

Overview of Autism



Time: Approximately 90 minutes including time for questions and answers. Session can also be broken into two 45 minute presentations. Break point is highlighted in script.

Set-Up: round tables are recommended to facilitate discussion. Approximately 3-4 people per table.

Materials: Chart Paper, Markers, Pens, myth buster cards, fact Sheet from Autism Society of America, Video Clips of Children with Autism (commercially available: *Families with Autism, Let Them Stand Tall*:

<http://www.cds.hawaii.edu/main/products/videos/product001.php>), Family Guidelines

Learning Objectives

1. Participants will be able to identify the 3 areas of impairment associated with autism spectrum disorders
2. Participants will be able to identify the learning characteristics of children with autism.
3. Participants will be able to use the information about learning characteristics to learn about your grandchild
4. Participants will be able to identify myths associated with autism and respond to those myths with facts they have learned in the presentation.

Slide 1 Overview of Autism

- Introduction of presenter. Highlight personal and/or professional experience working with people with autism. As an icebreaker have participants find people who match them on the following characteristics:
 - Favorite hobby
 - Favorite restaurant
 - Favorite season
- Participant introduction. Share name with the large group, say the following: their name, the age of their grandchild and whether their grandchild lives locally or in another community

Slide 2 Learner Objectives

- Read objectives

Slide 3 Did You Know

Hand out the autism fact sheets from the Autism Society of America. Highlight the main points as follows.

- Autism is a spectrum disorder: All children with autism share a certain set of characteristics (impairments in communication, socialization and narrow interests and behaviors), this looks different for each child. Children with autism are as unique as finger prints.
- Show a video clip of Matthew's story from the *Families with Autism* video and Keisha's story. Matthew is a college student who represents the higher end of the autism spectrum. Keisha is a young child who does not have much language. She and Matthew represent different points on the autism spectrum, yet they both have autism.
- About 20-25% of people with autism do not have any mental retardation. They are some times referred to as High Functioning or having Asperger's Syndrome. (Tsai, 1999).
- Autism affects boys at 4 times the rate that it affects girls. (ASA 2001).
- It is currently a source of debate as to whether the number of cases of autism is truly increasing or whether we are just better at diagnosing, we identify children younger and younger and we have broadened the definition of autism. (CDC, 2007).
- What we DO know is that vaccinations **do not cause** autism (refer them to the Center for Disease Control website). We know that genetics and pre and postnatal environmental factors seem to play a role (Harbin 2004). Current studies, suggest that increased exposure to new environmental pollutants, the increased survival of premature infants, genes interacting with the environment, infectious diseases, infection during pregnancy and a disturbance of brain development in utero may influence the development of autism.

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Slide 4 Autism

- Each point will be fully discussed

Slide 5 Communication

- A delay in language is usually the first red flag for parents.
 - Ask the participants “when do children typically begin to speak?” (single words between 10-14 months).
- Some children with autism do not develop functional language. They are not able to use language reliably to get their wants and needs met.
- Children with autism may also have difficulty understanding what other people are saying.

Slide 6 Communication

- Some children may have difficulty using language in a social situation, like having a conversation
- Echolalia example: You say to a child “Do you want some juice?” he says “Do you want some juice?” Repeating it right back
- Delayed echolalia example: The child who knows all the words to Peter Pan. “Look Wendy follow the star to Neverland” or Wheel of Fortune “Thousands of fabulous prizes....”
- Practical use of language. The same child that can recite the words to Peter Pan, or Wheel of Fortune may have a hard time asking for help tying his shoes.

Slide 7 Social Interaction

- Understandably, if you have a hard time using language, you’ll have a hard time making friends
- Some people with autism have low levels of social interest
- Some people with autism have high levels of social interest but don’t know how to go about it. Social interactions can feel like a foreign language.
- ACTIVITY
 - Ask the group to line up across the room. One end of the room will represent people whose idea of a good time is spending the evening with 300 of their closest friends. The other end of the room will represent people whose idea of a good time is sitting alone with a good book, a cup of tea and their cat. Participants place themselves at different points along the continuum of socializing. Point out that it’s the same for people with autism in terms of the levels of their social interests.
- May not understand or use body language or facial expressions. Think about things we use other than words to get our point across. How much of a message would be lost if you just heard the words? (Example: emailing and how easy it can be to misunderstand the message).
- Motivation- Social praise may not be very motivating to them.

Slide 8 Narrow Interests/Repetitive Behaviors

- The difference in their interests can be focus (e.g. the shape, weight and color of bowling balls or license plates) or intensity (only wants to watch Tortoise and the Hare Cartoon)
- Can adhere to rituals that are disruptive- like having to be first through the door or smelling people’s hair).
- Stereotypies (pronounced Stair-ee-ot-o-pees) are repeated movements that appear to be purposeless (rocking, handflapping). Although these movements may appear to be purposeless they can serve a calming function for the person with autism.
- Focus on part of toy- may turn the toy truck upside down and spin the wheels.
- Behavior is a form of communication. Because children with autism have a hard time using language sometimes they use behavior to communicate



Slide 9 Video Guide

- ACTIVITY
 - *Families with Autism, Let Them Stand Proud* Yuuki's story
 - Participants divide their paper into 3 columns: communication, socialization, behavior
 - Write down the characteristics of autism that Yuuki displays that fit into each category.
 - Discuss items written by volunteers. Highlight overlaps.

Slide 10 Revisiting Autism

Review the take away messages thus far before going on to Learning Characteristics

**Break
OR**

This is also a natural break point if you need to break this session into two learning opportunities

Slide 11 Learning Characteristics

In the next several slides we will discuss the learning characteristics of people with autism and how that impacts your interaction and relationship with your grandchild

- Case studies to go along with each learning characteristic are included
- You may also want to look at the Family Guidelines hand-out (provide Family Guideline hand-out). Some families complete this information as a helpful guide to those less familiar with their child. This information may also be useful for you. Consider completing this information with your son or daughter.

Slide 12 Concrete/ Literal Thinkers

Case Study: Mary is Ethan's grandmother. Ethan is 9 years old and has autism. Ethan's mom tells Mary that Ethan is very concrete and literal. Mary is not sure what that means. She is trying to build rapport with Ethan and says, "you are the apple of your mother's eye." Ethan goes into the kitchen, gets an apple and holds it up to his mother's eye. Then Mary understands what his mother was saying about Ethan taking everything literally.

- The children's story book character Amelia Bedelia is an example of literal thinking. Amelia is a concrete literal thinker who works as a maid. When her employer tells her to dust the furniture, she throws dust all over it. When her employer tells her to change the towels in the bathroom, she changes them by cutting holes in them. She doesn't understand why her employer gets so angry and says "You should have told me to UNDUST the furniture and take the dirty towels down and put clean towels up". That's what we mean by concrete literal thinkers.

Slide 13 Concrete/Literal Thinkers

- ACTIVITY
- Have the participants choose one of the sayings provided or choose one that they use often. Have them draw a picture of what that might mean to the person with autism and share with the group!

Slide 14 Overselectivity

George is a grandparent who loves to read to Jose, a child with autism. He reads the story of Little Red Riding Hood to Jose. When he's finished, he asks Jose what the story was about. Jose was focused, not on the story, but on the contents of the basket that Little Red Riding Hood brings to her grandmother's house so he tells George, "It was a story about jam and tea."

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Slide 15 Overselectivity

- Highlight the main point of the task or activity
 - For example a child might overselect the size of the portrait of the president on a 5 dollar bill. When he sees an old bill with a smaller portrait, he thinks it's a totally different bill. He's cuing into the size of the head rather than the relevant features of the number 5, the word five or the fact that it's a picture of Lincoln.
 - What this means for you: You would say "Look it's a 5 dollar bill, it has the number 5, it has the word five. It has a picture of President Lincoln." Then show different examples of the old bill and the new bill. Pointing out the similarities (number, words, president).

Slide 16 Lack of Generalization

Margaret is a grandparent who is helping her teenage granddaughter Maria learn to pick up after herself. She teaches Maria how to pick up dishes in the kitchen and put them in the sink. When she takes Maria out to McDonalds and asks her to clear the table and return her tray, Maria freezes and doesn't know what to do.

- Because children may not be cue into the relevant information of a task or activity, they may have difficulty transferring learned skills to a different setting, situation or person.

