



# Autism and Faith Communities:

Welcoming and Supporting Individuals and Families

#### About the toolkit

Practicing one's faith is important to many people with Autism Spectrum Disorder (ASD) and their families. Families often turn to their faith communities for understanding, acceptance, and support. Yet, often they struggle to find a faith community that is comfortable and confident in how to welcome and include them.

Many faith communities want to welcome and include these families. They recognize that their faith community is missing the presence and participation of special needs families. Yet they lack an understanding of autism and feel ill-equipped and unprepared in how to invite, welcome and support them in their congregation.

Faith community leaders may also feel unprepared when parents turn to them with concerns about their child's development or they observe developmental red flags in a child in their congregation. As trusted confidants, faith community leaders can play a critical role in identifying young children with signs of autism, and their advice is vital in helping families access the services they need.

This toolkit is a non-denominational, practical guide to help faith communities:

- recognize and talk with parents about developmental concerns for their child,
- welcome and include special needs families into the life of the faith community
- connect families and faith communities to resources for ASD diagnosis, treatment, and care

We hope this toolkit will encourage and equip faith communities to invite, support, include, and celebrate these special needs families.

While the focus of this toolkit is on people with autism and their families, the information is also pertinent for people with other intellectual or related developmental disabilities.

### Beyond the toolkit

If you would like help in welcoming individuals with autism to your faith community, ASNC can help. In every NC county, ASNC has Autism Resource Specialists who are experienced parents of children with autism and trained autism advocates. You can find contact information for the Autism Resource Specialist in your community here: www.autismsociety-nc.org/resourcespecialists. ASNC also offers workshops that might be helpful; you can find the workshop schedule at www.autismsociety-nc.org/workshops or ask your Autism Resource Specialist.

If you would like to read more, please refer to the end of the toolkit for additional information sources that are recommended by the ASNC Advocacy, Clinical, and Bookstore staff. To keep updated on the latest books and DVDs, we invite you to browse the ASNC Bookstore at www.autismbookstore.com.

ASNC's local chapters across North Carolina are also an excellent place to connect with other families, ask for recommendations, and learn from their experiences. Chapters are volunteer-run and offer support and education on a wide variety of topics. To find one near you, please go to our website: www.autismsociety-nc.org/chapters.

In addition, ASNC offers an array of services for individuals with autism. Please visit www.autismsociety-nc.org to learn what is available in your area.

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Addendum \_\_\_\_\_\_\_14

The primary purpose of the toolkit is to increase autism awareness and early identification by reaching minority and underserved populations through faith-based organizations in association with Maternal and Child Health Programs, A14-1287-001, 2014-16.

It was developed through a collaboration of three organizations: the Autism Society of North Carolina (Maureen Morrell MPH), the UNC-CH Carolina Institute for Developmental Disabilities (Rebecca Edmondson Pretzel, Ph.D.), and the UNC-CH Allied Health Science Department (Elizabeth Crais, Ph.D., CCC-SLP, and Sallie Nowell, M.S. CCC-SLP).

### Part 1:

## Recognize and talk with parents about developmental concerns

### Why is early identification of developmental concerns important?

According to CDC estimates, 1 of every 59 children in the United States has an autism spectrum diagnosis. In North Carolina, the prevalence rate is higher than the national average at 1 in 57 children.

Signs of autism can be identified in some infants as early as 12 months of age and in many toddlers by 18 months.

The earlier children are identified and start therapeutic intervention services, the sooner the child and family receive the assistance and support they need. A child's future success in school and social environments can be improved by early therapeutic intervention services that target communication, sensory responses, and behavior.

Getting help early also supports families to successfully manage the challenges and concerns they have in meeting the needs of their loved one with autism.

### How can faith communities help with early identification?

Faith communities are in a unique position to assist with the early identification of children with ASD and developmental delays. They are often the spiritual and social center for a family and one of the first places that a young child may go regularly before starting school.

Parents who have concerns about their child's development may talk with their clergy, church leaders, or staff before approaching a healthcare provider. They may ask their faith leaders for information, advice, resources and support.

Sometimes it is the faith leaders or staff who have concerns about a child's development. They may notice the red flags or warning signs of ASD or a delay in development before the family does. For example, teachers who provide care for children in a nursery or church preschool may recognize when a child is not meeting typical milestones for his or her age.

Whether it is the parents or faith leaders who first raise the developmental concern, the good news is early intervention can improve the quality of life for children and families.

