



## Approaches to Providing Medical Care

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Not surprisingly, two of the major challenges in autism—difficulties with communication and social interaction—pose significant challenges for provision of health care. Acute disease can present in various ways in a person with limited verbal ability, for example, irritability, decreased appetite or refusal to eat, acute weight loss, or in behavioral changes such as head banging or **self-injury**. Difficulties with social interaction and sensitivity to change may mean a child does not like to be touched or won't cooperate when being examined, and even the most minor procedures can pose challenges. The rapid pace of medical care can further exacerbate these difficulties as does the volume of patients needing care. This is very challenging when the care provider is unfamiliar with the individual or where the environment is unfamiliar and overstimulating (e.g., the emergency room). For persons with autism the long-term goal is to help them participate as much as possible in the process of getting good health care and leading a healthy lifestyle (Volkmar & Wiesner, 2009).

Preventive care is particularly important. Routine screening by physical exam and laboratory testing can detect problems early—when treatments can prevent more severe or permanent conditions. It cannot be emphasized enough that regular well-child visits are critically important. Participation in these visits helps the provider and patient get to know each other. This facilitates care provision when the individual is ill. Regular screening for common health problems and immunizations is also part of this process.

As we discuss further on in the chapter the adoption of a medical home model for care facilitates coordination of care and helps make optimal use of resources.

Other challenges arise given our complex health care system. These issues can come about through difficulties concerning insurance, for example: finding providers who accept certain insurance plans or, for adults, finding an insurance provider. Often health care is delivered by different providers, for example, specialists such as psychiatrists, neurologists, psychologists, or speech pathologists can all be involved. One important way to prevent this problem, as we discuss subsequently, is having a medical home with a provider or provider group who takes a leadership role in integrating care and services. A number of more general and more specific resources are available (e.g., Durand, 2014).

In this chapter, we discuss some of the issues involved in providing quality health care to individuals on the autism spectrum. We review some practical approaches to making visits more successful, coping with the emergency department and hospitalization, coordination of care issues, and the medical home for individuals with ASDs. Some excellent resources are available for families, and we include them in either the References or the “Suggested Reading” list at the end of this chapter. Unfortunately it is also important to note that there is very little scholarly work, much less research studies, relevant to health care for adults with ASDs (Piven, Rabins, & Autism-in-Older Adults Working Group, 2011; also see Howlin, 2014). We conclude the chapter with a discussion of practice guidelines and evidence-based treatments.

## HELPING MEDICAL VISITS BE SUCCESSFUL

Parents and the doctor and his or her staff can take steps to make visits to the office successful (see Box 3.1). This starts with making regular visits go well. Routine visits are important for many reasons. Having the child become familiar with the doctor’s office and procedures when he or she is well also makes cooperation during an illness much more likely. Routine visits also offer the chance for preventative care. Several steps can be taken to facilitate successful medical visits: (1) preparation of the child for the visit, (2) being sensible about visit schedules and waiting time, (3) planning

activities to help keep the child occupied, and (4) giving extra time for examination to enable the child to be more familiar with procedures and the examiner (Volkmar et al., 2014; Volkmar & Wiesner, 2009).

### BOX 3.1 MAKING MEDICAL VISITS SUCCESSFUL

#### **Prepare the Child for the Visit**

- Picture books, visual schedules, or even the various computer applications available for autism (e.g., showing a schedule, the physical office, pictures of the staff and doctor) may be helpful.
- For children who are interested provide play medical equipment.
- For parents there are various books (including board books for the child) to minimize the newness of procedures.

#### **Schedule**

- Schedule appointments early in morning or afternoon—minimize waiting time.
- If possible have a quiet (separate) waiting area.
- If possible have staff members who know (or come to know) the child well.

#### **Activities**

- Have favorite activities available for the child if possible.
- Use the phone or iPad to keep the child occupied—potentially showing information to help the child familiarize him- or herself with what will happen.

#### **In Conducting the Physical Exam**

- Be deliberate, predictable, consistent, and thoughtful—do more intrusive things at the end of the exam.
- Give the child extra time for processing.
- Keep language simple.
- Encourage (reinforce) cooperation and compliance.
- Try to end on a positive note (for parents and child).

