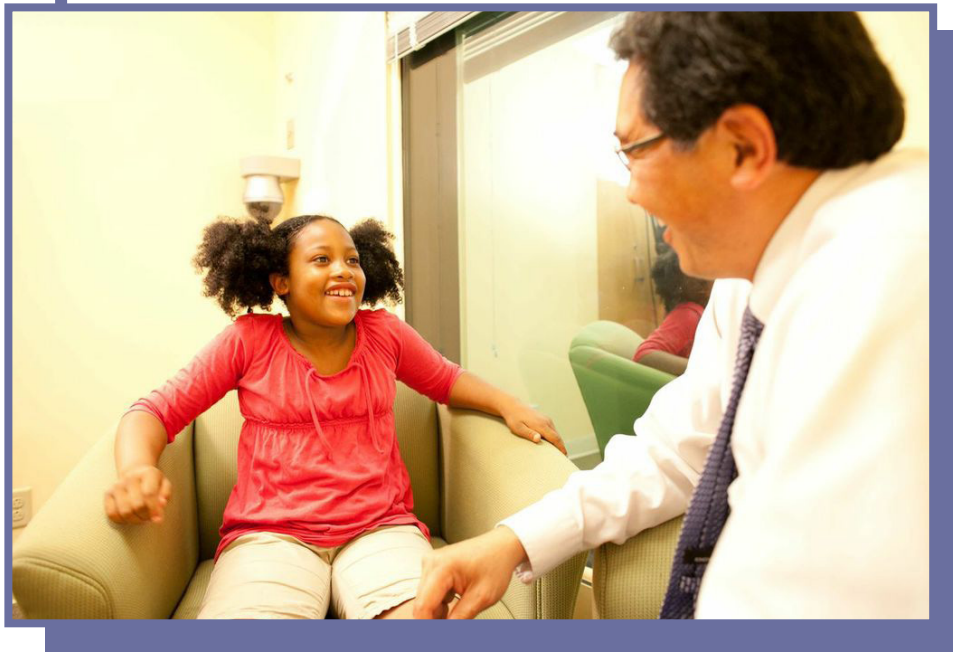


Having an Electroencephalogram (EEG)



*A Guide for
Providers*



These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported in part by cooperative agreement UA3 MC 11054, Autism Intervention Research Network on Physical Health (AIR-P Network) from the Maternal and Child Health Bureau (Combating Autism Act of 2006, as amended by the Combating Autism Reauthorization Act of 2011), Health Resources and Services Administration, Department of Health and Human Services to the Massachusetts General Hospital.

Table of Contents

Introduction	p.2
What is Autism Spectrum Disorder?	p.3
Characteristics of Autism Spectrum Disorder	p.4
Why is This Tool Kit Important?	p.5
Why does an ASD Diagnosis Matter when a Child Needs to Have an EEG?	p.5
Preparing Families for the EEG Procedure	p.7
Sleep Deprivation and Overnight EEGs	p.7
Hospital Resources and Contact Person	p.7
Things to Consider before Starting the EEG	p.8
Ways to Involve the Child and Parent during the EEG	p.8
How Else Can Staff and Families Collaborate to Improve the EEG Procedure?	p.9
What Else Do Families Need to Know?	p.10
Visual Supports	p.10
Sample Teaching Story	p.12
Understanding Sensory Issues and How to Help Children with ASD Cope	p.14
Tips and Strategies for the EEG Procedure	p.15
Understanding Challenging or Aggressive Behavior	p.16
References	p.17
Resources	p.18
Acknowledgments	p.18

Appendixes

Appendix A: Pre-EEG Parent Questionnaire	p.19
Appendix B: Sample Distraction Items	p.22

Introduction: This tool kit was written for providers who work with children with autism spectrum disorder (ASD) who need to have an EEG (electroencephalogram). It gives information about ASD, the unique aspects of the diagnosis that are important to consider, ways that parents and caregivers can help prepare their child before the procedure and how to help children and families during the actual EEG.

At the end of this tool kit, there are several appendices that you might find helpful:

- **Appendix A** is a sample questionnaire that you can go over with parents before their child has his or her EEG to learn more about the child’s communication skills, sensory differences and behavior.
- **Appendix B** contains suggested toys and activities that can help distract a child during the procedure.

A separate tool kit was developed for parents and caregivers of children with ASD. Your hospital or clinic might already have information prepared that you can send to families ahead of time, which can be a great resource. If not, we hope that you will consider creating resources that are unique and specific to your location. You can also share the parent tool kit developed by Autism Speaks with families. The tool kit for parents is available for download at: <http://www.autismspeaks.org/family-services/tool-kits>.