Faith communities provide a critical support to families when they help families connect to community resources for developmental screening and when appropriate, developmental evaluations, diagnosis, and early intervention services.

"Learn the Signs.
Act Early" is a federal campaign to help every child reach his or her full potential. Familiarize yourself with typical developmental milestones as well as red flags for ASD.
The campaign website (www.cdc.gov/ncbddd/

actearly) has useful resources as does the

toolkit.

Resources section of this

### What are the warning signs of ASD and developmental delays?

Autism Spectrum Disorder is a developmental disability that can cause significant social, communication, and behavioral challenges. Many people with ASD have different ways of learning, paying attention, communicating, or reacting to things.

ASD is typically diagnosed in children, but it is a lifelong disorder that affects individuals of all ages. ASD is a spectrum disorder that affects individuals differently and with varying degrees of severity; no two people with ASD are the same.

The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

#### What are the signs of ASD that we can recognize by age 2?

#### Social-Communication/Interaction Difficulties

- Delayed language development
- Loss of words that the child once said regularly
- Lack of responsiveness to people, may not look when name is called (despite normal hearing)
- No showing, giving, or pointing to objects to share interest with others
- Unusual rhythm of speech
- Abnormal eve contact
- Lack of facial expressions
- Limited enjoyment in activities with others. For example, may not want parents to read/look at books together.
- Limited interest in social games such as peek-a-boo or Itsy Bitsy Spider unless they involve a physical component like tickling, bouncing, or chasing
- Lack of imitation of others
- Little interest in other children
- Not yet using simple pretend play such as feeding stuffed animals

#### **Restricted/Repetitive Behaviors**

- Unusual play
- Attachment to certain objects or parts of objects for extended periods
- Over- and/or under-reaction to sounds, tastes, touches, and other sensations
- Irregular sleep rhythms
- Interest in looking at certain things like lights and fans

### Shy temperament or Autism Spectrum Disorder?

Parents may wonder whether some of their child's interactions or relationship difficulties may be due to shyness. This table adapted from the CDC highlights some key differences.

Shy Temperament	Autism Spectrum Disorder
Quiet and withdrawn in new settings	Does not seek to share enjoyment, interests, or achievements with others
Slow to develop friends and play with others	Failure to develop peer relationships appropriate to developmental level, prefers to play alone
Tends to look away from others or look down	Marked impairment in use of eye contact even with familiar people and family
Takes a long time to become comfortable in new or group settings	Lack of emotional or social reciprocity, does not understand the back and forth nature of communication

### Temper tantrums: When should you be concerned?

While many young children have tantrums (e.g. "terrible twos"), at what point should parents become concerned and feel that the tantrums may represent a broader issue?

- More than 10-20 in a 30-day period
- More than five each day
- Regularly last more than 25 minutes
- Aggression toward self/others
- Unable to calm self
- Exaggerated responses to daily activities cause tantrums
- Tantrums occur with no apparent trigger

### How do you communicate comfortably with families about their developmental concerns?

### Refer the family to an ASNC Autism Resource Specialist

if they need to speak with a parent who is also a trained advocate and can help them navigate the resources for autism diagnosis or early intervention services. In addition, see the Resources section of this toolkit.

### When the parent approaches you

- Realize that a parent has come to you because they feel a level of comfort and trust.
- Your primary role is to be a warm, caring presence in the discussion
- Be sure you're in an environment where you can converse privately.
- Listen to what parents tell you. Don't dismiss their concern.
- Remember you do not need to be an expert. After the conversation, you can help them find an expert for advice and evaluations.
- Share your observations if you have also seen examples of the parents' concerns.

- But also talk about the strengths and things the child can do.
- Ask whether they have spoken with the child's doctor and whether the doctor has raised any concerns. If not, encourage them to ask the child's doctor for a developmental screening.
- Encourage them to trust their instincts and be persistent if others doubt their concerns.
- Share other local resources you feel might help, (see TIP below)
- Remind the family that while you may not have the answers, you want to be a support to them throughout this process.