Slide 17 Lack of Generalization

- We want to avoid setting up a "Fake McDonalds with faux money and faux food" If you want them to learn to order food at a Mc Donald's go to McDonalds, use real money and teach them to order real food.
- ACTIVITY
 - Have participants choose 1 skill to work on in pairs or groups of threes. List all of the places you could work on that skill.

Slide 18 Distractibility

Mike has a very active young grandson named Antoine. Mike tells Antoine to go get his sneakers on so they can go play at the local park. Antoine is gone for a few minutes. When Mike goes to check on him, he finds that Antoine has gotten distracted by a thread hanging out of his sock and has pulled it and pulled it until he has completely shredded his sock.

- Temple Grandin Ph.D., and arguably the most celebrated person with autism is a professor at Colorado State University. When describing her own autism, she often says her "filtering system doesn't work".
- ACTIVITY
 - Participants get really quiet and think about the ambient noises, and visual distractions in the training room. Share with the group- record their responses on chart paper. (noise from the projector, computer, coughing, street traffic, overhead lights, etc.). Imagine how difficult it would be to pay attention to this lecture if their filtering system didn't work. Add to that the internal states that can be distracting like hunger, stress, exhaustion, sickness.

Slide 19 Distractibility

- Before you take your grandchild somewhere, remember to consider their "filtering system" Also, ask your grandchild's parents if the they have had a previous experience in the setting, and how they prepared.
- If the parents report that a particular setting is difficult for the child consider alternatives Chose a different store- that's less visually stimulating, find out when the lull is at the museum, sit away from the speakers, but near an exit and give your grandchild permission to leave with you if necessary

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Slide 20 Visual Learners

Cecilia is a grandparent of a young girl named Patricia. Cecilia is trying to get Patricia to go into the library and Patricia is refusing by whining and sitting down on the pavement. Cecelia draws a picture of the library followed by a picture of the park and says "Look, first library, then park." Patricia understands what she is being asked to do. She gets up and goes into the library.

- Children with autism learn best by what they see. They may struggle to understand what you're saying, but if you show them, they have a better chance of understanding.

Slide 21 Visual Learners

- What this means for you: Think of alternative ways to communicate a message if they don't seem to understand. It works best to pair words with gestures, pictures, written words, and an example in the form of the finished product.

Slide 22 Need for Routines and Rituals

Esther has a grandson, Josef. Esther and Josef and his mother are walking to his favorite playground to go on the swings. Construction on the street requires that they take a detour. Josef starts to cry and hesitate. His mother explains that he ALWAYS walks the same way to the park and what seems like a small inconvenience for us is a big disruption for him.

- This also makes generalization difficult because they've learned something one specific way in one specific place and it's hard to change.
- Asset, Liability or both? Both!
- Discussion- It is a liability when the routines are disruptive- having to smell every persons hair, always having to be the first through a doorway.
- It's an asset when it's a functional routine that keeps them organized like always brushing and flossing teeth before bedtime.

Slide 23 Need for Routines and Rituals

- What this means for you:
 - Be aware of routines and rituals. If they are not disruptive it is okay to follow the routine or ritual
 - Talk to parents and other family members about how to be supportive and how to encourage flexibility for when change is necessary

Slide 24 Motivation

Paul's grandson is Asif. Paul has figured out that the most motivating thing for Asif is NOT food, candy, toys, etc. but rather a spin in his father's office chair!

- Good job and verbal praise may not be meaningful or motivating to a child with autism. Be specific with the verbal praise "Way to go, finishing your work!" and PAIR it with an object or activity that is meaningful to them.

Slide 25 Guess What's in the Box

- Reinforcement is delivered AFTER a child does something positive. The idea is that they are more likely to do something if they receive reinforcement.
 - This is a reinforcement bin that belongs to a 6 year old with autism. A reinforcement bin or a list of reinforcements is a collection or list of the items, people or activities that the child would find most valuable and would be willing to work for. It contains his most precious items that he is willing to work for.
 - Have the participants guess what's inside. List on chart paper.

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Slide 26 The Contents of the Box Revealed!

- Chances are no one guessed PVC piping and a feather duster. Motivation is different for everyone – some people like to play bridge, others like to go to the movies, some like to read, some like to play golf. The key is finding out what motivates the child with autism. Sometimes you have to think outside the box – like PVC pipe!

Slide 27 Communication

Pat's grandson Rudy is a young man who is headed to college next year. Pat and Rudy have been talking about going to the movies all week. They arrive at the theater and find out that the movie is sold out. Under most conditions Rudy is very articulate. He is so disappointed and upset that he starts to cry loudly. Pat takes out his notebook and a piece of paper and writes down "It's okay Rudy, we can go to the next show. Right now, we can go look at your favorite books in the bookstore." He hands this to Rudy for him to READ.

- As we mentioned earlier, understanding and using language is NOT their premium cable channel.
- Recall a time when they were so stressed (traffic stop, really angry, sad, frustrated, really happy, very surprised). What happened? Was your language affected? Describe what that felt like. Multiply that by 10 to understand how difficult that situation could be to a child with autism who has difficulty with language.

Slide 28 Communication

- What this means for you
 - When your grandchild is upset- TALK LESS., DO NOT TALK MORE. Talking may increase their stress and make the situation worse. Figure out how you could point, draw, write, show etc. But talk less!!!!
 - Have a back up system available. Try to remember to carry a small notebook and pen with you at all times. Use the notebook to write or draw the message or solution. For example, you're in the store and it's too loud, your grandchild begins to scream. He reads so you write in your notebook "You need a break, let's go outside now." And show him the note. If he doesn't read, draw a picture. You don't have to be an artist. Stick men work just fine.

Slide 29 Myth Busters Activity

- ACTIVITY
 - Participants will work in pairs. Give each pair 1 mythbuster card and one blank card. Read the myth and based on this lecture, work with their partner to write the fact on the myth buster card.
 - Have 1 person from each group read their myth and the other person from the group read the fact. Post the facts on the wall around the room and allow the participants to do a gallery walk of the facts.

Slide 30 Questions

Recap of what the participants have learned.

- The 3 core areas of impairment are:
 - Communication
 - Socialization
 - Behavior
- Autism is 4 times more common in boys than girls.
- No two people with autism are exactly alike though they share a common set of characteristics
- Autism is a spectrum disorder.
- People with autism learn best by seeing
- Participants may want to share questions, observations or experiences at this time. If questions are raised that are beyond the trainers expertise, please refer them to the list of recommended readings.

MODULE TWO

Families



Time: Approximate Time 60- 90 minutes WITH grandparent panel
Approximately 30-45 minutes WITHOUT grandparent Panel

Set-Up: Round tables are recommended to facilitate discussion. Approximately 3-4 people per table.

Materials: Chart Paper, Markers, Video Tape (e.g. Families with Autism, Let Them Stand Tall Prompted to Sunny's story or another video tape of video clips of children with autism and their families), list of resources for parent training (if available)

Facilitator Note: This section of the curriculum may be very emotional for participants, particularly those who are just learning about their grandchild's diagnosis. Sensitivity must be in the forefront.

Slide 1 Families

- Ask the group if any of them have had the experience of being a care provider for their grandchild with autism or for another family member with a disability, or chronic medical condition?
 - As they are comfortable, invite them to share this experience with the group. What were some of the joys, what were some of the stressors of this experience? What type of support from others did they find particularly helpful?

Slide 2 Learning Objectives

- Today we are going to talk how having a child with autism impacts your and your family
 - Discuss some of the challenges (e.g. grief and stress)
 - Discuss some of the ways in which you can offer support to your family (e.g. emotional support, respite, sibling support, information gatherer)

Slide 3 Who is Your Family?

- Who are members of your family?
 - Families may be multi-cultural, multi generational, gay and lesbian, biological, foster, adoptive, traditional. Each family defines their own members
 - Some of you may also be "distant" grandparenting. You too can play a role in your family supporting your grandchild with autism. We will discuss ways in which you can support from a distance

Slide 4 Family Stress

- Let's talk about the typical stresses associated with raising children without disabilities. All families experience stress with child rearing. It is HARD WORK!
- Raising a child with a disability is more stressful than raising a child without disabilities. Research suggests that raising a child with autism is more stressful than any other disability category or health impairment including childhood cancer.
 - Research sources on family stress: (Holroyd & McArthur, 1976; Donovan, 1988; Donnenberg & Baker, 1993).
- Having a child with autism is stressful for your family. The parents of your grandchild are experiencing significant stress. As a family member you are also experiencing stress. By working together to meet the needs of your grandchild all family members can decrease their stress levels.

