# FOR FAMILIES IN CRISIS

### A Quick Reference and Lesson Guide

Children with Special Needs: Autism

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# Scenarios and Assessment

\*\*\*This reference guide will specifically address autism spectrum disorder. Because this guide will address autism at a high level, it will only discuss base symptoms and ways to care for them.\*\*\*

### **Scenarios/Case Studies**

- A. Scenario #1
  - 1. Callie recently has been diagnosed with autism spectrum disorder (ASD) and lives with her family. Anytime they get together, there is lots of fun and laughter. Callie's usual role is observing rather than participating. One day her sister grabbed her by the arm and invited her to join them. Callie pulled away from her sister while yelling and crying that she did not want to be touched.
- B. Scenario #2
  - 1. Otto is an eight-year-old boy who loves school. Every day he sits in the same desk, places his jacket on the same hook, eats at the same table at lunch, and engages in other routine practices. One day there was a fire drill at school, and while the other children adhered to protocol, Otto became upset. He flipped his desk over and began screaming that the fire drill was not supposed to happen and that he was not going anywhere.
- C. Scenario #3
  - 1. Melissa and her mother attended a birthday party. When her mother turned her back to talk to someone, a little girl came up to Melissa and introduced herself. The little girl asked several questions, but Melissa simply said, "Hi," and stared at her. Assuming Melissa was being mean, the little girl walked away.

### **Definitions and Key Thoughts**

- A. Does my child have autism spectrum disorder (ASD)?
  - 1. What is autism? It is a developmental disorder consisting of delays in and problems with social interaction, language, and a range of emotional, cognitive, motor, and sensory abilities (Greenspan & Wieder, 2006). Although currently there is not a cure for autism, there are effective ways those coping with it can be cared for that will enhance normalcy in their lives and the lives of those around them. For the most accurate results, it is recommended the child be professionally evaluated.
  - 2. The ASD levels of severity are as follows (American Psychiatric Association [APA], 2013):
    - a) Level I (requiring support)
      - (1) Has trouble initiating social interactions and responding or engaging socially. Inflexible behavior interferes with daily functioning including

changing activities, and lack of organizational skills hinders independence.

- b) Level II (requiring substantial support)
  - Even with assistance, there are noticeable deficits in verbal and nonverbal social communication. Responses are limited or abnormal. Displays inflexible and repetitive behaviors interfering in daily life functioning and exhibits opposition when changing focus or activities.
- c) Level III (requiring very substantial support)
  - There is a significant lack in verbal and nonverbal social communication skills and there is minimal interaction with others. Inflexible and repetitive behaviors cause severe interference in daily functioning. Exhibits strong opposition in changing focus or activities.
- B. Key Facts:
  - 1. Some people who have autism also have epilepsy, which is a condition that causes seizures (Bleach, 2001).
  - 2. Those with autism read and process human expressions and emotions in a different part of the brain (Greenspan & Wieder, 2006).
  - 3. Once caregivers help build relatedness and communication skills, certain less desirable behaviors tend to recede (Greenspan & Wieder, 2006).
  - 4. Studies have shown a high percentage of children with autism can reach all the fundamental emotional and developmental milestones (Greenspan & Wieder, 2006).
  - 5. Because autism is not a disease, there is no cure; however, some behaviors can change over time with intentional effort.
  - 6. Some persons with autism struggle with reality-based thinking because it is challenging to engage in the outside world-as opposed to fantasy (Greenspan & Wieder, 2006).
- C. Myths:
  - 1. Those with autism do not have the ability to love or experience an intimate relationship.
  - 2. Those coping with autism cannot learn to think abstractly or make inferences (Greenspan & Wieder, 2006).
  - 3. It is not possible for people with autism to communicate and think creatively (Greenspan & Wieder, 2006).

### **Assessment (Interview)**

- A. Questions parents can ask themselves about their child (Greenspan & Wieder, 2006):
  - 1. Does the child enter into a state of shared attention?
  - 2. Does he engage with you with warmth and intimacy?
  - 3. Is he able to interact with you in a purposeful way?
- B. How to care for children with autism:
  - 1. Engaging with the child
    - a) Know your strengths and weaknesses as they relate to the child
      - (1) Are you aggressive, bossy, overprotective, easily irritated, or prone to withdraw?
      - (2) When the going gets tough it is beneficial to respond by being:(a) Soothing and emotionally supportive.

