

# Medical Home Services for Autism Spectrum Disorders



Waisman Center  
University of Wisconsin–Madison  
University Center for Excellence in Developmental Disabilities  
National Medical Home Autism Initiative



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The Waisman Center is dedicated to the advancement of knowledge about human development, developmental disabilities and neurodegenerative diseases. It encompasses both an Intellectual and Developmental Disabilities Research Center designated by the National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities designated by the Administration on Developmental Disabilities

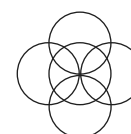


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*“... Medical Home as an innovative quality improvement strategy for pediatric chronic conditions using a collaborative self-management model to provide safe, effective, patient- and family-centered, timely, equitable care. It can improve clinical outcomes, optimize resource utilization, and increase family and provider satisfaction.”*

William E. Schwab, M.D.  
Professor, Department of Family Medicine  
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### ***Purpose of this report***

The purpose of this report is to describe how the concepts and principles of the Medical Home can be utilized by health care practitioners, clinicians, educators, administrators, policymakers, families and individuals with Autism Spectrum Disorders (ASD) and others to foster a collaborative approach to promote the early identification of children with ASD and entry of those children into a full range of appropriate community based services. More specifically, this report:

- Describes current prevalence and understanding of autism spectrum disorders as reported by national agencies and organizations.
- Summarizes challenges that families and professionals face as they work to provide early diagnosis of children with ASD and assure access to comprehensive, coordinated, continuous and culturally competent services.
- Describes the principles of Medical Home for Children and Youth with Special Health Care Needs as promoted by the Maternal Child Health Bureau (MCHB) and the American Academy of Pediatrics (AAP) through the National Center for Medical Homes for Children with Special Needs.
- Describes a conceptual framework within which key partners can perform key functions across service activity areas to ensure early identification and continuous services for children with ASD and their families.
- Facilitates dissemination of the ASD Service System Guidelines for Medical Home Primary Care Practice (referred to as ASD Service System Guidelines) developed by the ASD Service Guideline Workgroup (ASG Workgroup), through a cooperative agreement with the Health Resources and Services Administration's Maternal Child Health Bureau (MCHB) to promote discussion and interaction among various stakeholders as they work to coordinate efforts to improve systems of care for children / youth with ASD.

### ***Prevalence of Autism Spectrum Disorders***

Over the past decade, the number of individuals in the United States diagnosed with Autism Spectrum Disorders (ASD)—including Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS)—has risen dramatically, from two per 1,000 children 15 years ago to six per 1,000 children in 2007. The Centers for Disease Control and Prevention (CDC) report issued on February 9, 2007 indicates that prevalence rates of Autism Spectrum Disorders (ASD) in children are 5.2 to 7.6 per 1,000, or one of every 152 children. ASD is the fastest growing developmental disability, affecting more children than Down Syndrome, childhood cancer, type 1 diabetes, or cystic fibrosis. The rapid growth in the number of children diagnosed with ASD is an urgent concern for families, ASD services providers, and Federal, State, and local agencies. The current lack of appropriate ASD resources including the supply of trained professionals to meet the growing needs sets this as a priority area for increased funding and enhanced quality improvement strategies.

**ASD as a Medical Condition:** In response to the rapid increase in ASD – which many consider at epidemic levels – the National Institute of Health (NIH) initiated a focused and coordinated approach to the clinical research agenda through the efforts of a federal Interagency Autism Coordinating Committee (IACC)<sup>1</sup>. As a result, there is now an understanding that ASD is a neuro-developmental medical condition associated with unique abnormalities in brain development, rather than a mental health or behavioral disorder. More research is necessary to 1) help us understand why brain abnormalities seen in children and adults are not universally present, 2) develop reliable biological markers for ASD, 3) improve methods of assessment of treatment options and results, 4) determine if there are interrelationships between genetic and environmental factors that may affect or result in biomedical abnormalities that contribute to ASD.

### *Challenges that must be addressed*

Families of children with ASD and the professionals who are working to assist them face a number of challenges as they strive to meet the service needs of children and youth with ASD. These challenges can be grouped into four categories:

**#1: Identification of children with autism** Parents often struggle to obtain an accurate explanation for their child's atypical behavior, communication and overall development. Their struggle is complicated if their primary care providers are not trained or supported to readily respond to their concerns by recognizing the early warning signs for ASDs, by giving adequate time and attention to routine developmental assessment, and by referring on for further diagnostic workup if problems are suspected<sup>2</sup>. In addition, while increasing attention is being given to diagnostic instruments that are based on the symptom patterns of infants and children<sup>3</sup>, diagnosis remains challenging with very young children because the symptoms are complex, different and evolving<sup>4</sup>.

**#2: Gaining entry into effective intervention programs** Families and service providers are faced with the difficult task of sorting through a wealth of information and research about programming approaches to work with children with ASD<sup>5</sup>. A 2001 report by the Committee on Educational Interventions for Children With Autism reports increased understanding about some of the factors that contribute to successful intervention, such as (1) entry into an intervention program as soon as the child is suspected of having an ASD, (2) intensive educational programming for at least 25 hours a week, year round, (3) functional spontaneous communication, (4) social instruction delivered throughout the day in various settings, (5) cognitive development and play skills, and (6) proactive approaches to behavior problems<sup>6</sup>. Despite consensus on these elements, programs throughout the country have not yet determined how to capture and direct the necessary level of resources in order to apply these findings to individuals engaged in direct service delivery at the local level. Particularly in rural areas of the country, there is lack of consultants with expertise in ASD or training programs to support and prepare providers working with this population<sup>7</sup>.

**#3: Working from a family-centered perspective** Seltzer et.al.<sup>8</sup> describes three ways in which families are impacted by having a child with autism. First, in comparison to parents of children with other types of developmental disabilities, parents of children with autism experience greater stress, depression, anxiety and other negative mental health outcomes. Second, the consequences for the family of having a member with autism are pervasive and lasting, and will change from childhood to adolescence. While in the earlier childhood years families welcome treatment programs to provide the best opportunities for responsive and normal functioning, in adolescence, families recognize that their child's level of functioning or capacity for a transition toward independence may not change dramatically. Third, social support and the use of specific coping strategies can ameliorate or buffer the magnitude and impact of stress among families. These findings demonstrate that autism intervention strategies must be considered within the context of the overall family and their circumstances, needs, culture and preferences.

**#4: Coordinating the organization and delivery of care** For many families the care and support required to raise their child with ASD is very complicated and requires access to multiple service sectors including primary and specialty health care, early intervention and special education services, social, public health and home health services, and other community resources such as child care and respite care. As families and care providers strive to access these services, they find themselves interacting with a wide array of agencies and providers working from different missions, eligibility criteria, and funding mechanisms. These families often experience extreme difficulty and frustration gaining access to services, and may be unsure where to get assistance. Through recent work of MCHB, the American Academy of Pediatrics and others, primary care pediatricians and other professionals caring for children with special health care needs now generally acknowledge that a "Medical Home" can help to address this issue by assuring access to comprehensive, coordinated care within the pediatric setting. Within this model, a single point of entry for access to services is identified, and a specific plan for care and treatment is designed and implemented in an organized way among the variety of health care and other professionals serving the family<sup>9</sup>. This standard of care is appropriate for all children, but is especially critical for children and youth with ASD and other special health care needs.

***Promoting  
Medical  
Homes for  
children with  
ASD***

Several national groups including the Maternal and Child Health Bureau, the American Academy of Pediatrics, the American Academy of Family Physicians and others have promoted the concepts of Medical Home as an approach to comprehensive, coordinated health care for all children, including those with ASD. A key point of understanding within the Medical Home framework is that the Medical Home Primary Care Practice (MH-PCP) is responsible for health promotion as well as preventive and on-going routine care. The Medical Home practice also serves as a central point of coordination for chronic conditions and for working with other community based providers and agencies to assure that the individual and family have access to the full range of services they need and are eligible for. A MH-PCP routinely monitors development and screens to identify children with developmental delays and disabilities including ASD. If delays or disabilities are confirmed, they will make appropriate referrals so that treatment and intervention can begin early. Practitioners working within this Medical Home framework have ongoing and effective communication with the children, youth, and families under their care, and they learn to partner with the families to address needs. A proactive team approach is used to manage ASD as a chronic condition within the Medical Home. This requires coordination of the more complex services and systems such as health and education, as well as co-management with specialists and assistance with transitions, especially to adulthood. The Medical Home helps families connect with other community-based organizations and provides support and guidance in finding needed resources. While all children should have access to a Medical Home that is accessible, family-centered, compassionate, comprehensive, continuous, coordinated, and culturally effective, it is especially important for children with ASD and other special health care needs requiring a wider array of specialized community services and supports than typically developing children.