## DENTAL CARE

Prevention is a critically important aspect of dental care and one that is often overlooked or avoided given the multiple difficulties of a child with ASD (Lai, Milano, Roberts, & Hooper, 2012). Children who have inadequate prevention are at risk for major problems as they age, for example, dental pain may cause self-injurious behavior and untreated dental problems can lead to other medical problems—sometimes severe ones. A growing body of work on dental care for children with autism is available (see the “Suggested Reading” list at the end of the chapter). One large survey (Kopycka-Kedzierawski, Auinger, Kopycka-Kedzierawski, & Auinger, 2008) assessed dental status and needs of a large nationally representative sample of children and adolescents with and without autism. About half of the children and adolescents with autism were reported to have excellent or good dental status (as compared to nearly 70% of typically developing children). Given the increased rates of accident and injury it is not surprising that traumatic dental injuries may be even more likely in children with ASDs (Altun, Guven, Yorbik, & Acikel, 2010).

Guidelines on caring for individuals with autism for professionals are available (e.g., Green & Flanagan, 2008) as are guidelines and suggestions for parents to encourage successful dental visits (Marshall, Sheller, Williams, Mancl, & Cowan, 2007; Volkmar & Wiesner, 2009). As with visits to the family doctor or pediatrician, a variety of procedures may be used to prepare the child. Engaging in some toothbrushing and dental care will facilitate cooperation with the dentist (other predictors of successful dental visits include overall cognitive and communicative ability and the ability to sit for a haircut). Box 3.2 provides some suggestions for ensuring good dental hygiene.

### BOX 3.2 STEPS FOR PARENTS IN ENSURING GOOD DENTAL CARE

- Start early. Toothbrushing should be started as soon as the teeth begin to come in. Parents should try to make this an enjoyable game or have a special (favorite) activity after.
- Try different toothpastes. Different flavors are available. Brushing without toothpaste is better than not brushing at all!
- Talk to the dentist (also maybe to the pharmacist) about ways to give the toothbrush a taste that is interesting.

- For children who don't tolerate the toothbrush, work on a plan to help introduce it.
- Try brushing teeth in front of a mirror. Sometimes children are interested in watching themselves. You can also try toothbrushing as a family activity (occasionally children with autism will get into the swing of this).
- If the child won't brush her teeth, encourage water drinking immediately after meals (to try to clean out as much food as possible from the teeth and give the bacteria that cause cavities less food to grow on). You can do this with a bottle for very young children or through a straw or squeeze bottle for older children.
- Think about other approaches. Some children like mechanical things and might be willing to try an electric toothbrush or one of the water irrigators.
- Avoid foods that are known to cause cavities. This means limiting sweets, particularly sticky sweets. Some foods are particularly likely to stick to children's teeth, such as fruit roll-ups and dried fruits such as raisins. Keep in mind that many drinks have large amounts of sugar as well. Try to encourage use of other (nonsweet) foods as snacks. For children who receive foods as reinforcers, try to encourage a range of foods.
- If the child has motor difficulties talk with the occupational therapist or physical therapist about adapted toothbrushes that may give the child more stability and control.
- For more-cognitively able children (those who can follow verbal direction), disclosing tablets (which show areas where more brushing is needed) might be helpful and instructive providing visual feedback to child and caregiver.

## **SPECIAL HEALTH CARE SITUATIONS: EMERGENCY DEPARTMENT AND HOSPITAL STAYS**

The fast pace of medical care, particularly in emergency department (ED) settings, can present challenges for the child with ASD. A lack of familiarity with ASD on the part of ED staff members may also complicate the situation, sometimes further worsening the child's anxiety or behavior.

Parents can be effective advocates and a comforting presence. The primary care provider should be contacted if at all possible and certainly should be included in any follow-up.

Although some literature exists for ED staff on children with disabilities in general (e.g., Grossman, Richards, Anglin, & Hutson, 2000), specific information on autism for these professionals has been minimal. This lack of information (and training) can also be a problem for emergency responders. Schools should have basic information needed for emergency situations, and use of a Medic-Alert bracelet can be helpful in indicating allergies, medications, conditions, and so on. On the ED side, it is important to avoid overstimulation of the individual, to keep the pace of interaction somewhat slower than usual, and to listen to reports of parents or school staff members who will know the child best. Obviously in some truly urgent situations this is not possible and the bare minimum of facts may be all that can be conveyed. Guidelines for parents are available (e.g., Volkmar & Wiesner, 2009). The more cognitively able individual may present special sources of confusion for ED staff members who should be helped to understand the nature of the social disability present (Raja & Azzoni, 2001). Education of staff members is also helpful (Nadler, 2014).

