Over the last decade, the subject of autism has been magnified in the minds of the general public, as well as in the consciousness of child development, education, medicine, and public health professionals. Autism, once thought of as rare, is now recognized as occurring much more commonly than believed and affecting not only individual children and families but the health care, early intervention and educational systems as well. In the not too distant past, autism was thought to effect approximately 4 or 5 children in 10,000.1 More recent studies have reported incidence of 1 to 2 per 1,000 with some surveys reporting even higher incidences.2, 3, 4 In Rhode Island, the number of children between ages 3 and 21 years receiving special education services who reportedly have one of the autistic conditions increased from 30 to 605 between 1993 and 2002.5 The number of children in Rhode Island with one of the autistic conditions is estimated as being well over one thousand. Virtually every pediatric practice is likely to have at least one child with an autistic condition.

Autism and autistic spectrum disorders (ASD) represent a heterogeneous group of disorders with marked variability in their presenting characteristics of qualitative differences in reciprocal social interaction and communication and with restrictive behaviors that become apparent in early childhood. These children present the pediatric care provider with challenges in screening, diagnosis, treatment, and management. Both residents in training and practicing pediatricians report autistic children among the more challenging groups of patients for whom they provide care. Nevertheless, most providers remain willing to provide care and to improve the level of care that they provide.6, 7

Over the last decade, The American Academy of Pediatrics, through its Medical Home Project, has promoted the role of pediatricians and family physicians in the care of children with and without special health care needs.8 Among the provisions of the Medical Home are a range of clinical and supportive services.9 These are the provision of primary health care including surveillance and screening, care management, referral and coordination of care, education and guidance for the child and family, advocacy and support and the transition of health care as the child matures.10 The American Academy of Pediatrics has published an extensive technical report on the pediatrician's role in the diagnosis and care of children with any of the autistic spectrum disorders.11 The Academy has also joined with the United States Department of Health and Human Services and other organizations to promote the A.L.A.R.M. Project to improve professional understanding of autism and to encourage screening and early referral for diagnosis and intervention.12, 13

Increasing awareness of autism and autistic spectrum disorders is perhaps the most important initial step. The first “A” in A.L.A.R.M. indicates that “Autism is prevalent.” Autism, Autistic Spectrum Disorders and other developmental disorders occur with greater frequency than previously believed; autistic disorders occur in more than one child in five hundred while other developmental or behavioral disorders may occur in as many as one child in six.2

"L" denotes “listening to parents”. Parents of children diagnosed with autism at an age older than 3 years frequently have reported concerns about their child’s development to a health provider by the time the child is eighteen months old; but parents report lengthy delays between reporting their concerns and referral. Parents’ concerns may sometimes not point to a specific developmental disorder, but, more often than not, do indicate the need for more formal screening. Surveillance by asking questions related to child development should be part of the routine health maintenance examination for all children. This will improve the early identification of children with developmental problems when the parents do not report any specific concerns.

The second “A” stands for Acting Early. Some general surveillance questions can be red flags for identifying children at risk of developmental disorders. (Table 1)

A more formal screening process for Autistic Spectrum Disorder can be carried out during routine well-child examinations or selectively for children thought to be at risk based on answers to surveillance. (See the discussion by Drs. Gargus and Yatchmink this issue).

Because there is an increased risk of an approximately 10% occurrence among the siblings of children with autism, the health care provider should monitor the social, communication, adaptive and behavioral development of the siblings of autistic children, not only for signs of autism but other cognitive or developmental disorders as well.

The next recommended step in A.L.A.R.M. is “R” for referral of children who are at risk for any developmental disorder, including Autistic Spectrum Disorders, to an Early Intervention program and to a developmental specialist for a diagnostic evaluation. The primary care provider can move this process along by obtaining an audiologic examination of hearing and a speech and language evaluation. Referral should be made as soon as a developmental risk is identified. This should be done even prior to the formal diagnosis of developmental disorder. Referral should also be made to a developmental specialist for a definitive diagnostic evaluation. This will ensure that the child will be promptly evaluated and enrolled in therapeutic services while the family receives support services.

