Providing family-centered care for families and patients with autism spectrum disorders: a guide for healthcare professionals

Kacie Wilson
Bank Street College of Education

Follow this and additional works at: http://educate.bankstreet.edu/independent-studies

Part of the Clinical and Medical Social Work Commons, and the Pediatrics Commons

Recommended Citation

This Thesis is brought to you for free and open access by Educate. It has been accepted for inclusion in Graduate Student Independent Studies by an authorized administrator of Educate. For more information, please contact kfreda@bankstreet.edu.
Providing Family-Centered Care for Families and Patients with

Kacie Wilson
Child Life Department
Bank Street College of Education

Mentor:
Troy Pinkney-Ragsdale

A thesis submitted to Bank Street College of Education in partial fulfillment of the
requirements of the degree of Master of Science in Child Life.

© Katherine Kacie Wilson, 2013

Kacie Wilson
Abstract

While the literature and research that supports the need for services for children with autism spectrum disorders (ASD) is abundant, there is still a lack of services in practice across pediatric healthcare settings throughout the United States. The purpose of this thesis is to provide healthcare professionals in the pediatric healthcare setting with the necessary tools to provide high quality family-centered care to children with ASD and to their families. Child life specialists in the healthcare setting can help to support and educate other healthcare professionals and can offer play opportunities for children with ASD to help them master and cope with their experience. Child life specialists can also psychologically prepare children with ASD to reduce the amount of anxiety surrounding medical visits and procedures.
# Table of Contents

Acknowledgements 7
Rationale 8
Definition of Autism Spectrum Disorders 9
Literature Review 12
Promoting Family-Centered Care 16
Communication 25
Medical Procedures: Helpful Tips 28
Role of Child Life 30
Resources to Suggest to Families 35
Resources for Professionals 37
References 38
Appendix A: Suggested Questions to Ask Families 43
Acknowledgements

I would like to thank Troy Pinkney-Ragsdale for her assistance and commitment to providing excellent mentoring and advising in the creation of this work. I would also like to thank my family and friends for their unwavering support of my studies.
Rationale

According to Cohen (1998), the most common theme across biographical accounts of people with autism is fear during their childhood, regardless of the situation that the child is encountered with. The overwhelming and consistent state of fear that has been described, when mixed with the typical anxieties surrounding medical visits and procedures, can be unbearable and traumatic for children with autism spectrum disorders (ASD). In order to help cope with this fear, rituals are set in place by families of children with autism spectrum disorders to help ensure stability and predictability (Cohen, 1998), and it is critical that this routine be continued as much as possible during a child’s visit to the hospital.

There is an overwhelming amount of research and evidence-based practice statements that have been published that support the need for high quality family-centered care to be implemented into pediatric healthcare settings for children with autism spectrum disorders. This research has not been transitioned into practice at many pediatric healthcare settings. The purpose of this thesis is to create a simple guide for healthcare professionals that can be easily implemented into practice when working with children with autism spectrum disorders and their families.
Definition of Autism Spectrum Disorder

The American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) classifies autism as a pervasive developmental disorder, a term meant to indicate “severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities” (American Psychiatric Association, 1994, 65). Autism spectrum disorders can range from mild to severe in symptoms, and the exact nature of the symptoms varies. Scientists and researchers have not yet found a biological marker, despite the belief that autism may be a neurological disorder with a strong genetic component (Lord & Risi, 2000). Due to the absence of a biological cause at this point, autism spectrum disorders can only be diagnosed based on observed and/or described behaviors. The DSM-IV lists the diagnostic criteria of observed and/or described behaviors below:

1. “*Qualitative impairment in social interaction, as manifested by at least two of the following:*

   • *marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;*

   • *failure to develop peer relationships appropriate to developmental level;*
• a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest);

• lack of social or emotional reciprocity.

2. Qualitative impairments in communication as manifested by at least one of the following:

• delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime);

• in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;

• stereotyped and repetitive use of language or idiosyncratic language;

• lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

• encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;

• apparently inflexible adherence to specific, nonfunctional routines or rituals;
• stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements);
• persistent preoccupation with parts of objects.” (Center for Disease Control, 2013).