Remember that parents are the “experts” when it comes to their child. They can be an invaluable resource for their child (and providers) during the EEG procedure. It will be particularly important to approach family members and children as members of the team who each have important roles to play. For parents, their role might include helping the child sit calmly, providing them with rewards as necessary or helping them play a game that keeps their hands busy (so they do not pull at the electrodes). Including parents in the process may help increase their sense of competency and help the procedure go more smoothly. We hope the information in this tool kit will encourage communication between providers and families.



What is Autism Spectrum Disorder?

Autism spectrum disorder (often called “autism”) is a neurodevelopmental disorder that affects a person’s ability to communicate and socially interact with other people. People with autism spectrum disorder (ASD) can also have:

- Repetitive or stereotyped behaviors
- Focused interests that may be quite intense
- Strong preferences for routine or “sameness” or differences in how they respond to sensory input

Difficulties with social communication may include:

- Poor eye contact
- Few gestures
- A narrow range of facial expressions or no expressions at all, even when experiencing a strong emotion
- Trouble reading nonverbal social cues, like facial expressions or body language
- Inability to participate in a reciprocal conversation or play activity

There is huge variability in the cognitive and language skills of individuals with ASD. Cognitive skills may range from a significant intellectual disability to above average or superior intellectual abilities. Similarly, some individuals with ASD are nonverbal or minimally verbal while others are advanced in their language development and use. These wide ranges of ability underscore the importance of understanding a child’s unique profile and not making assumptions about his or her cognitive abilities based on verbal skills or vice versa.

*Remember that an individual may have differences in his or her expressive and receptive language skills. For example, a child may not use verbal language to communicate but might be able to understand verbal instructions. Check with a child’s parents or caregivers to learn more about his or her communication skills or areas of difficulty.

In 2013, the American Psychiatric Association published the fifth edition of the Diagnostic and Statistical Manual (DSM-5). In the DSM-IV-TR, which was used by clinicians prior to the DSM-5, there were several diagnoses under the category of Pervasive Developmental Disorders, including Autistic Disorder, Asperger’s Disorder, Rett Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Individuals with Autistic Disorder, Asperger’s Disorder, and PDD-NOS were often referred to as being on the autism spectrum, although they had different diagnoses. In the DSM-5, the diagnosis of “Autism Spectrum Disorder” is intended to capture all individuals on the autism spectrum. Even though the diagnostic labels have recently changed, the information in this tool kit is still appropriate for children who were previously diagnosed with Autistic Disorder, Asperger’s Disorder or PDD-NOS. The most important thing is to approach each child individually, regardless of his or her diagnosis, in order to understand their profile of strengths and areas of difficulty.

Characteristics of Autism Spectrum Disorder

Even though ASD can look very different from person to person, there are some common characteristics that you might see. Many individuals with ASD have difficulty understanding abstract language and can be quite literal. They may respond well to visual information instead of auditory information and may use repetitive language or engage in repetitive motor movements. Some people with ASD are very interested in the sensory aspects of objects, such as how they smell or feel. It is also common for individuals to be very sensitive to sensory input, such as lights, sounds and touch. They may try to avoid situations where there are loud sounds or bright lights or get upset when faced with them. Individuals with ASD may have trouble with transitions and changes in routine and may insist on following particular routines that are meaningful to them but might not make sense to other people.

Despite the fact that ASD is not a rare diagnosis, there are still lots of misunderstandings about people with ASD:

Myth: People with ASD are not affectionate and do not like to be touched.

Truth: Many people with ASD enjoy showing and receiving physical affection, such as giving hugs or engaging in rough-and-tumble play. Just like people without ASD, some individuals are more sensitive to touch or prefer to show affection in other ways.

Myth: People with ASD do not have emotions or do not express their emotions.

Truth: Although people with ASD may not express their emotions the same way as people without ASD, they experience a full range of emotions. Since individuals with ASD can have language difficulties, they express themselves in other ways rather than always “telling” people how they are feeling.

Myth: ASD is the result of bad parenting.

Truth: Autism is a neurobiological disorder. There is no scientific evidence that parenting practices cause autism. Parents often feel guilty or worry that they somehow caused their child to have autism, which is not the case.

Myth: People with ASD have savant or “splinter” skills.

Truth: Having savant skills is the exception rather than the rule.

Myth: People with ASD can't have conversations or relate to other people.

Truth: Due to the huge range of language skills in people with ASD, many individuals are able to have back-and-forth conversations with others. They are also able to establish and maintain close relationships with others.

Myth: Most people with ASD have below average cognitive skills.

Truth: Around 40% of individuals with ASD have low cognitive skills, meaning a large proportion of people with ASD have average or above average intellect.

Why is This Tool Kit Important?