#### When you notice a developmental concern

- Document your observation when a child acts in an unusual way on a consistent basis or is not meeting developmental milestones.
- Track the child's behavior in a variety of situations, such as snack or story time and group play.
- Discuss among your staff who is the best person to approach the parents. Select the person who has the parents' trust or who has the best information, for example, a church preschool or nursery teacher, youth minister, pastor etc.
- Arrange to speak with the parents in a comfortable, confidential, quiet place where interruptions and distraction will be minimized.
- First talk about the child's strengths and the things the child can do. Let them know the reasons you like their child
- Share with the family that you've closely observed the child's behaviors.
- Share your observations objectively "this is what I have observed..." "here's what I see during Sunday school" but show warmth and caring. Stick to specific and objective concerns.
- Describe, don't interpret. Use descriptive words about what the child did or did not do. For example, "the child left the play area when the other children

- came out there" instead of "the child didn't want to play with other children."
- Avoid judgmental or highly charged words such as "antisocial" or "behavior problem."
- Leave the diagnosis to the experts; you are simply sharing your concerns. Diagnostic terms such as autism or intellectual disability should NOT be used.
- Connect the behaviors you observed to concerns the parents may have already mentioned.
- Don't compare the child to other children in the class.
- Consider cultural differences and sensitivities.
- Ask whether they have spoken with the child's doctor and whether the doctor has raised any concerns. If not, encourage them to ask the child's doctor for a developmental screening.
- Reaffirm your relationship and partnership with the parents.
- Assure the family that while you may not have answers, you want to be a support to them throughout this process.
- Remember this is a tough conversation for the parents and they may need time to process it

### Part 2:

# Welcome and include special needs families into the life of the faith community

### What barriers prevent families with special needs from joining a faith community?

For families who have a child with autism, participating in a faith community can be a struggle.

**Children with ASD** may have challenging behaviors and complex needs that interfere with successfully participation:

- The environment may overwhelm them with a variety of sensory issues: large crowds of people, bright lights, strange sounds, loud music, unfamiliar smells, and rituals.
- They may have limited verbal skills and have difficulty paying attention to a speaker when language is not understood.
- Sitting for long periods of time may be difficult.
- Children with autism may have difficulty understanding the usual social rules and find it hard to make friends.
- They may be unable to communicate their confusion and need for assistance.
- There may be safety issues for those who have a tendency to wander.

#### Parents may struggle to participate as well.

- The parents are often serving as full-time caregivers with little to no help and may be under a great deal of stress.
- Physically, lack of sleep and demands of the activities of daily living leave them depleted.
- Financially, the mounting costs of therapy, treatments, and adaptive equipment are a worry.
- Relationally, parents may worry about the impact on siblings and their marriage.
- Additionally, their past experience may make them fearful of new situations.
- Since ASD is not a physical disability, they have endured the stares, whispers, or disapproving glances by those who do not understand their child's behavior.
- Their child has often been misunderstood as being spoiled and ill-disciplined and their parenting judged as inadequate.
- Saddest of all, many families have been asked to leave faith communities because of their child's behavior, leaving families feeling rejected and isolated.

### What barriers prevent faith communities from including families with special needs?

"During recent Easter celebrations, my thoughts turned to the many families who would not be participating in a worship service because they have a child with autism. Many families have told me that they tried to attend

"The truth is that most families with children with autism cannot make it to the door of a worship service, so faith leaders don't see the need."

Judy Clute, Autism Resource Specialist worship but it was just too difficult, or that they haven't found a place of worship where their child is truly accepted. I felt the same way for years. The truth is that most families with children with autism cannot make it to the door of a worship service, so faith leaders don't see the need." – Judy Clute, Autism Resource Specialist

Faith communities are often unaware of the families' need and desire for assistance and support. When they become aware, there may be an understandable response of fear of the unknown

In our training with faith communities to include special needs outreach, here are the concerns we hear most often:

- I want to help, but I have never worked with special needs before.
- I don't have any formal training.
- I don't have any special skills.
- What if it does not work out?

The good news is all of these concerns can be resolved and overcome!

### How can faith communities and families with special needs work together?

Building a bond of acceptance between faith communities and individuals with ASD and their families has mutual benefits. By welcoming individuals with ASD and being open to accommodating their needs, faith communities can reduce the isolation these families may experience and offer a place of refuge. Finding a supportive and inclusive faith community can empower these families to grow in their faith walk. In turn, these families can enrich their faith community and become involved and contributing members.



The faith community grows when they welcome all families to be involved. It teaches those in the faith community about compassion and understanding of individual differences and challenges.