**The Importance of Collaboration and Coordination** A successful Medical Home focuses on a range of linkages that are essential in order to put in place a comprehensive set of services and resources to meet the needs of children with ASD and their families. These include collaborations among primary care pediatric clinics, early intervention and education systems, parent organizations and other community agencies such as Early/Head Start, child care, public health and mental health. When using an appropriately coordinated approach, these partners depend upon one another to provide services within their scope of practice, and they collectively work together to identify and address the service gaps and system barriers for children with ASD and their families. Each of these partners commit to understanding the scope, boundaries and challenges of each others services and resources. For example, community programs work to understand the constraints within medical practices such as limited amount of time with patients. Conversely medical practices work to understand the constraints most community programs confront, including higher enrollments and inadequate funding. These collaborations are designed to ensure that no matter where a family enters the system, they will be connected to a medical home that will provide appropriate relationship-based medical care, parent to parent support, and care coordination.

The National Center of Medical Home Initiatives website, maintained by AAP is a rich resource that includes a variety of tools to help practitioners understand and promote medical home practices <http://www.medicalhomeinfo.org/>. In addition, recommendations for services for children with autism spectrum disorders can be found at the following AAP webpage. <http://www.aap.org/healthtopics/autism.cfm>

***Development  
of ASD Service  
Guidelines for  
Medical Home  
Primary Care  
Practices***

In response to the growing national concern about the prevalence of ASD, the original Federal Interagency Autism Coordinating Committee (IACC) implemented major initiatives to expand research and improve ASD services. In 2004 the IACC established a Services Subcommittee to identify strategies to improve and expand existing ASD services as well as coordinate those services across systems. The Services Subcommittee established an Expert Working Group to describe best practices, identify significant system constraints, and develop an ASD Services Roadmap with strategies and recommended actions. (Available at <http://www.waisman.wisc.edu/nmhai/publications>.)

**Importance of Interdisciplinary Professional Preparation** One of the most pressing challenges identified in the ASD Services Roadmap was the shortage of highly qualified professionals to serve children with ASD. Significant gaps exist in professional knowledge about ASD and no widely accepted or widely implemented service guidelines are available to serve as the basis for training curricula. The lack of capacity permeates all aspects of the service systems including primary health care, subspecialty clinics, developmental therapists, educators, mental health professionals, and behavior specialists, among others. Gaps in knowledge and training experiences within and across disciplines often result in delayed or fragmented services for children and families. Interdisciplinary and cross system approaches to assessment and intervention are important in the early identification of ASD and the provision of comprehensive, ongoing services and supports. A key recommendation of the ASD Services Roadmap was that ASD specific professional guidelines be developed and promulgated. This recommendation was adopted by the Services Subcommittee in 2005 as one of several short-term actions to address the Roadmap recommendations. Professional preparation is one strand addressed throughout the service system guidelines to illustrate the interactive and interdependent role of the medical home and other community partners.

**The ASD Service System Guidelines** were developed by an ASD Service Guideline Workgroup (ASG Workgroup) supported by the National Medical Home Autism Initiative through a cooperative agreement with the MCHB. The ASG Workgroup was a diverse group comprised of members with special ASD expertise—service providers, educators, professional associations, community program coordinators, and family members of individuals with ASD. The ASG Workgroup initially met in late 2005 to discuss the purpose and target audience for the ASD Service System Guidelines and to share information on the status of other ASD Service Guideline development efforts. They agreed that the care of children and families with ASD should occur within the context of a primary care medical home practice; however, the working group recognized that the lack of adequate resources and reimbursement for services provided by physicians caring for children in a medical home setting would be a limiting factor in implementation. This resulted in the ASG Workgroup decision to focus the guidelines on action steps for the overall system of ASD services to support the medical home approach. The American Academy of Pediatrics, the Autism Treatment Network (ATN) and others were in the process of developing ASD intervention and treatment guidelines, thus this activity was intended to complement those efforts.

The guidelines were presented for review by the Interagency Autism Coordinating Committee in November 2006. They were then disseminated to a broader group of stakeholders with the intent to foster further and continued discussions within the existing medical home partner groups and the broader network of partners who are addressing ASD across the nation.

### **Development of ASD Service Guidelines for Medical Home Primary Care Practices**

In March 2007 the National Medical Home Autism Initiative (NMHAI), through a cooperative agreement with the MCHB, convened a *Family Forum: Family Perspectives on Autism Service Guidelines for the Medical Home* which included families of children and youth with ASD, state autism system representatives and representatives from the MCHB CSHCN National Resource Centers. The goal of this meeting was to review and discuss the ASD guidelines and determine how to facilitate implementation. The meeting included a multi-disciplinary mix of professionals from eight states and five resource centers who represent all 50 states. The consensus of the meeting was that the medical home principles in the guidelines were descriptive and helpful, but that the system requirements should include a stronger family and youth focus. The rich discussion and input from the meeting resulted in changes to the guidelines that incorporated a stronger family voice in the system requirements. In addition, families articulated the following critical points of consensus that serve as a challenge for efforts to improve the system of ASD services:

- Autism is a chronic medical condition with underlying genetic and environmental causes. ASD is treatable with medically necessary interventions—physical, behavioral, and therapeutic.
- There is a crisis in ASD, not just because the rates and trends in prevalence have increased, but because the service system lacks an adequate number of trained and well-distributed professionals at all levels. The service system is fragmented / broken and needs to be restructured, and funding and reimbursement levels are inadequate to provide quality services.
- Children, youth, and adults with ASD face unique challenges, and providers and communities need to be more accepting and competent in integrating them into accessible service systems and into society.
- As the growing number of children with ASD become adolescents and then adults, the failure to plan for their transition and the lack of adult services will be a significant concern to families and to the nation.
- Medical home services within the broader context of cross systems coordination should be made available to all children with special health care needs.
- Common ASD definitions for service eligibility and reimbursement are needed across multiple systems.

On December 6 and 7, 2007 a conference entitled “Getting the House in Order: Creating Medical Home Solutions for Individuals with Autism” was sponsored by the National Medical Home Autism Initiative and The Autism Program of Illinois. This conference was held in Title V Region 5 with participation from Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin. The ASD Service System Guidelines were introduced on the first day of this conference and used as a tool to stimulate discussion regarding ASD services over the course of the two day conference. (Refer to Resource #3.)

**“... As the parent of a child with autism, I know that it makes a difference when you have the support of a Medical Home. There’s help as you struggle to understand what services are out there - or not out there ... We finally feel like our son is receiving comprehensive health care to address all of his needs ... But the big difference is that when you have a Medical Home, you’re not alone ...**

Amy Dawson  
Parent of a child with autism

***Systems  
Framework for  
ASD Services  
within the  
Medical Home***

The framework on the following page identifies the components of a medical home model that promote collaborative services for individuals with autism and their families, as well as those with other developmental disabilities.

**Key Partners**

are those individuals and agencies that have a significant role to play in the delivery of coordinated community services.