Individuals with ASD are at significantly higher risk of epilepsy compared to individuals in the general population. Recent research suggests that while the rate of epilepsy occurs at 1-2% in the general population, it is commonly reported to occur in 33% of individuals with ASD (Spence & Schneider, 2009). Individuals with ASD and a co-occurring intellectual impairment have an even higher risk of epilepsy. Therefore, these individuals are likely to be referred for EEGs. Many medical personnel who interact with children with ASD may have little experience with this population and not know what to expect. One of the purposes of this tool kit is to provide general information about ASD so providers feel more comfortable when working with children with ASD and their families. Another very important purpose is to help providers identify what information they can gather from families ahead of time to make the procedure as safe and successful as possible. Finally, this tool kit will offer some suggestions regarding how to approach or adjust the EEG procedure to meet the individual needs of a child and his or her family, while making sure the integrity of the data is maintained.

Information or suggestions from this tool kit will also hopefully:

- Help improve communication between families and providers about what each person involved in the EEG procedure can expect
- Improve the efficiency of the procedure and help with patient flow
- Reduce parent and child anxiety about EEGs
- Help the child be cooperative and safe during the EEG
- Improve parents' confidence in their ability to help their child complete an important medical procedure

Many individuals with ASD may need to have subsequent EEG procedures or other medical procedures in their lifetime. If providers can understand ways to minimize distress and foster success for children with ASD (and their families) during an EEG procedure, they can also help these individuals feel more confident about future procedures or medical appointments.

Why does an ASD Diagnosis Matter when a Child Needs to Have an EEG?

There are multiple ways an ASD diagnosis may impact a child's experience when he or she has an EEG:

Communication Difficulties

- Children with ASD may not understand why they need to have an EEG or what is going to happen to them during the procedure, even if an adult has tried to explain the procedure to them.
- They make take things literally. For example, if a nurse tells the child it will take 60 minutes to set up for the EEG and it ends up taking 70 minutes, the child might get upset.
- Some children with ASD understand more language than they produce. Just because a child with ASD does not speak in complete sentences does not mean he or she does not understand what people are saying.
- Other children might talk a lot but not understand as much language. When working with these children, it helps to use shorter, simpler explanations or instructions.
- Some children might want to understand everything that is going on. Providers who work with these children will need to explain each step instead of giving them a summary at the beginning of the procedure.

Trouble with Social Interaction

- An EEG procedure usually means meeting new people. A child with ASD may be nervous or uncomfortable with this and not know how to express emotions appropriately.
- Lots of children with ASD show fewer facial expressions than other children, so it can be harder for people to know how they are feeling. However, this does not mean that people with ASD have less intense feelings.
- Children with ASD may have trouble reading nonverbal social cues, like facial expressions or body language. They may need explanations about what other people are thinking or feeling.

Preference for Routine or Familiarity

- Some children may be very familiar with going to the doctor and might have had either good or bad experiences in the past. For other children, going to a hospital or clinic might not be a part of their everyday routine. A child with ASD may be upset by the new environment and all of the activities that go along with the visit (i.e., spending time in a waiting room, meeting new people, needing to sit still for an extended period of time).

Sensory Differences

- Many individuals with ASD are sensitive to sensory input. They may have strong positive or negative reactions to sounds, smells, sights, tastes, textures or human touch.
- The EEG procedure includes many different types of sensory input, some of which the child has probably never experienced before.

You will learn more about each of these areas and how to work with children with ASD as you read through the tool kit.

Preparing Families for the EEG Procedure

If at all possible, create a written document that you can send to the family ahead of time so they have a chance to review the procedure and learn what to expect, what to bring, etc. Keep in mind that families will have varying levels of education and reading ability – adjust medical language or jargon accordingly.

Sleep Deprivation and Overnight EEGs

If a child needs to have an overnight or sleep-deprived EEG, make sure to explain what this means to families and why it is important to track their child's brain activity while they are sleeping. A child may have had a routine EEG in the past that only lasted a couple of hours in total.

Sleep deprivation prior to an EEG can be stressful not only for the child having the EEG, but also for other family members. Children with ASD are more likely to have sleep difficulties to begin with, so asking parents to disrupt their schedule may feel particularly difficult for the family. When possible, try to work with families to find appointment times that will minimize the negative effects of sleep deprivation. For example, late afternoon appointments should be avoided if the family needs to deprive the child of sleep the night before. It may also help to make specific recommendations about sleep deprivation based on the child's age.