There is a saying in the autism community that goes, "If you have met one child with ASD, you have met one child with ASD." It is very important to develop a unique relationship with each child and family. Remember, you do not have to be an expert; what you need is the desire and heart to accept and include. Assure the parents that you want to provide them with a positive experience in this faith community.

Get to know their child. Not only their needs, but also their unique gifts, talents, interests, and strengths.

- Ask about the child's interests, likes, dislikes, gifts, and talents.
- Does their child have any special talents or gifts that they would like to share?
- Ask about their struggles and challenges and what they need to be successful.

Ask the family what their goals are.

- · What are you hoping for your family?
- What are you hoping for your child?
- What kind of supports or accommodation does your child need?

Initially, you can gather the information you need with an open conversation. Eventually, you will need more detailed information about the child before you serve him or her – find it in the accommodations section of this toolkit.

Don't judge; understand that challenges may keep the family from being as involved as they would like. It may be helpful to learn about their past experiences in faith community to better understand their fears, concerns or expectations. Remember, families that have a child with autism have the same needs as other families: a need to belong, a need to be accepted, a need to be supported, and the desire to live out their faith.

### How does our faith community get started?

Start the conversation: Ask families with special needs what they are looking for and how your community can be welcoming and inclusive of people with ASD. Ask them about barriers to their participation in your community.

Talk to other faith groups in your community that have started special needs ministries. Their leaders and members can provide valuable advice.

Gather a team to explore outreach to special needs families. Include leaders from your faith community, members who have experience working with individuals with ASD, family members of children with ASD, and individuals with ASD themselves. If your community does not have any members with ASD expertise, invite professionals from the community such as local parents, teachers, and therapists to committee meetings.

Educate the congregation: If your organization is small, talk to other faith groups about collaborating to meet the needs of your members. For example, you may not have enough members to do a workshop on ASD awareness or host a community event but you may have the resources to do this when collaborating with another group.

Develop a short- and long-term plan for promoting inclusion: Connect leaders in your organization with resources and training on counseling caregivers of children with ASD.

### How can our faith community make accommodations within existing programs?

First, support families who have loved ones with special needs. Make sure someone checks in with them and offers support during critical times such as the birth of a sibling, starting or changing school programs, and receiving a new diagnosis.

Invite families to bring their children with special needs to visit your faith community at a time when worship is not happening and very few people are around. Allow the child time to walk around and touch, smell, and experience the environment. Introduce staff members who will be working with the child. You may also want to introduce noises that may occur during the service, for example, music or bells. Provide the family with a visual schedule of programs or social narratives to use to prepare for future visits. (See page 12 to learn more about these.)

### **Educate**

Educate office staff and greeters or ushers who may be the first members of your organization to welcome an individual with ASD and their family.

#### Also train:

- leaders, clergy, and staff
- Members who volunteer as greeters or work an information desk volunteers
- Children's ministry leaders and staff
- Student ministry teachers and volunteers
- Special needs volunteers

Offer a family-oriented worship service where a little noise is not uncommon. Worship services that are presented verbally and visually, dramatically and musically, will reach those with different learning styles. Offer a toolkit that includes books or engaging toys to occupy children who are not able to pay attention to a service. Offer accessible seating, large-print bulletins, missalettes, or assistive listening devices, and communicate that they are available in bulletins or in other ways. For families that cannot attend religious services, consider making the service available digitally, either with audio or video.

Choose religious education materials that are adaptable for various kinds of learners, and incorporate music – children with autism (and many other special needs) love music. Talk to the family about how

they want their child introduced to peers in class. A simple discussion about the needs of the child and why rules and expectations may be different for them can be helpful for the other children. This discussion may offer an opportunity to talk about how God makes each of us unique. Create an intake form for your religious education program to gather information about children's strengths, needs, communication abilities, and behavior.



Here are some potential questions to include:

- How would they describe his/her social relationships?
- What methods of communication does he/she use?
- How does he/she let you know he/she needs something?
- How does he/she let you know he/she likes or dislikes something?
- What have been effective learning strategies?
- How do they help him/her learn new skills at home?
- Are there any aggressive or concerning behaviors?
- What are possible triggers of worrisome behavior?

