

# AUTISM/ASD GUIDELINES for MEDICAL HOME PRIMARY CARE PRACTICES

Autism (ASD) Guidelines for Primary Care Practice	Actions recommended of Other Systems To Facilitate the Primary Practice Guidelines	References and Resources
<p><b>General Principles for a Medical Home (MH) Primary Care Practice (PCP) for Children with ASD</b></p>		
<p>1. Medical Home Primary Care Practice (MH-PCP) providers should be aware of and implement Medical Home (MH) principles when caring for children, including those with ASD.</p>	<p><i>Professional accreditation organizations and training programs</i> should recognize the importance of training activities by:</p> <ul style="list-style-type: none"> <li>▪ Including Medical Home (MH) training as a required component of residency programs for pediatrics, family medicine and med-peds as well as training programs for mid-level providers e.g. pediatric nurse practitioner and physician assistant</li> <li>▪ Requiring resident and physician extender training programs to facilitate the provision of a MH.</li> <li>▪ Including competency items on board certification and re-certification exams that address MH principles especially as they relate to the care of patients with chronic conditions, such as ASD</li> </ul> <p><i>Funders (government, insurers and other health care payers)</i> should 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.</p> <p><i>Professional organizations</i> such as the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) and National Association of Pediatric Nurse Practitioners (NAPNP), should provide ongoing Continuing Medical Education (CME) training in the principles and implementation of a MH for the care of all children/youth, including those with ASD.</p>	<p>AAP MH Policy Statement (2001?)                      AAP Autism PS and TR (2001)                      AAP ASD Clinical Report (In development for 2007)                      AAP Developmental Screening and Surveillance PS (July 2006)                      RRC Policies and Procedures</p> <p><i>JDBP</i> (April 2006) article reveals ~50% of physicians surveyed reported that they had at least 10 children with ASD in their practice</p> <p>Prater, Zylstra. Autism: A medical primer. <i>Am Fam Prac</i> 66(9) 2002</p>
<p>2. The MH-PCP should be 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.</p>	<p><i>Residency and other training programs</i> should emphasize the important roles of staff at all levels in the practice in serving children with special health care needs such as ASD, and prepare staff for their role in office-based practice.</p> <p><i>Funders (government, insurers, other health care payers)</i> should provide capitated administrative payments and other enhanced reimbursements to compensate the</p>	<p>Liptak: Importance of providing parents with information about their child's condition (<i>Peds</i> 1989)</p> <p>AAP PS on parent-professional collaborations</p>

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	primary practice for the participation of receptionists, administrators, and physician extenders providing additional time/resources needed to provide intensive services.	Family Voices literature and training  MCH and PACER Center Parent-Professional Partnerships
3. MH-PCPs, in collaboration with sub-specialists and community agencies, should provide appropriate disorder-specific information (printed, electronic, etc.) on all aspects of ASD including definition and diagnosis of ASD, etiology, genetic, neuropath correlates, developmental and behavioral characteristics. Training and support should be provided to increase skills of families and caregivers in management of developmental and other aspects of ASD.	<p><i>Residency and other training programs</i> should emphasize the importance of parent education materials and teach residents methods for retrieving appropriate evidenced-based and consensus-based materials for distribution to patients' families.</p> <p><i>Professional organizations</i>, such as the AAP, AAFP and NAPNP should use member experts in various fields to develop evidenced-based training materials for distribution to parents by MH-PCPs.</p> <p><i>Funders (government, insurers and other health care payers)</i> should pay for a portion of the cost of providing information and training to families.</p>	
4. In accordance with the principles of Family Centered Care, MH-PCPs should recognize parents as valued partners and decision-makers in the care of their child and establish 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 should be considered in all decision making.	<p><i>Professional accreditation organizations and training programs</i> should recognize the importance of training activities in parent-professional partnerships and require all residency programs to implement one of the nationally recognized parent-lead curricula's. For pediatricians, this might ideally be done during their mandatory developmental pediatric rotations using existing curricula developed by parent advocates (e.g., Delivery of Chronic Care program (DOCC) now existing in 20 states)</p> <p><i>Government</i> should identify a lead public agency who should provide a system of electronic communication (such as a web page) to facilitate exchange of information among parents and professionals statewide. A service agency should support this participation with families who do not have access to the internet.</p>	New MCHB definition of FCC  DOCC literature explaining goals and activities  DOCC evaluation materials  MCH, PACER Center and Family Voices materials

