The Nevada Dual Sensory Impairment Project has been very busy this year!

- The 2016 Parent Conference was a success. Parents commented: “I’m happy and more aware thanks to the amazing presenters over the past two days,” “This conference was great. I always learn the most from parents,” and “Loved the format and content of the entire conference.” The planning survey was sent out for the 2017 conference; please look for it and help to plan this year’s exciting conference!

- The 2016 Summer Institute was on effectively communicating with and teaching students with severe, multiple disabilities. This year we are looking forward to another Summer Institute!

- NDSIP presented at the Nevada Association for the Education of Young Children (NevAEYC) conference on the importance of and strategies for identifying vision and hearing impairments as early as possible in order to provide appropriate interventions.

- NDSIP presented at American Council on Rural Special Education (ACRES) conference—on lessons learned from a statewide technical assistance project related to effective implementation of recommendations.

- NDSIP presented at the Assistive Technology (AT) Consortium—a brief overview of deaf-blindness and CVI, strategies to maximize vision/visual adaptations, and cues (touch, tactile, object).

- NDSIP recently conducted trainings with Nevada Early Intervention Staff in Carson City and Las Vegas on planning the transition from early intervention to school on an introduction to deaf-blindness.

- NDSIP had a table at the Partners for Awareness and Community Event—Journey of Hope.

- We have been conducting introductory visits across the state visiting with families that have recently become involved in the project as well as with teachers who are new to the project.

- Additionally, we have conducted numerous school, NEIS, and home TA (technical assistance) visits across the state: Dayton, Las Vegas, Reno/Sparks, and Carson City.
The contents of this newsletter were developed under a grant from the US Department of Education, #H326T130011. However, these contents do not necessarily represent the policy of the US Department of Education, and you should not assume endorsement by the Federal Government.

For past editions of our newsletter, visit our website: [http://www.unr.edu/ndsip](http://www.unr.edu/ndsip)
Western Regional Early Intervention Conference 2017

“The Western Regional Early Intervention Conference (WREIC) is designed to support professionals working with, and families of, children birth to five years old who are deaf/hard of hearing, blind/visually impaired, or deafblind. WREIC has been in place for over 30 years, making it one of the longest running, ongoing early intervention conferences in the country.”

Website:  http://wreic2017.com/

When:  June 14th (pre-conference full-day programs)
June 15 & 16 conference sessions
Where:  Scottsdale, Arizona

Sample sessions:
- Self-determination for children who are deafblind
- Orientation and mobility assessment for infants and toddlers with visual impairment
- Mealtime routines for infants and toddlers who are visually impaired

MEGA Conference 2017
Nevada Center for Excellence in Disabilities
Nevada Department of Education

Nevada’s Schools – from Ready to Action – Investments in Innovation

The 2017 Mega Conference, Nevada’s Schools – from Ready to Action – Investments in Innovation, and will offer quality professional development on how to provide effective instruction using innovative practices in the classroom and school setting.

Website:  http://www.nevadateach.com/mega-2017.html

When:  May 5 – 7, 2017

Where:  Harvey’s Hotel & Casino Lake Tahoe, at Stateline
Finding out your child needs glasses can be an unsettling experience, but it may also bring good news. Corrective lens can make a helpful difference both in your child’s education and in your child’s day-to-day life. They may allow your child to have an easier time seeing your face, seeing schedules (e.g., object or pictures schedules), working on a tablet/computer, completing homework, and/or reading or looking at a book. Glasses can help your child see and recognize important people in his/her life, make it easier for your child to find and play with his/her toys, and recognize objects and places. Glasses may cut down on eye strain and headaches. Glasses do not have to be a traumatic experience for you and your child.

Helpful terms from the American Association for Pediatric Ophthalmology and Strabismus

- **Ophthalmologist** – a medical doctor (a minimum of 8 years of medical training) who specializes in vision and eye care who can diagnose and treat all diseases of the eyes. An ophthalmologist can practice medicine and surgery in addition to prescribing eyeglasses and contact lenses.
- **Optometrist** – a healthcare professional (not a medical doctor) who provides vision care, such as eye exams, vision tests and prescribing glasses and contacts. Optometrists can detect certain eye abnormalities and prescribe a limited number of medications for some eye diseases.
- **Optician** – are technicians who design, verify, and fit eyeglass lenses and frames, and contacts. Opticians do not test vision, write prescriptions, diagnose, or treat eye diseases.