- What is helpful for holding his/her attention?
- Are they willing to share a copy of his/her Individualized Education Plan (IEP), or at least what accommodations are in place at school to help him/her learn?
- Does he/she have any dietary restrictions? Know
  the child's diet restrictions. Perhaps the parent
  would prefer to bring a snack from home if there
  are restrictions. Children with autism are often
  on special diets and are usually very sensitive to
  certain textures, smells, and flavors. If they need
  assistance, such as a special cup, or food cut into
  small pieces, etc., be aware of that as well
- Does he/she have any medical issues you need to be aware of?
- Cell phone number



Give opportunities to adults and children with disabilities to serve others within the worship service and in the outreach programs of the faith community. Recognize that each person has gifts and abilities, and consider the individual's strengths and preferences (and possible sensory issues) just as you would with volunteer positions for any other member. Ask parishioners with disabilities whether they would like to usher, bring up the gifts, proclaim the word, etc. Invite a parent to be on a committee and hold meetings at the family's house or have them call or video chat into the meetings. Urge the hiring of people with ASD if a position opens that's within their skill set.

Ask the person with the disability HOW you can help. Respect any refusal.

### What are some specific strategies to support individuals with autism?

#### Strategies to alleviate sensory issues

- If the individual is sensitive to bright lights, a cover can be purchased to soften lighting, especially fluorescent ones. If any of them are flickering, it can help to replace them or switch them off if you can.
- If they don't like loud noises, be sure to keep them at a distance from a cd player or instruments during music time. Is there unexpected loud noise in today's service/meeting? Can it be changed easily? If not, can you warn the individual first? Hard or reflective surfaces can cause echoing that makes it hard for some individuals to hear, especially in a crowd. Carpeting can help a lot, as can a quiet space to recover.
- If the child with autism prefers not to be touched during greeting time, then abide by that. For safety, check for sharp-edged furniture, small parts, electrical plugs, and cleaning materials.
- Provide a rest area somewhere quiet to go when needed. Individuals with ASD are coping with far more incoming information than most people, so they may need to pace themselves to avoid exhaustion.
- Routine and predictability are also vital; individuals with autism need to know what to
  expect. Will there be physical events like shaking hands during the service? Water being
  splashed about? Individuals may find this physically painful or scary. Letting them know
  ahead of time can help, and they should be asked whether it is physical contact is okay.
- Individuals with autism benefit from some information to help orient them to their surroundings. Show them the layout and provide a map if possible.
- Provide support by pairing the individual with a quiet, caring person who can be aware of them and lend assistance if requested. First check with the individual with special needs; respect their confidentiality and privacy.

#### Strategies to improve communication

- Ask caregivers about how their child communicates: verbal, nonverbal, and alternative or alternative strategies used by the child, such as taking your hand and placing it on something that they desire.
- Talk directly to the child, not to their caregiver. Even if the child does not speak verbally, they may understand what you say.
- If you don't understand what the child said, politely ask them to repeat themselves or show you what they want instead.
- Speak in simple sentences just at or one step above the level of communication that the child uses. For example, if the child speaks in two-word phrases, try to keep your sentences to four words or fewer if you want them to understand.
- Some children may need more time to process language and respond to you. Try counting to 10 in your head to give them enough time to process what you have said.
- Consider ways that you can combine visual information with verbal to help children with ASD comprehend lessons better and keep them engaged. It is helpful to use gestures or pictures to show what is going to happen next in the group (reading a book, having snack).
- Avoid using figurative language when speaking to children with ASD. They often have literal
  interpretations of what is said and could be disturbed by some religious language like "bird
  on fire."
- Give clear choices such as "do you want to color or play outside?" instead of asking openended questions such as "what do you want to do?"

- Choices are also easier to depict visually. For example, you could hold up pictures of activities and have the child point to or pick up the picture of their choice.
- Children who use augmentative and alternative communication (AAC) may prefer using
  picture symbols to choose songs, snacks or activities. They may also use a programmed
  voice output device to make choices, answer questions, recite bible verses or say prayers.

### Social Narrative: Shabbat Dinner

On Friday nights my family has a special dinner to celebrate Shabbat. At Shabbat dinner it is different because Grandmom and Pop-pop come and we eat in the dining room. Before we can eat dinner on Shabbat, we say three blessings. I will try to sit in my seat and listen to the blessings.

First Grandmom will light the candles and say the blessing. Then Poppop will say the Kiddish over the wine and then the Ha-motzi for the challah. I can cover my ears during the blessings if the singing bothers my ears, but I will still try to sit quietly in my seat. Sometimes waiting to eat is hard. I can count the blessings on my fingers to help me wait for them to be done.

