barriers to the improvement in health status for persons with mental retardation include attitudes by the public, governments, service providers, and, in some instances, even family members. The health needs of persons with mental

retardation do not register high enough on the priority scale to attract the resources and attention that they merit. Even where policies and laws exist that should provide a basis for needed services for persons with mental retardation, there is little attention to surveillance and enforcement.

Informants made a number of suggestions as to the most important actions that could be taken over the next decade in order to increase life expectancy and quality of life for persons with mental retardation. These include:

- Earlier, more adequate and frequent health screening;
- A more responsive general health system;
- Additional training and strong encouragement for health professionals to meet the needs of people with mental retardation;
- The development of a network of specialized tertiary referral health clinics to support the general health services and to provide a base for research and training;
- Adequate national data bases;
- Implementation of existing laws;
- Implementation of a mass awareness program through print and electronic media, including the internet, to better sensitize the public as to the nature and needs of persons with mental retardation;
- A firm stabilized health insurance system with adequate financing;
- Standardized, periodic screening targeting prevention and needed care;
- Better communication about the lives and personalities of persons with mental retardation, coupled with training in communications and ethics for care providers;
- Governments recognizing mental retardation as a special entity and enacting policies favorable to this group; and,
- Popularization of the idea of Special Olympics through which governments, the general public, professionals, and organizations can assist in health promotion and disease prevention efforts on behalf of persons with mental retardation.

Special Olympics Healthy Athletes - An Initial Approach to Addressing the Health Needs of Persons with Mental Retardation

Special Olympics has provided year round sports training and competition opportunities for persons with mental retardation for more than three decades. Over a million athletes of all ages participate in a variety of summer and winter Olympic-type sports. Special Olympics was started by Eunice Kennedy Shriver in 1968 because persons with mental retardation consistently were excluded from societal opportunities, including sports and recreation. She recognized that persons with mental retardation could accomplish significant things through sport, while, at the same time, finding meaning in their lives. Since that time, the public record of service and opportunity provided to persons with mental retardation through Special Olympics has been well documented, through extensive print and electronic media and a continuing stream of highly visible public events.

In recent years, Special Olympics has expanded its interest in the health of its athletes by supporting research activities, organizing medical symposia, and collaborating with international organizations on prevention issues.

Beginning in 1989, the health needs of persons with mental retardation were highlighted as a result of vision screenings initiated through the Sports Vision Section of the American Optometric Association. These initial screenings demonstrated that Special Olympics athletes had significant and highly prevalent vision impairments and that they were woefully lacking in quality vision care opportunities.

In the early 1990s, an additional program, Special Olympics Special Smiles, was created to address the unmet oral health needs of Special Olympics athletes. Like Special Olympics Opening Eyes, Special Olympics Special Smiles demonstrated that Special Olympics athletes had a significant unmet need for oral health care. Boston University's Goldman School of Graduate Dentistry provided the founding institutional home for Special Smiles and enabled the program to grow quickly.

What Is Special Olympics Healthy Athletes?

Special Olympics Healthy Athletes is a diverse program of health assessment, professional training, service provision, and referral for Special Olympics athletes. Special Olympics Healthy Athletes screening venues are conducted in conjunction with sports competitions at local, state, national, regional, and global levels. These programs are elective for Special Olympics Programs and Games Organizing Committees. Despite the non-mandatory aspect, Special Olympics Healthy Athletes Programs have been expanding rapidly, based on the recognition that they bring a new and valuable range of services and resources to Special Olympics

athletes. Special Olympics Healthy Athletes is not intended to be a comprehensive health care system, but rather is a short-term, limited, yet practical means for bringing a range of health services closer and more convenient to Special Olympics athletes and in a welcoming, respectful, and non-discriminatory setting.

Special Olympics Healthy Athletes programming includes:

- Direct health services delivery to Special Olympics athletes;
- Health education services for athletes;
- Athlete referral for needed follow-up care;
- Documentation of the health status and needs of athletes;
- Recruitment and training of health personnel in treating people with mental retardation;
- Advocacy for improved public policies in support of the health needs of people with mental retardation; and,
- Advancing knowledge about the delivery of health care to persons with mental retardation.

Range of Services Provided

Special Olympics Healthy Athletes program components offer the following range of personal health services, varying by discipline and specific screening protocols:

- Screening assessment
- Clinical examination
- Health education/counseling
- Preventive services
- Corrective services
- Personal preventive supplies
- Referral for follow-up care
- Interaction between athletes and specially

trained and motivated health care providers.