Additional topics to cover with parents of children who need to have an overnight EEG include:

- How to dress their child (i.e., in clothes that unbutton or unzip in the front or in pajamas)
- Any special items their child likes to use for eating, using the bathroom or sleeping (including ventilators or monitors if your hospital or clinic does not provide them)
- Diapers, milk or formula and bottles
- Any special toys or objects the child sleeps with and finds comforting, like a favorite stuffed animal or blanket
- Favorite bedtime stories
- All medications the child takes
- Specific instructions about whether they can leave their child's room (and for how long), who to contact if there is a problem with the equipment or if the child pulls an electrode off and who to contact if the child is having extremely challenging behavior or trouble sleeping

Hospital Resources and Contact Person

Due to the unique characteristics of ASD, many children with this diagnosis will benefit from additional preparation and support before undergoing the EEG procedure. Partnering with Child Life Specialists or other staff who have training in working with children with developmental disabilities can be a validating experience for families and help ensure that their child's comfort and safety is addressed ahead of time. Identifying a contact person in your clinic or hospital who understands the characteristics and associated behaviors of individuals with ASD can be an extremely valuable resource for families. If you are able to identify this type of contact person, make sure to include his or her information on materials mailed to the family ahead of time. When feasible, try to establish these collaborative relationships as soon as possible after a family is referred so staff can address parents' concerns and develop a desensitization plan if needed.

Things to Consider before Starting the EEG

- Remind parents that it might be difficult for their child to use the bathroom after you start putting the electrodes on and give him or her the opportunity to do so.
- Ask which position the child will be most comfortable in – some children may prefer to stay in their parents' laps.
- Some children may do better if the technician stands behind them as much as possible so they do not see the electrodes before they are placed. Other children might need to know exactly what is going to happen next.
- It might be helpful to apply the electrodes in an order that minimizes the chances the child will pull them off. Starting from the back of the head and working towards the forehead also gives the child a chance to get accustomed to the way things feel before the electrodes are applied to more sensitive areas such as the forehead.

Ways to Involve the Child and Parent During the EEG

- Children with higher verbal abilities might want to know each step of the procedure. Use vocabulary and explanations that are appropriate for their receptive language level and include sensory information about what is about to happen. For example, before using the prep scrub on the child's scalp, you can let him or her know that it might feel a little scratchy but will not hurt.
- Parents may also be able to reword or rephrase the explanations you provide in a way they know their child will understand.
- When appropriate and safe, allow children to explore the way the materials smell and feel.
- When possible and if parents think it will be helpful, give the child choices during the procedure. This might be as simple as letting him or her choose the color of the electrode wire that goes on next or where it should go (i.e., the back of the head or the forehead).
- Many children with autism interpret language literally and have difficulty understanding sarcasm or teasing. Therefore, try to use accurate and concrete language throughout the procedure.
- You can offer a child a mirror so he or she can watch the setup process and see the equipment as it is applied.
- Some children may enjoy receiving a sticker for each electrode placed on their head. Once you know how many electrodes need to be placed, you can draw that many boxes on a piece of paper so the child can visually track how many electrodes are done and how many are left.

How Else Can Staff and Families Collaborate to Improve the EEG Procedure?

One option that might work for some families is to visit the hospital or clinic in advance of the EEG to familiarize the child with the environment. If this is an option for your site, make sure families are aware of this possibility as some of them may feel reluctant to ask. Try to identify times when the clinic is less busy (and therefore more quiet) to reduce the chances that a child will get overwhelmed during this pre-EEG visit. Allowing children to see (or smell or hear) some of the EEG equipment can also be beneficial. Some parents may want to take photos of their child sitting on a hospital bed or holding an electrode. They can then look at these pictures with their child at home and talk about the upcoming procedure.

Another possibility is to have a staff member available to go through the procedure with parents and their child. The staff member can use a doll or stuffed animal to demonstrate how the electrodes will be applied and how the child's head will look once the gauze is wrapped around it.

If your hospital or clinic has behavioral psychologists, pediatric health psychologists or Child Life Specialists who are able to work with children ahead of time and practice desensitization exercises with them, make sure families are aware of this option.

Many parents may worry that their child will not be able to complete the EEG procedure, perhaps because of difficult past medical experiences. If parents express these concerns, it is still possible to acknowledge their reservations while remaining optimistic. For example, if a parent shares that their child typically needs to be restrained in order to complete medical procedures, emphasize how helpful desensitization and distraction can be for children with ASD. This can also be an opening for a conversation about what strategies the child's parents have found to be most helpful in the past.



What Else Do Families Need to Know?

Additional written information about how to help the child prepare for the EEG may also be helpful to send to families. This information might include tips for using visual supports or addressing sensory needs – both are described in more detail below.

Visual Supports

One type of visual support that many children with ASD find helpful is a teaching story. This is a type of story that can be used with children to help them understand a certain situation or experience beforehand and what to expect. This story can also remind the child of how they can respond or behave in a situation. Teaching stories are usually most appropriate for children who have some intact receptive language abilities. However, the complexity and length of the story should obviously be adjusted for the child's individual reading level.