When we are done with the three blessings, I can have a bite of challah. Then I am allowed to eat. If I try to sit quietly in my seat during the blessings, my whole family will be proud and we will have a special Shabbat dinner.

#### Social narratives

Social narratives are written and visual guides based on common events. They are often effective to prepare children with ASD for unfamiliar situations or environments where certain social behavior is expected.

- Writing a social narrative that explains the religious education routine and/or service may help a child with ASD feel more comfortable in those situations.
- Your organization may want to create a standard social story for your religious education that includes photographs of the actual spaces and materials used throughout the routine event. This could be customized for each child as needed.
- Children could use the social story to "practice" a religious education class at home with their parents.
- Some children may find the social story more helpful after doing a walk-through or practice visit of the religious education space.
- •Social stories can also be used to reduce behaviors that are unusual for the situation such as talking too loudly during religious services or sitting too close to others.

### Visual schedules and supports

Research suggests that many children with ASD benefit from seeing what is going to happen rather than simply being told verbally. Visual schedules are picture representations of each step in a routine that simplify the complex concepts of time and event sequencing.

- •Consider creating visual schedules for each religious education meeting. Go over the schedule when the child arrives; this is an appropriate group discussion with young children. Use the schedule to remind the child (and others in the group) what is happening now and what comes next.
- Create other visual cues on the schedule or throughout the lesson. For example, if the child often comments during story time, you can hold up a sign/signal for when it's appropriate to ask questions and comment and put the sign down when it's time to listen.

#### Peer modeling

Like many children, children with ASD often prefer to learn from their peers instead of being told what to do by adults. Peer modeling is a way to train caring children in the child's religious education class to support the child with ASD so that they require less adult support.

- Whenever possible, think of ways that a peer can assist the child with ASD instead of an adult.
- Consider assigning a "faith partner" to the child with ASD to sit with them through religious services and include them on the playground at events. The faith partner could rotate and be a special role for children in the child's class.
- Supervise peer models or "faith partners" to ensure that they treat the child with ASD respectfully like all other children in the class. Avoid having the child with ASD become a "class pet" and instead aim for equal inclusion.

#### **Preparation for transitions**

- Some children with ASD struggle with changes in routine and transitioning from one activity to another. Even if the child has a visual schedule that you can reference, preparation for transitions is important.
- Provide verbal and/or visual warnings ("5 more minutes") when the child needs to transition, especially if it's from a preferred activity to a nonpreferred activity.
- Use of timers (visual and online)
- Try to make transitions fun and stress-free whenever possible. Sing a favorite song while cleaning up or let the child keep a transition object: a toy or small part of the previous activity to hold while you set up for or walk to the next activity.
- Avoid overstimulation by offering alternate activities or modifying activities that
  may not be pleasurable to the child due to their sensory differences. For example,
  offer a pair of headphones to the child or a more quiet activity such as taking
  a walk if events in the room become too loud. Prepare the child for potentially
  overstimulating activities and when possible, give the child a choice between
  participating, participating in a modified way, or doing an alternate activity.
- Prepare the child and tell the child's parents so that they can prepare the child when major changes in routine are planned such as a teacher absence or meeting in a different location.





### How can our faith community create new programs to include families with special needs?

If your community does not already offer an ASD support group for parents, siblings, or individuals with ASD themselves, consider hosting one led by a member of your group or a community professional. Consider offering respite care during parent support groups with activities for children with ASD and their siblings.

**Buddy system:** Pair children with special needs with trained adults to assist them at whatever level is needed. Experienced volunteers trained by child psychologists and educators are a plus. If they choose to attend children's church, welcome them in and make any accommodations that you can. That means you may need an extra helper for just that child. Having peer buddies available would also be a great resource, especially for children or adults who are able to access the regular services and activities with minimal support.

**Parents' Nights Out (respite care):** Consider providing a child-care ministry for children with special needs and their siblings. Many parents of children with ASD or other special needs rarely get a night out and would appreciate the opportunity to go out and enjoy an evening to themselves as parents of typical children often do.

**Community outreach:** Some parents will not attend church because they believe their child with special needs will disturb others or cannot be entrusted to others. Go beyond the church walls and minister in the community by offering a modified worship service or family outreach activity to help build the relationship between church and families of children with special needs. For families of adults with special needs, provide transportation when at all possible.