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- (b) Warm and nurturing.
- (3) How do they play out in the family relationship as a whole?
  - (a) Family intimacy
  - (b) How does the family communicate with one another?
  - (c) Is there shared problem-solving?
- C. Language delay (Siegel, 2003)
  - 1. Echolalia
    - a) Immediate Echolalia
      - (1) Repeating a phrase or word for no reason.
      - (2) Shows that two necessary mechanisms for language and production are functioning, but that the child may only partially comprehend—if at all.
    - b) Delayed Echolalia
      - (1) Repeating phrases or sentences heard in the past (tone of voice included).
- D. Social Interaction (Siegel, 2003)
  - 1. Three dimensions of social learning disability
    - a) Lack of awareness of others
      - (1) Child fails to recognize things going on around him that others may notice
      - (2) Motivation is to please the self rather than others
    - b) Lack of response to social reward
      - (1) Lack of desire to please others
      - (2) Low response to social praise and physical affection
      - (3) Lack of concern about how her behavior affects others
    - c) Lack of social imitation
      - (1) Child does not learn through incidental or purposeful models
      - (2) No interest in rule-oriented or imitative (parallel) play.
      - (3) Does not change in response to peer pressure, norms, or interests.
- E. Be aware of the child's heightened senses (Verdick & Reeve, 2012).
  - 1. **Sight (eyes):** Lights may be too bright for the child or he may have difficulty tracking moving objects.
  - 2. **Hearing (ears):** Loud noises may be painful. The child may be unable to tune out background noises. He may have a strong reaction to sharp or high-pitched sounds.
  - 3. **Smell (nose):** Some smells may induce nausea or create a sick feeling. Child may sniff objects to send information to the brain.
  - 4. **Taste (mouth):** May have particular tastes (e.g., salty, sweet), avoid certain textures, or lick objects to discover taste and sensation with mouth.
  - 5. **Touch (skin):** Certain fabrics may feel unusually itchy or scratchy. A light touch may feel like a push. Touching may be resisted or craved. Pressure of tight hugs or clothing may be pleasurable.
  - 6. **Balance (inner ear):** May have difficulty balancing, walking on uneven surfaces, or using stairs., Can feel stressed when feet leave the ground. Can love or hate spinning.
  - 7. **Body (muscles and joints):** Coordination of body movements can be difficult as well as figuring out where body is in space. May bump into people or objects. May like to flop on soft furniture or cuddle under heavy blankets.

# Critique and Counsel

### **Biblical Insight**

- A. People with special needs are a part of the body of Christ. Those coping with disorders can sometimes be singled out; however, it is vital to keep in mind that although they may not be as involved in church they display God's workmanship. What are they used to reveal?
  - 1. The uniqueness of His creation—It is important to acknowledge the children of God differ not only in backgrounds, races, and ethnicities, but also in abilities and skill sets.
    - a) God created each of His children distinctively. A person's ability (or lack thereof) does not make that person any less important. Psalm 139:14 exclaims each person is "fearfully" and "wonderfully" made.
    - b) God created humanity in His image and expressed that "it was very good" (Genesis 1:27; 31). Therefore, nothing God created should be labeled as less than.
    - c) The abilities God gives His children were specifically designed by God for each person. Isaiah 64:8 expresses, "We are the clay, and You our potter; and all we are the work of Your hand" (NKJV). Some children with special needs are gifted in special arenas that can be used for the church or for personal fulfillment.
  - 2. The strength of the caregivers—God knows about circumstances before they occur; they are only a surprise to the ones experiencing them. These circumstances bring out inner qualities that were hidden and produce character.
    - a) Because God knows the beginning and end, He understands the challenges that lie ahead. During his flight from Saul, David acknowledged God's providence in Psalm 139:2–3: "Thou knowest my downsitting and mine uprising, thou understandest my thought afar off. Thou compassest my path and my lying down, and art acquainted with all my ways." It is important to take comfort in this.
    - b) During his lifetime Paul experienced times of joy and trials; however, he leaned on God to pull him through. Philippians 4:13 records that Paul could do "all things" with God's strength. When he was unable to produce what was needed to get him through, he acknowledged his dependence on God.
    - c) Outside of the joyous times, it can feel as though the trials are in vain. However, during those times God is producing patience, experience (which can be used as a testimony), and hope (that God will bring the believer through). (See Romans 5:4.)