Slide 5 Characteristics of Children with ASD related to family stress

- ACTIVITY: Work in groups of twos or threes. Think back to Module 1 *Overview of Autism*. What was learned around the characteristics of autism that would be a source of stress for families? What contributes to family stress in your family? Write the generated list on paper. These answers may include:
 - Difficulty expressing basic wants and needs
 - Child frustration may lead to aggressive or self injurious behavior
 - Stereotypic and compulsive behaviors
 - Challenges related to social skills
 - Deficits in leisure skills
 - Need for ongoing supervision
 - Sleeping and eating disturbances



Slide 6 Sources of Family Stress

- Reactions from society – Parents become fearful about taking their children with autism out into the community. They are often judged by others if their child engages in problem behavior. Parents often report that it's especially difficult to have a child with autism because it is “a hidden disability” meaning that a child with autism does not look any different from a child who is typically developing. As one mother reported “If my child was in a wheelchair and having a problem in the community, everyone would think I was a saint. When my son with autism, who looks just like everyone else, has problem behavior, strangers judge me to be a bad mother.”
 - Additionally, although the problem behavior in public may have only happened once, parents report that the stress they feel related to that incident is ongoing (Turnbull & Reuf, 2002)
- Feelings of isolation- parents begin to take their children with autism out into the community less and less. Their circle of friends becomes smaller becomes limited to the care providers in their child's life.
- Cultural/Ethnic/Religious Differences: for some families, beliefs foster a strong sense of not being able to ask for help for their child. They may believe they were given the child for a reason and would “never be given more than they can handle” These beliefs may result in the family's reluctance to seek out or accept assistance.
- Concerns over future care giving- Many parents worry, what will happen to my child when they are too old to attend school? What happens when I get too old to care for them? What happens to them when I die, who will take care of them?
- Finances- Many families have substantial out of pocket costs for additional therapies for their child. Most of these therapies are NOT covered by private insurance. A substantial number of mothers of children with autism quit their jobs to become full time coordinators for their children's therapies and education (Sperry et al, 1999). As a grandparent you may have to make decisions about financial support that you may want to contribute. Finances are a difficult topic for many families. Professional advice from financial planners with training in special needs may be helpful in providing guidance and ensure all family members are able to voice their needs appropriately
- Others?? Participants share what they think might be other sources of family stress.
- Feelings of grief-
 - As one mother reported, “I had to mourn the loss of the child I thought I was having and learn to celebrate the child I did have.” Feelings of grief often return as life milestones occur if the child with autism is not participating in those events. These may include: getting invited to birthday parties, going to the prom, learning to drive, getting their first girlfriend/ boyfriend.
 - As a grandparent you will also grieve the loss of the typical grandchild that you thought you were going to have.
 - There are many ways to cope with grief: talking to friends, clergy or a counselor, journaling and exercise can all be helpful.
 - By allowing yourself to talk about it, you will be surprised how many other grandparents have had to deal with the problems of a grandchild with special needs. Twelve percent of children are born each year with some type of disability. Every child is a special, wonderful human being. If you can see the child and not the disability you will be offering the child and the parents a great gift (Thompson, 2009).

Slide 7 Video Guide

- Play the video clip of Sonny's story here.
 - Participants share as a large group the sources of stress for this family.
 - Participants share as a large group, things this family has learned to celebrate.
 - Encourage those to share stories from their own experiences as they are comfortable.



MODULE TWO

Families

Slide 8 Marital/Relationship Stress

- Expectations related to birth of a child have to be readjusted. Couples may come to acceptance of the disability on different timelines. Some couples become closer and operate like a team. Some couples experience stress so extreme that the marriage may experience insurmountable obstacles.
- Without proper intervention, the child's challenges may increase as they get older.
- Stress can have a cumulative effect
- You may be providing support to your child to enable them to maintain their successful marriage with this increased stress of having a child with autism

Slide 9 Sibling Stress

- ACTIVITY: Participants work in twos or threes to generate what they think would be stressful for the brothers and sisters of children with autism. Record their answers on the flip chart. These answers should include:
 - Feelings of embarrassment in front of peers
 - Jealousy over the amount of time their parents devote to their sibling with autism
 - Frustration
 - Personal safety issues- if their sibling is aggressive or destructive
 - Trying to compensate- siblings tend to be "overly good" or more mature than their age would warrant.
 - Concern for parents- worry about their parents stress levels and the security of their family staying in tact.
 - Concerns for their role as future caregivers- questions about what happens when the parents die- will they become responsible for their sibling with autism?
 - Others??

Slide 10 Strategies to Address Family Stress

- Families report they find it helpful to seek support through the strategies listed on this slide.
- Ask participants if they can think of any additional sources of support in their particular community.

Slide 11 What Does This Mean for You

Given these stressors that your family is experiencing you can get involved and be part of the solution and support. By being here at this training you are taking a step towards learning about your autism and particularly about how your grandchild's autism is affecting your family. There are many things you can do.

Emotional Support

- One of the most helpful things you can do is listen. Remember that parents with children with ASD can become very isolated (refer back to slide 5). You may be the only adult conversation or contact with the adult world that parents have during the day.
- Advice giving can be tricky, even when it is solicited. If you listen you will be doing the parents a great service. If your advice is asked for you must truly be thoughtful in your response. It is so difficult for parents to not feel judged by others. Try to develop solutions together as a family vs. dictating what you think needs to happen.

Respite

Parents really need to take a break. Parents of typically developing children and parents of children with autism. You may be able to provide this respite break for parents. With support you can learn how to provide the care to your grandchild that she needs. Other sections of this training will talk about community activities and specific strategies that can lead to success in interacting with a person with autism. The child's parents will know best how to be successful. This time alone with your grandchild will also help you build a unique bond and relationship. It is okay to start small at first (spending an hour at home engaged in preferred activity) and grow your time together as you become more comfortable



MODULE TWO

Families

Sibling Support

This session has addressed some of the challenges that siblings of individuals with autism experience. You can be a support to your grandchild who is typically developing. With one on one time in activities such as visiting the park or sharing an ice cream cone your relationship will be nurtured. A grandparent who has time to listen may be exactly what a child needs to help them get their questions answered and ease their worries.

Information Gatherer:

Parents of children with autism are often in-need of information. Information can range from gathering family medical history to finding local camps that are good at supporting children with disabilities. You can be a wonderful resource as an information gatherer. This is also something that you can do if you are grandparenting from a distance.

Other

What are some other ideas you can think of as a way to offer support? Encourage group to share.

Slide 12: Review of Learning Objectives

We have covered a lot of ground in this session, and a lot of it quite emotional. You may have questions from the content. As have spoken about it can be stressful to have a grandchild with autism. There are lots of different stressors on your family. There are also ways in which you can cope with this stress. You can also contribute to your family's wellness by taking an active, supportive role in your family.

- Dismiss the group

OR

- Provide a short break prior to the optional panel. Have the panelists sit in a semi-circle in front of the participants. Be sure to have water and tissues available. Seat yourself on either end of the semi circle when you begin moderating the panel.

Optional:

Panel Discussion: Try to invite a total of 3-4 family members from different families (be sure to include grandparents!) to come in at the end of the presentation and serve as a panel. It is preferred that their family members are of different ages and represent the spectrum of ASD. So for example, you might invite families with a preschool aged child; elementary aged child; and a high school aged child.

The presenter will moderate a round robin panel. The panelists will sit at the front of the room or at the head table, be sure to have water available for them (and tissues). Be sure to give the panelists the questions AHEAD of time so they can think about their responses.

Question 1: Tell us about who is in your family

(allow each family member to answer before going on to the next question)

Question 2: When did you first notice there was something different about your child's development?

Question 3: How has having a child with ASD impacted your family?

Question 4: If you could tell these grandparents one thing they could do to support their families what would it be?

Then you may open up the discussion to the group of grandparents for a few questions. Be mindful that you will need to monitor the length of time that families answer to ensure everyone has a chance to speak and also limit the number of questions from the group to be mindful of the families' time.

Communication



Time: 45-60 minutes basic communication section
60-75 minutes (with supplement)

Set-Up: round tables are recommended to facilitate discussion. Approximately 3-4 people per table.