Tips for writing a teaching story:

- Make the story specific and personal for each child. This might mean including a suggestion for a coping strategy that a parent knows works for his or her child.
- Write the story from the first person perspective (“I will go to the hospital”) or a third person perspective (“Alex is going to the hospital”).
- Include accurate and detailed information that covers aspects of the situation that might be important for the child. For a teaching story about the EEG procedure, this will probably include the way things look, feel and smell.
- Consider including information about the 5 Ws: who, what, where, when and why.
- Use concrete and positive language (“I will try to sit still” instead of “I will try not to move around”).
- Pictures and photographs can be included and may be helpful for many children. If you choose to use pictures or photographs, make sure they have an appropriate amount of detail, but not too much. Sometimes children with ASD are very literal and might get upset if the pictures in a teaching story do not exactly match the real-life situation.

Carol Gray created a specific kind of teaching story called Social Stories™. For more information, go to www.thegraycenter.org/social-stories.

We wrote a sample teaching story on the next page that describes the EEG procedure. Remember that a teaching story usually works best when it is individually tailored for each child. However, your hospital or clinic may be able to create a teaching story that reflects your specific procedure or protocol. Here are some other websites that have EEG teaching stories:

www.maxishare.com/included/docs/eeg_book_printable.pdf

www.oneplaceforspecialneeds.com/main/library_eeg_test.html

Another support for families could be providing them with a link to a video that documents the EEG procedure. This is especially helpful for families who live far away from the hospital or clinic and cannot arrange a pre-EEG visit. Again, if your location does not have this type of video available, you can find examples online:

www.multicare.org/mary-bridge-video-eeg

www.youtube.com/watch?v=NSE4qbluUxl

Finally, consider creating a document you can send to families that contains pictures of relevant locations and equipment that the child will likely encounter during the EEG. This might include pictures of the hospital entrance, check-in desk, elevators, waiting room, hospital room and EEG materials (such as cotton swabs, gauze squares, electrodes, air hose). Then parents can use these pictures to talk with their children in a way that meets their language and cognitive levels.

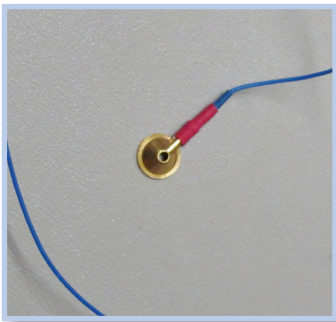


Sample Teaching Story

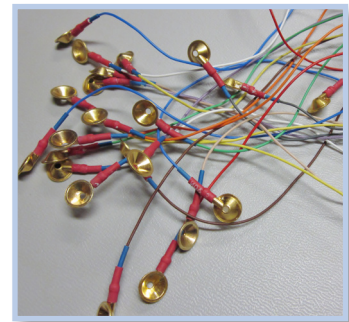
I am going to have something called an EEG test. An EEG test helps doctors learn about how my brain works. I will go to the hospital or a special clinic to have the EEG and might spend the night there. My mom or dad will be with me while the EEG happens. The EEG might feel weird or funny but it will not hurt. I can talk with my mom or dad before the EEG happens. They will help me figure out how to stay calm. I can bring favorite books, games or toys with me to the hospital.

I will start in the waiting room. My mom or dad will talk with people while I wait. I can read a book or play a game. We will go to a small room where I will stay with my mom or dad during my EEG. I will meet people who will help me with the EEG. I will meet someone called an EEG technician. I can ask anyone questions about what is going to happen if I forget. I will try to follow the directions. I will try to sit calmly during the EEG and play with the toys my mom or dad brought. This will help the EEG go faster.

The technician will bring out some supplies for the EEG. I will know about some of these things. Some things might be new. One of the new things is called an electrode. It looks like a little metal circle with a wire attached to it:



There might be lots of electrodes all together with different colored wires:



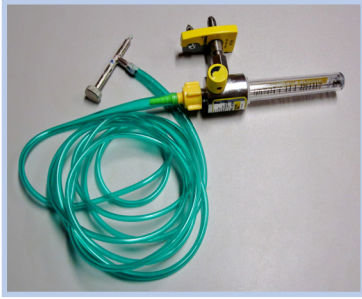
The technician is going to put a tape measure around my head and make little dots on my head with a pen. She makes these dots to know where to put the electrodes on my head. The technician might have to lean close to me while she makes the dots. She will be careful and will not hurt me.



Next, the technician will take a cotton swab and dip it into a paste that helps clean my head. When she touches my head with the cotton swab, it might feel scratchy or weird. Then she will put the electrode in that same spot. The electrode has a little bit of glue on it that will come off my head with shampoo when the EEG is over.

