



Early Hearing Loss Detection and Intervention

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Imagine, as a newborn baby, not hearing your parents welcome you in to the world with their love and praise. Imagine, as a toddler, being around other children, but not being able to hear what they say. It would be hard to play and talk with them if you could not hear their words and laughter.

Now imagine that same baby is not able to hear, but his parents find out before leaving the hospital that he did not pass the newborn hearing screen. His hearing is checked by an audiologist and Ear, Nose and Throat (ENT) doctor by 3 months of age. He gets hearing aids. A whole new world opens up to the baby. Sounds and gestures come together to make words and language is learned. Communication, listening, and talking with others brings more joy and meaning to his life.

Before the universal newborn hearing screen, many babies' hearing loss was unknown until about 2-3 years of age and caused major delays in speech and language development. Now most babies with hearing loss are picked up early on, around 2-3 months of age. Studies show that children whose hearing loss is picked up before 6 months of age and who get early care have higher speech, language, and cognitive skills than those who are picked up at a later age. It is vital that newborns with a failed hearing screen go on to get a full hearing test and visit with an ENT doctor by 3 months of age.

About 1 to 3 in 1000 babies are born with hearing loss. Some babies who are born without hearing loss are at higher risk than others for developing hearing loss as a young child. A list of risk factors is used to find out which children need one more hearing screen between 24 and 30 months of age.

The risk factors are children:

- who spent 5 days or more in the NICU
- with certain genetic syndromes known to have hearing loss (like Waardenburg syndrome)

- with a family history of childhood hearing loss
- born with deformities of the head or face (like Goldenhar syndrome)
- born with certain infections (like cytomegalovirus, rubella, herpes, and toxoplasmosis)
- with bacterial meningitis
- with severe jaundice as a newborn from high bilirubin
- with a history of asphyxia (very low oxygen) or problems during birth

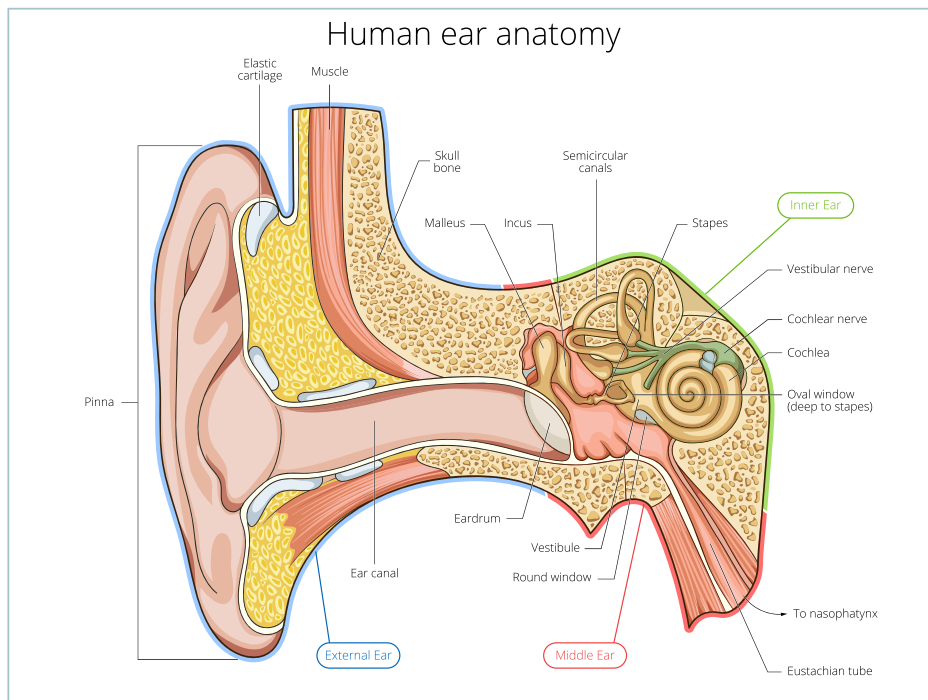
The care of hearing impairment or deafness depends on the cause. Some common types of hearing impairment are:

- **Conductive.** This means there is a problem with movement of sound from outside the ear, through the ear canal, and the ear drum to the cochlea.
- **Sensorineural.** A problem with the special nerve cells in the cochlea or with the auditory nerve which runs from the inside the ear to the brain.

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- An auditory neuropathy problem. The problem has to do with the way the brain processes the information about sound it receives.

Some children may benefit from just having tubes placed in their eardrums. Others may be able to hear with hearing aids or other amplification devices. Those who do not get help from hearing aids may be able to get cochlear implants; devices placed in the cochlea which fire up the cochlear nerve to provide hearing.