Materials: Flip Chart paper, Markers, Index cards

Optional Materials: Mr. Potato Head, Example of Augmentative/Alternative Communication systems

Slide 1 Communication- Strategies, Ideas and Supports

We are going to communicate using something besides spoken words. Provide each participant three index cards. On one card they are to write "Hi, my name is _____ and draw a picture of their favorite thing to do. On card 2 draw a picture of their favorite place to go. On card three draw a picture of their favorite food. They are going to choose someone in the group they do not know, or do not know well and **WITHOUT USING SPOKEN WORDS** introduce themselves to that person using only their cards. Then the person reciprocates. Afterwards participants will verbally introduce each other using the knowledge they gained from the cards.

Slide 2 Review

- Remind the participants of the 3 core areas of impairment for people with autism
 1. Communication
 2. Socialization
 3. Restricted and Repetitive behaviors and interests

Learning characteristics include being strong visual learners, a strong need for routine and that they may learn something in one place or with one person, but have difficulty applying that learned skill in other places or with other people.

Slide 3 Learning Objectives

- Focus today is on communication. Specifically we will discuss what it means to communicate, what is needed to communicate and how we use tools and strategies to support communication when the person does not use spoken language effectively.

Slide 4

- **ACTIVITY:** Ask the participants to list ways that we communicate. Put answers on a flip-chart (e.g. verbal language, gestures, facial expressions, tone)
- Make 2 columns on the chart paper, label one column, Words and the other column ways to communicate. Use the following example to start the conversation. Then have group choose one or two messages and evaluate how facial expression, gestures and tone can affect the message.

Words	VARIABLES/MESSAGE
"thanks a lot mom"	Facial expression of rolling eyes = sarcasm
	Voice volume of Shouting = anger
	Facial expression of smiling = appreciation

Slide 5 Types of Communication

- There are two parts to communication.
- Expressive- What we say or do to make our message understood by others. It is the **OUTPUT** part of communication. We do this by speaking and other methods of expressing ourselves
- Receptive- What we understand when others communicate to us. It is the **INPUT** part of communication. We do this by listening to people's spoken words and other methods of communication such as body language
- People with autism have difficulty with **BOTH** parts of communication. Getting their message across effectively- **OUTPUT** *and* understanding what people are trying to communicate to them- **INPUT**.
- This module will focus on expressive or **OUTPUT**. How can we support individuals with autism to get their message across.



Slide 6 Just Because You Can't Talk Doesn't Mean You Can't Communicate

Lots of communication can occur nonverbally. Also there are ways that individuals with autism can communicate their wants and needs even if they don't have the ability to speak. We are going to talk about different ways that individuals with autism can successfully communicate even if they don't talk.

Slide 7 What is Needed to Communicate

- There are elements that are important to have in place so that a person with autism can communicate effectively. Remember NOT being able to talk, is NOT the same as NOT having anything to say!

Slide 8 Understanding Cause and Effect

- Some individuals with autism do not know that their actions or communications can make something happen. For example a child may love bubbles but does not understand that by pushing a button on a bubble-maker they can CAUSE bubbles. This lack of understanding of cause and effect can occur with language also. We know that if we want something to happen we can use our words and ask. For example I can "ask" a co-worker if I can borrow a pencil if I don't have one with me. Sometimes children with autism end-up using inappropriate behavior because they are not able to use words or other method of positive communication to get their needs met.
- Example: Andre is 4 years old and has not acquired language yet. He loves to build Mr. Potato Head dolls. As he is playing with Mr. Potato Head he sees that his favorite choice for a mouth is missing. Andre can see it under the couch but he can't reach-it. Andre begins crying and then screams. When he cries, his mom will offer him juice because she thinks he might be thirsty, but that's not what he wants. He then screams and she offers to hold him, but that's not what he wants. Finally Andres Mom sits down on the floor with Andre to see if she can console him. When she does this Andre pushes her hand toward the couch where she sees the piece of the Mr. Potato Head toy. She is able to get the toy and finally meet Andre's needs.
- It would be great if Andre had a way to ask his Mom for the toy. Teaching Andre to use pictures is one way for him to learn Cause and Effect and become a successful communicator.

Slide 9 Understanding cause and Effect – Communicating with Pictures

- This is an example of a toy with a picture board. The items on the white board in the middle are pictures of all of the items that a child would need for Mr. Potato Head. This is one way to teach a child with autism how to more effectively communicate and learn cause and effect.
- The child hands over the pictures (cause), one at a time, to a peer or an adult and the peer or adult responds "nose" and hands over the nose (effect). This game can be used with children who do not have language, they hand over the picture, for children with single word language, they hand over the picture AND say the name or with children who can speak in complete sentences, they hand over the picture and say "I want eyes please."
- Given the opportunity to practice and learn that exchanging pictures can result in a CAUSE and a positive EFFECT, Andre will learn that he can effectively communicate in an effective and positive way.

Slide 10 What is Needed to Communicate – Something to Communicate About



Slide 11 What is Needed to Communicate – Something to Communicate About

- Think of the old saying practice makes perfect:
- Example:
 - Rose wants juice.
 - Rose asks for juice by giving you an empty glass
 - Instead of giving her a FULL glass of juice (and thereby limiting her opportunities to request to only once), you give her a small amount of juice which increases her need to practice requesting again and again.
- The more a child is expected to communicate and the more opportunities they have, the more successful and competent they will become.
- It is important to encourage communication with the children. They NEED practice!
- ACTIVITY
 - Participants work in groups of twos or threes. Assign each group an activity or location (e.g. meal-time, park, playing a board game)
 - Encourage them to think of things that would provide the child with several opportunities to practice.
 - Have each group report out the different opportunities a child would have to communicate and how multiple opportunities could occur (e.g. pushing on the swing at the park)

Slide 12 What is Needed to Communicate – Someone with Whom to Communicate

Slide 13 Someone with Whom to Communicate

- Often, adults take the role of initiator with the child becoming the responder. As a result, children may only communicate when someone else initiates.
- Communication is a back and forth process. There is a communicator and a listener. They switch roles throughout a conversation.
- Suggested strategy: Instead of always being the one to initiate the communication with the child, provide communication temptations that will allow the child to initiate. For example hold a preferred toy in your hand and wait for the child to initiate communication by asking you for the toy.
- ACTIVITY
 - Jackson loves to listen to CDs. He goes to the listening corner and has to request a CD to put in his player. He has a choice board to hand over a photograph of his favorite CD to his teacher.
 - Participants work in groups of twos or threes.
 - Use the activities from the “Need to Communicate” (e.g. meal-time, park, playing a board game) and describe how you could “tempt” the child to communicate
 - Share with the group and write down ideas on a chart paper.

Slide 14 Someone with Whom to Communicate

- This picture shows a strategy that was used to teach an 11 year old boy with autism, who did not have language, He was taught to step up to the counter and hand over the envelope to the cashier. On the outside of the envelope, the adult support had written: “I want 1 small pepperoni pizza and 1 small Sprite. Here is \$10.00. Please put my change in the envelope. Thank you!”
- He learned that he had someone with whom to communicate - the cashier.

Slide 15 What is Needed to Communicate - Something to Communicate About



Slide 16 What is Needed to Communicate - Something to Communicate About

- We all like to talk about things that are interesting to us. If something is NOT interesting, we tend to change the subject quickly or remain silent. In fact, at the beginning of this module, we had you draw pictures of your favorite things.
- The same is true for people with autism. Their communication systems, whether it's pictures, words, or written words, should reflect things that THEY find interesting.
- Ask a participant to share 5 favorite things that their grandchild would like to communicate.
- ACTIVITY
 - Have the participants make a list of 5 things they think a child would want to communicate about.

Slide 17 Something to Communicate About

- This picture illustrates items that are desirable to the child, which increases the likelihood that he will communicate.

Slide 18 Something to Communicate About

- Review their list of 5 communication topics. How many times would the child have during the day to use those messages? What good things would the child receive if he/she communicated those messages?

Slide 19 What is Needed to Communicate – A Way to Communicate

Slide 20 What is Needed to Communicate – A Way to Communicate

Slide 21 A Way to Communicate

- Most of us use things other than words to add to (or AUGMENT) our messages- ASK “what are some ways that you add to your message” Examples are provided on the slide, but have them elaborate giving specific examples.
- Sometimes, we don't even use words, we use an ALTERNATIVE to language to get our message across. ASK the participants for specific examples. These might include a stern look to your children during church with a finger held to your mouth.
 - Encourage other examples.
- AAC are strategies and devices that are used by people with disabilities who have trouble communicating effectively.
- AAC can be very simple, or it can involve very advanced technology - Steven Hawking is an AAC user!
- Some of the children you work with will have Alternative/Augmentative Communication devices that give them a way to communicate other than speech. Whether they use gestures, actual objects, communication rings, picture symbols, etc. you will need to make sure the devices are available for use in all settings. Take the device EVERYWHERE you go! We don't leave our tongues inside when we go out to play and children shouldn't leave their devices inside when they got out to play!
- The following slides are examples of Augmentative Alternative Communication

Slide 22 A Way to Communicate - Gestures

- Have participants guess what this child with autism is trying to communicate.
- Answer “STOP!”