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### Wise Counsel

- A. Autism and the church (Newman, 2011)
  - 1. Ten strategies to include those with ASD in the church:
    - a) Gather information about the person with ASD.
      - (1) Include on registration card: "Does your child have any special circumstances we should be aware of? This information will be shared only at your request, but it will allow us to better meet your child's individual needs."
      - (2) Identify ways to make church enjoyable. Invite the child to categorize class or service elements into "I like it." and "I don't like it." Include pictures of what takes place during each time.
    - b) Share information with those who need to know.
    - c) Monitor sensory input in church environment.
      - (1) Try offering a "break time" instead of a "time out" to allow the child to regain composure or control over sensory system.
      - (2) Do not insist on eye contact if visual input is overloaded.
      - (3) Try headphones or sound blockers to eliminate loud sounds.
    - d) Think alongside the person with ASD.
      - (1) Realize that his sensory system has been agitated (think about what the person could have seen, heard, touched) and consider what happened before the incident.
    - e) Make routines comfortable.
      - (1) Print the order of activities or service schedule (including pictures/graphics to represent each element) and create comfortable transitions.
    - f) Use advance-warning systems.
      - (1) Use concrete language carefully.
      - (2) Use a picture or word schedule and cross off or turn picture over when task is completed.
    - g) Close the communication gap.
      - (1) Identify and translate possibly confusing phrases or Scripture verses on the spot.
      - (2) Use visual aids for those with limited verbal skills.
    - h) Use visuals to reinforce what is being said.
    - i) Write stories to help people with ASD anticipate new situations.
      - (1) Describe specific events.
      - (2) Explain changes in programming.
      - (3) Describe expected behavior for worship and fellowship.
    - j) Teach instead of reacting.
    - 2. Where to begin with misbehavior (Newman, 2011):
      - a) Put the behavior in the context of who the person is. Listen for the message behind the action. It could be communicating: "I'm afraid," "My sensory system has been overloaded," or "You changed my schedule and I don't appreciate that."
      - b) Investigate cause(s) of behavior.
      - c) Spend time getting to know the person.

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- d) Proactive strategies
  - (1) Be prepared. Have a plan in place and make others aware of just-incase moments. Let the individual with autism visit and interact with leaders and the environment beforehand.
  - (2) Make sure environment is safe and comfortable.
  - (3) Make a log or journal of things that worked for the individual.
  - (4) Set up a system of rewards.
  - (5) Build a relationship.
  - (6) Do something unexpected.
    - (a) When misbehavior occurs try alternative solutions.
  - (7) Give choices.
    - (a) Have pictures of activity choices.
- e) Reactions to challenging behaviors
  - (1) Ignore when possible.
  - (2) Redirect when challenging behaviors begin to occur.
  - (3) Take a break. Go to a quiet or isolated area until behavior is under control.
  - (4) Emphasize natural consequences.
    - (a) If you trash a room, clean it up.
    - (b) If you hit someone, apologize.
    - (c) This approach teaches cause and effect.
- 3. Action plan (Newman, 2011)
  - a) Recruit a coordinator.
  - b) Form a special needs ministry team.
  - c) Develop an Individual Spiritual Formation Plan (ISFP) for each individual with special needs.
  - d) Offer ongoing support.



### **Application**

- A. Treatment
  - 1. It is important for parents who care for a child with autism to recharge regularly, which is an important form of self-care. The child can be put to bed early or watched by a trusted adult a couple of times each week.
- B. Treatment for language deficit
  - 1. There are three objectives when developing language skills and ideas:
    - a) Gestures–with words (emotional signaling)
      - (1) Communication is primarily taught through imitation.
      - (2) Facial expressions with words