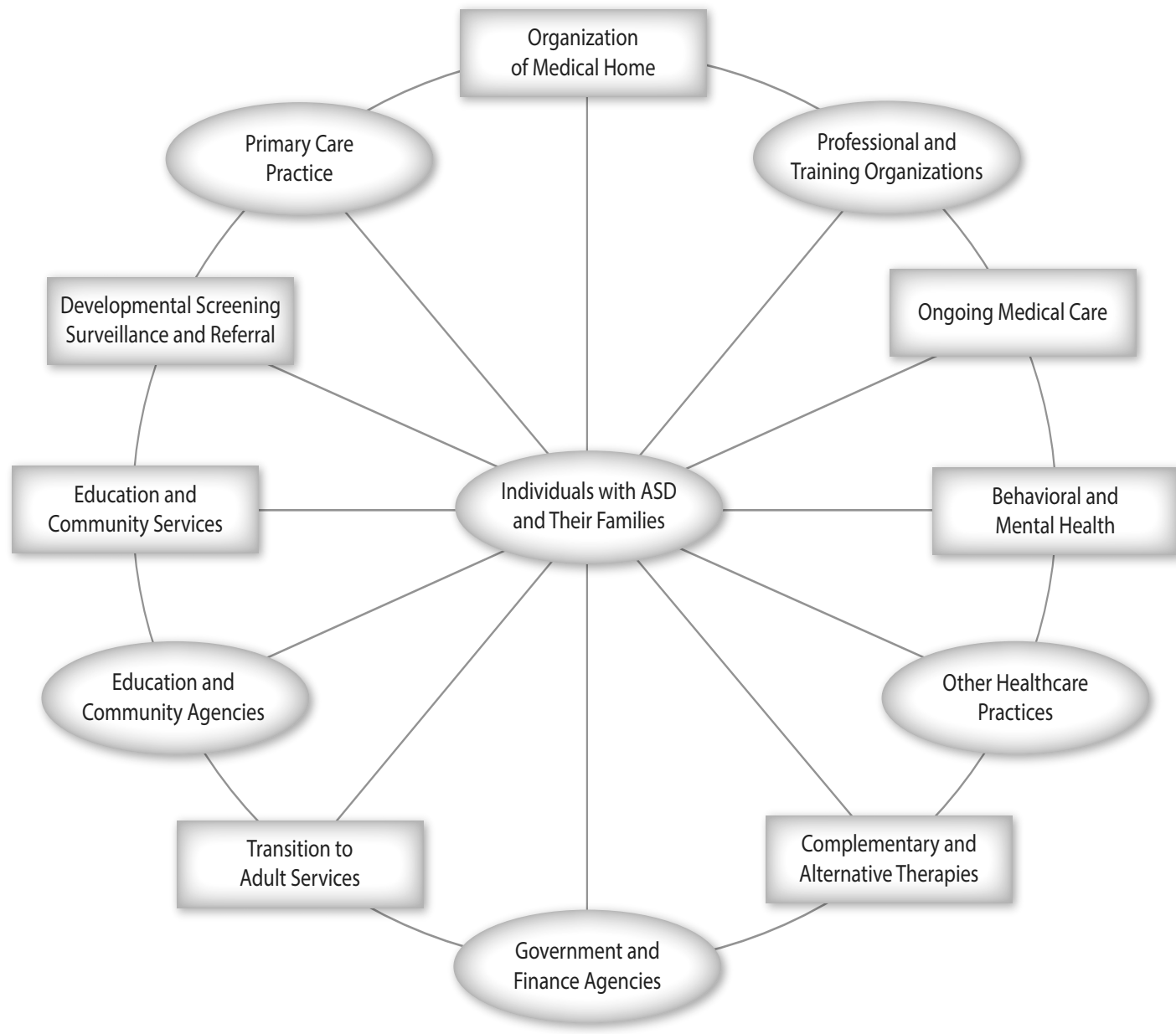
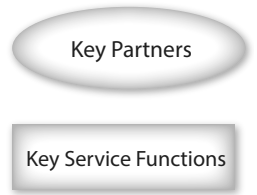
1. Primary Care Practice : pediatrician, family physician, nurse practitioner, physicians assistant, nurses, social workers and other office staff
2. Individuals with ASD and Their Families: Parents of children with ASD and their families, including children and youth with ASD
3. Other Healthcare Practices: specialists, and other health care providers
4. Professional / Training Organizations: residency programs, accreditation organizations, professional organizations and other training programs
5. Education and Community Agencies: early educators, teachers and administrators K-12, social workers, public health educators and professionals, and other community providers
6. Government and Finance Agencies: government service providers such as Medicaid, Insurance Providers and other health care payors

**Key Service Functions**

are described within the following areas of service.

1. Organizational Structure of the Medical Home
2. Developmental Screening, Surveillance and Referral
3. Ongoing Medical Care
4. Behavioral & Mental Health Services
5. Complementary and Alternative Therapies
6. Education and Community Services
7. Transition to Adult Services

**Systems Framework for ASD Services within the Medical Home**



## Organizational Structure of Medical Home

### Guidelines for Medical Home Primary Care Practice

1. The Medical Home Primary Care Practice (MH-PCP) is aware of and implements Medical Home (MH) principles when caring for children and youth, including those with ASD. (Refer to Resource #1.)

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Youth with ASD and their parents serve as teachers and mentors in medical school residency training and continuing education programs and contribute to the development of curriculum and office management tools to help prepare the MH-PCP practice for serving families with ASD. (Refer to Resource #2.)

Professional & Training Organizations

Accreditation/residency and training programs recognize the importance of the Medical Home (MH) principles by including MH practice training as a required component of pre-med, residency, and continuing education curriculum for pediatrics, family medicine, med-peds, and mid-level providers such as nurse practitioners and physician assistants. Board licensing and re-certification requirements include MH principles, especially as they relate to the care of patients with ASD and other chronic conditions.

Accreditation/residency and training programs include out of office/hospital rotations at the community level in service settings and in the homes of children, youth, and families with ASD and other chronic conditions.

Professional organizations such as the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP) and the National Association of Pediatric Nurse Practitioners (NAPNP) provide ongoing Continuing Medical Education (CME) training in the principles and implementation of a medical home for the care of all children/youth, including those with ASD. (Refer to Resource #3.)

Government & Finance Agencies

Funders/insurers and other health care payers reimburse MH-PCPs for the extra time required to provide a quality MH to children/youth. This includes the elements of planned care such as care coordination, co-management with specialists, and collaboration with community agencies required when children have developmental disorders such as ASD.

Organizational Structure of the Medical Home

Developmental Screening, Surveillance and Referral

Ongoing Medical Care

Behavioral & Mental Health Services

Complementary and Alternative Therapies

Education and Community Services

Transition to Adult Services



## Organizational Structure of Medical Home

### Guidelines for Medical Home Primary Care Practice

2. The MH-PCP is organized in a manner that involves the entire office staff in meeting the complex needs of the patient with ASD and his or her family and offers flexibility in the provision of services.

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Youth with ASD and their parents serve as resources and mentors to the MH-PCP administrative and medical staff who schedule appointments and receive ASD families at the office, helping to overcome communication and social barriers (e.g. provide communication assisted technology for non-verbal children or youth) and address special family needs related to ASD.

Families and advocacy groups advocate for improved reimbursement and funding to adequately compensate primary practice providers for the additional time and resources needed to educate and prepare all office staff to serve ASD families, involvement of involving families as mentors and partners to primary practice.

Professional & Training Organizations

Accreditation/residency and training programs emphasize the important role of staff at all levels of the practice in serving children with special health care needs such as ASD, and prepare staff for their role in office-based practices.

Government & Finance Agencies

Funders/insurers and other healthcare payers provide enhanced reimbursement or alternative forms of compensation, such as capitated administrative payments, to compensate the primary care practice for the additional time required of receptionists, administrators, physician extenders and other resources needed to provide intensive services.

Organizational Structure of the Medical Home

Developmental Screening, Surveillance and Referral

Ongoing Medical Care

Behavioral & Mental Health Services

Complementary and Alternative Therapies

Education and Community Services

Transition to Adult Services

## Organizational Structure of Medical Home

### Guidelines for Medical Home Primary Care Practice

3. The MH-PCP, in collaboration with sub-specialists and community agencies, provides appropriate disorder-specific information (printed, electronic, etc.) on all aspects of ASD including definition, diagnosis, etiology, genetic, neuropath correlates, developmental and behavioral characteristics to consumers and other community providers. (Refer to Resource #4.)

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Families and advocacy groups serve as resources to MH-PCP professionals, and to other families in order to share knowledge and information about their personal experiences with ASD and strategies they have used for treating ASD.

Professional & Training Organizations

Accreditation/residency and training programs emphasize the importance of education materials to increase knowledge and skills of families and caregivers about all aspects of ASD and teach residents methods for retrieving appropriate evidenced-based and consensus-based materials for distribution to patients' families.

Professional organizations such as the AAP, AAFP and NAPNP engage experts in various fields to develop evidenced-based training materials for distribution to parents by MH-PCPs.

Government & Finance Agencies

Funders/insurers and other healthcare payers recognize the need for additional value of offering materials, information and training to families. (Refer to Resource #5.)

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## Organizational Structure of Medical Home

### Guidelines for Medical Home Primary Care Practice

4. In accordance with the principles of Family Centered Care, the MH-PCP recognizes parents as valued partners and decision-makers in the care of their child and establishes regular, ongoing communication with reciprocal exchange of information. An important component of parent-professional partnerships is listening and acting upon parent concerns about their child's development and/or behavior. The physical health and emotional well-being of the entire family is included and considered in all decision making.

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Families in a collaborative partnership with MH-PCP providers are informed about federal, state, and local financing options, insurance benefits, and reimbursement mechanisms for chronic conditions and ASD, so that they can fully consider insurance and other financing options in efforts to maximize funding of services for children and youth with ASD.