The symptoms listed in the diagnostic criteria typically show at or around 18 months of age and the American Academy of Pediatrics recommends screening for autism spectrum disorders at the age of 24 months.
Literature Review

Autism in the Healthcare Setting

When a child enters the hospital, their entire world is turned upset down. They are in an unfamiliar setting, surrounded by unfamiliar people, overwhelmed by various sensations, and are thrown off from their typical routine that helps them get through the day. Their environment is unpredictable, and it can be extremely difficult for children with autism spectrum disorders to cope.

One major factor that can be difficult for children with autism spectrum disorders to cope with in the hospital is sensory overload (Cohen, 1998; Grandin, 1995). When one enters a hospital room or emergency department, it is common to hear high-pitch beeps from the monitors and IV pumps, see bright and fluorescent lighting, and to be surrounded and touched by many unfamiliar individuals. This does not even include the long list of sensations that one feels during any type of medical procedure. Many individuals with autism have an unusual sensitivity to sensory stimuli and are at risk of sensory overload (Cohen, 1998). If a child is at risk of sensory overload, sounds may be excruciatingly loud and frightening, smells may be very strong, touch may be painful, and light may be overwhelming. Moreover, light touch can feel more severe than firm touch, and can be more traumatic for children with autism spectrum disorders (Anzalone & Williamson, 2000). If these sensations are combined, which they often are in the hospital, it may feel unbearable and traumatic for a child with autism spectrum disorders (Cohen, 1998). It is important for healthcare professionals to look for signs of discomfort when a child with
autism spectrum disorders is in the hospital and stop the activity or sensation as soon as possible and give time for the child to recover (Anzalone & Williamson, 2000). For activities and sensations that cannot be paused, some children respond well to slowing the pace of the activity or the rate of which the sensation is inputted (Anzalone & Williamson, 2000).

Family-Centered Care
When working with children with autism spectrum disorders, it is vital that the healthcare professionals utilize a family-centered care approach. Family-centered care is a strengths-based approach to health care that is based on mutually beneficial partnerships between patients, families, and health care professionals” (Bell, Johnson, Desai, & McLeod, 2009; Hollon & Palm, 2007). Family-centered care was built on the recognition that while a child is affected by his/her health care experience, the family is also affected by the experience (Johnson, 2005). Family-centered care shares its development with the development of the child life profession in that both recognize the importance of meeting the psychosocial needs of children in the health care system (Bell, Johnson, Desai, & McLeod, 2009). Until the 1960s, hospitals considered a child’s family to be visitors and families were often not encouraged to be involved in their child’s care (Bell, Johnson, Desai, & McLeod, 2009). This method of service delivery began to disappear from hospitals as research emerged about the negative effects of separating children from their families and of depriving parents of their role as a caregiver during their child’s illness. Health care professionals realized that “play, preparation, and 24-hour visitation for
parents and families would improve clinical and developmental outcomes” (Bell, Johnson, Desai, & McLeod, 2009, p. 97).

The research on family-centered care supports the notion that families who work as a team with health care professionals are more satisfied, and their child’s medical and developmental outcomes, along with their knowledge and skills, are enhanced (Hollon & Palm, 2007). These families also feel more empowered and have a sense of control over their situation instead of fully relying on health care professionals (Julian & Julian, 2005). Moreover, when a family is able to give input about their child’s goals, treatment options, and possible barriers, it is easier for health care professionals to develop a plan in coordination with the family that can and will be carried out (Goldfarb et al., 2010). In family-centered care, the “priorities and choices of patients and families drive the delivery of health care…and a collaborative approach to decision making is the priority” (Hollon & Palm, 2007, p. 99). The goal of family-centered care is to not get a family to trust the health care professional’s recommendations, but to work as a team to make informed decisions together on what will work best for a specific child living in a specific family unit (Goldfarb et al., 2010). This includes recognizing that a child’s family, are the people who are constantly present in his/her life and who knows the child best, and that family participation is critical in helping a child cope.