Slide 23 A Way to Communicate – Actual Objects

- Ask participants, “If a child with autism handed over this object to make a request, what would they be saying?”
- Answer “A sprite” “time to brush teeth”



Slide 24 A Way to Communicate – Picture Symbols

- This little girl with autism has some language but cannot always get her message across.
- She carries around a ring full of pictures symbols of things that SHE wants and needs to communicate.
- Look closely at the picture.
- Ask participants “What is she communicating?”
- Answer “I have to go to the bathroom”

Slide 25 A Way to Communicate - Picture Symbols Book

- This three ring binder is one way to organize all of the picture symbols a child might use to communicate.
- Inside, pictures are organized into categories on different color coded pages.
- Outside is the communication strip and a couple of choices that reflect the current activity (snack).
- He puts the picture on the “I want _____ strip” and hands it over to the adult.

Slide 26 A Way to Communicate - Written Word

- This child can read and write. He is VERY bright.
- He does not have ANY spoken language.
- When he goes out into the community, the adult supports always make sure to take a write on/wipe off board and erasable markers.
- Here you see him at the beach, working with his adult support person to communicate to her that he wants to play in the sand first and then go in the water to swim.

Slide 27 A Way to Communicate - High Tech Device

- This is just one example of the many high technology devices that are available to people with disabilities that have difficulty communicating.
- To use this particular device, the child presses a button on a screen that might have a picture of “swing.” There is a voice output component, meaning that when he touches the picture, the device will say “I want to play on the swing.”
- Although these types of devices are very “high-tech” they can be simple to use to assist with communication.
- You do need to make sure that if your grandchild uses a device that it is with him any place he would need to communicate (which is everywhere!)

Slide 28 What this means for you

- Have participants look around the room at all of the ideas shared on the chart papers.
- Encourage the participants to share in groups of two or three, one idea or strategy that they would like to use with their grandchild with autism
- Have them also share these ideas with the larger group!

Slide 29 Review Learning Objectives



Slide 30 Choice Making

- Think of the number of choices you make each day (prompt the group - When to get up? what to eat for breakfast? what to wear? what chores to do? where and with whom they will sit with at this training? Others? Share with the group.
- How would you feel if all or most of your choices were made for you?
- Often, people with disabilities have most of their choices made for them by others.
- That can be very frustrating for the person with a disability and can lead to problem behavior.
- Providing choices is a good way to PREVENT problem behavior and promote the dignity of the person with autism.
- These next slides show strategies to provide choices to people with autism, even if they have no language.

Slide 31 Choice Making with Objects

- This child has no language and a significant intellectual disability.
- This is his object choice board.
- The object on the left is a set of headphones. They are used for listening to music.
- The object on the right is a waist pack. He takes that with him when he goes for a walk.
- When it is time for break, this child is presented with these two objects. The adult support says "What do you want to do?" The child makes a choice and hands over the desired object. Then he gets to have his break either listening to music or taking a walk.

Slide 32 Picture List of Choices

- This child understands line drawings.
- When he feels stressed or anxious, he has been taught to take a break.
- This choice board illustrates that during his break time, he can:
 1. Read a book
 2. Take a walk
 3. Sit down
 4. Lie on his back.

Slide 33 Picture List of Choices

- This child is encouraged to make choices throughout the day.
- Here you see the choices presented at Snack Time, Book Time, and Leisure Time.

Slide 34 Written List of Choices

- Bill can read.
- When he has free time, he can choose from this written list of choices.
- The list can be changed to reflect his changing interests or to introduce new choices.

Slide 35 Choice Making

- Choice is important.
- Having choices improves quality of life
- Think of opportunities you might be able to provide to increase your grandchild's' choice-making opportunities.

Socialization



Time: 60 Minutes

Set-Up: Round tables are recommended to facilitate discussion. Approximately 3-4 people per table.

Materials: Flip Chart paper, Markers, Index cards, hand-out on levels of friendship/degrees of disclosure

Optional Materials: Children's story books about emotions- Example: *On Monday It Rained*, by Cheryl Kachenmeister, plastic flower, birthday candle

Slide 1 –

Reflect back on the past week and think about what social interactions you have had, seeing someone you know in the grocery store or getting together for Sunday Brunch with your friends. There are different levels of interaction, some of them are planned and some of them occur by chance. There are different levels of friendship and different degrees of self-disclosure based upon levels of friendship. (*Provide Degrees of Disclosure Hand-out*) This hand-out shows a couple of visual displays of how socialization can change with degrees of intimacy and the importance of learning about self-disclosure with different groups of people. Individuals with autism require support to learn about socialization and interaction with friends, acquaintances and strangers.

So far, we've gone over the primary characteristics of autism including difficulty in communication, focused interests and repetitive behavior and difficulty with socializing. We've identified the learning characteristics of people with autism including that most individuals with autism learn best by seeing and doing, they can be very concrete in their thinking and that they might learn a skill in one setting but not be able to generalize that skill to another setting.

Why is working on socialization so important?

- Socialization is the basis for many other important skills. For instance, the social skill of getting someone's attention is needed for: asking for help, directions, information, etc.
- Socialization is often an important priority for families. Some of life's lessons are learned in a classroom. MOST of life's lessons are learned in the day to day interactions with our friends, families, communities and co-workers. Many families with children with autism report that they just wish THEIR child would get invited to a play date or a birthday party. You may have similar wishes for your grandchild.

Slide 2 Learning Objectives

Slide 3 and 4 Importance of Socialization

- Social Skills are the best predictor of positive, long term outcomes for people with disabilities. (Strain, 1987). This is particularly true for people with autism. Experience tells us that people with autism usually lose their employment because of their social skills. They know how to do their jobs they get fired because they didn't know how to appropriately socially interact with their co-workers.
- How well we get along with others in first grade is a strong predictor of success. Ravner & Knitzer (2002) studied children without disabilities. Long term risks of not getting along with others included poor mental health, dropping out of school, low achievement, and poor employment histories
- Social competence has to do with how well we get along with others ((Katz & McClellan, 1997).
- Think of a public figure that is not as successful as they COULD be, because they have poor social skills. Conversely, think of a public figure that is VERY successful, NOT necessarily because of their intelligence but because of their good social skills.
- The ability for children to get along with other children is the SINGLE BEST PREDICTOR of adult success (Hartup, 1992).



Slide 5 Recognize Their Feelings

Lots of children, especially those with autism, don't always recognize their feelings. Your grandchild's parents can help you identify how a child conveys their feelings. They may also be able to share strategies they use to help their child remain calm. You can help a child learn how to engage in strategies to help them remain calm when things are not going well. Deep breathing is often helpful. With young children we can use the example of "smell the flowers" and then "blow out the candles." Repeating this several times helps a child learn deep breathing.

This is an example of a communication board that a child who does not use verbal language may use to tell you what they are feeling. This is a sample of picture communication symbols like the ones that were seen in the communication module.

Slide 6 Help Children Manage Their Feelings

Children with autism may have difficulty understanding facial expressions from others. Using pictures can help children learn about facial expressions. At the library books can be checked-out that deal with feelings. When you are reading with your grandchild you can initially point out a picture and say "He's smiling, he feels happy." This can move to "he's smiling, how do you think he feels?" to finally pointing a smiling face and saying "How do you think he feels?"

This book *On Monday when it Rained*, is an example of a picture book that talks about feelings. Some children with autism need to have actual pictures instead of the picture communication symbols that we talked about on the previous slide.

Slide 7 Challenges

The difficulty people with autism experience recognizing feelings and understanding social situations may further challenge the child. For example we assume that every child LOVES birthday parties. But a child with autism may not understand that the presents are for another child, or that loud signing is appropriate. Sometimes, they might respond inappropriately to those feelings because they don't understand them. For instance, it is not uncommon for a child with autism to laugh, scream, cry or cover their ears if they hear someone crying. They don't understand the emotions of others, so their response may not be appropriate to the situation (Mac Donald, et al., 1989). Their body may just respond in an inappropriate manner. These challenges continue into adulthood (Sperry & Mesibov, 2005). This research showed that even into adulthood, people with autism had questions about how to get along with co-workers, how to make friends, and how to act appropriately in front of members of the opposite sex.