Depending upon the success of these devices and the level of hearing, some may choose sign language as a first means of communication. Others may use only spoken language. Many use some combination of the two forms of communication.

A child with hearing loss also qualifies for early intervention, a free service provided by a team of

therapists to help the development of learning, thinking, and communication skills. A speech language pathologist and teacher of the deaf and hard of hearing would be vital to the child's development of these skills. Services would continue through school as long as they are needed, up to age 21 years. The early detection of hearing loss, followed by early intervention of hearing loss, has been shown to be helpful in improving:

- Social
- Cognitive
- Academic
- Gross motor
- Communication skills
- Quality of life

Families often feel overwhelmed with the diagnosis of hearing loss in their children. There are many supportive services available to them such as:

- Iowa Hands and Voices is a parent-driven group which helps give support to families with deafness.
- Family to Family Iowa gives assistance to families of children with special needs.
- Alexander Graham Bell Association for the Deaf and Hard of Hearing aids research, education, and financial aid.
- The Iowa Early Hearing and Detection Intervention (EHDI) program keeps a database of hearing test results and works hard to make sure that all children of Iowa have newborn hearing screens, follow up, and care.

Together we can improve lives of children with hearing loss.



Did you know?

The new University of Iowa Stead Family Children's Hospital will open in December.

There will be 507,000 square feet of new construction plus 56,250 square feet of renovated existing space.

Last year, the UI Children's Hospital cared for 67,239 patients from every county in Iowa, nearly every state in the United States, and several other countries.



500+

**SPECIALLY TRAINED
PEDIATRIC NURSES**

40+

**PEDIATRIC
SPECIALTIES**

170+

**PEDIATRIC
PHYSICIANS & SURGEONS**

650

**UNDERGROUND
PARKING SPOTS**

7,557

LIGHT FIXTURES

5,100

TONS OF STEEL

8,324

ELECTRICAL OUTLETS

14

NUMBER OF FLOORS
12 above ground,
2 below ground

\$360

**APPROXIMATE COST
(IN MILLIONS)**

23

**HEIGHT (IN FEET) OF
MAIN FLOOR LOBBY**

164

FEET TALL
The tallest building
in Iowa City

12

MILES OF DUCTWORK

89

**CHAIRS SIZED JUST
FOR KIDS**

57

**EXCAVATION DEPTH
(IN FEET) FOR RAMP 2**

1,168

NUMBER OF DOORS

Screening, Diagnosing, and Treating Young Children with Autism

By Kelly Pelzel, PhD and Dianne McBrien, MD

Early Screening

Finding autism early is vital, because early treatment can be very helpful to the child and family. That is why the American Academy of Pediatrics (AAP) wants doctors to screen children's development at their well-child exams at 9, 18, and 24 or 30 months. The AAP also urges screening for autism at 18 and 24 months. The guidelines also stress screening any time families have concerns about their child. When screening for autism, doctors are looking for warning signs, such as:

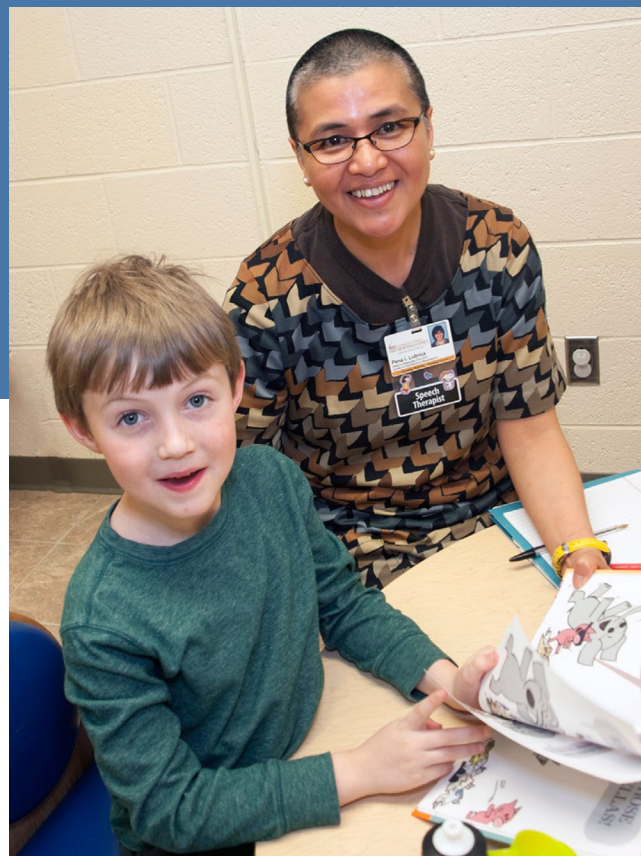
- not making eye contact
- not smiling when people smile at him/her
- not reacting to his or her name
- not making noises to get a parent's attention
- not wanting to play with others

If the doctor thinks there is a concern, the family will be sent to a clinic, like the Center for Disabilities and Development, and/or to an early intervention agency.

