#### SPECIAL OLYMPICS



Robert E. Schilken MD

Special Olympics Virginia athlete and Global Messenger Frank Stephens, wrote an open letter to Ann Coulter, a conservative political commentator, after she called President Obama "the retard" following Oct. 2012 debate



Dear Ann Coulter,

Come on Ms. Coulter, you aren't dumb and you aren't shallow. So why are you continually using a word like the r-word as an insult? I'm a 30 year old man with Down syndrome who has struggled with the public's perception that an intellectual disability means that I am dumb and shallow. I am not either of those things, but I do process information more slowly than the rest of you. In fact it has taken me all day to figure out how to respond to your use of the r-word last night.

I thought first of asking whether you meant to describe the President as someone who was bullied as a child by people like you, but rose above it to find a way to succeed in life as many of my fellow Special Olympians have. Then I wondered if you meant to describe him as someone who has to struggle to be thoughtful about everything he says, as everyone else races from one snarkey sound bite to the next. Finally, I wondered if you meant to degrade him as someone who is likely to receive bad health care, live in low grade housing with very little income and still manages to see life as a wonderful gift. Because, Ms. Coulter, that is who we are – and much, much more.

After I saw your Tweet, I realized you just wanted to belittle the President by linking him to people like me. You assumed that people would understand and accept that being linked to someone like me is an insult and you assumed you could get away with it and still appear on TV. I have to wonder if you considered other hateful words but recoiled from the backlash. Well, Ms. Coulter, you, and society, need to learn that being compared to people like me should be considered a badge of honor. No one overcomes more than we do and still loves life so much. Come join us someday at Special Olympics. See if you can walk away with your heart unchanged. A friend you haven't made yet, John Franklin Stephens Global Messenger Special Olympics Virginia

# Let me win. But if I cannot win, let me be brave in the attempt

Special Olympics Athlete Oath

#### The Foundation

- 1946 –Joseph P. Kennedy Jr. Foundation is established by Ambassador Joseph P. Kennedy Sr.
- Goal is to improve the way society deals with its citizens who have intellectual disabilities (mental retardation)
- 1947 Eunice Kennedy appointed as a trustee of JPK Jr. Foundation
- 1948 1956 JPK Jr. Foundation advocates for research into causes of intellectual disability (ID)



- 1957 Eunice Kennedy Shriver takes over leadership of the JPK Jr. Foundation
- 1958 Eunice and Sargent Shriver begin multiple tours across USA visiting institutions for ID, Recruiting physician-experts to be advisors to JPK Jr. Foundation
- 1959 JPK Jr. foundation donates \$1 millon to establish lab at Mass General -> focus on research into mental retardation first in the world
- Grants to other universities Stanford and Georgetown to advance further research
- ▶ 1960 JFK elected president, makes ID a priority
- 1961 JFK announces establishment of President's Panel on Mental Retardation

- Presidents Panel on Mental Retardation: report provides guidance to develop a "National Action to Combat Mental Retardation"
- Legislation -> National Institute of Child Health and Human Development (part of NIH)
- Approx. 600 million in federal aid for Mental Retardation programs
- More legislation for funding of community based centers for care of people with ID, & training for teachers of children with ID
- November 1963 JFK assassinated

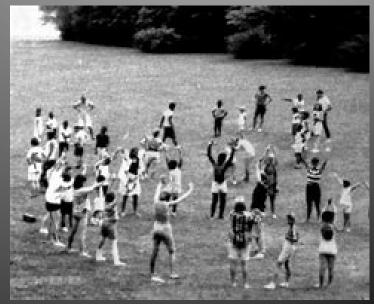
# The Beginning RESEARCH



- Physical exercise and activities for people with ID has positive effects that also carry over into the classroom, employment
  - Journal of Educational Psychology 1958

#### The Beginning of a Movement

- June 1962 Eunice Kennedy Shriver opens a summer camp for young people with ID at her home in Washington D.C.
- ages 6-16
- Volunteer counselors from local H.S. & colleges
- Experts in ID help train the counselors
- Interaction between children with special needs and typical children (1:1)
   "Camp Shriver"



#### The Beginning of a Movement

- July 1962 another camp for Children with ID-> Sunny Grove, opens in DC, supported by funds from JPK Jr. foundation
- This is followed by other day camps for children with disabilities



#### The Beginning of a Movement

- June 1963 2<sup>nd</sup> summer of Camp Shriver
- Summer 1963 Kennedy foundation expands camps nationwide