- b) Creating emotionally meaningful situations
  - (1) Build a symbolic world to increase ability to use language and ideas.
    - (a) The child may pretend to feed doll like her mother.
    - (b) The child may pretend to clean as is modeled around the home.
- c) Use elements of play to relate to child's favorite activities.
  - (1) If child plays with utensils, pretend she is a chef and parent is the helper.
  - (2) Dress up or act like a favorite character and engage with child using sounds and words.
- 2. Engage the child in play and ask questions pertaining to real life situations.
- 3. For the preverbal or non-verbal child, consult Siegel (2003), pp. 178–180; 186–187; 200–203.
  - a) Telegraphic speech and the "Lovaas accent"
    - (1) Talk in a way that adverbs, adjectives, and articles are used in a way that is a descriptive stimulus (SD)-as a fixed pattern.
    - (2) I.e. "touch K-N-E-E" or "touch M-Y nose".
    - (3) Picture Exchange Communication System (PECS)—a developed communication system where pictures are used as a means of communication
      - (a) Icons—a literal representation of an object as defined by packaging, a photo, texture, etc
- 4. Sequencing pictures—using pictures in a sequence to communicate desires
  - a) A child who wants to roll a soccer ball outside may present a picture of a ball and the sun or a doorknob.
- 5. Visual communication and consistent routines
  - a) For the child with autism who has poor (or lacks) verbal communication and is fixed on routine, it helps to have a visual schedule to communicate to the child what is going on.
    - (1) Label task with a picture and switch with Velcro backing to inform child of the order of routines (can be used in the car as well).
- 6. For the verbal child, consult Siegel, (2003), pp. 207; 219; 225–227.
  - a) Communicative "press"
    - (1) When a child desires an object, use key words and gestures to teach child to ask for it and add works like *mom*, *please*, and *thank you*.
  - b) Yesterday, today and tomorrow books
    - (1) Place a series of pictures of key events of the child's life from the past, present, and future in a loose-leaf binder. When the pictures are placed in sequenced order, the child can use them to retell the day, using language in a terse form.
  - c) Music, language and autism
    - (1) Pair words with music to help to teach language (include clapping, hitting an instrument, etc.)
- C. Treatment for social deficit (Siegel, 2003)
  - 1. Motivation
    - a) Children with autism desire to please themselves (their motivation) and will choose that *thing* even if it displeases someone else (Siegel, 2003).

- b) Pairing non-social and social rewards links social praise with a tangible reward. It should be used such that the child continues to respond to social praise when the reward is no longer used (later in life).
- c) Balance of rewards should keep child motivated, help him to become selfmotivated, and help him become independence in the future.
- d) Find out what the child likes including his sensory preferences (e.g., sight, taste, touch, smell, audio).
  - (1) Food reward
  - (2) A kiss on the cheek, high five, clapping, etc.
  - (3) Petting or feeding an animal
- e) Consider frequency of reinforcement.
  - (1) How often the child receives a reward for sticking with and completing activity successfully
- f) Token economies
  - (1) This involves deferring the reward until the end of an activity, the day, or a given time period (school semester, event, outing, etc.). Create a visual progress board.
- g) Play
  - (1) A child with autism may interact more with other children based on developmental age rather than chronological age.
  - (2) Play with groups of mixed ages (a family day care or another small setting is recommended) to allow interaction with peers on a developmental level.
  - (3) When adults participate in play, it should include repetition (to help the child gain mastery).
  - (4) For very avoidant or temperamentally sensitive children the two worlds can be bridged if the individual with autism believes things are being done on her terms. Adults engaging in play acting as a follower of the child can refer to Stanley Greenspan and Serena Wieder's "floor time" exercise (2006).
  - (5) A shadow aide helps the child join mainstream social situations. The aide stays close to the child and helps when needed (with social interactions, reading-words, gestures, facial expressions, when to imitate others, etc.).

### <u>Prayer</u>

God, we thank You for the courage and skills You have given these parents to care for Your child in a special way. We pray that You will strengthen and give them wisdom and give rest to the family. We ask that You will especially guide them in raising their child with the utmost love and care. We thank You for the talents and abilities You have given their child and pray that You will use him for Your kingdom in the way You see fit. We ask that You forever be present with him. In Jesus' name. Amen.

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# Recommended Resources

#### A. For the caregiver

Greenspan, S.I. & Wieder, S. (2006). *Engaging autism: Using the floortime approach to help children relate, communicate, and think.* Philadelphia, PA: The Perseus Books Group.

- Higashida, N. (2007; trans. 2013). *The reason I jump: The inner voice of a thirteen-year-old boy with autism*. United Kingdom: Sceptre.
- Siegel, B. (2003). *Helping children with autism learn: Treatment approaches for parents and professionals*. New York, NY: Oxford University Press.
- Verdick, E. & Reeve, E. (2012). *The survival guide for kids with autism spectrum disorder and their parents*. Minneapolis, MN: Free Spirit Publishing, Inc.