Psychological Preparation

Another major factor in helping children with autism spectrum disorders cope with their experience in the hospital is to prepare them psychologically for what will happen. The
The ultimate purpose of psychological preparation is to increase a sense of predictability for the patient and for the family, which is essential for children with autism spectrum disorders, and to increase control over difficult experiences (Goldberger, Mohl, & Thompson, 2009; Koller, 2007). By preparing a child and family psychologically for what will occur, the child will likely proceed through his/her experience with a low level of distress (Goldberger, Mohl, & Thompson, 2009; Koller, 2007). It is important, however, that the child be provided with sensory information, such as sights, sounds, odors, tastes, and tactile sensations that the child will consciously experience, along with the sequence of events that will occur (Goldberger, Mohl, & Thompson, 2009; Koller, 2007). For instance, if a type of IV medication feels cold when it is injected through the IV, it is important to tell the child prior to the injection so that the child can know what to expect. It is also helpful for children if the child life specialist compares the sensation and/or sequence of events to a similar situation that the child has already experienced successfully (Goldberger, Mohl, & Thompson, 2009). Overall, when a child is able to expect a sensation and/or a sequence of events, the child is able to move from being in a reactive state to a state of mastery, which allows the child to cope and adjust well (Anzalone & Williamson, 2000).
Promoting Family-Centered Care

As mentioned previously, family-centered care is a strengths-based approach to providing health care that is based on the contributions and collaboration of the medical team, which includes the patient, the patient’s family, which is defined by the patient and has no standard definition, and the healthcare professionals (Bell, Johnson, Desai, & McLeod, 2009). One of the key principles of family-centered care is recognizing that the most supportive relationships for children in hospitals are those provided by their families (Gaynard et al, 1998). Family members are the primary, ongoing caregivers for the child and they know the child best (Gaynard et al, 1998). Moreover, Family-centered care recognizes that the family is the constant in the child’s life and seeks to empower family members at every opportunity. (Bell, Johnson, Desai, & McLeod, 2009).

It is also important to recognize that families are at different places in their health care experience. Some families may be handling their child’s diagnosis and may not know which questions to ask their health care team while others have been helping to support their child through years of treatments and have learned what works best for their family based on their successes and failures (Goldfarb et al., 2010). Regardless of where a family is in their experience, child life specialists need to understand the family’s needs and how they want to work with their health care team (Goldfarb et al., 2010). Ideal care is delivered when the family is a primary member of the child’s medical team because they are the best resource for understanding the child’s past experience and what has been useful or upsetting in the past, as well as the child’s current needs (Goldberger, Mohl, & Thompson, 2009). Another part of working effectively with families requires that child
life specialists understand the family’s concerns, priorities, needs, and strengths, “which are shaped … by their cultural background” (Johnson, 2005, p. 427).

Child life specialists and health care professionals need to recognize that each family is a culture in and of itself and that the health care team should tailor their approach to each individual family’s needs and strengths and should assist them in a way that supports both (Bell, Johnson, Desai, & McLeod, 2009). One way of doing this is to ask patients and families how they would like to receive information, such as one-on-one meetings, in writing, verbally, etc, and to constantly check for understanding of the medical condition and about upcoming procedures (Bell, Johnson, Desai & McLeod, 2009) because “each family may need information presented in a different way and with a different frequency” (Goldfarb et al., 2010, p. 94). Additionally, asking families if they want to be involved in medical procedures can help counter the helplessness and anxiety that may come from observing one’s child’s discomfort (Goldberger, Mohl, & Thompson, 2009). Overall, good communication is the most important approach in working with families in the health care environment (Julian & Julian, 2005) and is a strong quality to have in a child life program (Bell, Johnson, Desai, & McLeod, 2009).

In order to promote high quality family-centered care and utilize good communication between the family and the rest of the medical team, it is essential that the healthcare professionals engage in a discussion about the family and child’s needs, strengths, and resources when meeting with the patient and family. Below are a list of questions, divided into two categories (inpatient and emergency care), that any healthcare
professional can ask the family of a child with autism spectrum disorders so that the patient and family receive the best care possible during their stay. Below each question that is suggested for healthcare professionals to ask is the rationale for why it is important to ask these specific questions. A list of these questions without the rationale statement is in Appendix A. It is also encouraged that the healthcare professional ask additional questions about the patient and family to gain a better understanding of their experience.

Emergency Visit Questions

*What are the child’s favorite activities or toys? Is there a toy that the child is soothed by?*

This toy or activity will be help you significantly during the child’s stay in the emergency department. For instance, this toy or activity can help motivate the child to get through a difficult experience or medical procedure. If the child has to get an IV during his/her stay in the emergency department, it can be helpful for the child to know that after he/she gets poked, he/she will get to play with a favorite toy. This toy or activity can also help reduce tantrums and keep the child calm during their stay. Keep in mind that many children with autism spectrum disorders find reward and are soothed by things that others would not find reinforcing or pleasurable.

