

STARTING POINTS FOR SERVICE COORDINATORS FOR CHILDREN WITH VISION and HEARING LOSS

This list is not meant to be all inclusive. Consider additions appropriate for the particular child and family you are serving. Be sure to obtain parental consent before contacting the ophthalmologist and audiologist or primary care practitioner and be mindful that some families may choose to share information with you directly.

- Refer the family to Perkins School for the Blind for specialty services related to vision loss. Contact:

Ruth Silverstein at 617-972-7332; Fax: 617-972-7231
email: ruth.silverstein@perkins.org
or Ann Ross at 617-972-7333; Fax: 617-972-7231
email: ann.ross@perkins.org

Families are welcome to contact Perkins staff directly.

- Connect with child's audiologist:
 - Type and degree of loss
 - Plans for amplification, cochlear implant (?)
 - Schedule for ongoing audiological visits
 - Any special concerns?
- Connect with pediatrician/primary care provider
 - Review needs for additional assessments – Ophthalmologist?
Geneticist?
- Check to see if eye doctor has referred child to Mass Commission for the Blind
- Refer the family to MA Deafblind Project at the New England Consortium of DeafBlind Projects www.necdbp.org 617-972-7515
- Review sections of Universal Newborn Hearing Screening Parent Information Kit with family. This is provided by the diagnosing audiologist. If the family does not have it, call Richard Wentworth for a copy. The Kit contains information about the services listed below.

Is the family interested in:

- Family Sign Language program?
- Referral to MCDHH Children's Specialist?
- Referral to Specialty Service Provider(s) for children with hearing loss?

List those in your area:

- Opportunity to talk with other parents of children with hearing loss? (Refer to Family Ties: 1-800-905-TIES (8437))

- Opportunity to talk with staff of Universal Newborn Hearing Screening Program (Refer to: Richard Wentworth at 1-800-445-1255 if they want to speak with a parent of a child with hearing loss; Amarilys Triana at 617-994-9816 if they prefer to speak in Spanish ~~are Spanish-speaking~~)

- Inform family about potential benefits, based on family's financial situation
 - DPH Hearing aid program for income eligible families. For information, contact Community Support Line at 1-800-882-1435
 - MassHealth/CommonHealth
 - Kaleigh Mulligan – info at Community Support Line 1-800-882-1435
 - Catastrophic Illness – info at Community Support Line
 - SSI
 - WIC
 - Food Stamps

- Keep tabs on:
 - Whether family has received unbiased information about communication approaches for children with hearing loss
 - Whether family has received information on the implications of a dual sensory loss
 - Early language exposure
 - Is family providing a language rich environment?
 - Are both parents involved in whatever communication approaches are being used?
 - Are childcare providers involved if learning ASL? (RCP may be able to help with childcare provider training)
 - How frequently the child is wearing hearing aids
 - Can parent troubleshoot the hearing aid?
 - Periodic in-depth assessment of child's language development
 - Need for early referral to LEA
 - (might be time to reconnect with MCDHH Children's Specialists and MCB)
 - Other adaptive equipment needs (e.g., FM system?)

- Refer family to www.e-advisor.us for information about vision loss and it's impact. The aim of this website is to enhance communication among parents, teachers, and doctors.

- Refer family to Perkins School for the Blind website: www.perkins.org

- Check to see if family is interested in:
 - opportunity to talk with other parents of children with vision and hearing loss

- Refer to Massachusetts Association of Parents with Vision Loss (MAPVI) at www.viguide.com/mapvi
- Refer to National Association of Parents with Vision Impairment (NAPVI) at www.napvi.org
- Refer to Federation for Children with Special Needs at www.fcsn.org
- Refer to Family Ties: 1-800-905-TIES (8347) or www.massfamilyties.org
- Refer to Family Voices: (888) 835-5669 or www.familyvoices.org

- developing advocacy and leadership skills
 - Refer to EI Parent Leadership Project at 877-353-4757; www.eiplp.org
 - Refer to MA Families Organizing for Change www.mfofc.org or 800 406-3632

- other sources of information about vision loss and hearing loss:
 - DB link at www.dblink.org National Family Association of DeafBlind at www.nfadb.org
 - web, books, videos
 - D.E.A.F, Inc. at www.deafinonline.org
617 254-4041 TTY/V
(serves primarily adults – but good to know about)