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<p>5. The MH-PCP should respect and competently serve multiple and diverse cultures of the children and families with ASD. The practice should be linguistically competent, including having culturally appropriate written materials and translators available.</p>	<p><i>Residency and training programs</i> for all office professional and support staff should include training to increase the sensitivity, awareness, and understanding of cultural norms and prepare staff to competently serve a culturally diverse client population.</p> <p><i>Funders (government, insurers and other health care payers)</i> should compensate for primary practices for appropriate on-site translators and other resources to ensure that there is appropriate language proficiency, signs, and written materials in the practice setting. This includes sign language.</p> <p><i>Social service, education, family support, and other community providers</i> should make their written materials and brochures available in the culturally appropriate language for the populations they serve and at the appropriate literacy level.</p>	<p>AAP PS on cultural competency</p>

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<b><i>Developmental Surveillance, Screening, and Diagnosis of ASD</i></b>		
<p>1. Well child care is an important component of the MH-PCP and includes monitoring for developmental and behavioral concerns. To accomplish this, the MH-PCP should:</p> <ul style="list-style-type: none"> <li>▪ Be knowledgeable about normal and abnormal child development</li> <li>▪ Conduct general developmental screening utilizing a validated screening tool and surveillance activities according to the AAP DSS PS <ul style="list-style-type: none"> <li>○ Surveillance, including listening to parent concerns, at all WC visits</li> <li>○ General developmental screening at 9, 18, and 24 or 30 month WC visits</li> </ul> </li> <li>▪ Utilize new screening codes.</li> </ul>	<p><i>Professional accreditation organizations</i> should recognize the importance of training in general developmental screening and surveillance activities by:</p> <ul style="list-style-type: none"> <li>▪ Identifying such training as a required component of training programs</li> <li>▪ Developing a standardized curriculum endorsing evidenced-based tools</li> <li>▪ Including competency items on certification and re-certification exams</li> </ul> <p><i>Residency and training programs</i> should provide training in developmental and behavioral screening and surveillance.</p> <p><i>Professional organizations</i> should provide CME training that will help MH-PCPs to develop innovative approaches to screening and surveillance activities, such as the use of physician extenders and computerized screening tools.</p> <p><i>Early intervention and educational systems</i> should support MH-PCPs by performing developmental evaluations in a timely manner to confirm the presence of developmental delays as is mandated by law.</p> <p><i>Funders (government, insurers and other health care payers)</i> should recognize the importance of and reimburse the MH-PCPs for extra time needed to conduct screening/surveillance activities. They should recognize the importance of and reimburse screening activities when more than one screen is recommended at specified WC visits. Insurers should recognize value/efficiency of using staff and physician extenders for DSS activities and reimburse efforts.</p>	<p>AAP DSS Policy Statement <i>Pediatrics</i>, July 2006</p> <p>Review of literature that supports developmental screening (see AAP DSS statement)</p> <p>AAP Autism PS and TR (2001) Filipek AAN Practice Guidelines AAP ASD Clinical Report (2007)</p> <p>AAP brochure: Is Your One Year Old Communicating With You?</p> <p>DBP web site explaining codes</p>
<p>2. The MH-PCP should also specifically monitor for ASD in all children. To accomplish this, the MH-PCP should:</p> <ul style="list-style-type: none"> <li>▪ Be knowledgeable about the early risk factors and clinical signs of ASD</li> <li>▪ Utilize ASD-sensitive surveillance tools at WC visits at 9 and 12 mos.</li> </ul> <p>Conduct ASD-specific screening on all</p>	<p><i>Professional accreditation organizations and training programs</i> should recognize the importance of training activities in conducting ASD-specific screening and surveillance activities by:</p> <ul style="list-style-type: none"> <li>▪ Identifying such training as a required component of training programs</li> <li>▪ Developing a standardized curriculum endorsing evidenced-based tools</li> <li>▪ Including competency items on certification and re-certification exams</li> </ul> <p><i>Funders (government, insurers and other health care payers)</i> should recognize the importance of and reimburse the MH-PCP for the extra time needed to conduct</p>	<p>ALARM First Signs ASD awareness program CDC Awareness program AAP Clinical Report (2007) AAP Tool Kit (2007)</p> <p>AAP brochure: Is Your One Year Old Communicating With You?</p>