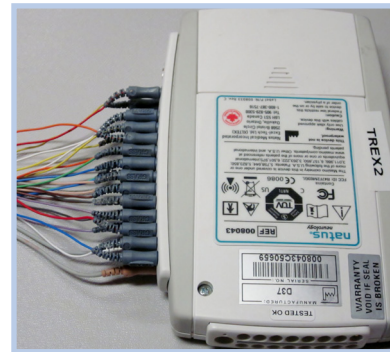
To help the electrode stay on, the technician will use a little piece of gauze dipped in a liquid that smells funny. I might not like the smell but I will keep trying to sit calmly. The technician will put the gauze over the electrode.





She might use a little air hose to help dry the liquid on the gauze. The air hose may be loud and sound like a tiny vacuum cleaner. It blows out cold air on my head. I can ask to use small earphones if the sound of the air hose bothers me. After the gauze is dry, my first electrode is done! The technician will put on more electrodes like this in different places on my head. She might also put some electrodes on my forehead and things that look like stickers on my chest. This is so doctors can see how my heart is beating.

Once all the electrodes are on my head, the technician will use more gauze and wrap my head up like a mummy. This is so all the electrodes stay where they are supposed to. The wires from the electrodes go into a box that keeps track of my brain waves.



My mom and dad will be proud of me for sitting still while all the electrodes were put on! After I have my mummy hat, I might need to look at a flashing light or blow into a pinwheel. I also might take a nap or spend the night in the hospital. This is so doctors can see the different waves my brain makes.

Once the EEG is over, the gauze squares will come off. We will use a special liquid to help get the gauze squares off my head. The liquid might feel slimy or greasy. I might need to wash my hair a couple of times to get rid of all the liquid. After that I will be all done with my EEG!



Understanding Sensory Issues and How to Help Children with ASD Cope

Many children with ASD have trouble with sensory processing (Marco, Hinkley, Hill, & Nagarajan, 2011). This means they respond to sights, sounds, tastes or other sensations differently than other people. Some children might over-respond, like starting to cry when they have something sticky on their hands. Other children under-respond and need a lot of input to react, like a child who enjoys deep pressure hugs and squeezes. Sensory over-responding is more likely to cause trouble during an EEG than under-responding. Many children with ASD do not like having their hair brushed or cut, wearing hats or people touching their head. Children who have these kinds of sensitivities might react to the EEG by feeling nervous, trying to get away or out of the room or acting aggressively. They might feel overwhelmed and not know how to handle the different sensations.

If families have some time between scheduling their EEG appointment and actually coming in, they can work with their child in the interim using desensitization techniques. There are a number of sample activities parents can do with their children ahead of time to help them get used to some of the touch, sound and smell sensory input they will encounter during the EEG. You can remind parents that they might need to practice these steps or activities a couple of times per week or day to have the most impact.

A separate tool kit was designed specifically for parents whose children are going to have an EEG and is available on the Autism Speaks website at <http://www.autismspeaks.org/family-services/tool-kits>. You can refer families to this resource as it contains specific recommendations about how to implement desensitization strategies and help address their child's sensory sensitivities.

During the actual EEG set-up, the following suggestions may help to minimize negative sensory reactions or general apprehension:

- Some children may respond well to hearing about each of the steps before they occur. Giving a verbal cue such as "Now I am going to put a tape measure around your head" may help decrease tactile defensiveness.
- When appropriate, consider allowing the child to touch and smell the materials such as the electrodes and the collodion. You might try rubbing a small amount of the adhesive on their hand so they can feel the texture.
- Ask parents whether they have ways of describing how things might sound, smell, or feel that their child can relate to. For example, if a parent knows that his or her child really enjoys playing in the sandbox, they might be able to compare the texture of the adhesive to having sand on the child's hand.
- If the procedure will involve an air hose, ask if the child would like to push the button to see how it works, what it sounds like, and how the air feels.

Tips and Strategies for the EEG Procedure

Children and their families may be feeling particularly anxious on the day of the EEG. Even if you have gathered information about the child ahead of time, it is always a good idea to ask parents the best way to approach their child before talking to or touching their child.

Some families may have had the opportunity to practice desensitizing their children for the components of the EEG procedure, while others will not know what to expect until they arrive. For the families who did not get a chance to prepare, it is particularly helpful to explain the steps of the procedure and ask questions about their child's cognitive and communication skills, as well as any sensory processing differences. (The sample [Pre-EEG Parent Questionnaire](#) in [Appendix A](#) of this tool kit may be a good starting point.)

Consider setting up the environment so that the child sees a fun toy or activity shortly after entering the room and is quickly engaged. Depending on the age of the child, it may also be helpful to have the EEG materials under a cloth or drape as they might look intimidating to some children (and parents).

One of the most helpful things you and parents can do is find a toy or activity that distracts the child during the setup process. Some families may bring engaging toys or electronics with them for the procedure, but others may not have the financial resources to do so. Having portable DVD players or handheld game consoles available at the hospital for these procedures can be a very useful strategy. Remember to include videos or movies that span a wide range of developmental ages and interests.