**Dual classrooms:** Oftentimes, children with special needs can participate in the same class as their age group, but at other times, they may need a quiet room especially designed for them when they are feeling overwhelmed or over-stimulated. Provide as many options as you can with trained volunteers who can be flexible to go into a mainstreamed or separate class as needed.

**Separate classroom:** The federal law IDEA calls for local school systems to educate children with disabilities alongside their typical peers whenever possible. Sometimes the supports needed for a child with special needs are best met in a separate classroom, and this may be a better option within the church programming for some children or adults as well. In this type of protective setting, parents or siblings may wish to be present, and this would be another opportunity to provide peer buddies alongside trained adult volunteers.

**Quiet place or sensory room:** As mentioned above, many children with special needs will find a typical classroom to be overstimulating and overwhelming at times. It would be optimal to have a quiet classroom with items designed specifically to help a child with special needs relax as needed. A good sensory room may include items such as soft beanbags, blankets, weighted lap pads or blankets, lights that are easily dimmed; soft play objects and access to soothing music.

**Meals:** Many families of children with special needs transport their children to numerous therapies and doctors' appointments and may have trouble finding the time to make home-cooked meals for their families on a regular basis. Consider having some members of your congregation sign up to provide home-cooked meals or even some meals that can be kept in the freezer for the difficult days a family may face.

**Care committee:** Many families of adults with special needs find that there are few opportunities and options available after their child leaves school, especially if they are unable to go to college or get a job. Consider having a committee of congregational members who would be willing to provide care of adults by providing connections to volunteer opportunities or by means of weekly social visits, shopping assistance, caregiver break-time, or babysitting, etc.

### **Additional Resources:**

### Early identification, family support, and treatment

Centers for Disease Control – Learn the Signs. Act Early www.cdc.gov/ncbddd/actearly

Autism Society of North Carolina www.autismsociety-nc.org

Carolina Institute for Developmental Disabilities www.cidd.unc.edu

UNC TEACCH Autism Program www.teacch.com

Disability Rights North Carolina www.disabilityrightsnc.org

NC Early Intervention Program www.beearly.nc.gov

### Faith-inclusion resources online

That All May Worship, An Interfaith Welcome to People with Disabilities www.aapd.com/publications/that-all-may-worship-2

Autism and Faith: A Journey into Community <a href="http://rwjms.umdnj.edu/boggscenter/products/documents/Autismandfaith-english2011.pdf">http://rwjms.umdnj.edu/boggscenter/products/documents/Autismandfaith-english2011.pdf</a>

The Inclusive Church: Helping Churches Successfully Include Children with Special Needs <a href="https://theinclusivechurch.wordpress.com/">https://theinclusivechurch.wordpress.com/</a>

Putting Faith to Work: A Guide for Congregations and Communities http://faithanddisability.org/projects/putting-faith-to-work/

Key Ministry www.keyministry.org

Nathaniel's Hope www.nathanielshope.org

Reality Ministries www.realityministriesinc.org

Joni and Friends www.joniandfriends.org/education-and-training

### **Faith-inclusion books**

**Autism and Your Church: Nurturing the Spiritual Growth of People with Autism Spectrum Disorder** by Barbara J. Newman

**Leading a Special Needs Ministry: A Practical Guide to Including Children and Loving Families** by Amy Fenton Lee

Spiritually Able: A Parent's Guide to Teaching the Faith to Children with Special Needs by David and Mercedes Rizzo

**Every Child Welcome: A Ministry Handbook for Including Kids with Special Needs** by Katie Wetherbee and Jolene Philo

Speechless: Finding God's Grace in My Son's Autism by Sandra Peoples

**Disability and the Gospel: How God Uses Our Brokenness to Display His Grace** by Michael S. Beates

Same Lake, Different Boat: Coming Alongside People Touched by Disability by Stephanie O. Hubach

### **Visual Supports**

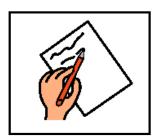
On the next two pages, we have provided some resources that you can use as examples to create your own visual supports to include individuals with autism in your programs and services. These can be photocopied and used as is, but we recommend creating your own with actual photos of your spaces.

First, we show a First/Then board and icons. These are often used with Velcro on the board and on each piece, so that you can easily change them out to show someone what will happen next.

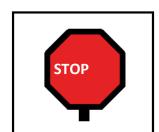
On the next page is an example of a social narrative. Social narratives are simple stories that focus the individual's attention on only the key details of a situation to help them understand what will happen. Please keep in mind, this is only an example. It is important to adjust the number and complexity of details to meet the needs of the individual.