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<p>children at the 18 and 24 month WC visits and at any visit when a parent raises a concern about ASD.</p>	<p>screening and surveillance to identify children with ASD and provide appropriate reimbursement for the cost of screening at 18 and 24 months.</p> <p><i>Community agencies (such as: WIC, Head Start) should support MH-PCPs by providing opportunities for coordinated activities whereby ASD-specific screenings can take place. These should also serve to increase awareness about early signs of ASD.</i></p>	<p>AAP booklet for parents: <i>Understanding ASD</i></p>
<p>3. The MH-PCP should implement 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.</p>	<p><i>Residency and training programs should 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.</i></p> <p><i>Funders (government, insurers and other health care payers) should provide appropriate reimbursement for screening and surveillance activities in very young siblings of children with ASD.</i></p> <p><i>Early intervention programs should develop and implement innovative and evidenced based interventions for the new young cohorts of infants and toddlers with early signs of ASD.</i></p>	<p>AAP Clinical Report(2007) AAP Tool Kit (2007) AAP PS and Tech Report (2001) Baby Sibs research data</p> <p>AAP brochure: Is Your One Year Old Communicating With You?</p> <p>NRC evidenced-based intervention data</p>
<p>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 should refer the child to:</p> <ul style="list-style-type: none"> <li>▪ The local early intervention program (if &lt; 3 years of age) or school (if &gt;3 years of age) for family centered developmental and/or ASD interventions.</li> <li>▪ To local sub-specialists (depending on PCP's level of comfort) with expertise in developmental disorders for confirmation of developmental or ASD concerns and definitive diagnosis.</li> </ul>	<p><i>Government and federal agencies need to insure that early intervention programs and schools are adequately funded and staffed with well-trained professionals.</i></p> <p><i>Early intervention and educational systems should support the MH-PCP by promoting access to services to eligible children through the development and implementation of an appropriate IFSP (&lt; 3 years of age) or IEP (&gt; 3 years of age) and maintaining communication with the PCP.</i></p> <p><i>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.</i></p> <p><i>Government and public agencies should provide funding for additional training slots to increase the number of sub-specialists qualified to make the diagnosis of ASD</i></p> <p><i>Insurers and other payers of health care must recognize the importance of an interdisciplinary approach to diagnosis and provide adequate re-imbursement to all</i></p>	<p>IDEA</p> <p>Indiana Model</p> <p>Model curriculums in NRC (2001)</p> <p>AAP PS and TR</p> <p>AAP ASD Clinical Report (2007)</p>

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<ul style="list-style-type: none"> <li>▪ To audiology</li> <li>▪ To local family support groups, including ASD specific groups.</li> </ul>	<p>team members.</p> <p><i>Community agencies</i> should be aware of family support groups and work with MH-PCPs to identify and facilitate access to parent support groups.</p>	
<p>5. The MH-PCP should conduct 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:</p> <ul style="list-style-type: none"> <li>▪ If co-existing global developmental delays (or mental retardation in the older child) are present then the PCP should order a high resolution karyotype and a DNA for FXS Syndrome i</li> <li>▪ 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)</li> </ul>	<p><i>Funders (government, insurers and other health care payers)</i> should 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.</p> <p><i>Professional accreditation organizations and mental health professional organizations</i> should recognize the importance of training MH-PCP professionals in the evaluation of children and managing ASD treatment.</p> <p><i>Sub-specialty clinics</i> should support the MH-PCP's request for assistance in evaluating the child and identifying subtle indicators for additional lab investigations.</p>	<p>AAP COCWD Clinical Report 2007</p>