Professional & Training Organizations

Accreditation/residency and training programs recognize the importance of training activities in parent-professional partnerships and require all residency programs to implement one of the nationally recognized parent-led curricula. For pediatricians, this might ideally be done during mandatory developmental pediatric rotations using existing curricula developed by parent advocates (e.g., Delivery of Chronic Care Program now existing in 20 states.)

Government & Finance Agencies

Government recognizes and/or appoints a lead public agency to organize and support a system of electronic communication (such as a web page) as a resource to provide current information on ASD and ASD related services to parents and professionals statewide. A service agency should support this participation with families who do not have access to the Internet.

## Organizational Structure of Medical Home

### Guidelines for Medical Home Primary Care Practice

- The MH-PCP respects and competently serves the multiple and diverse cultures of children with ASD and families. The practice is linguistically competent, including having culturally appropriate written materials and translators available.

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Families with diverse cultural backgrounds assess materials, educational booklets, and the overall cultural competency of MH-PCP practice. They also participate as trainers in efforts to strengthen cultural competency in serving children and families with ASD from diverse backgrounds.

Professional & Training Organizations

Professional organizations and other training programs provide professional development for office personnel and support staff that includes training to increase the sensitivity, awareness, and understanding of cultural norms and prepare staff to competently serve a culturally diverse client population.

Government & Finance Agencies

Funders/insurers and other healthcare payers compensate primary practices for appropriate on-site translators (including sign language) and other resources to ensure that there is appropriate language proficiency, signage, and written materials in the practice setting.

Education & Community Agencies

Community providers make their written and multi media materials and brochures available in culturally appropriate languages and literacy levels for the populations they served.

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## Developmental Screening, Surveillance and Referral

### Guidelines for Medical Home Primary Care Practice

1. Well child care is an important component of the MH-PCP and includes monitoring for developmental and behavioral concerns. (Refer to Resource #6.)

To accomplish this, the MH-PCP :

- Is knowledgeable about normal and abnormal child development
- Conducts general developmental screening utilizing a validated screening tool and surveillance activities recommended by AAP Developmental Surveillance and Screening Policy Statement
  - Surveillance, including listening to parent concerns, at all WC visits
  - General developmental screening at 9, 18, and 30 (or 24) month well child visits
- Utilizes new screening codes for reimbursement

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Families are educated about developmental milestones and are able to recognize early differences in development. Materials have been made available through the primary care practice and through outreach /advocacy activities provided by family advocacy and support organizations. Multi-Faceted approaches are recommended.

Families understand their role as a “partner” with the MH-PCP, are able to communicate their concerns about their child’s development and expect the MH-PCP to provide information about early childhood development.

Families have an expectation that MH-PCP will conduct developmental screening for all children within their practice in a standardized manner.

Professional & Training Organizations

Accreditation/residency and training programs recognize the importance of general training in developmental screening and surveillance activities, including the selection of evidence based screening tools, by requiring this as a standardized component of curriculum for pediatrics, family medicine, med-peds, and mid-level providers such as nurse practitioners and physician assistants programs. These programs provide ongoing CME opportunities to help the MH-PCP stay current with new information regarding screening and tools and to develop innovative approaches to screening and surveillance activities. Board licensing and re-certification requirements include knowledge of developmental and behavioral screening and evidence based tools. (Refer to Resource #7.)

Government & Finance Agencies

Funders/insurers and other healthcare payers recognize the importance of and reimburse the MH-PCPs for extra time needed to conduct screening/surveillance activities and appropriately reimburse for all screening activities when more than one screen is recommended at specified well child visits. Insurers recognize and value the efficiency of using office staff and physician extenders for developmental screening and surveillance activities and reimburse efforts.

Funders/insurers and other healthcare payers recognize the importance of and reimburse the MH-PCP for the extra time needed to conduct screening and surveillance to identify children with ASD and provide appropriate reimbursement for the cost of screening at 18 and 24 months.

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## Developmental Screening, Surveillance and Referral

### Guidelines for Medical Home Primary Care Practice

- The MH-PCP specifically monitors for ASD in all children at all well-child visits and conducts ASD-specific screening on all children at the 18 and 24 month well child visits and at any visit when a parent or other caregiver raises a concern about ASD. If a concern is raised prior to 18 months of age, an ASD-Sensitive screening tool should be used as specified in the above AAP references. (Refer to Resource #8.)

To accomplish this, the MH-PCP :

- Is knowledgeable about the early risk factors and clinical signs of ASD
- Uses ASD surveillance strategies as outlined in the AAP ASD Clinical Reports (Nov. 2007) and AAP ASD Tool Kit and PIR (Jan. 2008).

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Families expect the MH-PCP to use ASD sensitive surveillance materials to monitor for ASD at well child visits and conducts ASD specific screening for all children at well child visits at 18 and 24 month visits.

Professional & Training Organizations

Accreditation/residency and training programs recognize the importance of training activities that promote ASD specific screening and surveillance activities and require this as a component of all training programs using a standardized curriculum that endorses the use of evidenced-based screening tools and includes competency items on certification and re-certification exams. (Refer to Resource #9.)

Government & Finance Agencies

Funders/insurers and other healthcare payers recognize the importance of and reimburse the MH-PCP for the extra time needed to conduct screening and surveillance to identify children with ASD and provide appropriate reimbursement for the cost of screening at 18 and 24 months.

Education & Community Agencies

Community agencies such as WIC, Head Start and Public Health support MH-PCPs by providing opportunities for coordination of screening activities within their communities including identification of where ASD specific screenings are being offered. These agencies also provide materials and information to families to increase awareness about the early signs of ASD.

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## Developmental Screening, Surveillance and Referral

### Guidelines for Medical Home Primary Care Practice

3. The MH-PCP implements a heightened level of surveillance and screening in siblings of children diagnosed with ASD. This includes educating parents about the increased risk of ASD in subsequent children and the early signs of ASD.

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family  
Professional & Training Organizations  
Government & Finance Agencies  
Education & Community Agencies  
Other Health Care Practices

Families are knowledgeable about the increased risk of ASD in subsequent children and genetic links in families, and are vigilant regarding possible signs in younger children and communicate concerns to their MH-PCP as early as possible.

Accreditation/residency and training programs ensure that trainees are knowledgeable about the early signs of ASD and are trained to conduct screening and surveillance in siblings of children with ASD, using standardized ASD screening tools as they become available.

Funders/insurers and other healthcare payers provide appropriate reimbursement for screening and surveillance activities for younger siblings of children already identified with ASD.

Community providers are aware of the risks for siblings of children identified with ASD and assist in identification of access to insurance and other funding options for these families.

Physicians are aware of research programs for siblings of children with ASD and work with families to identify those who might be interested in participation in these programs.

## Developmental Screening, Surveillance and Referral

### Guidelines for Medical Home Primary Care Practice

4. When screening and/or surveillance techniques indicate developmental delays in any area, loss of social and/or language skills or any other developmental/behavioral disorder, the MH-PCP refers the child to:
  - The local early intervention program (if < 3 years of age) or school (if >3 years of age) for family centered developmental and/or ASD interventions
  - To local sub-specialists (depending on PCP's level of comfort) with expertise in developmental disorders for confirmation of developmental or ASD concerns and a definitive diagnosis
  - To audiology
  - To local family support groups depending on the nature of the concerns (e.g. autism groups, cerebral palsy, etc.)

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Families have information about the options for follow up when developmental concerns are identified. Education is provided to families about educational resources and other advocacy and support groups

Parents and youth know how to access resources outside of their health care organization.

Advocacy/support groups assist families to understand and identify appropriate educational and community resources. Inform families about the availability of parent support and special education advocacy groups.

Government & Finance Agencies

Governmental agencies insure that early intervention programs and schools are adequately funded and staffed with well-trained professionals. Blended funding options are considered.

Governmental agencies provide funding for additional training slots to increase the number of sub-specialists qualified to make the diagnosis of ASD.

Funders/insurers and other healthcare payers recognize the importance of an interdisciplinary approach to diagnosis and provide adequate reimbursement .

Education & Community Agencies

Early intervention and education support the MH-PCP by promoting access to services for eligible children through the development and implementation of an appropriate IFSP (< 3 years of age) or IEP (> 3 years of age) and maintaining communication with the MH-PCP.

Community agencies are aware of and recognize family support groups/educational advocacy organizations and work with MH-PCPs to identify and facilitate access to parent support groups/advocacy agencies.

Other Health Care Practices

Sub-specialty clinics especially ASD interdisciplinary clinics, should support MH-PCP by maintaining sufficient new patient appointments to minimize waiting time to no longer than one month. Support from other systems is imperative so that waiting for evaluations is not a "bottleneck" to access of autism-specific services. Reports back to the PCP are completed in a timely fashion.