The reason social interactions are so difficult is that there are few concrete rules; there are many subtle, elusive and dynamic rules that guide social conventions. You can help! As a grandparent you can go to places where other children play, like the community park. Sometimes a child doesn't know how to join-in; it is so complicated that some children stop trying. Some children may need time to just watch the other children. You may be able to facilitate the child's interaction. Simple interactions are great, such as:

- Social Greetings- Hello/ Good bye
- Getting someone's attention appropriately
- Introducing yourself
- Saying Please and thank you.
- Ending a Conversation
- Asking for Help

You can help the child be accepted by the other children and help a child with autism learn appropriate social skills and do what the other kids are doing



Slide 8 and 9 Strategies for Success

Slide 10 Interactive Activity

This teacher created an “ice rink” in her classroom. Students wore shoeboxes as skates and held hands and “skated” to the nutcracker ballet playing on the CD. They also made “hot chocolate” out of brown scrap paper and cotton balls and served each other. They also helped each other get dressed in the hats and mittens that were provided. This is one example of how a pretend play scenario was set up to encourage social interactions.

There are often particular peers that are good “partners” for children with autism. Peers that are curious, gregarious and outgoing are often good peer partners. It is important that a peer partner with a child with autism WANTS to interact with the child with autism.

Slide 11 Arrange Materials

These materials are arranged so that the children have to ask each other for the materials necessary to complete their activity

Slide 12 Arrange Environment to Encourage Interaction

This is an example of arranging the environment for interaction. The children could work on a puzzle together, an art project or have a tea party at the table. Playing board games is also a great way to encourage interaction around an activity. The environment can be arranged to be face-to-face to encourage socialization

Slide 13 Using names

Using a child’s name helps garner attention. Eye contact (which may be VERY difficult, or uncomfortable for the person with autism) is not necessary, but encourage children to turn their bodies towards the person with whom they are speaking and use their names when addressing them.

Slide 14 Reminder for Typical Children

Remind the children who do not have disabilities to: Stay with your friend, play with your friend, talk to your friend. You can start out with a short time frame of playing together and then build on that.

Slide 15 Write a Story

This is a simple story an adult wrote about their grandchild going to the park. Reading this story before going to the park might help the child learn to play with other kids at the park. Notice that it focuses on the POSITIVE and tells the child WHAT to do instead of WHAT NOT to do.

Slide 16 Remember

Slide 17 Closing Thoughts

Community Inclusion



Time: Approximate Time 30-45 minutes

Set-Up: round tables are recommended to facilitate discussion. Approximately 3-4 people per table.

Materials: Chart Paper, Markers, “My child has autism” cards available for order from www.autismbookstore.com. The My Child Has Autism Cards are something they could hand out to people when they are in the community if their grandchild with autism begins to engage in a behavior (i.e. hand flapping out of excitement or covering their ears because it’s too loud) and other people find the behavior odd

Trainer Notes: this module discusses community inclusion. It is extremely important that safety be discussed as an issue. Families need to discuss safety and always ensure that grandparents know the risks that the community entails.

Slide 1 Community Inclusion

- In previous modules we’ve learned about autism, specifically about the core areas of difficulty including communication, socialization and restricted behaviors and interests.
- We’ve also learned about the stress experienced by families of children with autism, due, in part, to the need for almost constant supervision. Autism can also be a hidden disability. Individuals with autism “look” typically developing. This can be challenging when community members do not understand that this child has special needs. This is why we have supplied you with “my child has autism” cards. You may find it helpful to have these cards with you when you travel in the community. You can give them to community members if they are inquiring about your grandchild.
- Today we are going to talk about supporting children with autism access the communities in which they live. Your volunteer duties may include taking the children out as part of a group, as part of a family outing, or on your own.
- The following presentation provides examples of children with autism successfully participating in their communities utilizing the strategies we’ve been learning.
- Ask the participants if any of them have successfully taken their grandchild with autism out into the community. Have them share how it went, what made it successful, what might have made it better, or what will they do next time.

Slide 2 Learning Objectives

Slide 3 Inclusion is a Principle, Not a Place

- Inclusion can extend to participation in community based activities as well, including family and neighborhood outings, church programs and accessing recreation and leisure activities in the community in which they live.
- The fundamental principle of inclusion is membership in a diverse society (Schwartz, 1998). We have the responsibility to support those rights and encourage people with disabilities to be fully included in our society. Diversity encompasses many variables including disabilities. People with autism are members of their communities. They have the right to be supported to learn the skills to help them access their community.

Slide 4 Inclusion is Successful with Preparation

- **Activity:** Work in groups of 2 or 3 to discuss what YOU think this statement means. Give 1 example of how we might prepare for one of the community settings (ie.g church programs, recreation centers) Example- You want to take your grandchild to the local pool. You might go there ahead of time and talk to the life guards and tell them that you’ll be bringing in a child with autism. You will also bring his visual supports that help him know what he needs to do while he is at the pool (change, shower, swim, shower, get dressed.) You may also tell the lifeguard that the pool might be loud for him, so at first he might scream and cover his ears. That’s okay. He might also resist getting out of the pool because he loves it so much.

Community Inclusion



Share with the lifeguard, you've got it covered, you've got his favorite reinforcer with you (Ipod, candy, trip to Mc Donald's afterwards, favorite toy etc.) that you will show him and remind him First he has to get out of the pool THEN he gets _____. Have the participants share their ideas with the larger group.

- Record their answers on chart paper.

Slide 5 To Ensure Success

- Think back to the learning characteristics of people with autism that were learned in Module 1. Consider the learning characteristics of difficulty with generalization and that the person with autism may cue into one detail of a task or activity and miss the relevant information about an activity. It is important for people with autism to learn the skills in the settings where they will need them.
- Successful programs encourage learning directly in the community
- It is important that frequent opportunities are available to practice skills in the same environment. Practice makes perfect.

Slide 6 Where Do Children in Your community Socialize?

- Activity: call out places where children in their community play. Record these answers on chart paper.
- Answers may include:
 - Children: Neighborhood playgrounds, Sunday school, organized sports, playgroups, clubs, lessons
 - Teens: teen church programs, skateboard parks, mall, cruising, hanging out at each other's houses, football games

Consider handing-out a community resource guide here. Sample guide enclosed in Module 5.

Slide 7 Structuring the Community

- The following slides give examples of strategies used to support teens and children with autism in their communities.
- In each slide, pay special attention to the strategy or support used to ensure a successful outing.

Slide 8 Increase Predictability of Activity

- People experience anxiety because they don't know what's going to happen, or the activities are out of their normal routine.
- This picture shows simple line drawings that are placed in order for the events that are going to occur. It says first bathroom, then van, then snack with the line drawings. These type of line-drawings are available for EVERY activity imaginable. If you think these pictures might be helpful you may want to consider purchasing the software to make them (www.mayer-johnson.com) or you can hand draw symbols or even download pictures from the internet.

Slide 9 Make Expectations Clear

- This ring of picture cards let's the children know what activity they are supposed to be doing.
- Being out in a big open space in the community can be very distracting.
- By showing the children this card, they know, it's time to sit down and sing songs in a circle.



Slide 10 Bring Communication Devices

- Remember from the communication module! Children who talk don't ever leave their tongues inside when they go out to play.
- Be sure that children who are using communication devices have them with them when they go out into the community.

Slide 11 Prepare them Ahead of Time

- When you know a certain situation is potentially difficult for your grandchild, prepare them ahead of time by showing them what the "rules" are for that situation.
- This board was used with a little girl would run up to strangers, hug them and touch their faces. The "rules" shown on this board are a strategy that shows the little girl the rules of the situation "no running, no hugging, no touching" but most importantly, it tells her WHAT TO DO INSTEAD- I can look at them, wave at them, say hi and stay with the group.
- This strategy was shown BEFORE the girl was out in the community. It was also brought with her in case she did see a stranger as a way to remind her of the things she could do.

Slide 12 People with Autism can be Included

- The next several slides provide examples of where children and teens go in their communities.