Unlike visits to the ED, hospitalizations are often planned in advance. This gives an opportunity for preparation with a tour and engagement between the patient and nursing or pediatric staff members (if they are available). In some cases procedures can be done so that the child is discharged on the same day. The individual's health care provider can facilitate the process of hospitalization. Various steps can be taken to minimize the individual's anxiety and make the hospital stay as pleasant (and short) as possible. Familiar activities, videos, materials, and so forth may help lessen the child's anxiety as will the presence of familiar family members. As much as possible the person's routines should be followed—including schoolwork if possible and relevant. Hospital staff members should be aware of the child's difficulties and take extra precautions about safety issues.

For surgical and other procedures careful explanation should be provided if possible. For elective surgery there is often an opportunity for the patient and parents to meet the staff members, see the recovery room, and so on (Volkmar & Wiesner, 2009). If necessary, medications can be used to reduce pain and anxiety.

Issues of care coordination for individuals with autism are complex. This complexity reflects several factors:

- Autism itself is associated with a wide range of clinical expressions and risk for other medical problems.
- Many services are provided in school settings.
- A very large number of disciplines are potentially involved in the care of the individuals.
- Patterns of treatment and entitlements to available services vary considerably with age and developmental level of the person (Lokhandwala, Khanna, & West-Strum, 2012).

Unfortunately parents of children with ASDs report themselves three times more likely than parents of other children with special needs to have difficulties in obtaining needed services (Montes, Halterman, & Magyar, 2009). Sadly, these unmet needs result in lower quality of health care and a more adverse impact on the family (Zuckerman, Lindly, Bethell, & Kuhlthau, 2014). Even if considering only potential medical specialists, a large number might be involved, for example, a neurologist, geneticist, mental health consultant, dentist, GI specialist, and sleep specialist. Within the schools the school psychologist, social worker, speech pathologist, occupational therapist, physical therapist, and educators and special educators are all frequently involved. Behavioral interventions may be provided in school or at home and also need to be well coordinated. An important function of the primary care provider, particularly in the context of providing a medical home for the individual, is to work to ensure that all the various specialists involved are aware of each other's work and, as much as possible, coordinated relative to the overall care plan.

One important potential ally in this effort is the school nurse or, in some cases, the school-based health clinic (Bellando & Lopez, 2009; Minchella & Preti, 2011). Although sometimes needing additional information and resources (Staines, 2010), the school nurse is in an unusual position of bridging the gap between school staff members and medical professionals and has a critically important function in coordinating communication and discussion among all the professionals involved in the care for individuals with ASDs who have concurrent medical problems.

Primary care providers can take several steps to improve coordination of care. First they can ensure that all the various professionals involved, particularly those prescribing medications or conducting treatments, are aware of each other and each other's work. The primary care provider is in an important position for providing overall monitoring and ensuring that members of the treatment team are neither working at cross-purposes nor ignorant of each other's efforts. At times, particularly when working with members of multiple disciplines, this can be a challenge, but it is an important one that needs to be addressed. The social worker or school psychologist can be an important ally in this regard, particularly when it comes to finding ancillary services.

## DRUG INTERACTIONS AND SIDE EFFECTS

It is not uncommon for the child, adolescent, or adult with ASD to be receiving multiple medications. Sometimes medications are added for new or emergent problems. At other times a second medication may be given to control for side effects of another one. It is important for the primary care provider to be kept in the loop regarding addition of medications to the treatment program. These new medications may be prescribed because of neurological issues (seizures) or behavioral issues (agitation, anxiety, irritability, mood, or sleep problems). They may be prescribed by neurologists or psychiatrists who may not always be aware of other relevant medical problems or concurrent medication interactions. These issues tend to arise as children become adolescents and adults, but there are other potential issues that can come up, and it is critical that the primary care provider is always involved and informed regarding changes in treatment programs.

## IMMUNIZATIONS AND AUTISM

The prevention of communicable diseases through immunization has been a major accomplishment in medicine during the last century. Unfortunately a single paper published some years ago in the *Lancet* (Wakefield et al., 1998) led to major concern that immunization with MMR might increase autism risk. Other concerns were expressed about the use of thimerosal (a mercury-containing preservative) in some vaccines. Both concerns led to panic among parents and decreasing vaccinations rates.