Qualified experts from the health disciplines within Special Olympics Healthy Athletes determine the appropriate contents and standards for their screening and service offerings, based on the state of science and clinical practice, with adaptations for the special population that is being served. Special Olympics program leaders along with the Special Olympics Global Medical Advisory Committee and legal staff monitor and approve overall program scope and

practices.

In 2001, more than 100 Special Olympics Healthy Athletes screening clinics will be conducted. This includes screening events at local, state, national, and international levels. Also, beginning in 1999, several additional health disciplines were pilot tested for the first time as Special Olympics Healthy Athletes components. They include: hearing; physical therapy; dermatology; and orthopedics. Screening clinics in these disciplines have been conducted at a number of Games in the U.S. and abroad, and further growth in these and other medical disciplines is anticipated.

Special Olympics Healthy Athletes Program Findings

In addition to the health services that Special Olympics athletes receive through the Special Olympics Healthy Athletes Program, valuable insights have been gained as to the health status and needs for this population group. As reflected in the Yale University literature review (8), Healthy People 2010 (3), and feedback by key informants from different countries, there is a general lack of information as to the health status and needs of persons with mental retardation. Further, available data generally are from small institutionally based studies or administrative records of public agencies.

Specific advantages of the data derived from Special Olympics programs is that the population served is substantial and includes athletes of all ages from around the world. Literally tens of thousands of Special Olympics athletes have been screened through the Healthy Athletes Program to date. Further, the data have been collected using standardized protocols developed by experts in the field (e.g., U.S. Centers for Disease Control and Prevention).

Limitations in the data that must be recognized include the large number of examiners involved, the limited sensitivity of the survey instrument in some cases to detect quantitative differences in levels of disease (e.g. oral health screening instrument), and the convenience aspects of the population being reported on - i.e., athletes participating in Special Olympics events are not fully reflective of the larger community of institutionalized and non-institutionalized persons with mental retardation worldwide. As pointed out in the Yale University literature review, there appear to be certain health advantages or disadvantages to individuals based on their residential status. A number of disease conditions may be more prevalent among individuals with milder retardation living in freer environments where they must make conscious choices to avoid health risks (e.g. tobacco use) or to practice healthy habits on their own (e.g. oral hygiene, physical exercise, etc.). Nevertheless, there is little doubt that that Special Olympics

Healthy Athletes data make a valuable contribution toward understanding the health status and needs of persons with mental retardation and planning programs and policies to address unmet needs.

Vision Health of Special Olympics Athletes

Nearly 10,000 athletes have received vision assessments through the Special Olympics Opening Eyes Program since its inception. It is anticipated that in 2001, due to a program expansion facilitated by a major, multi-year grant from the Lions Clubs International Foundation, an additional 6,000-7,000 athletes will directly receive such screenings. Findings have been fairly consistent over several years of assessments. Special Olympics athletes had not received adequate vision care in terms of timeliness and many require corrective services. Over 60% had not received a vision assessment in the past three years. Between one-fifth and one-third of athletes required glasses for the first time or replacement glasses. In many instances, athletes were wearing prescriptions that were found to be grossly inaccurate. The prevalence of astigmatism (44.2%) and strabismus (17.8%) were high. A high percentage of athletes examined would be classified as legally blind according to World Health Organization criteria.

Many anecdotal reports identified athletes who, after receiving eyewear through the Special Olympics Opening Eyes Program, could, for the first time, see the finish line, their friends and families cheering for them. In a number of instances, coaches and family members reported that the new eyewear literally changed the personality of individual athletes and immediately enhanced their quality of life, while reducing certain risks (e.g. injury from falls or collisions). Many athletes additionally have received prescription swim goggles or prescription or plano safety sports glasses intended to prevent sports injuries.