#### WHY?

Sept 1962 – Saturday Evening Post article "Hope for the Retarded" Eunice Kennedy Shiver revels her sister has an Intellectual disability



Rosemary Kennedy



"Watershed in changing attitudes towards people with retardation"

#### Physical Activity & Recreation

- ▶ 3<sup>rd</sup> Camp Shriver occurs −>1964
- Kennedy Foundation -> assembles experts to develop year-round recreation programs
- 1965; 6 universities offer specialty degrees in recreation for people with ID
- EKS announces National Physical Fitness Program for the Retarded

- 4<sup>th</sup> Camp Shriver opens 1965
- More research published: "physical fitness for the Mentally Retarded"
- 1966 EKS proposes nationwide sports contests for people with ID
- Camp Shriver like day camps provide summer activities for 7000 children

### Special Olympics Games

- 3/29/1968 EKS announces plan for "Olympic" style games for children with ID
- 7/20/1968 1st
   International Special
   Olympics held at Soldier
   Field
- 1000 athletes from US & Canada
- 200 +events
- 12/2/1968 Special Olympics officially incorporated



#### Special Olympics Games

- ▶ 12/1971 USOC gives approval to use the name "Olympics"
- 8/1970 2<sup>nd</sup> SO in Chicago: 1500 athletes 50 states, P.R., Canada & France.
- 8/1972 Los Angeles (UCLA)2,500 athletes -> US & 3International
- 8/1975 Michigan: 3200 athletes.10 countries
- 2/1977 1<sup>st</sup> SO Winter Games
- Colorado. 500 athletes-> skiing & skating.
- 3 major networks cover the event
  - Celebrities join in



## Special Olympics Games World Wide

- By mid 80's SO in 50 countries
- 1986 United Nations launches the International Year of Special Olympics
- ▶ 1987 ABC -> primetime broadcast summer games
- IOC officially endorses & recognizes Special Olympics



### Special Olympics Evolution

- ► 1988 Special Olympics Unified Sports Initiative launches
  - SO athletes & partners





#### **Unified Sports**

- School based programs in PA, include:
  - Bocce
  - Track and Field
  - Soccer
  - 270+ in 2022
  - 300+ in 2023
- Community based programs:
  - Badminton, basketball, bocce, bowling, football, golf, swimming, sailing, table tennis, volleyball, etc.
- 1.4 million participantsWorld wide



#### Special Olympics-World Wide

3/1993 – 5<sup>th</sup> SOI winter games. First games held outside US in: Schladming, Austria







#### Health Initiatives

- //1995 Healthy Athletes debuts in USA
- 1/1997 Healthy Athletes debuts worldwide







#### HEALTHY ATHLETES

- Screening program done at sporting events
  - usually at larger sectional meets or state meets
  - Athletes "referred " for further treatment
- Dentistry -> Special Smiles
- Vision Screening ->Opening Eyes (lions club)
- Hearing -> Healthy hearing
- \*Increased Physical Activity -> FunFitness
- \*Podiatry -> Fit Feet

#### SOPA -MedFest

- Pre-participation physicals
- Station based approach
- basics:
  - Height, weight, vitals, medical & ortho
  - Can add on other parts: vision, dental, etc
- Volunteer
  - Physicians, nurses, trainers, residents



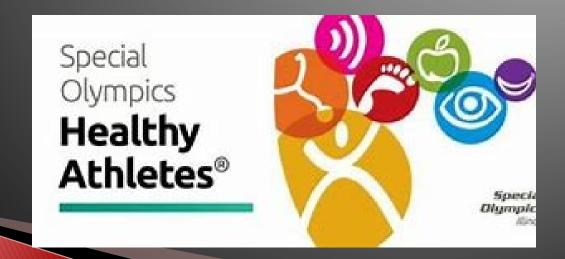




- 6/2003 Ireland holds
   1st summer games
   outside the USA
- 2006 SO surpasses2.5 million athletes
- 10/2007 Shanghai hosts summer games: over 7500 participants from 164 countries
- 8/11/2009 Eunice Kennedy Shriver dies



- 2/2013 winter games held in PyeongChang
- Healthy Athletes screen 2,569 athletes in a day
- 5/2014 4.5 million athletes competed in 94,000 events



- 7/2015 Golisano Foundation donates \$25 million to the Special Olympics Global health
- previous gift of \$12 million in 2012)





- 7/2016 5.3 million athletes and unified partners
- ▶ 170 countries
- ▶ 108,000 competitions
- 2018 Special Olympics celebrate 50 yrs.



#### What is Intellectual Disability?

Intellectual disability (or ID) is a term used when a person has a condition impacting their cognitive functioning and skills, including communication, social and self-care skills.