A body of strong research now has failed to show any connection between autism and immunization. These concerns were increased by extensive media coverage, but these issues have been extensively examined and the link between immunization and autism has been discounted (Offit, 2008). Primary care providers should continue to encourage parents to engage in sensible immunization programs. Clearly, if more children remain unimmunized there will be a growing threat of the return of illnesses such as measles, mumps, and rubella.

## **RISKS ASSOCIATED WITH MEDICATION USE**

With increasing age, behavior-modifying medication use becomes more common. We discuss these agents in greater detail in following chapters in this book but emphasize that the primary care provider should always be careful to review current medications, including psychotropic medications and any alternative-complementary treatments. There are a number of likely reasons for medication use to increase with age. Behavior-modifying medications are frequently started, at least as trials, in childhood and increase with age. For the school-age child a stimulant may be used for attention issues, and some of the atypical neuroleptics may be used for irritability and agitation. In adolescence, particularly for more-cognitively able and more verbal individuals, problems with anxiety or depression may lead to trials of SSRIs. In adulthood increased behavioral difficulties, particularly in the absence of good programs, and the pressure for speedy treatment effects often lead to multiple agents being used (in our experience the greatest number of medications we've seen used—all for behavioral or psychiatric issues—is 10!). In their sample of nearly 500 adolescents and adults with ASD the average number of agents used was 1.6 with more than 60% of the sample taking at least one medication (Stoddart et al., 2013). Poor insurance coverage, involvement of multiple providers, and poor monitoring contribute to overuse of medication and the potential for side effects and drug interactions. Long-term monitoring is important because for some agents such as the neuroleptics, routine use—over time—may be associated with adverse effects. For some individuals it is the case that such use can be justified but should be carefully monitored and, as appropriate, the individual and parents or guardians should be involved in decision making.

In any initial contact it is important for the primary care provider to review current and past medication use and be alert for a history of significant side effects, allergies, and adverse reactions. Be alert to the common confusion of allergies and side effects. Issues of interactions and side effects can also arise with alternative and complementary treatments, for example, with high doses of vitamins or use of treatments that potentially have serious metabolic side effects.

## NEW MODELS OF CARE: THE MEDICAL HOME

As noted there is a growing role for the primary care provider to coordinate the many providers of health care and to serve, at times, as a liaison to schools and other services providers. This has led to the development of new conceptualizations of the role of the primary care provider so that the emerging best practice model for pediatric primary care is the medical home. The American Academy of Pediatrics (AAP) originally developed the medical home model to address the needs of children and youth with special health care needs (American Academy of Pediatrics, 2002). A **medical home** is a primary care practice that provides health care that is comprehensive including preventive, acute, and chronic care; coordinated across primary and specialty care; accessible; continuous from birth through the transition to adulthood; family-centered; compassionate; and culturally sensitive. It should emphasize a partnership with families. The primary health care professionals should assume a major role in coordinating care with the team of other care providers.

The medical home model is now seen as the standard of care for all children but is an approach that is especially effective for those with special needs. A review of 33 studies supports the fact that when children with special health care needs receive their primary health care through a medical home, their health status, timeliness of care, family-centeredness, and family functioning are improved (Homer et al., 2008).

Because of the particular complexity of conditions experienced by children with ASDs, the medical home model of health care delivery is especially tailored to meet their needs. These children are reported to have less comprehensive and coordinated care and greater unmet needs, when compared to the broader cohort of children and youth with special health care needs. Several studies based on national survey data found that

parents of children with autism were less likely to report care consistent with that in a medical home such as family-centered, comprehensive, or coordinated, and less satisfaction with their children's primary care than were parents of children with other special health care needs regardless of severity of condition, personal characteristics, or insurance status (Brachlow, Ness, McPheeters, & Gurney, 2007; Carbone et al., 2010; Carbone, 2013). They were more likely to report difficulty in accessing subspecialty care and less likely to be offered help with education, therapy, or support groups.

When receiving care through a medical home, however, families report improved health and decreased financial burdens (Golnik, Scal, Wey, & Gaillard, 2012). The functions of a medical home that are central to health care for children with ASDs include developmental screening to identify signs and symptoms at the earliest point in time, referral for more comprehensive evaluation and intervention, coordination of care with specialists and all other agencies and professionals involved, ongoing monitoring and management of ASD and coexisting medical problems, medication management and support, education for families in seeking interventions including complementary and alternative medicine, and **transition** to adult services.