There are many free programs to help families who are concerned about their child's development and behavior.

Iowa's Regional Autism Assistance Program (RAP) can:

- screen for autism
- offer support for families waiting for an autism evaluation
- *Learn the Signs, Act Early* is a federal program with the goals of early autism diagnosis, early autism treatment, and autism research. Free tools for families can be found on the website: <https://www.cdc.gov/ncbddd/actearly>.
- Early ACCESS and Early Childhood Special Education are free treatment services for children who have not yet started kindergarten. These programs are offered without a diagnosis. Iowa families with concerns about their young children should seek an Area Education Agency (AEA) evaluation right away to see if they can get services.



Early Diagnosis

Sometimes psychologists, psychiatrists, and developmental pediatricians work on their own when checking a young child for autism. They often work in teams.

A team might have:

- a developmental pediatrician or child psychiatrist
- a psychologist
- a speech-language pathologist

Other team members might be

- an occupational therapist
- an audiologist
- a social worker

An autism team evaluation can take place over more than one day, or it may be done in several hours. There are many tasks. These are:

- Diagnostic interviewing
- Watching the child's social and play skills and behavior
- Reviewing or getting information on the child's skills, such as:
 - hearing
 - thinking
 - communicating

When there are concerns, young children often complete the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), or a similar evaluation. Behavior seen during the ADOS-2 is scored using set rules. Some skills scored in these tests are:

- Eye contact
- Pretend play
- Interest in interacting

After all tasks are done, the provider(s):

- Think about their findings and compare them to the official symptoms of autism spectrum disorder
- Share results and diagnosis with caregivers
- Give advice about treatment and support

If a child is diagnosed with autism, RAP can offer family-to-family support. RAP also helps Iowa families get autism services in their local area. They make matches based on the families' needs and goals. They help families connect to the level of treatment and support they want.

Early Treatment

Early treatment can be critical to a child's future and can help with communication skills, thinking skills, social skills, and motor skills.

- The treatments that are recommended depend on:
 - child's age
 - skill level
 - symptom severity
 - whether or not there are other diagnoses

There are a lot of treatments for young children with autism. Now many have studies showing they help build children's skills. Some of the treatments with research support are:

- Applied Behavior Analysis
- Naturalistic Developmental Behavioral Interventions
- Speech/language therapy
- Other communication treatments (e.g., augmentative communication)

A lot of treatment is often suggested (e.g., 25 hours of intervention per week). Early treatment is a good investment. Children who have early treatment tend to have better long-term outcomes.

Important Websites and Phone Numbers

American Academy of Pediatrics:

aap.org

Learn the Signs: Act Early:

cdc.gov/ncbddd/actearly/index.html

Regional Autism Assistance Program (RAP):

chsciowa.org/regional-autism-assistance-program.asp

(866) 219-9119, extension 2

Early ACCESS (0-3 years old):

educateiowa.gov/pk-12/early-childhood/early-access

(888) 425-4371

Early Childhood Special Education (ECSE):

educateiowa.gov/pk-12/early-childhood/early-childhood-special-education

Reliable Information on Treatments that Have Been Studied:

aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Autism.aspx

nationalautismcenter.org/national-standards-project

asatonline.org

autismpdc.fpg.unc.edu

We have many ways you can stay connected



CenterLines–News you can use from the Center for Disabilities and Development Newsletter is going electronic! Would you like to get the newsletter by email?
If so, email us at:

CenterLines@uiowa.edu

Please give your name and all email addresses where you wish to have the newsletter sent. We will still mail copies to those who want them.



Door Monkey



Assistive Technology for Autism Related Wandering

There are many effective assistive technology devices (AT) to keep kids who have Autism safe. Below are just a few to show you the range from very low tech to higher technology devices. They are easy to find by checking online or at: Stead University of Iowa Children's Hospital Safety Store: uichildrens.org/safetystore

Stop Signs: Placed on doors or windows, these visual prompt stickers make your child stop—or even pause for a moment—which can be critical to preventing a tragedy.

Door Locks

The Door Monkey door lock for interior doors was new to me and I liked many of its features.

Door/Window Alarms These battery-operated alarms are super easy to install and make a loud sound or send a notice to your cell phone.