Three requirements to be diagnosed with an Intellectual Disability:

IQ is below 70 Impacts
in 2 +
adaptive
areas

Mainfests before the age of 18



#### Cognitive Impact of ID

#### • Intellectual Functioning:

- Language development
- Reasoning
- Problem solving
- Planning
- Abstract thinking
- Judgment
- Academic learning
- Learning from experience

#### • Adaptive Functioning:

- Conceptual skills
- Social skills
- Practical skills



6.5 million people in the U.S

#### Demographics



More common in low income countries

1 - 3 % of global population

More common in males

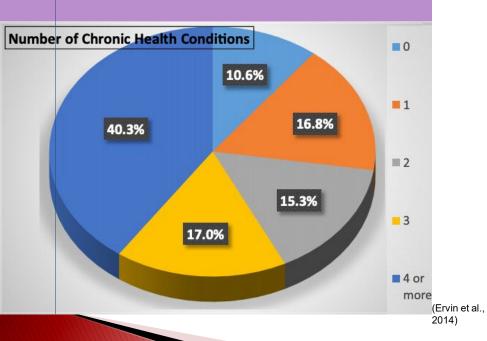
## Diagnostic Groups

Most common syndromes associated with intellectual disability:

- 。Down Syndrome
- 。Fragile X Syndrome
- 。Fetal Alcohol Syndrome
- 。Cerebral Palsy
- Autism Spectrum Disorder



#### Comorbidities



- Obesity
- Cardiovascular conditions
- Diabetes
- Hearing/Vision Loss
- Epilepsy
- Asthma
- Arthritis
- Sensory Deficits
- Psychiatric Disorders
  - Anxiety
  - <sub>o</sub> Depression
  - o ADHD
- Mobility deficits
- Fractures/Osteoporosis

#### Health Barriers

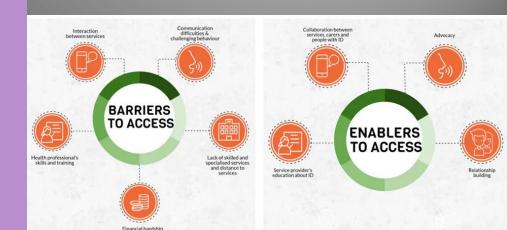
- Inadequate access to quality health care
- Preparedness of health care professionals
- Lack of policies to protect people with intellectual disabilities
- Diagnostic overshadowing
- Attitudes of some health care professionals



# What you can do as a healthcare professional/future professional?

#### Addressing those Health Barriers:

- Providing health services to individuals with ID
- Information provided in an accessible format
- Ensure equality of services for people with ID&ensure their needs are met



#### Health Disparities

Myth 1: Health care professionals are well-prepared to treat people with ID.

Fact 1: The majority of health care professionals are not educated on how to treat people with ID. In one study, 56% of medical students in the United States reported that graduates were "not competent" to treat people with ID.<sup>2</sup>

Myth 2: People with ID have better access to health care than people without ID.

People with ID face significant barriers accessing health care. People with ID have lower rates of preventative health practices, such as dental hygiene, physical activity, preventive screening, and management of chronic conditions.<sup>3</sup> Moreover, people with ID often struggle to find a doctor that knows how and is willing to treat them and, once they get to a doctor's office, challenges with communication and provider knowledge about ID can create additional barriers.<sup>1,2,4</sup>

<sup>2</sup> Holder, M. (2004). CAN project: Curriculum assessment of needs. Washington, DC: Special Olympics. Inc.

<sup>3</sup> Lewis, M. A., Lewis, C. E., Leake, B., King, B. H., & Lindemann, R. (2002). The quality of health care for adults with developmental disabilities. Public health reports, 117(2), 174.

<sup>4</sup> Kerins, G., Petrovic, K., Gianesini, J., Keilty, B., & Bruder, M. B. (2004). Physician attitudes and practices on providing care to individuals with intellectual disabilities: an exploratory study. Connecticut medicine, 68, 485-490.

## Health Disparities

- Myth 3: When people with ID die younger than the general population, it is due to factors associated with their disability.
- The majority of premature deaths for people with ID are due to a lack of health care access and utilization. People with ID die younger than the general population (average of 13 years for men, 20 years for women), as a United Kingdom study found in 2013. The majority of the premature deaths for people with ID were due to delays or problems investigating, diagnosing, and treating illnesses and with receiving appropriate care, while people in the general population who died prematurely passed away due to lifestyle factors.<sup>5</sup>

<sup>5</sup> Hollins, S., & Tuffrey-Wijne, I. (2013). Meeting the needs of patients with learning disabilities. BMJ: British Medical Journal, 346.