Oral Health of Special Olympics Athletes

Oral health assessments have been provided to approximately 20,000 athletes through the Special Olympics Special Smiles Program over the past seven years. Most screening clinics have been conducted in the United States, although it is anticipated that major program growth, starting in 2001, will take place outside the United States. Special Olympics Special Smiles utilizes an assessment instrument developed by CDC especially for Special Olympics. The instrument was designed to be reliable when used by a variety of trained examiners under varying conditions. This comes at the expense of providing great quantitative detail. Thus, as an example, an athlete would be assessed for obvious dental decay in at least one tooth. If such were the case, the assessment form would be marked "yes". However, if several teeth for an athlete had obvious decay, the "yes" category

likewise would be marked. Thus, there would be no apparent distinction when examining data as to the extent of dental disease in an individual athlete. This protocol differs from more sophisticated epidemiological studies conducted periodically by federal and state governments that precisely quantify the presence of dental disease down to relatively small caries lesions on individual tooth surfaces. The limitations of government studies, however, is that they fail to include an adequate number of individuals with mental retardation to provide meaningful results or they fail to identify individuals by disability category.

Notwithstanding the limitations in data derived from the Special Olympics Special Smiles screenings, a good overall picture emerges of the oral health status and needs of Special Olympics athletes. The 1999 Special Olympics World Summer Games in Raleigh, North Carolina are representative. For the over 2,200 athletes of all ages examined, nearly 20% reported pain in the oral cavity, the vast majority attributed to tooth pain. Much untreated dental decay exists in Special Olympics athletes. Nearly one-in-three had active dental decay (untreated) in molar teeth and more than one-in-ten had active decay in pre-molar or anterior (front) teeth. Less than one-in-ten screened athletes had preventive dental sealants present on any molar teeth.

There is a clear need for more professional care to be made available to this population. More than 40% of screened athletes were in need of professional care beyond the level of routine, maintenance care, and more than one-third of these needed urgent care. There were substantial differences between U.S. and non-U.S. athletes in terms of needed professional care. Nearly half of non-U.S. athletes were in need of care beyond routine maintenance care compared to 28.4% of U.S. athletes. Urgent care was required nearly three times as often (19.9%) for non-U.S. athletes as for U.S. athletes (7.1%).

During 2000, 35 Special Olympics Special Smiles screening clinics were conducted, serving nearly 10,000 athletes. While the results from site to site demonstrated some variations in individual measurement categories, overall the data were consistent with the athlete data gathered at the 1999 Special Olympics World Summer Games.

Hearing Health of Special Olympics Athletes

The Special Olympics Healthy Hearing Program is much newer than the Special Olympics Opening Eyes or Special Smiles Programs. The first hearing screening was conducted as part of the Special Olympics World Summer Games in 1999. A second large-scale event was conducted at the 2000 Special Olympics European Games in Groningen, Netherlands.

During the European Games, 529 athletes were screened at the Special Olympics Healthy Hearing venue. The athletes were from 61 countries. Screenings including

otoscopic examination of external ear canals, otoacoustic emissions (OAE) hearing tests, pure tone audiometry, and tympanometry to screen middle ear function. Twenty-six percent (26%) of the athletes failed the hearing screening as compared to a general population rate expected to be under 5%. Of this group, 52% did not pass tympanometric screening, suggesting the presence of a conductive (probably medically correctable) hearing loss. Conversely, 48% passed the tympanometric screen, which implies that they failed the hearing screening due to a sensorineural (permanent) hearing loss.

Of the nearly three-quarters of the screened athletes who passed the screening protocol, one-in-five had ear canals blocked or partially blocked with cerumen (ear wax), reflecting a lack of ear hygiene and professional care. The results from the Groningen screening were similar to those compiled at the 1999 Special Olympics World Summer Games.

Overweight as a Risk factor for Special Olympics Athletes

According to Healthy People 2010 (3), the prevalence of overweight individuals is on the rise with 11% of school age children and 23% of adults being classified as obese. The prevalence of obesity in the population with mental retardation has been reported as more common than in the general population. Obesity has been implicated as a major preventable health risk factor for the general population. These risks include a higher prevalence for these individuals of cardiovascular disease, cerebrovascular disease, diabetes mellitus, and certain types of cancer.

For the first time during a World Special Olympics Games, in Raleigh, North Carolina in 1999, nutritional assessment and education were included in the Healthy Athletes Program. This was stimulated by the increasing focus on the nutritional status of both under and over nutrition in the general population. For Special Olympics athletes who train and enter athletic competition, under or over weight, representing poor nutritional status, may affect general wellbeing and performance. Ten hundred and sixty six (1066) Special Olympic athletes were assessed by anthropometric measurements. These included height and weight used to calculate Body Mass Index ($\text{weight (Kg)} / \text{ht (m}^2\text{)}$) for each athlete. There were 421 athletes from the United States and 645 from other areas of the world.