Temporary Tattoos Colorful and fun, these might be a good option for vacations or even around town.

ID bands can be a simple solution that communicate who to call in an emergency and can also communicate other health information.

Shoe ID Tags Great for kids who can't tolerate wearing an ID bracelet. These are water-resistant and attach easily to shoes with velcro.

My Buddy Tag can be worn on the wrist or ankle and is connected to your phone or iPad to alert you when your child wanders away or out of your area.

There are many available GPS systems that are more appropriate for older children and young adults:

SafetyLINK can work with school and home:

safetylabs.org/b2c/autistic#autistic

AngelSense: angelsense.com

EZ100 Personal Emergency Notifier and

GPS Tracker: eye-zon.com

Freedom Watch: lok8u.com

SafetyNet Tracking: safetynettracking.com

And if your child has a cell phone, there are tracking apps like *Find my Friends* or *Lassy Project* which has features to quickly send out an Amber Alert.

Funding Support for Anti-Elopement/Wandering Devices

Assistive technology (AT) can help people with autism spectrum disorder from wandering away. AT can be as simple as building a fence. It can also be something like using GPS tags to find someone who wanders away and gets lost. AT devices may be costly. But there is financial help for families and caregivers of people with autism.

Funding Sources

Some funding sources for AT devices are:

- The Iowa Medicaid Waiver Program has seven waivers in its home and community-based services (HCBS) waiver program.
- National groups like Autism Speaks and ACT Today.
- Local charities in Iowa like Children at Home, the Shayla Bee Fund and the Henry K. Peterson Foundation.

Online crowd-sourced funding—or crowdfunding—is also an option. It offers a new way to raise funds to support a cause or meet a need. This can help raise money to pay for AT devices. With crowdfunding you need to have the Internet, using a computer or smartphone. It uses social media to share news about the fundraising.

Provider Highlight



Jennifer Luria

Social Services
Iowa State University (BS)
University of Iowa School of Social Work (MSW)

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Government Funding

The Edward Byrne Memorial Justice Assistance Grant Program gives funding for AT devices. Local police departments can apply for this funding for families and providers. Learn more about this program from Dennis Wiggins at the Iowa Department of Public Safety at dennis.wiggins@iowa.gov or 1-515-725-0311.

Added Support to Stop Elopement and Wandering

Support to stop wandering can be more than funding for AT devices. Families and caregivers of people on the autism spectrum with wandering issues should get in touch with their local police to learn about other support. This also lets the police know you might need their help if a loved one wanders away.

The best advice from Iowa Compass: don't give up! Get in touch with us for more tips and support. Find Compass online at www.iowacompass.org or call 1-800-779-2001.

What is a social worker?

Social workers help individuals and families in many ways. At the Center for Disabilities and Development, I work as a therapist and clinical coordinator. I also help organize research projects, do psychosocial assessments, and give referrals for services.

How many years have you been practicing?

I have been practicing as a social worker for over 14 years. Before graduate school, I worked with children with disabilities in their homes, schools, and community. I worked in childcare, and as a respite/SCL provider.

Why did you choose your field?

At first I went to school to be an elementary special education teacher and then went to Washburn School of Law for a year, but I realized that I really wanted to be working with children and families in a hands-on way.

What areas interest you in your field?

Working with small children and their parents. I really enjoy the humor and small victories that children bring every day. I also enjoy working in the fragile X clinic, transition clinic, and promotion of positive sexual expression and abuse prevention for people with disabilities.

Who benefits from seeing a social worker?

It is helpful for all patients to see a social worker because we are able to assess for needs and give referrals to services.

Why did you choose CDD?

I have always wanted to come back to the University of Iowa. I love being a Hawkeye! I strongly believe in our team and the work we do each day to help the lives of children and families.

Provide a quote about what you would say to a patient and family coming to the CDD for the first time to see you?

"Welcome to the CDD! Thank you for choosing us!"

CenterLines

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CenterLines is published quarterly. We encourage subscribers to also read our partner newsletter *Possibilities in Education and Training*. You can find these and others on our website at uichildrens.org/cdd and then clicking on the link for newsletters on the right.

CenterLines, the newsletter of the Center for Disabilities and Development at University of Iowa Stead Family Children's Hospital, is published four times a year. It provides families with current information on child and adult development, issues affecting

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people with disabilities, and resources available to them and their families.

The newsletter is available in print, in Spanish, and also by email.

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The role of the information in this newsletter is not to provide diagnosis or treatment of any illness or condition. We strongly encourage you to discuss the information you find here with your health care and other service providers.