#### KEY FINDINGS:

#### SPECIAL OLYMPICS HEALTH RESEARCH



84% of health care providers feel better prepared to treat people with ID as a result of volunteering with Healthy Athletes.8



52% of medical deans report that their students are "not competent" to treat people with ID.<sup>2</sup>



People with intellectual disabilities are much more likely to have unidentified and/or untreated health issues. For example, among Special Olympics athletes globally, 3 in 10 fail a hearing test.



98% of family members agreed or strongly agreed that they will make healthy lifestyle changes for their family as a result of participating in Family Health Forums.



Health care professionals reported positive changes in their perceptions of the abilities of people with ID after volunteering with Healthy Athletes. The greatest changes were around the abilities to 'describe their health to doctor' and 'act appropriately toward strangers'.



Between 2012-2015, more than 37,000 athletes have been engaged in wellness opportunities through Special Olympics Health programming.



As of 2016, 1.9 million health screenings have been conducted, helping athletes and families understand their health needs.



Globally, adults with intellectual disabilities (SO athletes) are more than two times as likely to be obese compared to adults without intellectual disabilities



Healthy Athletes helps athletes and parents identify health issues and get needed care. Among U.S. athletes who needed to see a dentist after Special Smiles, 66% of those who returned to Special Smiles had resolved their health issue. Still, this means that 34% of those athletes who needed care did not receive it.



# SOPA Winter games

- Event has been held at 7 springs since 2015
- 350 athletes & 168 coaches
- Alpine skiing
  - Beginner
  - Novice
  - Intermediate
  - advanced
- Cross country skiing
- Snow shoeing



### SOPA

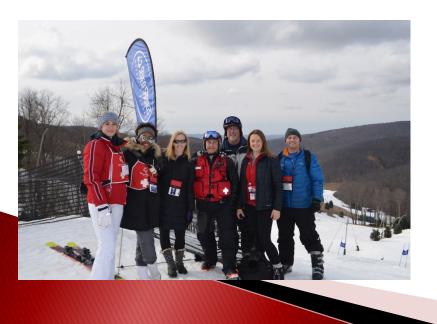
Medical Director for the Winter Games

- 2 Medical Coordinators
- 7 Athletic Trainers –certified
- 16 student athletic trainers from Duquesne, Cal U & FLA
- 3 Primary Care SportsMedicine Fellows



















## SOPA Summer Sports Camp

- 1 week long sleep over camp
- Antiochian Village, Bolivar PA
- 200 campers 14-64 y.o.
- Camp counselors (high school & college age)
- Coaches
- Administrators





## SOPA Summer Sports Camp

- Athletes learn/practice new sports
- Swimming, basketball, softball, tennis, volleyball, golf, bocce



# 10 Tips for Working With People With Intellectual Disabilities

- 1. Do not call them kids. Athletes range from ages 2 to 78+!
- 2. Use clear, simplified language and try speaking slower, not louder. Our athletes have an intellectual disability of varying degrees, but they are not all necessarily hard of hearing—speaking more loudly won't make them understand you better.
- 3. **Set expectations.** Many of our athletes need to know ahead of time what will happen. As you go through your procedures, describe what you will be doing now, and perhaps the next one or two steps that will follow as well.

# 10 Tips for Working With People With Intellectual Disabilities

- 4. Treat them as you would your peers. Do not speak down to them. They love a good joke, tease, or challenge just like we do.
- 5. **Draw boundaries.** Do not allow them to get away with bad behavior—just as you wouldn't allow someone without intellectual disabilities to behave badly.
- 6. Ask them their thoughts and allow them to answer. Don't put words in their mouths.
- 7. **Ask if you can help them** before acting and assuming they actually need help.

# 10 Tips for Working With People With Intellectual Disabilities

- 8. Expect to get a lot of questions. Many of our athletes are very curious about what you are doing and also just about you. If the questions get too invasive, it's okay to say, "I'm not comfortable with answering that."
- 9. Have fun and enjoy their candor! Be prepared for their bluntness. Our athletes are very honest.
- 10. Be enthusiastic, upbeat, and professional. And if it's overwhelming, it's also okay to ask for a break to reset where your mind is.