Slide 13 During a Field Trip to the police Station

- What strategies do you think might promote success at the police station? All group call out:
 - review a picture board of the behaviors that are expected at the police station- Inside voice, sit and listen, follow the police officer to look at the building, ask questions
 - develop a schedule for the activities at the police station
 - visit the police station prior to talk to the police about the visit

Slides 14 At the Beach

- What strategies do you think might promote success at the beach? All group call-out:
 - pictures of the order of events- change clothes, pick a swim buddy, stay with your swim buddy, get out of the water, shower off, put clothes back on, get in the van
 - reinforcement for getting out of the water for children who love to swim

Slide 15 – Grocery Shopping

- A word or picture shopping list can help a child with autism remember what to purchase.

Slide 16- At the park

- Here you see a young girl visiting the park, using her communication system and enjoying one of her favorite activities – looking at the koi!

Slides 17 At the Park

- Here you see another park outing. Notice the tarp set down on the lawn. This gives the child information about WHERE to sit by defining the space. Something that simple can be used to prevent the problem behavior of running all over the park and away from where you would like to sit
- If something does go wrong, that's okay. Remember you may have had 15 minutes of challenge but 2 hours of fun! Even when you prepare challenges can happen. That's okay, this was a learning opportunity and perhaps you can try again with a few different strategies – don't get discouraged.

Community Inclusion



Slide 18 At the Movies

- ACTIVITY: your turn
- You are the grandparent in this picture.
- You are getting ready to take your grandchild into the movies.
- What will be on those cards that she's showing him to explain to him the following:
 - What is going to happen in the movies
 - What are expected behaviors in the movies.
- Work in groups of 2 or 3 to come up with these strategies.
- Share them with the larger group

Slide 19 People with Autism Can be included

- Anywhere and Everywhere
- With proper planning people with autism can be included and participate as members of their community.
- The more you and your grandchild with autism experiences success, the more confidence you will both build.
- Remember, with preparation community inclusion can be successful

Behavior



Time: Approximate Time 60- 90 minutes

Set-Up: round tables are recommended to facilitate discussion. Approximately 3-4 people per table.

Materials: Chart Paper, Markers, Case Studies

Optional Materials: Video clips from Center for Social Emotional Foundations of Early Learning
<http://www.vanderbilt.edu/csefel/>

Note for the trainer:

It will be important to preface any of this training with the idea that grandparents will need specific support from their grandchild's parents regarding children with who run away, or who have significant problem behaviors including aggression or self injury.

Please advise participants that if they have **ANY** concerns about challenging behavior they should speak with the child's parents.

Slide 1 Title Page Behavior

- For a welcoming exercise and to integrate the group further, have the participants find people who match them on the following characteristics:
 - Has the same number of grandchildren _____
 - Shares the same favorite TV show _____
 - Has a birthday in the same month _____

Participants will need to interview each other to find out this information and find matches.

- Have participants recall that in previous modules we have learned about the 3 areas of challenge for people with. (socialization, communication and restricted and repetitive behaviors and interests)
- In today's module we are going to focus on behavior.
- Sometimes, due to their communication and socialization difficulties, people with autism use problem behavior to get their wants and needs met.
- This module explores what problem behaviors might look like, and what we can do to prevent this in the first place or to keep problem behaviors from happening again. Planning ahead for behavior challenges will prevent most problems.

Slide 2 Learning Objectives

Slide 3 From the Point of View of the Child with Autism

- It's important to understand WHY problem behavior is being used by the child. Sometimes problem behavior is due to difficulty understanding the demands and expectations of an environment or activity.
- We learned in the communication module that often times, children with autism do not have a reliable way to communicate. Sometimes, behavior is their way of telling us about what they want and need.
- Problem behavior is sometimes the result of the difficulty they experience initiating and sustaining social interactions and relationships with other people.
- While children without autism might realize, "I shouldn't do this (behavior) because then (consequence) will happen" Children with autism are often unclear about the consequences of their actions. A child with autism may not understand cause and effect. Example (a child with autism might not be clear that if he smashes a toy out of frustration, the toy is no longer functional.) Have participants give other examples. Answers might include, (running away from an adult in a crowded place- the consequence of that might be getting lost, hurt, abducted; jumping from a high Jungle Gym in the playground- the consequence might be getting hurt, breaking a bone). *Adapted from the National Research Council's (NRC), Educating Children with Autism 2001.*

Behavior



Slide 4 From an Adult's Perspective

- Understandably, when a child is engaging in problem behavior, adults sometimes see things differently. That problem behavior might look like:
 - Lack of compliance- "He's just not listening"
 - Tantrums- "He's spoiled and used to getting his own way"
 - Destruction of property "He's spiteful and just ruined his toys"
 - Aggression "He scares me"
 - Self- Injury When a child focuses his/her aggression on themselves- this could be head banging, head hitting, biting themselves, falling to the floor.
- Adults sometimes just see and label the behavior, without considering WHY the behavior exists.

Slide 5 A Grandparents Perspective

- Ask the grandparents to describe a time the child engaged in problem behavior.
- Ask "How did that make you feel?" "What did you do to try to modify the child's behavior?" What were the results?"
- Record responses on the chart paper- responses might include- He's a difficult child, he didn't like me, I must not be doing a good job as a grandparent- Others?
- If nobody has an example, utilize the following scenario. *You are spending time at your grandchild's house. The child's father is home but he is working in the office. You are in the living room with the child. The child starts to cry and fuss a little bit. You attempt to comfort the child and offer choices of activities. You are not able to discern what the child is trying to communicate with their behavior. The child begins to yell loudly and the father comes into the room. The father interprets that the child is probably hungry and prepares a snack for the child. The child goes to the table and calmly eats a snack.*

Slide 6 Important Point to Ponder

- Adults have to consider WHY behaviors exist. Then the challenge becomes, helping the child find a better alternative to getting their message across.
- When considering problem behaviors, we must also think about what triggers behavioral problems. For example: a child might see another child with a preferred toy in the sand-box at the park, it triggers a desire for that item. They try to take the toy from the other child.

Slide 7 Similarities and Differences

- Many of the behaviors we see in children with autism also occur in young children without disabilities.
- Ask- Participants to share stories about their children or grandchildren (without disabilities) who may have engaged in tantrumming behavior, in particular during the "Terrible Twos"
- Share with them that even Self injury and repetitive behaviors (rocking, hand flapping) occur in infants without disabilities but disappear as the kids become more mobile during the first 1-2 years of life. Berkson et al., (1999) found that 19 % of typically developing college students engage in body rocking.
- The differences are that for children with autism in particular they engage in problem behavior more frequently. The behaviors are more intense and they continue to exist for a much longer period of time than for children without disabilities.
- Ask them to provide ideas about why there is a decrease of problem behaviors seen in kids without disabilities as they get older, but not necessarily for kids with autism? Answer: because of the language impairment- kids without disabilities are gaining language and language becomes their reliable means for getting their wants and needs met.

Behavior



Slide 8 Why Challenging Behavior Occurs

- Why Problem Behavior occurs can be divided into 3 broad categories:
 - To get something (Access)
 - To get out of something (Escape/Avoid)
 - For Sensory purposes (It helps them access or escape/avoid some sort of sensory information).
- We will look at each of these reasons “why” behavior occurs individually

Slide 9 Access

You are at Patricia’s house. Her mom is doing laundry while you play with Patricia in the living room. Patricia sees her favorite toy up on a shelf out of her reach. She does not have the language to ask for the toy. She moves towards the shelf where the toy is located and begins crying and then screaming. No one is really sure what she wants. In an effort to soothe Patricia, you hug her. Patricia becomes so frustrated she begins biting her hands.

Ask: “Why is Patricia most likely biting her hands?” Access, Avoid or Sensory?

Does the child want something? What is she trying to get from engaging in this behavior?

Slide 10 Avoidance/Escape

You are in the community with Carl. You and his mom take him to the YMCA Mother’s Morning Out program. While his mom works out at the gym you agree to stay with him in the program. Carl does not like circle time at the Mother’s Morning Out program. All of the kids have to sit in a circle and sing songs every day. Carl does not like sitting so closely to the other children. He does not understand the songs. When the group leader says “Time for Circle” Carl falls to the floor. He refuses to go and begins screaming if adults try to physically assist him.

Ask: “Why is Carl most likely on the floor and screaming?” Access, Avoid or Sensory?

Does the child want something? What is he trying to get from engaging in this behavior?

Slide 11 Sensory- Self Regulation

You take Kim a teenager with ASD to the community pool to swim. Kim is so excited that she begins rocking her body back and forth. The families at the pool notice Kim’s rocking and move their children away from her.