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<b><i>Ongoing Medical Care After Diagnosis</i></b>		
<p>1. The MH-PCP should provide the full range of preventive visits and treatment of associated medical disorders or co-existing conditions (e.g., seizures) and assure that children with ASD continues to have ongoing well child care, and chronic care treatment and surveillance.</p>	<p><i>Professional accreditation organizations</i> should provide training for primary providers in recognizing and managing ASD associated medical disorders or co-morbidities (e.g., seizures) and assure that children with ASD as part of routine care.</p> <p><i>Community agencies and providers</i> should acquire knowledge about medical issues related to ASD, associated features/ co-morbidities, what information must be provided to medical providers to assist in appropriate management.</p> <p><i>Funders (government, insurers and other health care payers)</i> should provide appropriate coding to cover reimbursement for frequent and complex ongoing care services including monitoring for new signs and symptoms.</p>	
<p>2. The MH-PCP should monitor developmental progress, particularly regarding medical issues which may have an impact on progress, for example, but not limited to:</p> <ul style="list-style-type: none"> <li>▪ Sensory impairment (vision or sight) which may be related to other conditions (retinopathy of prematurity ROP) or medical disorders such as otitis media.</li> <li>▪ Gastrointestinal symptoms (gastroesophageal reflux, constipation, feeding selectivity— may be interrelated).</li> <li>▪ Regression in development may be marker for medical issues (onset of seizures or other diagnoses, storage disorder, Rett’s Disorder).</li> <li>▪ Anxiety and depression.</li> </ul>	<p><i>Educational System multidisciplinary evaluation</i> teams of developmental practitioners (e.g., psychology, speech/language therapists, others) should provide feedback to MH-PCPs regarding developmental and/or medical co-morbidities (e.g., seizures, anxiety, ADHD symptoms, others), concerns about regression, and issues of family functioning.</p> <p><i>Professional Organizations</i> should provide educational materials and training opportunities to support MH-PCPs in determining appropriate medical investigation for co-morbidities and/or etiology.</p>	<p>Medical investigation references – see ref list.</p>

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3. The MH-PCP should inform the educational system of co-morbid conditions in their patients to facilitate shared responsibilities in monitoring and addressing developmental issues?	<i>Educational systems, agencies and therapists</i> should develop collaborative relationships and share information with the MH-PCPs through the families.	
4. MH-PCPs should collaborate and communicate with families to assist them with ongoing access to community systems and resources and to inform them of medical factors which must be taken into account	<p><i>Educational systems, agencies, and therapists</i> caring for the child should collaborate with medical providers (MH-PCP and other medical agencies) to learn about medical factors that may have an impact on progress</p> <p><i>Community agencies and providers</i> should establish ongoing consistent communication with MH-PCPs and families to share information and assist in accessing resources.</p> <p><i>Funders (government, insurers, other health care payers)</i> should provide appropriate coding to cover reimbursement for parent education about care planning and assistance in helping parents access community services.</p>	<p>ATN Ladders</p> <p>Filipek, 99,00 AAP TR, 01</p> <p>AAP CR, in development 07</p> <p>Contrast Shevelle AAN/CNS with use of GDD</p>
<b>Behavioral and Mental Health Care</b>		
1. The MH-PCP should understand, monitor, and help manage the range of behavioral and emotional difficulties common to children with ASD including co-morbid behavioral difficulties—hyperactivity, inattention, aggression, agitation, irritability, obsessiveness, self-injury, disruption, sleep disruption and others. The MH-PCP should provide ongoing verbal and written feedback to educational system regarding these co-morbid behavioral difficulties.	<p><i>Professional accreditation organizations and mental health professional organizations</i> should recognize the importance of training providers, families, and educational professionals in managing behavioral and emotional difficulties (general and ASD-specific).</p> <p><i>The educational system and community providers</i> should provide ongoing verbal and written feedback to mental health personnel and PCP regarding progress of symptoms under treatment, new symptoms and other problems related to behavioral and mental health issues.</p>	<p>ATN supp 06</p> <p>Psychiatric guidelines 99</p> <p>AAP CR 07</p>