## Developmental Screening, Surveillance and Referral

### Guidelines for Medical Home Primary Care Practice

5. The MH-PCP conducts a complete history and comprehensive medical evaluation including birth history, a thorough review of all body systems, physical examination for dysmorphology, and neurologic evaluation to identify indicators for a lab investigation for the etiology of the ASD:
  - If co-existing global developmental delays (or mental retardation in the older child) are present, then the MH-PCP should order a high resolution karyotype and a DNA for FXS Syndrome
  - Otherwise the lab work up should be individualized based on history and physical exam (i.e.: seizures, regression, neurocutaneous lesions, Rett symptoms, pica, + Fm Hx)

### Recommendations for Systems Development and Coordination

#### Professional & Training Organizations

Accreditation/residency and training programs recognize the importance of training MH-PCP professionals in the evaluation and treatment management of children and youth.

#### Government & Finance Agencies

Funders/insurers and other healthcare payers provide reimbursement for comprehensive office visits when necessary to determine a possible etiology of the ASD and should provide reimbursement for appropriate lab investigations as recommended in the AAP Clinical Report.

#### Other Health Care Practices

Sub-specialty clinics support the MH-PCP's request for assistance in evaluating the child/youth and identifying subtle indicators that may require additional lab investigations.

Ongoing Medical Care

Guidelines for Medical Home Primary Care Practice

- 1. The MH-PCP provides the full range of preventive visits and treatment for associated intensive medical disorders or co-existing conditions (e.g., seizures, learning disabilities, fragile X) and ensures that children and youth with ASD continue to have ongoing well child care and surveillance and prompt treatment for acute and chronic medical conditions.

Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Families and youth are educated about the range of ASD medical disorders, co-existing conditions and the benefits, risks, and side-effects of medications that are associated with ASD treatment.  
Families are empowered as active participants in making choices about treatment options and ultimately determining care for their child or youth with ASD.

Professional & Training Organizations

Accreditation/residency and training programs provide training for primary providers in recognizing and managing ASD associated medical disorders or co-morbidities (e.g., seizures) as a part of both routine care and ongoing chronic care.

Government & Finance Agencies

Funders/insurers and other healthcare payors provide appropriate reimbursement coding and adopt alternative funding models that cover the cost of frequent, complex, and continual services for ASD including ongoing monitoring.

Education & Community Agencies

Community agencies and educators have knowledge about medical issues related to ASD including associated medical disorders and co-morbidities.

Organizational Structure of the Medical Home

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## Ongoing Medical Care

### Guidelines for Medical Home Primary Care Practice

2. The MH-PCP monitors developmental progress and medical/mental health issues that may underlie developmental failure/regression or may have an impact on behavioral symptoms, for example, but not limited to:
  - Sensory impairment (i.e., vision or sight) which may be related to other conditions such as retinopathy of pre-maturity
  - Sensory hypo/hyper responsiveness
  - Gastrointestinal symptoms (gastroesophageal reflux, constipation, feeding over-selectivity—may be interrelated)
  - Onset of seizures or other diagnoses, storage disorder, Rett's Disorder)
  - Disordered sleep
  - Anxiety and depression

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Families and youth are educated about the relationship between developmental delays and underlying medical problems and are made aware of the choices in treatments available to address the underlying medical issues. Access to augmented communication technology is available to families to facilitate communication with the non-verbal child about symptoms (e.g., pain, discomfort, physical or medical needs.)

Professional & Training Organizations

Professional organizations provide educational materials and training opportunities to support MH-PCPs in determining appropriate medical investigation for co-morbidities and/or etiology and in recognizing the potential impact of underlying medical issues and pharmacology on developmental progress.

*“...In working with the National Medical Home Autism Initiative on implementing developmental screening, I was impressed that the use of the screening tool opened the door to conversations about what parents were concerned about, providing me with the teachable moment. The developmental screening tool provides me with an understanding of parent concerns, and when combined with my observations of the parent and child in the exam room, provides a more complete picture of the child.”*

Mark Rosenberg, M.D., Pediatrician  
Chicago Illinois

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## Ongoing Medical Care

### Guidelines for Medical Home Primary Care Practice

3. The MH-PCP, with parental consent, informs the early intervention/educational system of co-occurring (co-morbid) conditions in their patients to facilitate shared responsibilities to monitor and address medical and developmental issues.

### Recommendations for Systems Development and Coordination

#### Education & Community Agencies

Early intervention and educational system multidisciplinary developmental teams ( e.g., psychology, speech/language therapists, school nurses and social workers) and MH-PCP share information and observations and work in collaboration to address developmental and/or medical co-morbidities (e.g., seizures, anxiety, ADHD symptoms, medication side-affects), concerns about regression, and issues of family functioning.

*“... We strongly feel that pediatric practices that care for children with autism and other complex medical needs will do a better job with a team approach that includes a master’s level person to assist with care coordination and social work.”*

Francis Rushton, MD, Pediatrician  
Beaufort, South Carolina

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## Ongoing Medical Care

### Guidelines for Medical Home Primary Care Practice

4. The MH-PCP collaborates and communicates with families to assist them with ongoing access to community systems and resources. The MH-PCP informs these systems, within the context of HIPPA guidelines, of medical factors which must be taken into account when delivering services.

### Recommendations for Systems Development and Coordination

Government & Finance Agencies

Funders/insurers and other healthcare payors provide appropriate coding for reimbursement or develop alternative comprehensive funding approaches that provide reimbursement for case management services. Reimbursement is adjusted to reflect level of need and severity of ASD.

Education & Community Agencies

Educational systems, community agencies, and therapists collaborate with medical providers (MH-PCP and other medical agencies) to learn about medical factors that may have an impact on the progress of individual children and youth.

Community agencies establish ongoing consistent communication with MH-PCPs and families to share information and assist in accessing services such as family support, parent organizations, respite, after school programs, therapists, and financial support, etc.

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## Behavioral and Mental Health Services

### Guidelines for Medical Home Primary Care Practice

1. The MH-PCP understands, monitors, and helps to manage the range of behavioral and emotional difficulties common to children and youth with ASD including co-occurring behavioral difficulties—hyperactivity, inattention, aggression, agitation, irritability, obsessiveness, self-injury, disruption, sleep disruption and others. The MH-PCP provides ongoing verbal and written feedback to the early intervention/educational system regarding these co-occurring behavioral difficulties.

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Families are encouraged by the MH-PCP to discuss behavioral and emotional issues and are given the skills, resources and tools to communicate these challenges to medical providers, community support programs, and the educational system.

Families are encouraged to share the impact of ASD on their own physical and emotional well-being as well as that of siblings without ASD. Families are supported in seeking therapy, respite, and other intervention strategies to address their unique service needs.

Professional & Training Organizations

Accreditation/residency and training programs recognize the importance of training providers, families, and educational professionals in understanding functional behavior assessment (FBA), managing behavioral and emotional difficulties (general and ASD-specific), and in making appropriate referrals to seek behavioral intervention strategies.

Professional organizations recognize the importance of training PCPs, families, and educational professionals in managing behavioral and emotional difficulties (general and ASD-specific).

Education & Community Agencies

Community agencies, early intervention and education systems provide ongoing verbal and written feedback to mental health personnel and PCP regarding new symptoms and other issues related to behavioral and mental health.

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## Behavioral and Mental Health Services

### **Guidelines for Medical Home Primary Care Practice**

2. The MH-PCP evaluates possible underlying medical causes of behavioral difficulties, as maladaptive behaviors should not automatically be assumed to be part of ASD. Examples include: head banging, GER with irritability, back arching, sleep disruption, neurological abnormalities, dental conditions. The MH-PCP also monitors medical and behavioral side effects of medications, for example but not limited to: weight gain, hyperlipidemia, and decreases glucose tolerance due to atypical antipsychotic.

### **Recommendations for Systems Development and Coordination**

*Professional  
& Training  
Organizations*

Accreditation/residency and training programs recognize the importance of training providers, families, and educational professionals in understanding underlying medical causes of behavioral difficulties in children and youth with ASD and the effects of medications prescribed for these conditions.

*Education &  
Community  
Agencies*

Community organizations determine processes for translation of medical terminology into language more clearly understood by families and youth.