Tips to make a trip to the eye doctor easier:

- Before going to an optometrist or ophthalmologist, call ahead and ask if the ophthalmologist or optometrist has experience working with children with special needs. If the staff does not have experience working with a child with special needs, consider trying to find an office that does.
- Ask if they have experience fitting frames to the face of a child with unique facial features (for example, microtia, a condition in which a child has only one ear; many genetic conditions are signified by facial features of slightly different proportions).
- Ask if you and your child can visit the office before the appointment so your child can become familiar with the office and the equipment.
- Ask if the staff will allow extra time for your child to process the information
- Ask what times are the quietest or least busy and make an appointment accordingly
- Ask the eye doctor if there is a charge to re-fit your child’s glasses if the glasses get bent
- For more ideas and information, see our Tip sheet: Questions for Your Eye Doctor

When you and your child go to get the new glasses, there are two important things to verify before you start encouraging your child to wear his or her glasses.

- **The frames must fit your child’s head correctly.** It is important to work with your child and his or her doctor to pick out frames that are appropriate and comfortable.
  - Make sure the frames do not pinch your child’s nose or ears. This may require several trips to the eye doctor to fine tune; make sure to take the time and plan for multiple trips to ensure the glasses are comfortable. There are many different ways for glasses to stay on your child’s face – frames curling behind ears are only one option – ask about the options available and determine what is most comfortable for your child.

Continued
B. When trying on glasses, have your child play – glasses fit differently when lying on your back, than when sitting in a chair, or looking down to examine something on the ground. Make sure the glasses are comfortable and positioned correctly for your child in all of the positions he/she may play and work in.

C. Remember, even with modifications (like a sports band to hold the glasses in place), to have your child play in a variety of positions; the modification may work great when sitting, but may fail to hold the glasses in the proper place when your child is looking down.

D. If you are having trouble getting the eye doctors to understand how the frames are not working for your child, take pictures of the situations in which the frames are uncomfortable. (More on this below.)

E. If your child’s glasses get bent, simply make an appointment with the eye doctor to get the glasses re-fitted to your child’s face.

- **The lenses must match your child’s prescription and that prescription must be accurate and current.**
  
  If your child is having a hard time wearing the glasses or if his vision is not improved with the glasses, have the prescription checked.

  A. Remember, your child’s vision may change throughout time. For example, a prescription may work one year, however, your child’s vision may change, so the prescription may not work the following year.

  B. To have your child’s prescription checked, make sure to take the glasses with you to the eye exam.

  C. It is important to ask if your child should only wear the glasses during certain activities or throughout the day.

**Remember, your child needs time to adjust to the prescription.** Your child’s vision with glasses is different from what had previously been his normal vision – this change in vision might make your child feel disoriented, dizzy, and/or uncomfortable until he gets used to the prescription. It might take time for your child to realize that he sees more clearly with glasses.

**Ideas on how to help your child tolerate wearing glasses:**

- If possible, have your child help pick out his/her own glasses. If your child helps to choose the glasses, she may like the glasses much better and be more inclined to wear them.

  Consider purchasing a really cheap pair of glasses or sunglasses (e.g., dollar store, supermarket) and practice wearing the glasses. Practice taking the glasses on and off and let the child experience what wearing glasses will feel like. If the glasses you buy for practice actually correct vision, then remember to take the lenses out so that the child does not get blurry vision from the practice glasses. Make it fun to wear the practice glasses!

- Initially, have your child wear her glasses during an activity she enjoys where the lenses will make the most difference (e.g., reading books, watching a movie, playing with toys, doing an art project). This allows your child to see the glasses really do make a difference. Make sure this activity is an interactive one between you and your child and that your child enjoys the activity.

- Build time into your child’s daily routine for wearing glasses. Initially, this time may be very short (e.g., 2-5 minutes). As your child demonstrates tolerance (e.g., does not complain, fight to prevent you from putting the glasses on her face, throw the glasses), gradually increase either the number of times per day the child wears the glasses OR the length of time the child wears glasses.

- Very slowly build up the length of time your child is required to wear glasses.

- Gradually, increase the number of activities in which your child is required to wear glasses.

  A timer may help your child tolerate wearing glasses – when the time is up, the glasses come off. Again, initially set the timer for short periods of time. For some children a visual timer may be helpful.

- **Provide lots of praise for your child whenever she wears her glasses,** keeps them on for the designated period of time, does not complain when you put them on her, puts on her glasses independently, etc.

- Initially, small rewards may be helpful (e.g., stickers, tokens, special toys that are only for wearing glasses). Deliver the reinforcer if your child keeps her glasses on for the designated amount of time.
Just as important as learning how to wear glasses, is learning to take glasses off in an appropriate manner. Teach your child to always hand his glasses to an adult when he takes them off. Praise your child for giving his glasses to an adult, even if he takes them off before the designated time. For example, you might say, “Thank you for giving me your glasses. It is not time to take them off yet” and put the glasses back on your child.