### To join the Survey, go to

# PollEV.com/Ortho2022

Enter your name
answer every question
click **SUBMIT** at the end



# Special Olympics

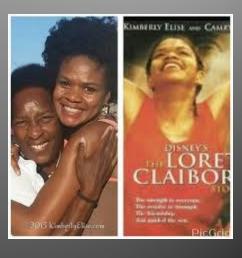
# Loretta Claiborne











## Get involved



## Speaking to Athletes

https://www.youtube.com/watch?v=nc9aAY6-ujQ

# Introduction to Special Olympics

#### Mission:

To provide year-round sports training and competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in a sharing of gifts, skills, and friendship with their families, other Special Olympics athletes, and the community.



Special Olympics was created in the early 1960s when Eunice Kennedy Shriver saw how unjustly and unfairly people with intellectual disabilities (ID) were treated



In addition to sports training and competition, Special Olympics provides free health screenings through Healthy Athletes for:



(Special Olympics, 2020)

# VERBAL COMMUNICATION

- Treat them like adults if they are an adult
- Be flexible & adaptable
- Use clear, concrete language
- Provide specific instructions
- Use person-first language
- Ask them their thoughts
- Be enthusiastic, upbeat, professional, and have fun



<sup>\*</sup>More information can be found on page 20 of the guide



## PERSON FIRST LANGUAGE

Do say	Do not say
Person who has/ person with/ person who has experienced	Victim of/ crippled/ suffering from/ afflicted by. Do not use words that invite pity or reinforce impressions of frailty or dependence.
Wheelchair user/ person who uses a wheelchair	Wheelchair bound or confined to a wheelchair. Remember that a wheelchair can represent freedom to its user.
Person with a disability	Invalid. Don't equate illness with disability.
Person who has epilepsy	Epileptic. Remember this is a person first not a medical condition.
Person who has cerebral palsy	Spastic
People with disability/ with autism	The Disabled/ The Autistics. This makes people with disabilities seem like a group who are separate from the rest of society

(IDRS 2009

### NONVERBAL COMMUNICATION

- Athletes will compensate for impairments by building nonverbal communication skills
- When being receptive nonverbally, athletes will:
  - Watch for your smile
  - Pay attention to gestures
- As the health professional you can:
  - Watch for signs of confusion
  - Use more than one method of communication to reinforce what you are saying
  - Utilize eye contact
- Tip: Be attentive to your own non-verbal gestures

\*More information can be found on page 21 of the guide



# Healthy Habits

### What:

- Healthy Habits are conducted in high traffic areas. Healthy Habits are interactive education stations that help build awareness of how healthy habits affect sport performance and everyday life.
- Topics focus on endurance, recovery and internet safety, and education is provided through interactive games and discussions, and reinforced with giveaways related to topics.
- How: Class B Volunteer role
- A Class B volunteer is someone with casual or limited contact with athletes, such as Event Volunteers.

# Performance Stations

### What:

- Performance Stations are events held at, or near, the field of play at competitions that are designed to educate and activate athletes and their supporters in the tenets of fitness: nutrition, hydration and physical activity.
- Performance Station events will remind participants and volunteers that physical fitness is an important part of the mission of Special Olympics. Emphasis should be placed on the athlete and Unified Partner experience, but coaches and parents/caregivers may also gain knowledge and ideas from this event.

### How: Class B Volunteer role

A Class B volunteer is someone with casual or limited contact with athletes, such as Event Volunteers.

# Healthy Athletes

### What:

 Non-invasive screenings designed to offer additional support at no cost to our athletes and their families.

### How:

- Medical students are registered as Class B volunteers.
  - Licensed professionals are registered as Class A volunteers. Class A volunteers must complete their background check through SOPA. The background check is valid for 5 years.

## Medical Volunteer

### What:

- The Medical Volunteer plays an important role in ensuring the health and safety of the athletes at Fall Festival. Volunteers are stationed at competition venues, dining halls, and Olympic town, and are responsible for attending to minor injuries of athletes, which typically includes administering bandages and ice packs for cuts or bruises. Medical Volunteers are required to be CPR certified. They are also expected to notify the Medical Committee via radio of any incidents with major injuries so that EMS support can be dispatched to the location as soon as possible.
- They will also assist the Security Committee and volunteers when addressing incidents.

### How:

Medical students are registered as Class B volunteers.

Licensed professionals are registered as Class A volunteers. Class A volunteers must complete their background check through SOPA. The background check is valid for 5 years.

# HEALTH CARE EXPERIENCES OF INDIVIDUALS WITH ID

- Recognizing the Patients' Health
   Needs
- Impaired Doctor-Patient
   Communication
- Carer's Mediating Roles during
   Consultations
- Patient's Autonomy & Self Determination