Screening for ASD should be incorporated into well-child visits at 18 and 24 months of age. The challenges to universal screening for ASD include concerns about the accuracy of existing validated instruments, the time and costs involved, comfort in managing children with ASDs before other services and supports are in place, and limited resources in the community once the diagnosis is made (Hyman & Johnson, 2012). However, child health providers report several barriers to serving children with ASDs that include lack of necessary skills such as recognizing signs and symptoms and addressing the medical and behavioral comorbid conditions, lack of time and resources to provide extensive care coordination, and lack of familiarity with local resources unique to children with ASDs (Williams, Tomchek, Grau, Bundy, Davis, & Kleinert, 2012).

Because of the special challenges in treating children with autism, specific efforts may be needed to ensure optimal care is provided in a medical home model. Golnik et al. (2012) evaluated a primary care medical home designed specifically to address the needs of children with ASDs at the Fairview Children's Clinic in Minneapolis. Elements of this

medical home included individualized care plans, care coordination with ASD-specific resources including dentists, tools to improve patient visits including ASD-specific toys, longer visits, and pictures and stories written in tailored formats. They found that designing a medical home specifically to address the unique needs of children with ASDs results in an increased likelihood of children receiving care that meets medical home criteria as well as increased satisfaction among parents of children with ASDs. In a qualitative study that included focus groups with pediatricians, the following resources were cited as helpful to them in providing a medical home for children with ASDs: a website of community resources, evidence-based guidelines for younger children with ASDs, and insurance-reimbursed care coordinators.

## **PRACTICE GUIDELINES AND EVIDENCE-BASED PRACTICE**

As we discuss in other chapters, a number of evidence-based treatments and programs are now available, and the literature on medical problems associated with autism has grown significantly. Several practice guidelines are now available, and although these take somewhat different approaches, it is interesting to see that they converge in many ways (Isaksen, Bryn, Diseth, Heiberg, Schjolberg, & Skjeldal, 2013; McClure 2014; Volkmar et al., 2014). Similarly a number of excellent scholarly reviews and research papers have now appeared on medical conditions and problems associated with autism (Coury, 2010; Levy et al., 2010). Fortunately there is a tiny but growing literature on medical conditions in adults with autism (Burke & Stoddart 2014). We will revisit the issue of evidence-based interventions and programs in Chapter 5 relative to educational interventions.

## **SUMMARY**

As in the rest of medicine an ounce of prevention is worth a pound of cure! Familiarity with typical patterns of vulnerability and strength can lead to informed medical practice that engages individuals and their families more fully in the health care process and anticipates and prevents some major long-term health problems. From early in life a series of steps can be taken with parents to make well-child and sick visits more successful. Anticipating the child's needs by having a familiar routine, use of visuals (books, schedule,

apps), avoiding excessive waits, having familiar materials or activities to help with waiting, thinking about the need for a more consistent and informed approach, and giving extra time will help. If well-child visits go better, then sick visits will also go more smoothly. For older children, adolescents, and adults an awareness of the typical age-related issues and concerns as well as those more specific to ASD is helpful.

Preventive dental care is also important. Unmet dental care needs can lead to major difficulties later in life—even later in childhood. The use of an experienced pediatric dentist can be very helpful but even a dentist in general practice can take steps to engage the child in tolerating dental visits and encouraging good dental hygiene.

Children with autism are at increased risk for accidental injury, and some data show increased ED visits; often these can be minimized if there is a strong working relationship with the primary care provider. Steps to facilitate the ED visits as well as hospitalizations (particularly if anticipated) can make life less stressful for the individual with ASD and his or her caregivers (and the hospital staff members).

Given the number of potential medical and mental health problems, particularly as individuals age, it is especially important that the primary care provider be familiar with all medications being taken as well as any engagement in any relevant complementary and alternative treatments (diets, vitamins, and so forth). The use of the medical home approach is strongly associated with higher levels of health care and more efficient health care delivery. As the evidence base for treatments and intervention procedures has grown, a number of practice guidelines and resources for clinicians are now available and provide a good initial reference for the primary care provider confronted with a sometimes dizzying array of treatments.

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