First

Then

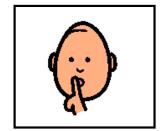




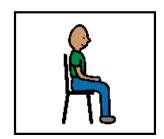












### **Sample Social Narrative**

**10:15 - 10:25** Snack & bathroom break





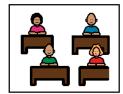
**10:25 - 10:35** "Getting Started" Discussion/Activity



**10:35 - 10:40** Line up and Move to Large Group Room



**10:40 - 11:10** Large Group Lesson



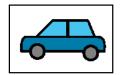
**11:10 - 11:30** Learning Activity



**11:30 - 11:35** Prayer Time



**11:35 - 11:45** Parent Pickup



### **About Autism**

Autism Spectrum Disorder (ASD) refers to a group of developmental disabilities — including classic autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger's Syndrome — that affect a person's ability to understand what they see, hear, and otherwise sense. It is a brain disorder that affects communication, social interaction, and behavior.

Individuals with ASD typically have difficulty understanding verbal and nonverbal communication and learning appropriate ways of relating to other people, objects, and events. No two people with ASD are the same. As its name implies, ASD is a spectrum disorder that affects individuals differently and with varying degrees of severity. Additionally, ASD is often found in combination with other disabilities.

It is estimated that up to 1 out of every 68 children has some form of ASD. Evidence suggests that the prevalence rate in North Carolina is even higher than the national average, at 1 in 58. More than 60,000 individuals live with ASD in North Carolina.

The overall incidence of ASD is consistent around the globe, but it is five times more prevalent in boys than in girls. ASD knows no racial, ethnic, or social boundaries, and family income, lifestyle, and educational levels do not affect the chance of occurrence. While ASD is typically diagnosed in children, it is a lifelong disorder that affects individuals of all ages.

### What Causes ASD?

Although it was first identified in 1943, to this day no one knows exactly what causes ASD. However, research to discover its cause is ongoing. Many researchers believe that there is a strong genetic component. Some research suggests a physical problem that affects the parts of the brain that process language and information; other research points to an imbalance of brain chemicals. A variety of possible external or environmental triggers are also being studied. It is possible that ASD is caused by a combination of several factors.

### **Signs and Symptoms**

People with ASD may have problems with social, behavioral, and communication skills. They might repeat behaviors and might not understand change in their daily activities. Many people with ASD also have different ways of learning, paying attention, or reacting to things.

#### A person with ASD might:

- have severe language deficits or differences
- talk about or show interest in a restricted range of topics
- not point at objects to show interest, such as an airplane flying over
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled or might cuddle only when they want to
- appear to be unaware when other people talk to them but respond to other sounds
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
- have trouble expressing their needs using typical words or motions
- laugh, cry, or show distress for no apparent reason
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- be oversensitive or under-sensitive to pain
- lose skills they once had (for instance, stop saying words they were once using)



The Autism Society of North Carolina is the leading statewide resource organization serving people across the autism spectrum throughout their lifespans. We understand the challenges of the autism community because we work with individuals with Autism Spectrum Disorder (ASD) every day.

ASNC works to directly improve the lives of individuals and families affected by autism through advocacy, training and education, and direct services.

**Advocacy:** We are the only autism-specific advocacy organization in North Carolina, and it is the heart of what we do. We find resources for families, assist with school issues, educate families through workshops, help individuals navigate the services system, and host local support groups. We also give those with autism a voice in public policy by maintaining relationships at the state legislature and other policy-making entities.

Autism Society of North Carolina 5121 Kingdom Way, Suite 100 Raleigh, NC 27607

> 800-442-2762 (NC only) 919-743-0204

info@autismsociety-nc.org www.autismsociety-nc.org

Connect with us on social media:

facebook.com/AutismSocietyofNorthCarolina twitter.com/AutismSocietyNC **Training & Education**: We focus on evidence-based best practices that empower self-advocates, families, and professionals. We also work to increase understanding and acceptance of people with ASD in the community.

**Services:** ASNC is a direct care service provider, and a recipient of the highest level of accreditation by the Council on Quality Leadership for exemplary service provision. Individuals with ASD receive a variety of residential, recreational, vocational, and community-based services that are designed to meet their needs, interests, and strengths.