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<p>2. The MH-PCP should evaluate possible underlying medical causes of behavioral difficulties, as maladaptive behaviors should not automatically be assumed to be part of the “ASD” itself. Examples include:</p> <ul style="list-style-type: none"> <li>▪ Otitis media (with head banging or ear hitting)</li> <li>▪ GER with irritability, back arching and/or sleep disruption</li> <li>▪ Neurological abnormalities</li> </ul>	<p><i>Professional accreditation organizations and mental health professional organizations</i> should recognize the importance of training PCPs, families, and educational professionals in managing behavioral and emotional difficulties (general and ASD-specific).</p> <p><i>Community agencies, educators, and providers</i> should establish and support a system for behavioral evaluation of the child and the development of a positive support plan. One example is the completion of a Functional Behavioral Assessment by skilled clinicians and development of a positive support plan.</p>	
<p>3. After medical investigation of other potential causes for atypical behavioral issues, the MH-PCP should provide medical treatment (e.g., medication pharmacotherapy as appropriate in collaboration with mental health specialists) and collaborate with behavioral and/or mental health professionals and specialists to develop a treatment plan. 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.</p>	<p><i>Government and federal, state, and local agencies</i> should give priority to increasing the resource capacity (e.g., adequate staffing and training) for referral to mental health or behavior specialists (psychologist or psychiatrist) for diagnostic evaluation and treatment.</p> <p><i>Funders (e.g., Medicaid; behavioral health, insurance, others)</i> should 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 FBA evaluations.</p> <p><i>Mental Health specialists</i> should support the MH-PCP’s request for assistance in evaluating the child for mental health issues and developing and managing the treatment plan.</p>	
<p>4. The MH-PCP should work closely with families and educate them about potential medical treatments.</p>	<p><i>State and/or local MH/MR agencies</i> should develop a community resource directory of behavioral and mental health resources to support the MH-PCP in educating families about resources and available medical treatments.</p>	

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<b><i>Alternative Therapy Options for Ongoing Care</i></b>		
<p>1. MH-PCP should understand range of complementary and alternative medical (CAM) interventions, in common use by parents of children with ASD as well as their potential risks and the medical care that may be necessary to address potential side effects.</p>	<p><i>Medical schools and professional organizations</i> such as the AAP, AAFP and NAPNP in cooperation with parent advocacy groups should provide educational resources and training about the range of CAM alternatives and related references, studies, guidelines and reputable web sites to assist them in understanding the benefits and risks and supporting parents to make responsible choices about CAM.</p>	<p>AAP toolkit 07 AAP CR 07</p> <p>Sandler—placebo effects of CAM</p> <p>AAP CAM PS (in final review to be released in 2007)</p>
<p>2. MH-PCP should provide parents and 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.</p>	<p><i>Community agencies</i> should establish ongoing forums for bringing medical and behavioral providers, parents, caregivers, and educational personnel together to share information and open communications about CAM through verbal, written, lecture formats.</p>	
<p>3. MH-PCPs should support families by maintaining an open and honest relationship with the family about their rationale for pursuing CAM treatments including the costs, benefits and possible harm of CAM treatments. They should respect the motivation of parents to seek any treatment that might help their child and understand that families will make the final decision on treatment options.</p>	<p><i>Parent and ASD specific advocacy groups</i>, should provide mechanisms for educating medical caregivers (e.g., CME) about types of CAM, the reasons families pursue treatments, 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 strategies</p> <p><i>Local and state agencies and parent support groups</i> should collaborate with medical providers to develop mechanisms to educate the public – including (but not limited to) written material, reference articles, (reputable) websites</p>	<p>Nichols IYC 01 CAM Ethics Cont Peds 04 Ped Annals 04</p> <p>Levy /Hyman Many articles Contemp Peds MMRDRR 05</p> <p>Rosenbaum Internet article IYC 03</p>