Ask: “Why is Kim most likely rocking?” Access, Avoid or Sensory?

Does she want something? What is she trying to get from engaging in this behavior?

Slide 12- Remember

- Due to the challenges they have with social skills and communication, children with autism are especially at risk for developing behavioral problems
- No magic solution - No single approach has proven to deal effectively with problem behaviors for ALL children with autism.
- An Ounce of Prevention- Prevention is critical and should be the primary focus especially for young children with autism.
- We need to focus on preventing the behavior from happening in the first place by anticipating situations that might be difficult for the child and preparing them to be successful in those situations.
 - Parents are often the best resource. Ask questions; learn from their experience with their child.
 - The Family Cheat Sheet (from Module 1) is helpful. Have families complete this cheat sheet.
- Think about what situations or tasks seem to be consistently hard for the child.
- Think about how to prepare the child for those situations or what you can do to change the situation before the child has to encounter it again.
- We also must consider WHY the behavior exists in the first place.

Behavior



Slide 13 What You Can Do to Help

- We are going to look at examples of what you can do to help a child with their problem behavior.
- We will focus on strategies that give the child some control over their world.
- For more information see: Koegel et al., 1999

Slide 14 Help the Child Understand the Rules

This picture board was shown to a child before library story time started and then shown to them throughout as a reminder during the activity time. The adult also pointed to the thumbs up good sitting drawing to reward the child for good sitting.

Slide 15 Help the Child Understand the Steps of a Task or Activity

This child had a hard time understanding that there were steps to follow in getting ready for dinner. He thought that when the food was cooking, and he could smell the food it was time to eat. This checklist was developed to help him know when it was time to eat dinner.

Slide 16 Help Prepare the Child for Changes in Routine

This little book was made using pictures that family members and care providers contributed. This child had a very hard time if someone other than mom came to pick him up after school. Using pictures of family members, the adults were able to prepare the child ahead of time about who would be picking him up from school that day. This PREVENTED the tantruming behavior from occurring because he was not caught by surprise when it wasn't mom.

Slide 17 Adjust Demands for the Child

We all have good days and tough days. The same holds true for children with ASD. When you notice your grandchild seems to be having a tough day, reduce the demands. In this example, the adult noticed that the child was having a tough day. So rather than having him do 16 math problems (and possibly a tantrum) the adult reduced the demands to just 4 problems. The child got all of the problems correct and avoided having problem behavior. Now at another time, you can increase demands but it's important to be sensitive to what kind of day the child is having and adjust accordingly.

Slide 18 Help the Child Understand the Order of Events

This child loved to go to Chuck E. Cheese, but instead of eating, he would just run to the video games and then it was REALLY difficult getting him to leave. Using objects that represented the activities at Chuck E. Cheese, this child could be shown the steps of the outing.

- Ride to Chuck E. Cheese in the Car
- Eat Pizza
- Play Games
- Ride Home

This helped significantly as the child could be shown ahead of time the order of events and throughout the visit he could be shown the objects and reminded of what was going to happen next.

Slide 19 Teaching a Better Way to Get Their Needs Met

- As we mentioned before, too many times, the focus is on making the problem behavior STOP. While that's tempting, we have to consider WHY the problem behavior is being exhibited by the child. Then we have to think of a solution that is AS EASY and AS EFFECTIVE as the problem behavior. We can help the child learn a better way to communicate and get their needs met.
- Remember the message can be in three general categories: access, escape/avoid and sensory

Behavior



Slide 20 Give Them A Way to Communicate

- Scenario- Bill used to grab things from other people. These things included toys, food, activities.
- Ask “Why does Bill grab things?” (ACCESS)
- Solution: In this slide you see that Bill was taught to get peoples’ attention and request what he wanted using this simple board with pictures and written phrases on it. (Bill could read, but he had limited language).

Slide 21 Give them a Way to Ask for a Break

- Scenario- When Debbie needed a break; she would fall out of her chair and start screaming. Or she would try to run away.
- Ask “Why does Debbie fall out of her chair and scream?” (AVOID)
- Solution: Debbie was taught to hand over this card instead of throwing herself on the floor when she needed a break. Handing over the card REPLACES the behavior of throwing herself on the floor. The important thing to remember is that the card has to be honored every time, until Debbie is consistently using the card instead of the behavior.

Slide 22 Provide a Place Where they can go for a Quiet Break

- Scenario – Jose’s class was very busy during center time. She became overwhelmed by the noise and visual activity. He would put his hands over his ears and hum.
- Ask “Why does Jose put his hands over his hears and hum?” (SENSORY)
- Solution: provide a quite space where a child can decrease the sensory experience of the environment.

Slide 23 Let the Child Choose Activities

This child likes art, but often has a specific activity in which he would like to participate. By providing an array of activities he can choose his preferred items for art and is more likely to engage in the activity appropriately.

Slide 24 Provide Rewards When Appropriate

- Scenario: Kelly did not like to get dressed after swimming
- This picture reminded Kelly that once he got dressed he had access to a highly preferred item – Candy! Not all children prefer candy and some children are not allowed to have candy. The reward can be adapted to reflect the preferences of each child.

Slide 25 Help Them Practice Different Solutions to Problem Behavior

- This is an example of a solution kit for a young child. It has also been used successfully with children without disabilities. Many parents use this in their homes, day cares and community settings. It is helpful basically anywhere that a child will have to interact and share resources with other children. Here’s how it works:
- These pictures can go on a wall. When a problem arises, for example two children want the same toy- the adult refers them to the solution kit. Using the pictures (that they have been previously taught) the kids work together on a solution. If the kids can’t come to a solution, the adult intervenes and gets “The peace rug”. At this point, the adult takes the object of conflict and the children and the adult sit together on the peace rug until they can come to a mutually agreeable solution. Think about all of the skills very young children both with and without disabilities can learn from this- sharing, trading, negotiation, compromise. What wonderful life long skills that we could all benefit from learning.

Behavior



Slide 26 Help Them Learn to Calm Down

- Often times we tell children “calm down” or “settle down”, assuming that children know what that means or how to do it. A simple way to teach calming to even very young children (both with and without disabilities) is to say “Smell the flowers” “Blow out the Candles” (3 times). When first teaching this, some people use actual flowers and birthday candles. Then have the children touch their 10 fingers (and count if they are able). This gives the children an important, practical and life long skill for calming down.
- This is a visual that can be used to remind a child how to calm-down
- It is also important that we remain calm when helping a child calm down. It is easy to become upset or overwhelmed when a child is having a difficult behavior. By staying calm and collected you are modeling for the child what is expected. By staying calm you will also be able to think effectively and support the child with greater success.

Slide 27 There are Lots of Ways You Can Help

Slide 28 When Problem Behavior Happens

- Sometimes problem behavior will happen. When it does, try to visualize these circles. Ask yourself the following questions
 - What could I change in this environment to help the child- Is it too loud, too crowded, too hot?
 - What could I do change about this ACTIVITY that the child is being asked to do? Is it too long, too boring, too easy, too difficult, is it meaningful?
 - What could I do about rewarding the child? Are the rewards powerful and meaningful to the child? Does he/she get rewarded often enough? Is he/she clear what they have to do to earn a reward? Do they know what their reward is in advance?
- Control is invasive, dangerous and doesn't teach the child anything. If a child is in imminent danger, for example about to run in the street, keep them safe and be sure that you can contact someone for back-up (e.g. parents or care provider) (*Emphasize that not everyone with autism runs or engages in challenging behavior*).

Slide 29 Success in Action

Optional: If time allows show the following video clip from the CSEFEL website:

<http://www.vanderbilt.edu/csefel/> Resources- Training Modules- 3a Video clips 2- Brendan before Positive Behavior Support (PBS) Video clip after Positive Behavior Support (PBS)

- Have group discuss the before and after library scene.
- What did the mother do in the second scene that was reflective of the strategies outlined here?
- Answers might include: She prepared him ahead of time, SHOWED him where he was going, reduced her language, showed him what was going to happen in the library and started out with a positive activity. She also kept it short and successful.

IF NO VIDEO IS AVAILABLE USE ONE OF THE CASE-STUDIES

Slide 30 In Conclusion

- That there are three general categories of why challenging behavior occurs: access, avoid or sensory
- We've learned that we have to help children with autism learn alternatives to problem behavior that are as effective and as immediate as the problem behavior.

Prepare, prepare, prepare to keep problem behaviors from happening in the first place!