*Does the child have any sensory issues?*

Take a moment to reflect on your personal sensory issues. Many individuals are bothered by a type of noise, a smell, a kind of touch, and/or a type of light, and some individuals react differently to these sensations than others would expect. A child with autism
spectrum disorders often has difficulty processing some sensations, which can lead to the child being in sensory overload. It is important for the entire healthcare team to be aware of any sensory issues and how to work around those sensory issues as much as possible. For example, if the patient needs to roll up his sleeve for an IV placement, but has sensory issues with touch, it is important to ask the patient’s family how they address getting dressed and undressed at home to help make it easier for the patient. Additionally, if the patient is sensitive to high-pitch beeps, it is important to silence the IV pump and/or the monitor because the beeping may feel assaulting to the patient. It is also important to be prepared for how the child may react to a sensation and to try to control the environment as much as possible to reduce any sensory issues. If the child does have any sensory issues, notify the entire medical team immediately.

**What techniques do you use to manage difficult behaviors?**

It is important to be prepared in case the patient exhibits a difficult behavior while they are in the emergency department. Ask the family what they do at home to manage difficult behaviors before a difficult behavior arises and help them manage the behavior in a similar way in the emergency department. Follow the family’s lead with management of difficult behaviors because every child reacts differently to various situations and stimuli.

**What kind of distraction techniques would help the child during a medical procedure?**

Once you find out from the family what distraction technique they believe would work best with the child, it is important to have the technique available for any medical
procedure that they child may experience. If the child has more than one procedure completed during their stay, use the same distraction technique for every procedure. Consistency and predictability are important, especially if the distraction technique works.

**Inpatient Stay Questions**

**How does the child manage transitions and changes in daily routine? If the child has difficulty with transitions, what are some ways that make transitions easier?**

Transitions and changes in routine can be difficult for some children with ASD. Some families have established ways to help their child transition between activities. It is important to ask the family how they manage transitions and changes in the daily schedule since there will be several changes in the child’s schedule during his/her hospitalization. It is also important to learn how to make transitions easier for the child in case the parent cannot be available to help during times of change.

**Please describe a typical day or routine.**

By asking a family to describe their child’s typical routine, the healthcare professional can get a better sense of what the child is used to doing. In collaboration with the family and the medical team, a daily schedule can be made for the child’s inpatient stay that is as close as possible to the schedule and routine that the child has at home. Examples of what should be included in the schedule are medication times, eating times, play times, hygiene routines, and bedtime. It is suggested that the schedule be posted in the patient’s room in a visible place for all staff to see.
What are the child’s favorite activities or toys? Is there a toy that the child is soothed by?

Please see the rationale statement for the same question listed in the section above titled Emergency Visit Questions.

What types of toys and activities does the child not enjoy?

Some children with autism spectrum disorders have specific interests in only certain toys, activities, and/or topics of discussion (Autism Speaks, 2013). It is important to ask the family if there are any toys and activities that the child does not enjoy, tends to avoid, and/or has a difficult time managing behavior when the toy and/or activity is introduced.

Does the child have any sensory issues?

Please see the rationale statement for the same question listed in the section above titled Emergency Visit Questions.

What kinds of therapies and services does the child currently receive? Does the child receive any services at school?

By asking this question, the healthcare team can get a better picture of the child’s developmental level and the child’s ability to communicate. The healthcare team can learn what the child is currently working on and what the child’s strengths are. If the child receives services at school, the child life specialist can communicate with the
child’s teacher with the parent’s permission to attempt to continue services while the child is in the hospital.

**What techniques do you use to manage difficult behaviors?**

Please see the rationale statement for the same question listed in the section above titled *Emergency Visit Questions*.

**What kind of distraction techniques would help the child during a medical procedure?**

Please see the rationale statement for the same question listed in the section above titled *Emergency Visit Questions*.