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<b><i>Community Services and Coordination of Care</i></b>		
<p>1. The MH-PCP should be comprehensive in its approach while working in collaboration with specialty care providers – this includes involvement and responsibility in ongoing prevention, wellness, routine medical management, and care coordination for the child.</p>	<p><i>Government and federal / state agencies</i> need to develop new models of primary care/specialty care communication and co-management</p> <p><i>Professional organizations</i> for specialty care physicians should emphasize the importance of integration and coordination with medical home primary care practices within their training programs.</p> <p><i>Health Care Specialists</i> need to be actively involved in supporting the Medical Home Primary Care Practice. This includes implementation of a mutually understood co-management care plan that promotes efficient use of resources, sharing of information about progress and treatments, and sharing information with the medical home practice as part of the comprehensive system</p> <p><i>Funders (government, insurers and other health care payers)</i> should expand service codes in order to adequately reimburse for the time needed to provide appropriate care coordination and services provided by primary and subspecialty care providers</p> <p><i>Funders (government, insurers and other health care payers)</i> should develop strategies similar to CMS Chronic Care Model for coverage of enhanced services for the care of children with ASD</p>	
<p>2. The MH-PCP needs to develop a comprehensive health care plan including periodic reassessment in conjunction and coordination with other health providers (e.g. OT/PT, audiologists) and the educational system providing services to the child (patient). Written documentation of needed community services should be included.</p>	<p><i>Government and federal/state/local agencies</i> should facilitate the development of a mechanism that would allow for ongoing sharing of information in the comprehensive health care plan between practices, families and other systems</p> <p><i>Government and federal /state/ local agencies</i> should 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 to services.</p> <p><i>The educational system</i> under the requirements of IDEIA 2004 should work with the MH-PCP to coordinate the child’s individual health care plan developed by the school with the comprehensive health care plan developed by the MH-PCP. The school nurse should contact the MH-PCP to obtain information for inclusion in the individual plan.</p>	

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	<p><i>The educational system</i> should develop a process for including primary care provider and nurse as members of the school planning team for the child's health care plan.</p>	
<p>3. The MH-PCP should participate in efforts under the Social Security Act/Olmstead Supreme Court Decision to achieve an integrated system of community services including health, education, and social services. The MH-PCP should coordinate and link with the multiple systems and agencies that support ASD services and advocate for collaboration among those systems.</p>	<p><i>Government and federal / state and local agencies</i> should develop mechanisms that allow for communication and coordination between the medical home and all other systems. These systems include but 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.</p> <p><i>Funders (government, insurers and other health care payers)</i> should provide financial support and /or reimbursement for coordination of care for children with special health care needs</p> <p><i>Funders (government, insurers and other health care payers)</i> should provide financial support for the development of a system for integrating services for children with special health care needs</p> <ul style="list-style-type: none"> <li>▪ <i>Community Organizations</i> should proactively collaborate and coordinate services with the medical home</li> </ul>	

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<b>Youth Transition to Adult Services</b>		
<p>1. MH-PCPs should work with the youth, family and other community and educational programs to develop an individualized transition plan prior to the age of 14yrs. This transition plan should address the stated goals of the youth and family and include:</p> <ul style="list-style-type: none"> <li>▪ Medical</li> <li>▪ Mental health</li> <li>▪ Educational</li> <li>▪ Social</li> <li>▪ Post secondary education</li> <li>▪ Self advocacy/self determination</li> <li>▪ Employment</li> <li>▪ Community living (incl. access to long term supports like DD waivers)</li> <li>▪ Financial planning</li> <li>▪ Special needs Wills</li> <li>▪ Communication</li> </ul>	<p><i>Educational System</i> needs to prepare youth for adult roles with increasing independence and should work in coordination with the PCP and the youth and family in order to ensure that development of the transition planning and the IEP or 504 plan will include health support information and will provide for adequate transition to adulthood. This should be the substantial focus of mandated educational services for early youth through age 21.</p> <p><i>Families and youth</i> should be encouraged to facilitate the development of responsibility and independence early (chores, appropriate behaviors, ADL skills) to ensure that children with ASD have every opportunity to function independently in the community as an adult</p> <p><i>Government, Federal, State and Local agencies</i> should provide for programs that assist youth with ASD with identification of employment opportunities (i.e., State vocational rehabilitation programs)</p> <ul style="list-style-type: none"> <li>▪ Specific knowledge and skills in working with individuals across the spectrum of ASD are necessary for agency staff.</li> <li>▪ Resources should be identified to assist with ongoing health and related needs such as transportation, job skills training and social skills development.</li> <li>▪ Employers should be encouraged to participate in programs that provide volunteer mentor programs and offer employment opportunities for youth with ASD</li> </ul>	<p>IDEA 2004</p> <p>ATN</p> <p>Cohen, Peds 05 re prognosis</p> <p>Transition supp</p>
<p>2. MH-PCPs should assist the youth and his/her family in the identification of adult health care resources and providers</p>	<p><i>Professional accreditation organizations and training</i> programs should recognize the importance of education, training and support resources to enhance their ability to care for persons with ASD.</p> <p><i>Adult healthcare systems</i> should 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 should be involved in the care planning process and relationships should be fostered prior to the transition in care</p>	