Other children may enjoy playing with “fidget” toys or playing games with their parents. Providing children with a small basket of “fidget” toys might help keep their hands busy. Please see [Appendix B](#) in this tool kit for suggestions of toys and activities to have available for families.

When talking with parents about taking the electrodes off, you might want to describe the consistency of the product you use and the fact that it can leave children's hair quite greasy. Parents will appreciate knowing that it could take two or three shampoos to get the product out.



Understanding Challenging or Aggressive Behavior

You have likely witnessed children with or without ASD exhibit challenging behavior during the EEG procedure. It is important to recognize that aggressive behavior from children with ASD is often the result of anxiety, confusion about what is happening and/or reactions to the sensory aspects of the procedure. Because many children with ASD have a hard time understanding, processing and expressing their emotions, they might “show” their feelings through behavior, especially when they are anxious. Many children with ASD demonstrate challenging behavior when they are anxious because they do not know how to communicate what they are feeling.



Having parents or caregivers complete the Pre-EEG Parent Questionnaire at the end of this tool kit (or a similar questionnaire developed by your site) will help identify areas of potential difficulty. This can help facilitate a conversation between family members and the EEG technician about how to best support the child during the procedure. It may be helpful to troubleshoot potential scenarios ahead of time. For example, if a mother indicates that her son kicks people when he is upset, you can ask, “What can our staff do if that happens to support you and your child?” If your hospital or clinic has a policy regarding the use of restraints, share this information with parents ahead of time so they have the opportunity to ask questions.

If a child does exhibit challenging behavior during the EEG procedure, try to collaborate with his or her parents and focus on what you would like the child to do (“Lift your chin up”) instead of what he or she should stop doing (“Don’t move your head”). Remember that what helps some children the most is being very quiet or saying as little as possible. If a child is acting combatively or aggressively toward you, try to remain calm. It may help to reposition yourself so the child cannot reach you or to ask the child’s parents to actively engage their child in some other activity or form of distraction. Maintain a calm and reassuring tone of voice when talking to the child and his or her parents. If there is a possibility that using restraints will be necessary, explain this process to families and gauge their level of comfort with this option.

REFERENCES

Marco, E.J., Hinkley, L. B. N., Hill, S. S., & Nagarajan, S. S. (2011). Sensory Processing in Autism: A Review of Neurophysiologic Findings. *Pediatric Research*, 69, 48R-54R.

Paasch, V., Hoosier, T. M., Accardo, J., Ewen, J. B., & Slifer, K. J. (2012). Technical Tips: Performing EEGs and polysomnograms on children with neurodevelopmental disabilities. *The Neurodiagnostic Journal*, 52(4), 333–348.

Spence, S. J., & Schneider, M. T. (2009). The Role of Epilepsy and Epileptiform EEGs in Autism Spectrum Disorders. *Pediatric Research*, 65, 599-606.

Zaremba, E. K., Barkey, M. E., Mesa, C., Sanniti, K., & Rosen, C. L. (2005). Making polysomnography more “child friendly:” A family-centered care approach. *Journal of Clinical Sleep Medicine*, 1, 189-198.

RESOURCES

The Autism Speaks Family Services Department offers resources, tool kits, and support to help manage the day-to-day challenges of living with autism www.autismspeaks.org/family-services. If you are interested in speaking with a member of the Autism Speaks Family Services Team contact the Autism Response Team (ART) at 888-AUTISM2 (288-4762), or by email at familyservices@autismspeaks.org.

ART en español al 888-772-9050.

ACKNOWLEDGEMENTS

This tool kit was developed by the following individuals: Lindsay Washington, Ph.D., Rocky Mountain Human Services, Aurora, Colorado; Terry Katz, Ph.D., JFK Partners, Autism and Developmental Disabilities Clinic, University of Colorado School of Medicine & Child Development Unit, Children's Hospital Colorado; Reet Sidhu, M.D., Department of Neurology, Division of Child Neurology at the Columbia University College of Physicians and Surgeons, New York, New York; Ann M. Neumeyer, M.D., Child Neurology, Massachusetts General Hospital for Children, Boston, Massachusetts; Tim Benke, M.D., Ph.D., Departments of Pediatrics, Neurology, Pharmacology, Otolaryngology, and Neuroscience Program, University of Colorado School of Medicine/Children's Hospital Colorado, Aurora, Colorado; Patti LaVesser, Ph.D. OTR/L, JFK Partners and Department of Pediatrics, University of Colorado School of Medicine, Aurora, Colorado; Markelle Springsteen B.S., CCLS, Ambulatory Care, Children's Hospital Colorado, Aurora, Colorado.