**How does the time of day affect the child’s behavior?**

Some children with autism spectrum disorders may have difficulty coping during certain times of the day, whether it is due to the routine of the child’s day or the mood that the child is in during a certain part of the day. For example, just like some individuals consider themselves to be a ‘morning person’ while others do not, children with autism spectrum disorders have the same preferences, except these children are not able to cope with the time of day as well as most typically developing children. It is important to be sensitive to the child’s strengths and needs, and adjust their care throughout the day as much as possible to better accommodate their needs.
**What does your child do that makes you happy?**

By asking a question that focuses on the child’s and family’s strengths, the healthcare professional can get a better look at what the child means to the family and how they work together as a unit. A question such as the one listed above allows the family “to define themselves in ways other than their medical diagnosis” (Botta, 2009, p. 153).

**Family Experiences: What is it like?**

There have been a few testimonials from families of children with autism spectrum disorders about their experience that are important for healthcare professionals to recognize in order to best empathize with them. Lord and Risi (2000) state that often by the time that a family meets an expert in autism, they have already accrued a variety of diagnoses and opinions that describe their child’s behavior. Prior to diagnosis, the day of diagnosis, and the moments that follow for the rest of their child’s life, a family goes through an emotional rollercoaster as they grieve and cope with their child’s condition.

Cohen (1998) describes a parent’s reaction to his child being diagnosed with an autism spectrum disorder as: “What is often stolen away by autism is the joy of being a child and the joy of being a parent. What is lost too is a sense of unlimited potential” (p. 63). Another parent has a similar viewpoint on his grief surrounding his son’s diagnosis with an autism spectrum disorder:

“You have to throw out your expectations. ‘He’s a chip off the old block.’

‘Apple doesn’t fall far from the tree.’ ‘Like father, like son.’ I would wager that all fathers, when they find out they’re going to have sons, immediately
start setting expectations for the boys. “He’s going to be a quarterback”. Or, “I can’t wait to put a golf club in his hands.” When the realization of having a child with autism hits you, as a father you experience a huge sense of loss. It’s a father’s right to be a peewee league coach, isn’t it? The faster a father can let go of those expectations, the better it will be for everyone involved – his wife, his child, his other children, and himself” (Fowler, 2011, p. 9-10).

Other family members of children with autism have found comfort in being empathized with by other families of children with special needs. For example, Welcome to Holland tells a story of how families cope with having a child with special needs. Similarly, Welcome to Beirut tells a story of the war that families must fight when they have a child diagnosed with autism. In both stories, however, families come to realize that Holland and Beirut are beautiful places with a lifetime of joy despite going through some difficult times. Moreover, Fowler (2011) also describes the ambivalent feelings that surround having a child with an autism spectrum disorder. For example, when trying to describe the experience of being a parent of a child with special needs, Fowler states:

“I am not painting a clear picture if I don’t include the many blessings that come as part of parenting a special-needs child. Of course there are blessings. We are constantly laughing with joy at the things William says and does and the tone is one of celebration, because we know that he has worked hard to progress day by day” (Fowler, 2011, p. 25).
Communicating with Non-Verbal Patients

When communicating with patients who have limited or no speech, it is important for all healthcare professionals to know that a lack of speech does not guarantee a lack of understanding (Cohen, 1998). Testimonials of individuals with autism spectrum disorders tell of similar experiences – throwing a tantrum out of anger from not being able to communicate his/her wants or needs. Fowler (2011) states that, as a parent of a child with an autism spectrum disorder, it is difficult to not understand what your child needs or wants. One autistic individual, Temple Grandin, stated that the only way that she could communicate as a child was to scream (Cohen, 1998).

For children with autism spectrum disorders who have difficulty with speech, it is important to ask the family how the child communicates at home. Many children with autism spectrum disorders have good visual skills but have difficulty in processing and producing speech (Cohen, 1998). Many children with autism spectrum disorders use visual supports through the use of communication boards and/or PECS, which is a picture exchange communication system that allows children to hand an adult a card with the picture of the item that they are requesting on it. Other visual supports that are available and may be useful are First, Then Boards, which can help encourage a child to experience a difficult task in order to get a reward (Autism Speaks, 2012). For example, in the healthcare setting, a First, Then Board can be used for a blood draw by giving the child a card that states and illustrates, “First, feel poke. Then, play with car.” However, it is
important to not introduce visual supports for the first time in the healthcare setting because it may cause more confusion and upset for the child. The healthcare professional should ask the family if they use visual supports at home before exposing the child to any visual support system.

