Non-Profit Partners In EHDI

14th Annual Early Hearing Detection & Intervention Meeting
March 10, 2015

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* Lylis Olsen, MS, MPH, CCC-A
  * Consulting Audiologist, AzEHDI Coordinator and HEAR for Kids Project Manager, Grant writer

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Learning Objectives:

* Identify potential Non Governmental Organization (NGO) partners
* Describe roles in EHDI programs that are uniquely suited to NGO partners
* Apply Arizona experiences to opportunities to your state
NGO Partners
Foundations and Organizations

* Small
  - The EAR Foundation of Arizona
  - Hands and Voices
  - Desert Voices
  - Sertoma

* Large
  - Arizona Community Foundation
  - Virginia G. Piper Foundation
  - Nina Mason Pulliam
  - Valley Anesthesiology Foundation
  - St. Lukes Health Initiatives
  - March of Dimes
  - American Academy of Pediatrics (AzAAP)
Governmental Restrictions

- Lobbying
- Legislative or media contact
- Community level grants or fundraising
- Procurement systems
- Receiving financial, equipment, and hearing aid donations
- Receiving payments from individuals or systems for registration fees
- Restrictions on ability to pay for meetings which entail food and beverage, meeting space, and speakers
- Sharing or loaning equipment
Legislative Initiatives
Improving Public Health Outcomes

Lobbying  Educating  Communication
2005
* Established mandatory reporting, public health surveillance system, education and inclusion with advisory committee

2014 HB 2491 Newborn Screening Program
* Mandates Hearing among the panel of newborn screens
  * 98% of Arizona babies have been receiving a NBHS however not mandated in Arizona until the updated legislation this past session.
* March of Dimes-Legislative Affairs Team, the Newborn Screening Advisory Committee and other nonprofits focus on other newborn screenings (CCHD & SCID)
Policy

* Working together to update/change policies which impact hearing screening practices, standards, reimbursement
* Unilateral vs. bilateral eligibility for Early Intervention
* Medicaid and Insurance coverage for Hearing Aids, Cochlear Implants and Implanted Hearing Aids
* Access to appropriate technology
* Input on Administrative Rules
* Contribute to Needs Assessment
Direct Services

HEAR for Kids

* 15 years
* ~$200,000 each year
* Grant and Donation funded
* Newborn Hearing Screening Voucher Partnership with Pediatrix
* Voucher for assessment from community providers
* Loaner hearing aids to any child
* Permanent Hearing aids for those meeting financial qualifications
* Repair and replacement of Cochlear Implant parts and processor
* FM for 0-3

BASICS

* Provide vision and hearing screening to 0-5
* Provide equipment and training to providers
Professional Education

* Leverage their board members and staff to speak openly and discuss issues with providers, medical specialists, and health systems from non-mandatory but best practices
* Many NGOs have dedicated funds for grand rounds, in-services, and other professional trainings
* NGOs have the ability to develop and distribute curricula, materials, and training tools without the cumbersome bureaucratic process
Professional Consultation and Technical Assistance

* Provide expertise
  * Audiology
  * Early intervention
  * Public Health
  * Technical writing/Grant writing
* Part time and as needed assistance
* Community liaison
* Coordination of projects across agencies and organizations
Research

* EFAz’s research program and molecular biology laboratory from 2003-2013
* Studied the genetic basis of hearing related diseases
  * Ongoing human pathologic studies of inner ear disorders
  * Focus on identifying determinants of cholesteatoma pathology

MiMi Macias, PhD


Laryngoscope, 2010 Nov; 120 (11): 2258-63. doi: 10.1002/lary.21141. Increased amphiregulin expression as a biomarker of cholesteatoma activity. Macias MP¹, Gerkin RD, Macias JD.
“Hi, I am from the government. I am here to help.”

* NGOs are often neutral and viewed as neutral when working with school districts, faith-based organizations, and parent groups to provide education and support

* NGOs do not have restrictions on organizing, coordinating, and leading activities

* NGOs have quicker response time to requests and operate outside an 8-5, Monday through Friday schedule
Volunteers and Supporters

- Fundraising
- Community Events
- Legislative/Policy
- Office Support
Arizona Experiences

AzEHDI Professional Training + Chapter Champion + Parent and Family Activities

2014 EFAz Survey of Early Childhood Hearing Screening Programs
Learning Objectives and Discussion

* Learning Objectives
  * Identify potential Non Governmental Organization (NGO) partners
  * Describe roles in state EHDI programs that are uniquely suited to NGO partners
    * Legislative
    * Policy
    * Equipment and Hearing Aids
    * Professional Training
    * Professional Consultation and Technical Assistance
    * Research
    * Parent and Community Education
  * Apply Arizona experiences to opportunities to your state