Specialty frames companies that make glasses to customer specifications – for example, these companies advertise they make glasses for children with special needs and unique facial features (e.g., different facial proportions, children with one or no ears, children who wear hearing aids of all types). These companies are not endorsed by NDSIP – this is a list simply for your convenience:

Specs4us - https://www.specs4us.com/
Spokiz – https://spokiz.com

References


Images retrieved from Google Images on February 27, 2017
What are ear tubes?

A tympanostomy tube (also known as a grommet, T-tube, ear tube, pressure equalization tube, PE tube, ventilation tube, or myringotomy tube) are very small plastic or metal tubes surgically inserted into the eardrum. Ear tubes are frequently put into the ears of children who have frequent ear infections and/or persistent fluid buildup behind the eardrum (in this case, the fluid does not drain). “An ear tube creates an airway that ventilates the middle ear and prevents the accumulation of fluids behind the eardrum” (Mayo Clinic, 2013). Frequent ear infections and/or fluid buildup behind the eardrum causes hearing loss and, therefore, can affect speech development.

Why are ear tubes put in?

The Eustachian tubes are a pair of narrow tubes that run from each middle ear to high in the back of the throat. By opening and closing in the throat, the Eustachian tubes help to regulate air pressure in the middle ear, refresh air in the ear, and drain normal secretions from the middle ear (Mayo Clinic, 2013). Upper respiratory infections or allergies can cause swelling, inflammation, and/or mucus to buildup in the Eustachian tubes, which can cause the tubes to become blocked. When the tubes are blocked, fluids build up in the middle ear. “Ear tubes provide an alternative airway to keep the air in the middle ear refreshed, allow for normal drainage, and equalize the pressure in the ear” (Mayo Clinic, 2013).

“This problem is more common in children, in part, because their Eustachian tubes are narrower and more horizontal — factors that make them more difficult to drain and more likely to get clogged” (Mayo Clinic, 2013). As children grow, their Eustachian tubes gradually become more vertical; therefore, they drain more easily.

What conditions cause ear tubes to be placed?

Most commonly, ear tubes are placed in the ears of children who have one of the following conditions:

- Middle ear infections (otitis media) – in general, frequent ear infections are defined as three or more distinct episodes in 6 months or four or more episodes in a year. The placement of ear tubes may help to prevent reoccurring ear infections (Mayo Clinic, 2013).
- Chronic otitis media – is a term that refers to long lasting infections of the middle ear that do not resolve with antibiotic treatment.
- Chronic suppurative otitis media – is a term that refers to a persistent ear infection that results in perforation or tearing of the eardrum.
- Otitis media with effusion frequently results in hearing loss. According to the Mayo Clinic (2013), hearing loss can lead to delays in speech development, communication problems, behavior problems, and poor school performance.

How are ear tubes placed into the ear?

Ear tubes are place in the ear through surgery by an Ear, Nose, and Throat (ENT) surgeon. The surgery is very fast; it typically takes approximately 15 minutes. The child is put under general anesthesia for this procedure. Ear tube surgery is outpatient; that is, the child typically can go home 1-2 hours after the procedure. The surgery consists of the following steps: (1) a small incision is made in the eardrum (myringotomy) with a small scalpel or laser; (2) fluids are suctioned out of the middle ear; and (3) the ear tube is inserted into the hole in the eardrum.

After surgery, the child may be prescribed ear drops.
(e.g., for up to 10 days) to help prevent post-surgery infection and/or minimize fluid discharge from the ear. A follow up appointment to check the function of the ear tubes will be scheduled to occur shortly after the surgery. Follow up appointments will be scheduled to occur throughout the year after surgery (e.g., every 3 months). Depending on the type of ear tubes used, your child may have to wear ear plugs while swimming or bathing to keep water out of his/her ears. Some types of ear tubes allow the child to swim and bath without ear plugs.

Post-surgery, contact your ENT doctor if the child has persistent pain; hearing problems; balance problems; or yellow, brown, or bloody discharge from the ear(s).

What are the benefits of ear tubes?

“Ear tubes help restore ventilation and drainage of the ear. Ear tube placement often results in:

- Reduced risk of ear infections
- Restored or improved hearing
- Improved speech
- Improved behavior and sleep problems related to frequent or persistent ear infections” (Mayo Clinic, 2013)

Reduction or elimination of the feeling of pressure in the ears and pain associated with the pressure

The child will not feel the ear tube in his/her ears.

How are the tubes removed?

In the majority of cases, ear tubes fall out within 6 to 12 months without any intervention (as the child’s ear grows, the tubes are pushed out); the hole in the eardrum heals and closes on its own. In some cases, the tubes need to be removed and the hole in the eardrum may need to be closed surgically.