With the help of technology, some visual supports have been made easily accessible on tablet devices. Various applications, or apps, have been made available to help children with autism spectrum disorders communicate. Many of these apps are customizable and are free to download on a tablet. These apps can be used for social communication, medical procedural support, psychological preparation, and to express other needs, concerns, or wants.

Regardless of whether a family chooses to use a visual support system to help their child communicate, healthcare professionals should talk to the child as if the child was able to verbally respond. It may also be useful to use short sentences and directives (Autism Speaks, 2012). For example, “Please sit here” gives the child more direction than “Why don’t you come sit over here?” Children with autism spectrum disorders will likely not understand that the question posed is a request (Autism Speaks, 2012).

**Communicating with Verbal Patients**

Just as with non-verbal patients, it is important to use short sentences and directives when communicating with a child with autism spectrum disorders. As mentioned previously, a child with autism spectrum disorders will take every word said literally, and it is
important to be as concrete as possible with language. It can also be helpful to remind the patient of what the safe thing to do during their stay is and to praise them regularly for specific, desirable behaviors. For example, if a child is showing any effort in staying still during a procedure, the healthcare professional can praise the child by stating, “Good staying still.”

In order to psychologically prepare a child with autism spectrum disorders using verbal communication, it can be helpful for the child if the healthcare professional sings the words of the preparation. For example, using the tune of the song *The Wheels on the Bus*, a child life specialist can psychologically prepare a child for an IV placement by singing ‘The rubber band on your arm feels tight, tight, tight, before you get an IV’, or, ‘The wipe on your hand feels cold, cold, cold, before you get an IV’. Many children with autism spectrum disorders engage and listen when a singsong voice is coming from an individual who is visible. Another method of communicating verbally with a child with autism spectrum disorders is to bounce up and down while playing and/or having a conversation. Moreover, rocking the child back and forth during play and/or conversation can be useful as well. These methods are typically best for children with vestibular sensory interests who soothe through self-stimulation and movement. Lastly, for any child with autism spectrum disorders who has difficulty with eye contact, it can be helpful to use puppets to engage the child in conversation.
Medical Procedures: What To Do and Helpful Tips

When a child with an autism spectrum disorder is waiting to see a doctor, get a scan completed, and/or complete a medical procedure, one tip that could greatly help the child, his/her family, and the rest of the medical team is to reduce the wait time as much as possible. In the emergency room setting, it is important to advocate for children with autism spectrum disorders to be seen before typically developing children who do not need urgent care. In inpatient or clinic settings where procedures are scheduled throughout the day, it can be helpful for every individual involved to advocate for the procedure to be scheduled either as the first appointment in the morning or the first appointment after lunch. Children with autism spectrum disorders have a difficult time coping with long waits, and may have a negative behavioral reaction if they have to wait too long.

Once the child is in the exam room, it is vital that all healthcare professionals lower their voices and speak only when necessary. As mentioned previously, most children with autism spectrum disorders are at risk of sensory overload, and loud noises can feel painful. It can be helpful to assign one individual, ideally the child life specialist or a family member, to talk to the patient throughout any procedure, and to advocate for only one voice to be heard at a time. Moreover, it can be helpful to dim or turn off the lights in the room, especially if the lights are fluorescent because children with autism spectrum disorders are able to see the strong flickering of fluorescent lighting (Cohen, 1998).
can also be helpful to reduce the number of people in the room to decrease the amount of stimulation that the child is taking in.

Prior to the procedure, it can be helpful to use visual supports (please see section on *Communicating with Non-Verbal Patients*) or to lay out the medical equipment that the child will be consciously exposed to in the order that they will be used for the procedure. By knowing what the next step will be and the accompanying sensations, the child can better cope with and process the experience.