Behavioral and Mental Health Services

Guidelines for Medical Home Primary Care Practice

- 3. After medical investigation and treatment of any identified medical causes of challenging behaviors, the MH-PCP collaborates with behavioral and/or mental health professionals and specialists to develop a treatment plan and, when appropriate, participates in psycho-pharmacotherapeutic management. The MH-PCP may need to refer to a behavioral and/or mental health specialist for additional support if the child’s treatment plan is complex.

Recommendations for Systems Development and Coordination

Government & Finance Agencies

Government (federal, state, and local) authorizes and implements a crisis allocation program to increase the number of trained mental health professionals including psychologists, psychiatrists, behavioral and mental health therapists, and pediatricians trained for diagnostic evaluation and treatment of ASD.

Government authorizes a crisis financing provision under Medicaid waivers that uses severity measures for high risk ASD children for developmental regression that authorizes immediate access to expanded coverage for ASD services under Medicaid.

Funders/insurers and other healthcare payors provide appropriate levels of funding for behavioral treatments by mental health agencies, practitioners and/or behavior (health) therapists including appropriate funding for resources to provide complex evaluations such as Functional Behavioral Analysis.

Education & Community Agencies

Community agencies (such as foster care, juvenile justice, emergency responders, crisis centers, homeless shelters) that interact with youth with ASD --receive education that will help them understand ASD and the special needs of impacted children and youth.

Other Health Care Practices

Mental Health specialists support the MH-PCP’s request for assistance in evaluating the child/youth for mental health issues and with development and management of the treatment plan.



## Behavioral and Mental Health Services

### Guidelines for Medical Home Primary Care Practice

4. The MH-PCP works closely with families to educate them about potential mental/behavioral treatments and interventions.

### Recommendations for Systems Development and Coordination

#### Education & Community Agencies

State and/or local mental health agencies maintain a community resource directory of behavioral and mental health resources that identifies services for specific age groups and specific aspects of ASD. This supports the MH-PCP in educating families about resources and available medical intervention and treatment.

*“... Even though agencies, programs and services are organized and funded differently in each state, common themes have emerged from the cross system discussions we’ve held within the National Medical Home Autism Initiative... Everyone is struggling with funding avenues, identifying and applying evidence based practices, enhancing capacity for early identification of ASD, and fostering important family, provider and community partnerships. Despite these challenges, state partners have demonstrated tremendous commitments toward systems change.”*

Linda Tuchman-Ginsberg, PhD  
Waisman Center, UW-Madison

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Complementary and Alternative Therapies

Guidelines for Medical Home Primary Care Practice

- 1. The MH-PCP recognizes the range of complementary and alternative medicine (CAM) interventions that parents commonly use or consider using for their children with ASD, evaluates their scientific merits, and understands potential risks and any medical care or monitoring that may be necessary to address potential adverse effects.

Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Families share information about the alternative therapies they have used or are exploring in order to assist the MH-PCP in understanding the range of possible interventions.

Professional & Training Organizations

Professional organizations such as the AAP, AAFP and NAPNP in cooperation with parent advocacy groups provide educational resources and training to MH-PCP's about the range of CAM alternatives and related references, studies, guidelines and reputable web sites in order to promote understanding of the benefits and risks associated with each alternative intervention, and to help MH-PCP assist parents in responsible decision-making about CAM.



## Complementary and Alternative Therapies

### **Guidelines for Medical Home Primary Care Practice**

2. The MH-PCP provides parents, other medical and behavioral providers and educational personnel with specific information on the positive and negative (potential side-effects) of CAM issues related to the CAM's they are considering. The PCP works with families to evaluate information and help them distinguish between empirically validated treatment options from those that are unproven and potentially ineffective and/or harmful.

### **Recommendations for Systems Development and Coordination**

*Individual  
with ASD and  
their Family*

Families jointly participate, with the MH-PCP, in developing and offering training programs that promote discussions about CAM – keeping an open mind, sharing information, seeking additional information from web and other resources (e.g., hot line), discovering evidence and stories and discussing implications for an individual child and family.

*Education &  
Community  
Agencies*

Community agencies establish ongoing forums (share calendar) for bringing medical and behavioral providers, parents, caregivers, and educational personnel together through verbal, written or lecture formats to share information and open communications about CAM.

**Guidelines for Medical Home Primary Care Practice**

3. The MH-PCP supports families by maintaining open and honest communication with the family about their reasons for pursuing CAM treatments including the costs, benefits and possible harm of CAM treatments. The MH-PCP respects the motivation of parents to seek any treatment that might help their child and understands that families will make the final decision on treatment options.

**Recommendations for Systems Development and Coordination**

Individual with ASD and their Family

Advocacy/support groups provide mechanisms for educating medical caregivers (e.g., CME) other community groups and families about types of CAM, the reasons families pursue treatments, and potential side-effects. Continue to develop resources for up-to-date information regarding CAM treatments, including the status of evidence based support (or lack of support) for these interventions. Consideration is given to the needs of individual child/youth and their specific ASD diagnosis.

Government & Finance Agencies

Government /federal, state, and local agencies should develop common and inclusive definitions for ASD and ASD services across federal and state agencies. The newly reconstituted IACC under the Combating Autism Act should be supported and given responsibility to develop the definitions.

Education & Community Agencies

Community agencies and educational systems collaborate with medical providers to develop mechanisms to educate the public – including (but not limited to) written material, reference articles, (reputable) websites.



## Education and Community Services

### **Guidelines for Medical Home Primary Care Practice**

1. The MH-PCP has a comprehensive approach to ongoing prevention, routine medical management, and care coordination for children and youth with ASD while working in collaboration with specialty care and other providers.

### **Recommendations for Systems Development and Coordination**

*Individual  
with ASD and  
their Family*

Parents and youth are informed of the role and functions of care coordinators (within the MH-PCP) and others who facilitate integration of services across all systems to support families. Families understand their right to give or withhold consent in the sharing of confidential information.

*Professional  
& Training  
Organizations*

Accreditation/residency and training programs for specialty care physicians emphasize the importance of integration and coordination with MH-PCP.

*Government  
& Finance  
Agencies*

Government (federal, state, and local agencies) develop new models of primary care/specialty care communication and co-management. Funders/insurers and other healthcare payers expand service codes in order to adequately reimburse for the time needed to provide appropriate care coordination and services.

*Other  
Health Care  
Practices*

Health Care specialists are actively involved in supporting the MH-PCP. This includes implementation of a mutually understood co-management care plan that promotes efficient use of resources, sharing of information about treatment, interventions, and progress with the medical home practice as part of the comprehensive system.

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## Education and Community Services

### Guidelines for Medical Home Primary Care Practice

- The MH-PCP develops a comprehensive health care plan in partnership with the family and other professionals, including periodic reassessment in conjunction and coordination with other health providers (e.g. OT, PT, audiologists) and the early intervention/educational system providing services to the child/youth. Written documentation of needed community services is included.

### Recommendations for Systems Development and Coordination

#### Individual with ASD and their Family

Parents encourage collaboration among MH-PCP, early intervention and the educational system. They provide informed consent for sharing information among professional partners, including results of developmental evaluations to confirm the presence of developmental delays, program eligibility determinations and the IFSP/IEP.

#### Government & Finance Agencies

Government (federal, state, and local agencies) facilitate mechanisms that allow for appropriate sharing of information among practices, families and other systems.

Government (federal, state, and local agencies) develop and disseminate flexible strategies and best practices to bridge the gap across health and education systems, recognizing that different definitions and requirements can be barriers to access of services.

#### Education & Community Agencies

Early intervention and educational systems and MH-PCP know one another and collaborate to maximize resources for screening, diagnosis, and treatment of children with ASD:

- With consent from the family, early intervention/education programs will share information with the MH-PCP on eligibility determination and the outcome of developmental evaluations to confirm the presence of developmental delays, IFSP, and IEP.
- The MH-PCP participates as appropriate in education system meetings about children and youth with ASD.

The educational system works collaboratively with the MH-PCP to develop an individual health care plan for the child/youth, that is consistent with and coordinated with, the comprehensive health care plan developed by the MH-PCP. The school nurse establishes ongoing communication with the MH-PCP when appropriate.

The educational system has a process for including the primary care provider and/or nurse as members of the school planning team for the child's health care plan. Sharing of evaluations is conducted across systems (e.g. medical, educational).



## Education and Community Services

### **Guidelines for Medical Home Primary Care Practice**

3. The MH-PCP participates with other community services to achieve an integrated community system of services that includes health, education, and social services. The MH-PCP coordinates and links with the multiple systems and agencies that support ASD services and advocates for collaboration among those systems.

