Preparing Health Professionals to Support Health and Well Being for People with Intellectual and Developmental Disabilities

An Interdisciplinary Perspective

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Special Olympics Today

Sports at the core:
- 32 Olympic-type sports
- 49,778 annual competitions
- World Games every two years
- Major Regional Games

Broad scope:
- Programs in 170 countries
- 3.7 million athletes
- 275,000 coaches
- 847,000 volunteers
But....

How did a sports organization...

Become a public health organization???
We Really Had No Choice!

BE A FAN OF ACCEPTANCE, DIGNITY, AND THE HUMAN RACE.
# Health Disparities

Findings from past four Special Olympics World Games (average age=25)

<table>
<thead>
<tr>
<th>HEALTH PROBLEM</th>
<th>PERCENT (%)</th>
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</thead>
<tbody>
<tr>
<td>Untreated Tooth Decay</td>
<td>45.7%</td>
</tr>
<tr>
<td>Referred for Urgent Follow Up Care</td>
<td>12.1%</td>
</tr>
<tr>
<td>Failed Hearing Tests</td>
<td>25.2%</td>
</tr>
<tr>
<td>Low Bone Density</td>
<td>13.4%</td>
</tr>
<tr>
<td>Eye Disease</td>
<td>11.3%</td>
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<tr>
<td>Gait Abnormalities (feet)</td>
<td>41.6%</td>
</tr>
<tr>
<td>Bone Deformities</td>
<td>15.1%</td>
</tr>
</tbody>
</table>
Convening healthcare providers and our athletes to improve health:
Special Olympics Healthy Athletes®
Goals of Healthy Athletes

• IMPROVE access and health care for Special Olympics athletes at event based health screenings.

• Make REFERRALS to local health practitioners when appropriate.

• Cultivate SYSTEMS of care at the local level.

• TRAIN Health Professionals and Students (15,000+/year).

• ADVOCATE for improved health policies and programs for persons with intellectual disabilities.

• Collect, analyze and disseminate DATA on the health status and needs of persons with intellectual disabilities (Electronic Health Record).
Personal Health Record
SO Athlete PHR Pilot Program

A secure, comprehensive life-long electronic personal health record online and portable offline

- Used by athletes, carers and healthcare professionals
- Anywhere in the world, multilingually

Uses core strengths of communication and mobile technology to:

- Provide 2-way interactive cellphone access to personal health record, alerts, reminders, care plans and health promotion
- Guarantee continuity of information
- Transform co-ordination of care
- Achieve long-term improvement in health
Convening Healthcare Providers and Our Athletes to Improve Health:
Special Olympics Healthy Athletes®

- 1.2+ million health screenings
- 90,000+ healthcare professionals trained
- 75,000+ eyeglasses distributed
Training of Healthcare Professionals

Surveys of 2,500 Med & Dental School Deans, Residency Directors and Students

• 81% of medical school students say they are not getting any clinical training and 66% say they are not getting enough classroom instruction

• Over 80% of Deans say that “lack of curriculum time” is the primary reason

• Three-quarters of students say they are interested in treating people with ID as part of their career

On average, in the US, a person with ID would have to contact 50 doctors before finding one who had specific training and experience in treating people with ID; it is likely worse elsewhere in the world.
Special Olympics Provider Directory

- Web-based data of healthcare providers in the US who are willing to be contacted for care by our athletes
- Currently, there are only 1732 members across the US listed in the database, an average of approximately 5 per Healthy Athletes discipline per state.
Training healthcare professionals...

Curricula developed in concert with the American Academy of Developmental Medicine and Dentistry and support from Lions Clubs International and CDC:

• Medicine
• Psychiatry
• Dentistry
• Vision
Training healthcare professionals...

Student Dental Clinic of Universidades Nacional de El Salvador, providing free follow-up care for athletes referred from Healthy Athletes while receiving hands-on training.
What Is the Focus? – Patient View

• Health
• Well Being
• Fairness
• Self Determination
• Decency and Dignity
• Freedom from Pain
• Security and Self Confidence
• “Good Life”
What Is the Focus? – Provider/Policy View

• Morbidity
• Mortality
• Disease Burden
• ROI
• “Entitlement”
• Scope of Practice
• Access
• Life Years/Quality Life Years
Who Are the Key Players?

Physicians, Specialists, Developmental Nurses, Educators, Other Health Professionals, Advocacy Organizations, Government Officials, Behaviorists, Researchers, Economists, Statisticians, Epidemiologists, Policy Leaders, Politicians, Actuaries, Voters, People with ID/DD, Family Members...
And That’s the Challenge