During the procedure, calming techniques can be effective when they are used consistently. If one calming activity has proven to work for the child based on the family’s input and/or based on trial and error, it is important to stay with that specific activity rather than jump from one to another. One calming technique that can be used with the child’s and family’s permission is to apply firm, downward pressure to the shoulders of the child and/or give the child bear hugs with the child facing away from the doctor (Anzalone & Williamson, 2000). Temple Grandin, an individual with an autism spectrum disorder, states, “many autistic children crave pressure stimulation even though they cannot tolerate being touched” (Grandin, 1995). Prior to touching the child, tell the child that you will touch them and give the child time to process the sensation (Grandin, 1995).
Role of Child Life

A child life specialist has a wide and expanding skill set that can be applied to numerous situations that a child may be facing. In addition to providing support and empathy and being a listener for a child and the family, a child life specialist is also the expert of child development on the medical team (Hicks, 2005). Although a child’s family is the expert on the child, the child life specialist can provide knowledge to the medical team regarding the developmental impact of hospitalization. Additionally, a child life specialist has a vast amount of knowledge on the importance of therapeutic play and is able to provide opportunities for children to cope through therapeutic play, along with the ability to provide developmentally appropriate education to children and ample coping strategies for various situations that a child may encounter (Hicks, 2005). Other skills that a child life specialist possesses are the ability to be patient, empower children and families facing a variety of situations, and build therapeutic and trusting relationships with children and families (Child Life in the Health Care Setting: A Family Centered Care Approach, Class Discussion, October 25, 2011). With the research conducted through the Phoenix Research Project in 1983, the foundation for child life theory was established and the field of child life grew from play to a field that requires a large skill set from child life specialists (Child Life Council, 2010). Child life specialists believe that procedural preparation, advocating for family centered care and pain management, and teaching coping strategies are as important to the field of child life as play (Wojtask & White, 2005). Additionally, the role of child life is to support parents, whenever possible, as leaders in the delivery of support to their children. Some parents may be
unsure of their role, and may need welcoming and guidance to participate along with the other members of the team (Goldberger, Mohl, & Thompson, 2009).

Psychological Preparation and Procedural Support

“Once a child and family’s needs for preparation have been assessed, the task of the child life specialist is to provide information that will make events seem as predictable as possible, and realistically influence children and families’ appraisal that they have adequate coping resources to manage the impending events. Simultaneously, it is ideal to plan and actually rehearse ways to cope with the anticipated stressors. This active rehearsal is at the heart of psychological preparation” (Goldberger, Mohl, & Thompson, 2009, p. 180).

Just as the child life specialist provides psychological preparation and procedural support for typically developing children, the child life specialist can provide these services to children with autism spectrum disorders. Some of the aspects of psychological preparation and procedural support may be similar, however, most aspects are adapted when working with a child with an autism spectrum disorder. As mentioned above, rehearsal of relaxation and coping techniques is at the heart of psychological preparation (Goldberger, Mohl, & Thompson, 2009), and it is important for children with autism spectrum disorders to be taught how to best cope with medical procedures. For younger children, encourage them to practice deep breathing by blowing a pinwheel or blowing bubbles. For older children, encourage muscle relaxation techniques, such as squeezing
or stretching muscles and relaxing them, or guided imagery. Another similar aspect is to provide choices to children with autism spectrum disorders before and during a medical procedure just like a typically developing child would. For example, the child life specialist can ask the child which finger he would prefer the pulse-oximeter to be attached to or if he would like the nurse to count to three before he feels a poke.

If the child has a planned visit to the hospital, encourage the family to write a social story explaining in as much detail as possible what will happen at the hospital with the assistance of the child’s teacher and/or therapist. Regardless of the purpose of the visit, it is important to introduce anything and/or anyone that is new to the child in detail. For example, if the healthcare team needs to bring in a tech to help hold the child still for an IV placement, the child life specialist can introduce the tech by stating, “This is Sally. Her job is to help remind your arm to stay still while the nurse looks at your arm. It is important that your arm stays very still for your IV because it is the safe thing to do. Sally will touch your arm now.” It can also be helpful for the child life specialist to expose the child to certain items that he/she may have a strong reaction to before they are used during the procedure based on the family’s input of their child’s sensory vulnerabilities. For example, while allowing a child to smell and feel the texture of an alcohol wipe, the child life specialist can introduce the equipment by stating, “This is a wipe to clean your hand. The nurse needs to clean your hand before you feel a poke.”
Play

In order to minimize the amount of stress and anxiety a child may endure during his/her hospitalization, child life specialists provide children with play opportunities that support the expression of feelings and understanding of their health care experience (Child Life Council, 2002). Moreover, play provides children with an opportunity to restore and heal themselves after a difficult experience (Jessee & Gaynard, 2009). Erikson suggested that play provides children with a way to cope and reflect on difficult experiences and gives the child a sense of mastery over the situation (Jessee & Gaynard, 2009).