### **Recommendations for Systems Development and Coordination**

#### *Government & Finance Agencies*

Government (federal, state and local agencies) develop mechanisms to facilitate communication and coordination between the MH-PCP and other systems. These systems include but are not limited to: mental health; early Intervention; education / special education; behavioral health—public and private; first responders/law enforcement/juvenile justice; foster care/day care/respice; Rehabilitation; community-based family support and advocacy programs; insurance—public/private; and medical service providers including primary care and sub-special care providers

Funders/insurers and other healthcare payors provide financial support and /or reimbursement for coordination of care for children with ASD.

Government (federal, state, and local agencies) provide financial support for the development of a system for integrating services for children with ASD.

#### *Education & Community Agencies*

Community organizations, early intervention and educational systems proactively collaborate and coordinate services with the MH-PCP.

## Transition to Adult Services

### Guidelines for Medical Home Primary Care Practice

1. The MH-PCP works with the youth, family and other community and educational programs to develop an individualized transition plan prior to the age of 14yrs. This plan addresses the stated goals of the youth/family and include:
  - Medical
  - Mental Health
  - Behavioral Health
  - Educational
  - Social/recreation
  - Communication assistive
  - Health assistive
  - Post secondary education
  - Self advocacy/self determination
  - Employment
  - Community living (incl. access to long term supports like DD waivers)
  - Financial planning
  - Special needs Wills
  - Communication

### Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Parents and youth are encouraged early on to develop responsibility and independence (i.e. chores, appropriate behaviors, and activities of daily living) to ensure that children with ASD have every opportunity to function independently in the community as an adult.

Parents and PCP identify and plan early for all areas of transition appropriate for the child/youth with ASD. Planning begins in advance of age 14.

Government & Finance Agencies

Government agencies (federal, state, and local) provide support for programs that assist youth with ASD with identification and location of employment opportunities (e.g., State vocational rehabilitation programs.)

- Agency staff have the necessary, specific knowledge and skills in working with individuals across the spectrum of ASD.
- Resources are identified to assist with ongoing health and related needs such as transportation, job skills training and social skills development.

Education & Community Agencies

The educational system prepares youth for adult roles with increasing independence and works in coordination with the MH-PCP and the youth and family to ensure that transition planning and the IEP or 504 plans include health support information essential for appropriate transition to adulthood. These elements are the substantial focus of mandated educational services for early youth through age 21.

Local employers are encouraged to participate in programs that provide volunteer mentor programs and offer employment opportunities for youth with ASD.



Transition to Adult Services

**Guidelines for Medical Home Primary Care Practice**

2. The MH-PCP assists the youth and his/her family in the identification of adult health care resources and providers.

Recommendations for Systems Development and Coordination

Individual with ASD and their Family	<p>Youth with ASD understand their role in maintaining their general health and are empowered to take responsibility for their health and physical needs.</p> <p>Family advocacy organizations and health providers provide youth and their families with the level of support needed to negotiate the systems of care, and transition successfully to the adult healthcare system.</p>
Professional & Training Organizations	<p>Accreditation/residency and training programs recognize the importance of education, training and support resources to enhance the ability of MH-PCP to care for children, youth and adults with ASD.</p>
Other Health Care Practices	<p>Adult healthcare systems develop a process that allows for identification of adult care providers and specialists at the early stages of transition planning. These adult care providers and specialist are involved in the care planning process and relationships are fostered prior to care transition.</p>

Transition to Adult Services

Guidelines for Medical Home Primary Care Practice

- 3. The MH-PCP involves youth with ASD as full participants in their own care in preparation for transition to adulthood. This includes facilitating understanding and awareness of diagnosis and increasing opportunities for youth/adult to become informed decision makers in their own care.

Recommendations for Systems Development and Coordination

Education & Community Agencies

Community agencies and disability service providers develop and implement educational programs for youth with ASD and other disabilities to enhance interaction with medical providers. Systems provide opportunities for youth with ASD to participate in community-based activities that promote self-determination, advocacy and independence. Peer education strategies may be particularly effective.



## Transition to Adult Services

### **Guidelines for Medical Home Primary Care Practice**

4. The MH-PCP facilitates access of youth to life skills services regarding friendship, sexuality, safety, community living, and health and money management.

### **Recommendations for Systems Development and Coordination**

*Individual  
with ASD and  
their Family*

Youth with ASD and/or their family identify and are empowered to use natural supports and resources such as libraries, faith organizations, and recreational activities available in the community. (Refer to Resource #10.)

*Government  
& Finance  
Agencies*

Government agencies (federal, state, and local) provide guardianship options for individuals with disabilities, including youth with ASD. Anticipation of long-term needs is a necessary consideration and an essential element of transition and estate planning.

*Education &  
Community  
Agencies*

Community agencies and disability service providers give support through community-based service coordination to assist individual transition from home to a community living arrangements. Resources provided are culturally and linguistically competent.

Living arrangements are available within communities to promote independence for youth and adults.

Local agencies provide programs that offer opportunities for connection with peers who have ASD and other disabilities in the context of full inclusion within the broader community.

Transition to Adult Services

Guidelines for Medical Home Primary Care Practice

- 5. The MH-PCP works in partnership with the youth and his/her family to ensure that transitional planning includes consideration of insurance and fianacial planning for adulthood.

Recommendations for Systems Development and Coordination

Individual with ASD and their Family

Youth with ASD and their families understand the importance of financial planning and are empowered to explore guardianship and other planning options at an early stage (when appropriate).

Government & Finance Agencies

Funders/insurers and other healthcare payors recognize ASD as a neurological disorder and provide adequate benefits and reimbursement for necessary treatments and interventions, including those on mental health services.

Medicaid, SSI, and other providers of supplemental health care coverage ensure that such programs are inclusive of individuals with ASD. Plans support appropriate reimbursement for transition services including care planning into adulthood for all persons with disabilities including children and youth with ASD.

## Resource Examples

### (1) CENTER FOR MEDICAL HOME IMPROVEMENT (CMHI)

Greenfield New Hampshire



CMHI has worked with teams of clinicians, families and care coordinators to implement care process improvements in the medical home.

The efforts of 10 primary care practices to improve their “medical homeness” results in significant clinical, functional, satisfaction and cost outcomes according to the families whose children w/ special health care needs they care for. CMHI provided ongoing structure with CME, practice visits, facilitation of improvement team efforts, links with community and other resources, and technical assistance and support for medical home improvement.

<http://www.medicalhomeimprovement.org/>

### (2) PARENTS AS TEACHERS

Minneapolis, Minnesota



Partnership with:

PACER Center – Champions for Children with Disabilities, Minneapolis, MN

The University of Minnesota and the Minnesota Department of Health

Parents as Teachers provide coordination, training, and support to pediatric residents at the University of Minnesota Medical School.

Training takes place during the resident’s rotation in Behavior and Developmental Pediatrics. The residents receive orientation and training from the Program Coordinator at the PACER Center, in the basic principles of family centered care, coordinated, comprehensive, and community-based care for all children with special health care needs as well as financial issues families, basic information about Medicaid, insurance and other financing options for services for children with special needs, including autism. After initial training, the residents visit families in their home setting and may accompany the family to a therapy visit, or event such as an IEP meeting to gain an understanding of family circumstances, needs, and challenges. The visit is followed by a processing session with the Project Coordinator and representative from the state department of health.

[www.pacer.org](http://www.pacer.org)

### (3) CONFERENCE MODEL FOR SYSTEMS DEVELOPMENT



GETTING THE HOUSE IN ORDER:  
Creating Medical Home Solutions for  
Individuals with Autism  
Title V Region 5  
December 6 and 7, 2007

The focus of this regional conference was to create state specific plans to advance the care of individuals with autism spectrum disorders and their families. The state planning team members nominated 12 people from their state as potential participants within the following 6 categories: medical providers, educational providers, families/caregivers, clinical consultants, public policy providers and government / funding providers.

Key strategies used to stimulate state wide system level discussions and plans included introduction of the ASD Service System Guidelines for the Medical Home Primary Care Practice as a tool to stimulate discussion and promote of the identification promising practices within each state. The second strategy was to engage each State in a facilitated Logic Model planning session. The outcome of this strategy will be the development of a state plan intended to enhance or increase system coordination for services and programs serving individuals with ASD and their families. These two strategies will offer opportunities to identify existing capabilities, in each state, as well as identify service system and coordination gaps, thereby providing the foundation for building on strengths identified to improve the availability and quality of ASD services within each state.

This conference has been used as a model for Learn the Signs. Act Early Summits in Title V regions 6 and 7 planned for spring 2008. These summits are sponsored by CDC and AUCD.