In addition, we would like to acknowledge the following individuals for their invaluable support, encouragement, and feedback: Chelsey Stillman, PA-C, MPAS, Neuroscience Institute at Children's Hospital Colorado, Aurora, Colorado; Sy Turner, R. EEG T., CLTM, BS., Neurophysiology Lab and Epilepsy Monitoring Unit at Children's Hospital Colorado, Aurora, Colorado; Helly Goez, M.D., Division Director of Pediatric Neurology in the Department of Pediatrics, Stollery Children's Hospital, Edmonton, Alberta. Finally, we are extremely grateful for the suggestions and feedback we received from the parents, caregivers, and providers in our focus groups. These individuals graciously offered to discuss and reflect on their own experiences so this tool kit could be a resource for other families.

The tool kit was edited, designed, and produced by Autism Speaks Autism Treatment Network / Autism Intervention Research Network on Physical Health. We are grateful for review and suggestions by many, including by families associated with the Autism Speaks Autism Treatment Network. This publication may be distributed as is or, at no cost, may be individualized as an electronic file for your production and dissemination, so that it includes your organization and its most frequent referrals. For revision information, please contact atn@autismspeaks.org.

These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported by cooperative agreement UA3 MC 11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS. Published August 2014.

Appendix A

Pre-EEG Parent Questionnaire

If possible, try to obtain this information in advance of the EEG so staff and technicians can be prepared for the child's visit and ask clarifying questions when the family arrives.

Patient Name:	_____		
Parent/Guardian Name:	_____		
Phone Number:	_____		
Child's Date of Birth:	_____	Child's Age:	_____
Child's Scheduled EEG Date:	_____		

Special Questions for Children with ASD

Communication and Behavior:

Is your child able to communicate verbally (i.e., does your child use spoken language to communicate)? Yes No

If no, how does your child communicate with you or let you know what he/she wants?

Does your child use nonverbal communication like gestures or pictures? Yes No

Please check any of the following that your child uses:

- Mayer Johnson Symbols Sign Language
- Picture Exchange Communication System (PECS)
- Sentence board
- Gestures
- Other communication device
- Other: _____

Will you be bringing a communication system with you? Yes No

How much language does your child understand? _____

Are there any symbols/signs that we can have available to assist with communication?

Are there any useful phrases or words that work best with your child to help him/her stay calm?

If you have talked about or practiced the steps of the EEG at home, are there certain words you have used that we can try to use during the actual procedure?
(For example, if a parent has talked to their child about "stickers" being put on his or her head, the EEG technician might be able to use the same language when applying the electrodes.)

Behavior:

Please list any specific behavioral challenges that you would like the EEG team to be aware of:

How can you tell when your child is starting to get nervous or upset?

Please check if your child engages in any of these behaviors when upset

- Trying to escape the situation or room
- Biting
- Hitting
- Kicking
- Screaming
- Crying
- Tensing up his/her body
- Throwing objects
- Getting very quiet
- Exhibiting self-injurious behavior
- Other: _____

When your child gets upset, what do you do? What would you like the staff to do if your child gets upset during the EEG procedure?

Remind the parents that they can feel free to bring objects that are comforting and/or enjoyable for their child for the EEG visit.

Sensory:

Please list any specific sounds or sensations that your child is sensitive to:

Does your child prefer quiet settings? Yes No

Is your child more comfortable in a dimly lit room? Yes No

Is your child sensitive to having his/her head or hair touched? Yes No

Is your child more comfortable in a clutter-free environment? Yes No

Does your child like to be touched lightly or firmly? _____

Please provide us with any additional information that may help us to prepare for a successful EEG experience:

Previous Experiences:

Has your child had an EEG before and if so, how did it go?

What do you think would have made the process easier for you?

Additional Information:

Would it help your child if the technician explained each step of the procedure to him or her?
Yes No

Would help your child if or she could explore the way the materials smell and feel? Yes No

Does your child enjoy making choices? Yes No

Would your child enjoy using a mirror to watch the setup process and see the equipment as it is applied? Yes No

How long can your child sit still, assuming he or she has a favorite toy or object to play with?

How does your child react to new people?

How does your child react to being in a hospital setting?

If possible, try to talk with the parents ahead of time about how staff should handle challenging behaviors from the child. It may be necessary to collaborate with the parents and develop a plan that will help the child be able to complete the procedure. Also discuss the possibility of a backup plan, which may include restraints (depending on your hospital or clinic policy and the parents' level of comfort with this option).

Once you have gathered this helpful information, make sure the people who need it (i.e., Child Life Specialists, technicians, nurses who are taking vitals before the procedure) have access to the information and behavior plan (if applicable) prior to the child's EEG procedure.

Appendix B

Sample Distraction Items

Bubbles



Cause-and-effect toys



Hand-held oil and water toys



Glitter wands



Books

(with flaps, musical buttons or hidden objects)