#### B. For the child

- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Bleach, F. (2001). *Everybody is different: A book for young people who have brothers and sisters with autism*. London, UK: National Autistic Society.
- O'Toole, J. C. (2013). *The Asperger's (secret) book of social rules: The handbook of not-so-obvious social guidelines for tweens and teens with Asperger syndrome*. London, UK: Jessica Kingsley Publishers.
- Rudolph, S. & Royer, D. (2015). *All my stripes: A story for children with autism*. Washington, DC: Magination Press.

#### C. For the pastor

Champions Club (2014) https://www.championsclub.org

Newman, B. J. (2011). Autism and your church. Grand Rapids, MI: Zondervan Bible Publishers.

## Taking it to the Church

### "Suffer the Little Children"

### Lesson Text

### "But Jesus said, Suffer little children, and forbid them not, to come unto me: for of such is the kingdom of heaven" (Matthew 19:14).

Sometimes those with special needs are looked upon as less than a child of God. When God told Abraham that He would make him a "father of many nations," there was no exclusion. The body of Christ is full of diversity beyond anyone's imagination; therefore, when someone is excluded due to circumstances beyond her control, it amounts to a dismissal of God's handiwork. James 2:8 states, "If ye fulfill the royal law according to the scripture, Thou shalt love thy neighbor as thyself, ye do well." In one sermon, Jesus told the crowd unless they would become like children they would not enter into the kingdom of heaven.

Perhaps Jesus communicated the importance of coming to Him as a child because children have an innocence and purity about them that adults do not always retain. He focused attention on children to highlight attainable qualities, the overarching one being humility. In Matthew 18:4, Jesus stated, "Whosoever therefore shall humble himself as this little child, the same is greatest in the kingdom of heaven." A child looks beyond appearances, is accepting of others, is dependent on God, and displays vulnerability in his relationship with God.

### Accepting one another

### "There is neither Jew nor Greek, there is neither bond not free, there is neither male nor female: for ye are all one in Christ Jesus" (Galatians 3:28).

A quality of humility is being accepting of one another and this requires understanding and tolerance. Demonstrating this characteristic of humility includes accepting those who have special needs. When it comes to important human qualities, children tend not to allow differences to cloud their judgment when it comes to relating to others. For believers humility entails recognizing the kingdom of God does not consist of one type of person but acknowledging each believer has a place. We must never reject people with special needs. The saints of God are "made to drink into one Spirit," and "the body is not one member, but many" (I Corinthians 12:13–14). These verses indicate the diversity that exists within the Kingdom. In preaching Christ, Peter stated that "God is no respecter of persons," showing that everyone deserved the gift of salvation (Acts 10:34).

### "[Love] beareth all things, believeth all things, hopeth all things, endureth all things"(I Corinthians 13:7).

Understanding and tolerance can only be demonstrated through love. When believers encounter those who are different from them, it is their calling as followers of Christ to communicate love. For children with special needs, this is offering validation in the form of empathy and having patience to help them navigate life, especially in the kingdom of God.

### **Dependence on God**

### "When I said, My foot slippeth; thy mercy, O Lord, held me up." (Psalm 94:18).

Another quality of humility found in children is dependence on God. Entrusting oneself to a person takes great faith. When a child with special needs has a sensory overload, the reaction is often a cry for help, communicating the message, "I cannot do this on my own; I need someone to rescue me!" A child in distress relies on his parents to relieve him from pain. The psalmist exclaims, "I will lift up mine eyes unto the hills, from whence cometh my help. My help cometh from the Lord, which made heaven and earth" (Psalm 121:1–2). God takes pleasure in being a refuge for His children; therefore, when a believer is in distress, he can cry out to God, his Father, for help. Before ascending into heaven, Jesus reassured the disciples He would always be with them (John 14:18). Jesus also explained that believers should not worry about the cares of this world but be assured of His divine providence (Matthew 6:30–34).

### Vulnerability

### "And he said unto me, 'My grace is sufficient for thee: for my strength is made perfect in weakness." (II Corinthians 12:9).

Paul boasted about his weaknesses, but in doing so he opened himself to divine intervention by exposing them. Still, some believers try to hide their weaknesses. Some have a misconception about what it means to be strong in the Lord. This is not always associated with blessings; most often, rather, a strong believer has experienced trials yet remained faithful to God. Vulnerability in a relationship with God takes courage and trust because it transfers power from the believer (tangible) to God (intangible). While this may be alarming for some, being transparent with God opens up the pathway for His power to do what the believer cannot do alone. This is how believers become strong. Their exposure of their weaknesses leads them to have that same power to withstand.

