



FAMILY HEALTH FORUM TIPS

PURPOSE: Family Health Forums are designed to engage families of those with intellectual disabilities (ID) in Special Olympics and offer an environment where parents and caregivers can gain direct access to health information, resources, and support. The goal and objectives are to:

GOAL: Conduct increased outreach to the families of those with ID in a diverse set of communities worldwide.

OBJECTIVES:

1. Provide families of Special Olympics athletes with direct access to community leaders, health care professionals, and social service providers;
2. Provide orientation to new families as to what Special Olympics is, the services provided through such initiatives as Healthy Athletes and Young Athletes, and other community-based programs for people with ID;
3. Provide health care professionals, community leaders and social service providers with the opportunity to learn more about the challenges that athletes and their families face, and explore ways to help facilitate better access to health care, education, and inclusive activities.

POTENTIAL TOPICS:

To be successful, Family Health Forums need to address the specific questions and concerns of local family members and need to be sensitive to the cultural and religious needs of the community. In addition to focusing on health, Special Olympics Programs may choose to include service related topics to support families, too. For example:

General Issues:

- Finding the right doctor for your child
- Advocating for your child during doctor's visits
- Recognizing signs and symptoms of a health or behavioral problem
- What to expect when you have a child with ID; adopting a child with ID
- The importance of finding the right doctor to treat your child's specific health care needs
- What to do when a physician refuses to treat your child
- Why pediatric health care providers can't or won't see adult patients
- Does your child need a neuropsychological evaluation before attending school?
- Estate planning/Guardianship
- Getting the right kind of educational plan in school (IEP / Special Ed)

Health Issues:

- Genetics testing
- Geriatric health problems
- Health Promotion: nutrition education, obesity, diabetes, hypertension and malaria prevention, tobacco avoidance and cessation, handwashing education, etc.

Sensory Development:

- Visual
- motor
- auditory
- balance
- reflexes

Supportive Services Available:

- Visual, physical, occupational and sensory integration therapy
- Psychological services and family counseling
- Community services
- Individualized education programs

New technologies:

- Stem Cell Research
- Hyperbaric medicine
- Chelation Therapy
- Integrative technology:

Including information from community partners and Special Olympics Program offerings is also important to consider. For example you might include:

- A member of the local Lions Club to speak to families about Lions Clubs International, the services offered at the local level, and the benefits of becoming a Club member.
- A description of Healthy Athletes, Young Athletes and Healthy Young Athletes (if offered), and why they are important, how family members can get their children to Healthy Athletes, find out results, and follow up as recommended.
- A question and answer period.

POTENTIAL FORUM SPEAKERS:

Family members, staff and community partners can all provide recommendations for speakers and Healthy Athletes Clinical Directors are key resources to help engage health experts and link you with professional organizations. You may also invite speakers from one or more of the following type of agencies:

- Local hospitals
- Universities
- Health ministries
- Health departments
- Advocacy groups
- Support service organizations could also be contacted to secure speakers on various topics.

Each Clinical Director should also be able to identify the appropriate professional organization that may provide expert speakers on specific health topics for people with ID. Some of these international professional organizations include:

College of Vision and Development (COVD) – www.covd.org

Optometric Extension Programs (OEP) - www.oepf.org

Developmental Delay Registry (DDR) - www.devdelay.org

US Autism & Asperger Association – www.usautism.org

Special Needs Alliance – www.specialneedsalliance.com www.specialneedsalliance.com

The Society for Developmental and Behavioral Pediatrics (SDBP) – www.sdbp.org

American Physical Therapy Association – www.apta.org

- APTA has a symptoms and conditions area on the website with some general information - www.moveforwardpt.com/SymptomsConditions.aspx
- APTA has Sections many of which have Speakers Bureaus who can provide experts in the field - www.apta.org/sections/

World Confederation for Physical Therapy – www.wcpt.org/groups

American Association on Intellectual and Development Disabilities – www.aamr.org

Association of University Centers on Disability – www.aucd.org

Be sure speakers know all the details about what you want them to do, when they should arrive, what AV equipment is available and how many attendees are expected. Ask them to bring enough handouts and other free materials for the entire group.

SETTING/LAYOUT

Family Health Forums can occur in different settings:

- 1) as a stand-alone event, outside of any other Special Olympics competition or event
- 2) during a Healthy Athletes or Young Athletes screening, or;
- 3) during a Special Olympics competition. There are advantages and disadvantages to each scenario.

Stand-alone event

Advantages:

- Allows family members to fully participate without any scheduling conflicts.
- Allows for the opportunity to invite other ID populations, who are not yet athletes, as a “recruiting” opportunity.

- Families would be given a unique opportunity to learn about the health and welfare challenges and opportunities their communities can offer as well as have the opportunity to meet with and have dialogue with other families about specific needs.
- Allows for collaboration with other agencies that have ID constituents.

Disadvantages:

- Transportation is required for families to attend an extra event.
- Childcare issues.
- Potential issues for families to secure time off work (depending on when the forum is.)
- May not reach families not already involved in Special Olympics.
- Requires SO staff to plan another event.
- Requires SO staff to secure an additional venue site.
- Appropriate activities may need to be planned concurrently for athletes and potential athletes so that families feel comfortable leaving their family member in order to attend the lectures.

During Healthy Athletes or Young Athletes:

Advantages:

- Allows family members to see what Healthy Athletes and Young Athletes are.
- Give athletes and potential athletes an important activity while allowing families to feel comfortable leaving to attend the lectures.
- Athletes are free to attend all HA venues without conflict of competition schedule.
- Provides the opportunity to invite other ID populations, who are not yet athletes, as a “recruiting” opportunity (as in MEDFEST.)
- Families would be given a unique opportunity to learn about the health and welfare challenges and opportunities their communities can offer as well as have the opportunity to meet with and have dialogue with other families about specific needs.
- Allows for collaboration with other agencies that have ID constituents.

Disadvantages:

- Transportation is required for families to attend an extra event.
- Potential childcare issues.
- Potential issues for families to secure time off work (depending on when the forum is.)
- May not reach families not already involved in Special Olympics.

- Requires SO staff to plan another event.
- Requires SO staff to secure an additional venue site.
- Requires someone to chaperone the athletes and non-athletes while parents are in the session.

During Existing Competition:

Advantages

- Captive audience of attendees.
- Gives families additional options during non-competition times.

Disadvantages

- Not all family members attend competitions.
- Free time for athletes and families are dictated by competition schedule.
- Requires SO staff to plan another event during competition.
- Requires SO staff to secure an additional venue at competition site.
- Restricts attendance to SO athletes/families.
- Less opportunity for community outreach among other agencies

PARTNERSHIP COLLABORATION:

Collaboration at the country level is aimed to increase opportunities for people with disabilities, particularly intellectual disabilities, to actively participate in their communities and access key health, educational and social services. Here are a few to consider in your planning process:

Lions Club International is already supporting vision programs as well as a number of pilot *FAMILY Health Forums*.

UNICEF plays a key role in raising awareness of the abilities and rights of children with intellectual disability.

Mattel's Team Mattel engages employees to volunteer around the world and creates the largest global corporate volunteer team in the history of the Special Olympics movement.