Because autism is a complex and
multifaceted condition, the definitive diagnosis and characterization of specific disabilities is best carried out by a team of experienced evaluators.\textsuperscript{15} Referral to a pediatric developmental specialist or autism diagnostic unit should be made as soon as possible to clarify the diagnosis and to document the child's developmental and behavioral challenges. The diagnostic assessment should be based on formal diagnostic criteria such as those published in the DSM-IV or the ICD-9. The Autism Diagnostic Interview - Revised (ADI-R) and the Autism Diagnostic Observational Scales (ADOS)\textsuperscript{16,17,18} are not only useful in establishing the diagnosis of Autistic Spectrum Disorder, but are invaluable in documenting the behavioral and developmental challenges that will need to be addressed in any behavioral or educational service plan.

Referrals to Early Intervention for children under age three and to special education services for those over three are key interventions. Early intensive communication and socialization-based interventions such as ABA (Advanced Behavioral Analysis) and TEACHH Programs have been shown to be among the most effective interventions in improving the child's ability to develop language and communication skills and in helping with social integration.\textsuperscript{19,20} Additionally, families should be linked up with support services such as the Autism Society.

The "M" stands for Monitor. Beyond monitoring, though, the primary care provider must also mentor the family through the subsequent learning and adjustment. After a definitive diagnosis of one of the Autistic Spectrum Disorders has been made, the primary care office must expand its role as a Medical Home not only to provide care but to insure access to primary and specialty care and care coordination. This should include monitoring of the child's overall health, immunizations and care of the typical illnesses and injuries of childhood. Because children with autism have similar health care needs as other children, the primary care provider must remain actively involved in the general pediatric care and not abrogate those responsibilities because of the diagnosis of autism. There should be continued surveillance for behaviors that might be related to or be outcomes of a child's autistic condition, such as altered eating, sleep patterns and toileting. Behavior problems may arise at times of physical stress, such as illness or the onset of puberty. Special consideration should be given for monitoring destructive, self-injurious or aggressive behavior. Progress in language development and behavior should be reassessed regularly.

After the diagnosis has been made, families may well return to their child's primary care provider for guidance about interventions, educational programs and treatments. Using a case-based learning approach, the pediatrician can become informed about Autistic Spectrum Disorders and be a valuable resource for the family. Consultation with a pediatric developmental and behavioral specialist is essential in the overall management of the care of the child with autism. Nevertheless, the primary care provider should be sufficiently versed in the care of children with autism to be able to answer basic questions. This may be particularly important in the areas of causation, intervention and those unproven treatments that promise improvement or even a cure. Recently the media has publicized a possible causative relationship between measles, mumps and rubella (MMR) immunization and autism. Despite several large studies failing to demonstrate any causative relationship, many in the public suspect a link.\textsuperscript{21,22} The primary care provider can offer information, clarification and reassurance for families. Parents can feel confused when presented with unproven treatments that promise improvement or even cure; e.g., dietary

---

**Table 1.**
Red Flag Screening Questions for Autistic Spectrum Disorders

- *No babbling by 12 months of age*
- *No pointing or other gestures by 12 months*
- *No single words by 16 months*
- *No two-word sentences by 24 months*
- *Any loss of language or social skill at any age.*

Other questions and observations focus more directly on autistic spectrum disorders, including; "Is your child able to:

- *communicate as well as other children his/her age?*
- *show good eye to eye contact?*
- *respond to his/her name?*
- *interact with people like other children his/her age?*
- *smile back at people reciprocally?*
- *wave bye-bye?*
- *point to objects to draw your attention to them?*
- *tell or show you what he/she wants or does he/she have to lead you by the hand to get things?*
- *bring you books or toys of interest to him/her simply to show you?*
- *play interactively with other children?*
- *play in a way that is typical of other children his/her age and gender?*
- *play with toys in a typical way?*
- *engage in pretend play if over 2 years of age?*
- *have the ability to calm him or herself in a relatively short time when upset or having a tantrum?*
- *get to sleep and remain sleeping all night?*

“No” or negative answers indicate the need for further evaluation.
manipulation, therapeutic intervention or medications, such as intravenous administration of secretin or chelation therapy. Several studies have shown those treatments to be of no value in altering behavior or function of autistic children. Yet some health care professionals support the use of secretin in the treatment of children with autism. The primary care pediatrician or family physician may be called upon to assist families in selecting interventions for their children.