### "Blessed is the man that trusteth in the Lord, and whose hope the Lord is. For he shall be as a tree planted by the waters, and that spreadeth out her roots by the river, and shall not see when heat cometh, but her leaf shall be green; and shall not be careful in the year of drought, neither shall cease from yielding fruit" (Jeremiah 17:7–8).

God compares a cursed man and blessed man, stating the one who trusts in Him will be blessed and forever established. Trusting in the Lord is a crucial element to having an active relationship with God. This comes easy to children because of their willingness to be open. It appears that trust is an innate quality of children. When trust is broken within a relationship, vulnerability becomes difficult; however, believers continuously experience trust in their relationship with

God. The psalmist declared, "And those who know your name put their trust in you, for you, O Lord, have not forsaken those who seek you" (Psalm 9:10, ESV). Just as a child seeks out help when he is in need, so should the believer when he is in need of God. Being exposed to a complex environment, some children with special needs must have a level of trust with their caregiver. Exposed to the elements of the world, believers are instructed to walk cautiously. Therefore, trusting in God is crucial in receiving heaven's reward.

### **Closing**

Joshua 1:9, KJV "Have not I commanded thee? Be strong and of a good courage; be not afraid, neither be thou dismayed: for the Lord thy God is with thee whithersoever thou goest" (Joshua 1:9).

Joshua was given charge by God to lead the Israelites into the Promised Land. Joshua probably questioned his ability to carry out the task successfully at some point. The journey of the believer to become like a child as God commanded can be a daunting task. However, just as God reassured Joshua that He would be with him on his life journey, the believer can be assured that God will be with him on his spiritual journey to become more childlike and receive an eternal reward.

### Supplement: Conversation with Brooke Pamer

Brooke Pamer pastors with her husband, Paul J. Pamer, at Apostolic Church in Barberton, Ohio. They have an 11-year-old daughter, Sullivan. They also had another daughter, Greyson, who passed away at the age of four due to a medical condition.

Greyson was born with special needs. The Pamers learned of her condition while she was in utero, so they understood she was terminal from the beginning. Brooke's experience in caring for Greyson gave her the opportunity to see "how God loves us in a way that nothing else in the world can teach you because it's an unconditional love that can't be reciprocated." A special needs child does not always have the ability to express love the way we expect. This shows how God gives and gives and expects nothing in return. God entrusted the Pamers to love Greyson.

Brooke recalled that during that time, extended family was the most important asset, but when they were not around, her husband was "my constant, my compass and rock." She learned how important community is in raising a child with special needs, that it is very true that "it takes a village." She remembered how her empathy for others increased, acknowledging at times that "on our worst day someone else is having a bad day too—or even worse than ours." She also learned that acceptance in the body of Christ is crucial because the church is instructed to "bear one another's burden and encourage one another."

In discussing the culture of the church as it relates to people with special needs, the Pamers emphasized the importance of being aware of "resources in the pews." Part of the responsibility of pastors is to know "the strengths and gifts of people in the church" as they can be used as "resources to help meet people's needs." Brooke encourages pastors who are working to integrate children with special needs into the congregation to approach the responsibility of care with the understanding that "one size does not fit all." Children with special needs should be

cared for on a "case-by-case basis," including "interfacing with the parents" to address specific needs of each child. It is important for every child to experience "love and acceptance from the body of Christ." Many times families find it difficult to attend a church because of the stigma attached to having a child that is "atypical," or, in some cases, a church may not be able to accommodate them. It is part of the job of the church "to break down every barrier."

When asked to describe the experience of caring for Greyson in three words, Brooke responded, "fear, grace, and peace. I would say in that order." In the beginning she was "gripped with fear," but she "experienced grace and learned to take it day-by-day," even having to extend grace to herself at times. God brought them to a "place of peace" that "transcended" their circumstances in the midst of caring for Greyson. Brooke Pamer encourages those who are in similar situations to "learn in the journey to extend grace and mercy to yourself." She reflected on a poem describing the parent who has to "let go of what you thought you were going to have.... In the beginning of the journey those things die, and you mourn." One has to "find a love and understanding in what you have been given—understand this is a gift and give it 100 percent." She stressed to give in a way that "if the opportunity is taken away from you, you have no regrets." Brooke advises parents not to be "afraid to advocate for your child. You know your child better than anyone. Don't take no for an answer. They deserve the best, and you can give that to them."