The Body Mass Index (BMI) measurements were standardized for age using the NHANES III BMI values. BMI values for children and adults have been standardized in the U.S., but there are presently no available established reference ranges for BMI for children and adults with mental retardation. Each athlete who volunteered was evaluated anthropometrically by obtaining height and weight. BMI percentile ranges across ages were then compared. BMI below the 5th percentile represented malnutrition and between the 5th and 15th percentile a risk of

under nutrition. BMI greater than 85th percentile represented obesity and greater than 95th super obesity with significant health risk factors.

For U.S. athletes, 3.3% were below the 5th percentile compared to 5.2% of athletes from other countries. The 5th to 15th percentile included 5% of U.S. athletes and 7.1% of athletes from other countries. There were 11.2% of U.S. athletes between the 15th and 50th percentile and 30.9% from other countries. For the 50th to 85th percentiles, there were 27.6% of athletes from the U.S. and 36.6% of other athletes. Fifty three percent (53%) of U.S. athletes and 20% of athletes from other countries were greater than the 85th percentile BMI, with 33% of American athletes and 7% of athletes from other countries greater than 95th percentile.

These findings reflect that the majority of U.S. athletes at the World Summer Special Olympics in 1999 were above the 85th percentile and, thus, were obese and 33% would be considered in a group with significant health risk because of super obesity. Whether these data represent all individuals with mental retardation, it is apparent the BMI values obtained from a majority of individuals who represent the Special Olympics athletes from the U.S. are at significant risk. More data for specific age, sex, living condition and diagnoses for nutritional status in the population with mental retardation need to be obtained. Also, the percentage of patients with Down syndrome relative to the general population with mental retardation is known to be more obese and may need to be studied separately. This large sample of Special Olympic athletes, although not representing the general mental retardation population, particularly for those from the U.S., indicated that these individuals may be at significantly increased health risk.

Thus, it is apparent that greatly increased efforts to work with athletes, coaches, families, teachers, health care providers, and program administrators in the area of diet, nutrition, weight control, and fitness are needed.

Training Health Professionals to Treat Persons with Mental Retardation

It stands to reason that for individuals with mental retardation to have their health needs met, there must be trained, willing health care providers available. As reflected in the Yale University literature review, a number of reports indicate that health care providers overall feel ill prepared and minimally motivated to treat persons with mental retardation, even for conditions found routinely in the general patient population. Health professional students receive little didactic exposure to the health needs of persons with mental retardation during their training and even fewer have meaningful clinical experiences with such patients.

Accordingly, Special Olympics has made it a priority to train health professional volunteers and to provide them with hands-on experience in serving persons with

mental retardation. Typically, health professional volunteers for the Special Olympics Healthy Athletes Program receive didactic training as to the nature of mental retardation, special health and social challenges faced by persons with mental retardation, special aspects of their own discipline relating to mental retardation, and effective techniques for rendering quality clinical services to this population. Volunteers additionally receive actual experience, lasting from several hours to several days, depending on the nature of the event, to provide service to and interact with Special Olympics athletes. They are accorded continuing professional education credit for this experience.

Consistently, health professional volunteers report their Special Olympics Healthy Athletes experience in extremely positive terms. Many individuals characterize the experience as the most meaningful professional encounter of their careers. Students typically become highly motivated to seek additional experience with special populations. Research conducted by Special Olympics clinical consultants on health professional volunteers indicates that volunteer optometrists have a reasonably high expectation for the capabilities of persons with mental retardation prior to their Special Olympics Healthy Athletes experience, and, that after their experience, they report even more positively in terms of what persons with mental retardation can accomplish in life and contribute to society. Oral health providers (dentists, dental students, dental hygienists) evaluated using the same instrument showed similar, albeit less consistent, results.

While the health services provided to Special Olympics athletes in conjunction with Special Olympics Games are valuable in their own right, they are minimal in the context of the overall health needs of persons with mental retardation on a year round basis. The ultimate goal of the Special Olympics Healthy Athletes program is to create a legacy of care for persons with mental retardation. The practicality of such a goal will only be apparent after additional research is conducted to determine whether, in addition to improved health professional attitudes, active commitments to outreach and the care of persons with mental retardation can be realized in providers' home clinics, hospitals and practices. Another important question is whether health professionals who have had such experiences subsequently reach out and encourage colleagues to become providers of care to persons with mental retardation. Only when this happens to a significant degree can the goals espoused in Healthy People 2010 (3) be achieved for all people.

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