References and Pictures retrieved from:


Ear image retrieved on May 19, 2014 from, https://www.google.com/search?site=&tbm=isch&source=hp&biw=1366&bih=657&oq=+parts+of+the+ear&gs_l=img.3...2938.7828.0.8506.23.13.0.0.0.0.0.0..0.0....0...1ac.1.44.img..23.0.0.eV07eshTGRA&q=parts%20of%20the%20ear#q=ear+infection&tbm=isch&imgdii=_
What is Kabuki syndrome?

Kabuki syndrome is a genetic disorder that can affect multiple body parts. Kabuki syndrome is recognizable by the very unique facial features that are present in people with the disorder. These facial features are: arched eyebrows; long eyelashes; long openings of the eyelids with the lower lids turned out at the outside edges; a flat, broadened tip of the nose, and large protruding earlobes (Genetics Home Reference, 2011). Recent statistics indicate that Kabuki syndrome affects about 1 in every 32,000 children born in the U.S.

Common complications of Kabuki syndrome:
- developmental delays and intellectual disabilities that can range from mild to profound
- seizures
- small head size (microcephaly)
- weak muscle tone (hypotonia)
- nystagmus (involuntary eye movements)
- strabismus (eyes that do not look in the same direction)
- short stature
- Skeletal abnormalities
- cleft palate
- dental problems, including hypodontia (unusually sharp teeth)
- heart abnormalities
- frequent ear infections
- hearing loss
- early puberty
- vision loss
- gastroesophageal reflux
- behavioral difficulties

Cause and Diagnosis

Researchers at the University of Washington identified mutations in the MLL2 gene as being attributable to as much as 75% of people who have Kabuki syndrome. With this recent discovery a blood test has been developed to assist in the diagnosis of the syndrome. In addition to the clinical blood test, a geneticist familiar with the syndrome will also likely need to be consulted. Geneticists most commonly make a Kabuki syndrome diagnosis by identifying 4 out of 5 of:

1. facial features common to the syndrome
2. skeletal abnormalities
3. immunological abnormalities
4. hyperextensible joints
5. recurrent infections


Treatment and Management

Due to the expansive nature of the disorder in its impact on multiple body parts and functions, children with Kabuki syndrome will likely need a myriad of therapies and supports to access their true potential. These therapies and supports may include occupational therapy, physical therapy, speech therapy, sensory therapy, feeding therapy, and educational supports and adaptations. In addition, these children will likely need assistance in managing their medical care throughout their lives. The following link is to a Medical Management Family Packet that can help guide parents in the medical management of their child’s Kabuki syndrome related issues:

http://kabukisyndrome.com/content/medical-management-family-package

With the proper healthcare and developmental interventions, children with Kabuki Syndrome can be expected to live long and productive lives.

References:

Common complications of Kabuki syndrome:
- immunological abnormalities
- hyperextensible joints
- recurrent infections
- dermatoglyphic abnormalities
- unusual fingerprint patterns
- intellectual disability
- short stature

Taken from http://kabukisyndrome.com/content/diagnosis

3. dermatoglyphic abnormalities
4. intellectual disability
5. short stature

Child with Kabuki syndrome
Hearing–Related Resources for Families

infanthearing.org
• National Technical Resource Center
• Serves professionals within state Early Hearing Detection and Intervention Systems
• Family support page—provides links to family organizations that can help families of children with hearing loss
• Educational and training videos, resource guides
• Hearing aid loaner bank programs
• State specific information (EHDI)

cdc.gov
Search: a parent’s guide for hearing loss
• Information regarding understanding hearing, hearing loss and your child, how hearing is tested
• Information regarding fitting a baby with a hearing device
• How to build language, start communicating
• Support groups, other services available to children with hearing loss and their families, adjustment, etc.
• National organizations and state contacts

http://www.agbell.org/
• Information on options and considerations on how to select a communication approach for their child
• Parent advocacy training courses
• Information for families and professionals
• Information on ages and stages of language development
• Financial aid programs
• Family resources
• Education, next steps for your child
• Bookstores
• And more

deafchildren.org
• Visual language resources; support for child development
• Readings and articles
• Resources for families, educators, and service providers
• ASL tutoring; conferences
• Organization founded by parents of deaf and hard of hearing children
• Resources for educators and parents

This user friendly guide is designed to help parents and teachers with transitions from early intervention to pre-school, kindergarten to first grade, transitions between grades or schools, etc.

This guide provides information to make the transition smoother for the student through having all important information regarding the student in one easy to reference place. It serves to consolidate critical information about the student to make his/her transition easier (for example, information on how the student communicates, instructional adaptations, what he/she likes or does not like, positive behavioral supports, problem-solving techniques, medical information).

If you would like a transition guide, please contact the Nevada Dual Sensory Impairment Project at
Phone: 775-784-6471
Toll free in Nevada: 877-621-5042
Email: mad@unr.edu