Children with autism spectrum disorders, however, have been described as often having difficulty engaging in play in a way that a typically developing child would do so. For example, it can be difficult for children with autism spectrum disorders to engage in fantasy or make-believe play. Stanley Greenspan, a leading theorist in therapeutic interventions with children, believes that intruding into the child’s world by matching the child’s behavior and focusing on the child’s affect to push the child to share attention with another individual and engage the child in play (Cohen, 1998; Greenspan, 2006). When engaging a child with an autism spectrum disorder in play, it is important for the child life specialist to follow the child’s lead, join in the play, and expand on what the child is doing (Cohen, 1998). If the child is avoidant, continue to be persistent while maintaining a playful affect (Cohen, 1998; Greenspan, 2006).
Educate and Advocate

One major aspect of the child life specialist’s role when working with children with autism spectrum disorders and their families is to share their knowledge and to share stories. Child life specialists can use informal observation and interactions with families to gather valuable information using the suggested questions listed previously and in Appendix A and through spontaneous conversations (Gaynard et al, 1998). It is important for the child life specialist to talk with families about their experience to find what works, what does not work, what they believe may make things easier in the future, and to share that information with other families and healthcare professionals that the child life specialist comes into contact with (Goldberger, Mohl, Thompson, 2009; Gaynard et al, 1998). Bell, Johnson, Desai, and McLeod (2009) agree that “fostering collaborative dialogue with the families, promoting communication throughout the experience, and continuously acknowledging the family as an integral part of the healthcare team are strong foundations in quality child life programs” (p. 102).

In addition to providing the information provided by families to the healthcare team, it is also important to share the information that is gathered with other families and with all staff who may be involved in the care of children with autism spectrum disorders. For example, the child life specialist can provide in-services to the child life staff and the multidisciplinary team about autism spectrum disorders.
**Resources to Suggest to Families**

It is important for healthcare professionals to assess the family’s place in the grief cycle prior to recommending readings, websites, and/or resources. Additionally, it is important to read the resource before suggesting it to a family to ensure that it is appropriate for their experience. It can be helpful to ask a medical librarian in Family Resource Centers that are available in most pediatric hospitals for more information about autism spectrum disorders.

**Families of Newly Diagnosed Patients**

Welcome to Holland

Welcome to Beirut

Parentingspecialneeds.org

Autism Speaks (autismspeaks.org)

Siblings of Children with Autism by Sandra Harris

Autism Special Interest Group (www.autismpppsig.org)

Behavior Analyst Certification Board (www.bacb.com)

Quack Watch (www.quackwatch.org)

Look at My Eyes by Melanie Fowler (also available in Spanish)

**Experienced Families**

Far from the Tree by Andrew Soloman

Autism Speaks (autismspeaks.org)
Siblings of Children with Autism by Sandra Harris

Parentingspecialneeds.org

A Different Kind of Perfect: Writings by Parents on Raising a Child with Special Needs

by Cindy Dowling, Bernadette Thomas, and Neil Nicoll
Resources for Professionals

Thinking in Pictures by Temple Grandin

Autism Speaks (autismspeaks.org)

Far from the Tree by Andrew Soloman (chapter on autism)

Temple Grandin, Featured Film, 2010

Welcome to Beirut

Welcome to Holland
References


Appendix A

Inpatient Stay Questions

- How does the child manage transitions and changes in daily routine? If the child has difficulty with transitions, what are some ways that make transitions easier?
- Please describe a typical day or routine.
- What are the child’s favorite activities or toys? Is there a toy that the child is soothed by?
- What types of toys and activities does the child not enjoy?
- Does the child have any sensory issues? If so, educate the child’s nurse!
- What kinds of therapies and services does the child currently receive? Does the child receive any services at school?
- What techniques do you use to manage difficult behaviors?
- What kind of distraction techniques would help the child during a medical procedure?
- How does the time of day affect the child’s behavior?
- What does your child do that makes you happy?

Emergency Visit Questions

- What are the child’s favorite activities or toys? Is there a toy that the child is soothed by?
- Does the child have any sensory issues? If so, educate the child’s nurse!
- What techniques do you use to manage difficult behaviors?
- What kind of distraction techniques would help the child during a medical procedure?