For more information on using this conference format as a model in your local community, state or region, please contact Georgia Winson at The Autism Program of Illinois [gwinson@thehopeinstitute.us](mailto:gwinson@thehopeinstitute.us) or Linda Tuchman-Ginsberg, at [tuchman@waisman.wisc.edu](mailto:tuchman@waisman.wisc.edu)

## Resource Examples

### (4) UNDERSTANDING AUTISM SPECTRUM DISORDERS

American Academy of Pediatrics (AAP)



This 44 page booklet, written for parents, provides critical information about autism spectrum disorders and answers all the most common questions asked by parents about ASD. ASD has lifelong conditions and this booklet will help identify early signs, symptoms, and the behavioral differences so that an intervention program can be started as soon as possible. Provides some suggestion on living with autism.

<http://www.aap.org/healthtopics/autism.cfm>

### (5) PUBLIC AWARENESS PROGRAM on Early Childhood Development



NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES  
**Learn the Signs. Act Early.**

Public Awareness Campaign to promote the importance recognition of early development and milestones for children with or without special health care needs.

Free materials available from the website.

<http://www.cdc.gov/ncbddd/autism/actearly/>

### (6) DEVELOPMENTAL SCREENING POLICY STATEMENT

American Academy of Pediatrics (AAP)



Early identification of developmental disorders is critical to the well-being of children and their families. It is an integral function of the primary care medical home and an appropriate responsibility of all pediatric health care professionals. This statement provides an algorithm as a strategy to support health care professionals in developing a pattern and practice for addressing developmental concerns in children from birth through 3 years of age. The authors recommend that developmental surveillance be incorporated at every well-child preventive care visit. Any concerns raised during surveillance should be promptly addressed with standardized developmental screening tests. In addition, screening tests should be administered regularly at the 9, 18, and 30 month visits

<http://www.medicalhomeinfo.org/screening/index.html>

### (7) ENHANCING DEVELOPMENTALLY ORIENTED PRIMARY CARE (EDOPC)

Illinois



Partnership with:

Illinois Chapter of the American Academy of Pediatrics (ICAAP),  
Illinois Academy of Family Physicians  
Ounce of Prevention Fund  
Advocate Health Care

EDOPC offers office-based presentations for primary care providers (professional development and training) and coordination of community services by working with practices to connect with their local community health providers, including Early Intervention.

Five presentation topics covered under this project, include Early Autism Detection and Referral, Developmental Screening, Social/Emotional Screening, Perinatal Maternal Depression Screening and Domestic Violence: Effects on Children.

<http://www.illinoisAAP.org/medicalhome.htm>

<http://www.illinoisAAP.org/DevelopmentalScreening.htm>



## Resource Examples

### (8) CLINICAL REPORTS



The National Center of Medical Home Initiatives for Children with Special Needs

Two New Autism Clinical Reports from the American Academy of Pediatrics:

- Identification and Evaluation of Children with Autism Spectrum Disorders (Clinical Report)
- Management of Children with Autism Spectrum Disorders (Clinical Report)

<http://www.medicalhomeinfo.org/health/autism.html>

### (9) AUTISM: Caring for Children with Autism Spectrum Disorders - A Resource Toolkit for Clinicians

American Academy of Pediatrics (AAP)



AAP has developed this multifaceted clinical resource to assist in the recognition, evaluation, and ongoing management of ASD's throughout your patient's life span. This all-new toolkit brings together a wealth of ready-to-use, practice-focused resources - all on a single economically priced CD-ROM.

The fully searchable CD-ROM puts an extensive library of ASD-specific solutions right at your fingertips.

<http://www.aap.org/healthtopics/autism.cfm>

### (10) PATHWAYS TO INDEPENDENCE NATURAL SUPPORTS PROJECT

Wisconsin



This five year natural supports project was designed with the goal to discover, support and disseminate creative and promising approaches for supporting youth with disabilities to participate more fully and naturally in school, work and community activities.

By offering mini-grant packages comprised of funding, ongoing technical assistance, and practical resources, we intend to increase the capacity of schools and communities to support youth with disabilities in accessing school and community opportunities that lead to the same relationships, work- and volunteer-related experiences, and community opportunities as their peers.

Funded by the Wisconsin Medicaid Infrastructure Grant through the Department of Health and Family Services Office of Independence and Employment and implemented through the Waisman Center, this project is designed to draw out the very best ideas and approaches for enhancing the full participation of youth with disabilities.

<http://www.waisman.wisc.edu/naturalsupports/>

## Acknowledgements

The ASD Service System Guidelines for Medical Home Primary Care Practices were developed by an Autism Service Guidelines Workgroup convened in July, 2005 by the National Medical Home Autism Initiative through a cooperative agreement with the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA). The diverse group included members with special ASD expertise—service providers, educators, professional associations, community program coordinators, and family members of individuals with ASD.

The 2007 Family Forum was convened to review and discuss the guidelines and their implementation. The meeting included a multi-disciplinary mix of professionals from eight states and five MCHB National Resource Centers.

The Guidelines were further reviewed by individuals who attended the ASD Service System Guidelines session at the ASA Annual Conference in July 2007, the AUCD Annual Meeting in November 2007, and the Getting the House in Order conference in December 2007.

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07/2005 - 10/2007

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***Family  
Forum:  
“Family  
Perspectives on  
Autism Service  
Guidelines for  
the Medical  
Home”***

03/2007 - 10/2007

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**2005 - 2008**

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## Endnotes

<sup>1</sup>P.L. 109-416, the Combating Autism Act of 2006, Title III, Section 399CC of the Public Health Service Act, as amended, mandated the reestablishment of the Interagency Autism Coordinating Committee (IACC) to coordinate autism spectrum disorder (ASD) research and other efforts within the Department of Health and Human Services (DHHS). In July 2007, Secretary Michael Leavitt delegated the authority to reestablish the IACC to the National Institutes of Health (NIH). The National Institute of Mental Health (NIMH) at the NIH has been designated the lead for this activity. Although the Committee's mission continues to focus on the efficient and effective exchange of information on autism activities, the new law expanded the responsibilities of the IACC, which was first established by the Children's Health Act of 2000 (P.L. 106-310), Title I, Section 104.

<sup>2</sup>American Academy of Pediatrics (2000) Fellows Survey. Elk Grove Village, Ill. AAP. (A national sample of 794 AAP members who provide primary care to children from birth to age 3 were surveyed. Overall most members agreed that pediatricians should inquire about a child's developmental status (94%) and felt confident in their ability to advise parents (80%). However two-thirds felt that they were not adequately trained to conduct developmental assessments. Other primary barriers reported were lack of time (80%), inadequate reimbursement (55%), and lack of non-physician staff to do developmental assessments (55%))

<sup>3</sup>Filipek PA, Accardo, PJ, Ashwal S, et.al., (August 2000) Practice parameter: Screening and diagnosis of autism, *Neurology*, 55:468-479.

<sup>4</sup>Rodgers S.,(2001) Diagnosis of Autism before Age of 3. In L. Clidden (ed) International review of research in mental retardation: Autism (Vol 23, pp. 267-294) San Diego; Academic Press. p.20.

<sup>5</sup>Sperry L, Whaley K, Shaw, E, Brame, K., (1999) Services for young children with autism spectrum disorder: Voices of parents and providers, *Infants and Young Children*, 11(4); 17-33.

<sup>6</sup>National Research Council (2001) Educating Children with Autism. Committee on Educational Interventions for Children with Autism. Catherine Lord and James P. McGee, eds. Division of Behavioral and Social Sciences and Education. Washington. DC: National Academy Press.

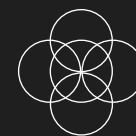
<sup>7</sup>Op.cit., Sperry., p 20.

<sup>8</sup>Seltzer MM, Kraus MW, Orsmond GI, Vestal C., (2000) Families of adolescents and adults with autism: Uncharted territory. In L. Clidden (ed) *International Review of Research in Mental Retardation: Autism* (Vol 23, pp. 267-294) San Diego; Academy Press.

<sup>9</sup>American Academy of Pediatrics, (1999) Committee on Children With Disabilities, Care Coordination: Integrating Health and Related Systems of Care for Children With Special Health Care Needs, *Pediatrics*, 104:978-981.

**“... Every child and family deserves access to a service system well-designed and prepared to meet their unique needs. Our challenge is to function as one service system with collective responsibility for assuring not only comprehensive health care through the medical home, but also partnership with families at all levels, adequate insurance/financing, early and ongoing surveillance/screening, easy access to appropriate community services, and transition to adult health care, work, and independence.”**

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