The primary care provider may also need to advocate on behalf of the child and family with schools and health care plans. At other times, questions will arise about the transitions that occur in the lives of families with autistic children as indeed in all families of children with special needs. The first and most critical transition is at the time of diagnosis when parents must come to terms with their child's severe and potentially life-long disability. At the same time parents must face enrolling their child in an early intervention program. Though this is accompanied by the expectation of improvement, it is an additional confirmation of the child's disability. Later there will be the transition from early intervention at age three to a special education school program. At any time during childhood there may be crises over the child's behavior or developmental lags. In early adolescence the transition of educational, social and health care will begin, ending in the transfer of the young adult to adult care and service systems. During each transition, the primary care provider may be asked to provide guidance.

The primary care pediatric provider, whether a pediatrician, family physician or nurse practitioner, plays a crucial, central and important role in the assessment of the child at risk of autism and in providing ongoing care after the diagnosis is made. The Academy of Pediatrics has recommended roles for the primary care provider in the diagnosis and management of children with Autistic Spectrum Disorders. Important points for pediatric care providers are listed in Table 2.

Though usually diagnosed in childhood and often considered a childhood condition, autism is a lifelong disorder with lifelong disabilities. The care of patients with autism needs to extend beyond childhood. Transition and transfer to adult care is an essential element for the autistic young adult. This will require improvements in training not only for providers of pediatric care but also for adult health care providers.

### References

7. Burke R, Cardosi, MA, Price A. Survey of primary care pediatrician on the levels of care provided to children with special needs. Unpublished data.

### Table 2. Fourteen Points for Providing a Medical Home for the Child with Autistic Spectrum Disorder and the Family

1. Be aware of the “Red Flags” for Austistic Spectrum Disorder.
2. Incorporate behavioral and developmental surveillance into health maintenance visits.
3. Use formal autism screening tools such as the Checklist for Autism in Toddlers (CHAT) or the Pervasive Developmental Disorders Screening Test-II (PDDST-II) when the possibility of Autistic Spectrum Disorders is suspected.
4. Refer to Early Intervention when any developmental risk is suspected.
5. Make an early referral to a pediatric behavior and developmental specialty team for a thorough diagnostic assessment when ASD is suspected.
6. Refer to a pediatric neurologist, geneticist and other specialists whose insights might be important in establishing causation.
7. Use case-based learning to improve knowledge and ability to provide care and support to the child and family.
8. After the diagnosis of Autistic Spectrum Disorders, put the family in contact with local and national autism support groups.
9. Assist the family of the autistic child to obtain emotional support, and refer to supportive and mental health services.
10. Partner with parents in a discussion of the diagnosis, treatment and intervention for the child, the parents and siblings.
11. After diagnosis, be vigilant for the developments of co-morbidities and specific sleep, eating and behavioral disorders, such as aggression or regression.
12. Advocate for the child and family with schools, service providers, state agencies and health insurers.
13. Be proactive at times of transition. Begin the planning process of transition to adult health care and service as early as 12 years of age with the transfer of care anticipated to take place as a young adult.
14. Provide a Medical Home with access to routine and coordinated care that is family-centered and culturally sensitive.

Robert T. Burke, MD, is Assistant Professor of Pediatrics, Brown Medical School, and Chair of the Committee for Children with Special Needs of the Rhode Island Chapter of the American Academy of Pediatrics.

Ann-Marie Cardosi, RN, BSN, is a staff nurse in the Pediatric Primary Care Center and the Primary Care Center for Children with Special Needs, Memorial Hospital of Rhode Island.

Ashley Price, MD, FAAFP, is an Assistant Professor (Clinical) of Family Medicine, Brown Medical School, and a family physician at the Cranston Community Health Center.

Alanna Teatom-Burke is a student at the University of New England School of Osteopathic Medicine.

Correspondence:
Robert T. Burke, MD
Department of Pediatrics
Memorial Hospital of Rhode Island
111 Brewster St.
Pawtucket, RI 02860
Phone: (401) 729-2582
Fax: (401)729-2854
e-mail: Robert_Burke@mhri.org