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	<p><i>Families and youth with ASD</i> have varying abilities to negotiate the systems of care, some families may need additional support from family advocacy organizations and health providers to successfully transition into the adult healthcare system.</p>	
<p>3. MH-PCPs should involve youth with ASD as full participants in their own care as part of their 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.</p>	<p><i>Community agencies and Disability Service Providers</i> should assist in the development of educational programs for youth with ASD and other disabilities regarding interaction with medical providers and systems and should provide opportunities for Youth with ASD to participate in community-based activities that help promote self-determination, advocacy and independence. Peer education strategies may be particularly effective.</p>	
<p>4. MH-PCPs should facilitate access of youth to life skills services regarding friendship, sexuality, safety, community living, health and money management.</p>	<p><i>Federal, State and Local governing authorities</i> need to consider developing guardianship options for individuals with disabilities, incl. youth with ASD, since this is an essential element of transition and estate planning and anticipation of long-term needs may be added considerations for these youth/adults and their families.</p> <p><i>Community Agencies and Disability Service providers</i> need to provide positions, such as a community-based service coordinator, to provide opportunities for assistance as the individual transitions from home to a community living arrangement. The resources must be culturally and linguistically competent to support diverse individuals and families. Living arrangements should be available within communities to promote independence for youth and adults. Local agencies should 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 if the youth is so interested.</p>	
<p>5. MH-PCPs should work in partnership with the youth and his/her family to ensure that transitional planning includes insurance and finances into adulthood.</p>	<p><i>Funders (government, insurers and other health care payers)</i> should recognize that an essential component of adequate insurance coverage for persons with ASD, throughout the lifespan, includes the recognition of ASD by insurers as a neurological disorder not subject to the policy limitations, including those on mental health services.</p> <p><i>Funders (Medicaid, and SSI and other providers)</i> of supplemental health care coverage should ensure that such programs are inclusive of individuals with ASD. These plans should require appropriate reimbursement for transition services including care planning into adulthood for all persons with disabilities including children and youth with ASD.</p>	

## Acronyms and Abbreviations

AAFP	American Academy of Family Physicians
AAP	American Academy of Pediatrics
ADHD	Attention Deficit Hyperactivity Disorder
ADL	
ASD	Autism Spectrum Disorder
ATN	
CAM	Complementary and Alternative Medicine
CDC	Centers for Disease Control and Prevention
CME	Continuing Medical Education
CMS	
DBP	
DD	
DOCC	Delivery of Chronic Care Program
DSS	
FBA	
FXS	Fragile X Syndrome
GER	
IDEA	Individuals with Disabilities Education Improvement Act
IEP	Individual Education Plan
IFSP	
MCH	
MH	Medical Home
NAPNP	National Academy of Pediatric Nurse Practitioners
NRC	
OT	Occupational Therapy
PCP	Primary Care Practice
PS	
PT	Physical Therapy
SSI	Social Security Income
WC	Wheel Chair
WIC	Women, Infants, and Children

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