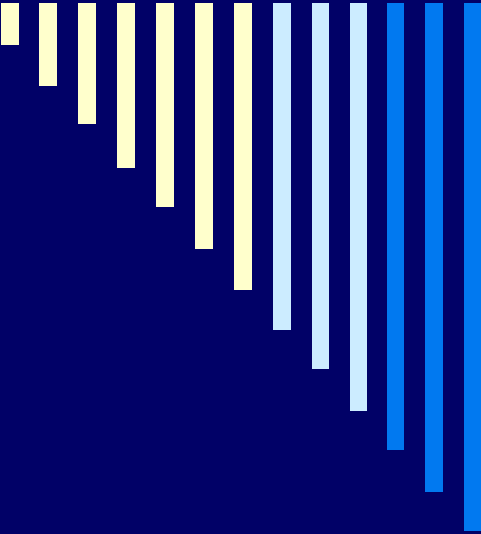


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# Autism/ASD Service Guidelines for Medical Home Primary Care Practices

**ASA National Conference – July 11, 2007**

**Christine M. Breunig, M.S., Project Coordinator, NMHAI and Beth D. Roy M.S., Consultant NMHAI**

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**national**  
**MEDICAL HOME**  
**Autism Initiative**

**Waisman Center**  
University Center for Excellence in Developmental Disabilities  
University of Wisconsin - Madison

Cooperative Agreement with  
Division of Services for Children with Special Health Care Needs  
Maternal and Child Health Bureau  
Health Resources and Services Administration  
US Dept of Health and Human Services

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# Workshop Goals

- Review Objectives of ASD Service Guideline
  - Present Process of Guideline Development
  - Obtain Input on Usefulness and Strategies for Dissemination and Implementation
  - Obtain Input on Promising Practices
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# Objectives of ASD Service Guidelines

- ❑ Define standard of quality for medical home primary care practices providing ASD services
  - ❑ Identify the role of families, professional associations, educational institutions, government, community and funders in support of ASD service system
  - ❑ Provide information and promote dialog as a catalyst for system change to strengthen service systems for autism spectrum disorder
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# Background on Initiative for Guideline Development

- Interagency Autism Coordinating Committee  
and ASD Services Roadmap Expert Working Group
    - [www.nimh.nih.gov/autismiacc](http://www.nimh.nih.gov/autismiacc)
  
  - President's New Freedom Initiative
    - "Community-Based Alternatives for Individuals with Disabilities"
  
  - Maternal & Child Health Bureau Programs  
for Children with Special Needs
  
  - National Medical Home Autism Initiative
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# What is a Medical Home Primary Care Practice?

- Primary Provider of preventive and on-going routine care
  - Central point of coordination for chronic conditions
  - Family-centered, compassionate, comprehensive and culturally effective provider
  - Adaptable to competently serve chronic conditions including ASD
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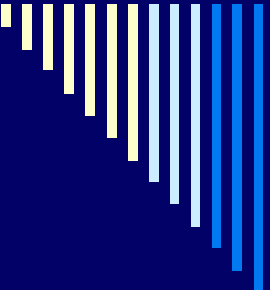


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# Family Forum

## A Perspective on ASD

- Autism is a chronic medical condition with underlying, but still not well understood, genetic and environmental causes.
  - ASD is treatable with medically necessary interventions—physical, behavioral, and therapeutic
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# Family Forum Perspective – there is a crisis in ASD!

- Increasing rates and trends in prevalence
  - Our service system lacks an adequate number of trained and well-distributed professionals at all levels
  - The service system is fragmented or broken and needs to be restructured
  - Funding and reimbursement levels are inadequate to provide quality services
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# Family Forum Perspective

- Providers at all levels need to be more accepting and competent in integrating children and youth with ASD into society
  - The failure to plan for transition of children with ASD to adults is a significant concern
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# Family Forum Perspective on Service Systems

- Common ASD definitions for service eligibility and reimbursement are needed across multiple systems
  - Implementation of the expanded medical home for ASD care must be done within the broader context of systems for all children with special needs
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# The Scope of Autism/ASD Service Guidelines

- General Principles for ASD Medical Home
  - Surveillance, Screening, and Diagnosis
  - Ongoing Medical Care after Diagnosis
  - Community Services/Coordination of Care
  - Youth Transition to Adult Services
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# ASD Service Guideline Format

- GUIDELINES FOR MEDICAL HOME  
PRIMARY CARE PRACTICE
  - GUIDELINES FOR SYSTEMS  
DEVELOPMENT AND COORDINATION
  - PROMISING PRACTICES
-



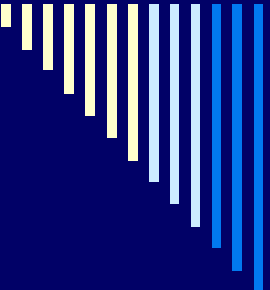
# General Principles for an ASD Medical Home

- 1.
- The Medical Home Primary Care Practice (MH-PCP) is aware of and implements Medical Home (MH) principles when caring for children, including those with ASD.
  - *Parents and youth with ASD*
  - *Professional accreditation organizations and training programs*
  - *Professional accreditation organizations and medical school, residency programs, and other professional training programs*
  - *Professional organizations*
  - *Funders (government, insurers and other health care payers)*



# General Principles for an ASD Medical Home

- 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.
  - *Parents and youth with ASD*
  - *Families and family advocacy groups*
  - *Residency and other training programs*
  - *Funders (government, insurers, and other health care payers)*
-



# Developmental Screening And Surveillance

- 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 :
    - 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.
  - *Families*
  - *Families*
  - *Families*
  - *Professional accreditation organizations*
  - *Funders (government, insurers and other health care payers)*
  - *Funders (government, insurers and other health care payers)*
-



# Ongoing Medical Care after Diagnosis

- 1.
  - The MH-PCP should provide 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 assure that children and youth with ASD continue to have ongoing well child care, and chronic care treatment and surveillance.
  - *Families*
  - *Families*
  - *Professional accreditation organizations*
  - *Community agencies and providers*
  - *Funders (government, insurers and other health care payers)*
-



# Ongoing Medical Care after Diagnosis

## BEHAVIORAL AND MENTAL HEALTH

- 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-morbid 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 educational system regarding these co-morbid behavioral difficulties
  - *Families*
  - *Families*
  - *Professional accreditation organizations and mental health professional organizations*
  - *Professional accreditation organizations and mental health professional organizations*
  - *The educational system and community providers*



# Ongoing Medical Care after Diagnosis

## ALTERNATIVE THERAPY

- 3.
- The MH-PCP supports 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. The MH-PCP respects 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.
- *Parent and ASD specific advocacy groups*
- *Local and state agencies and parent support groups*
- *Government*



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# Community Services/Coordination of Care

- 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
    - **Families** are informed
    - **Government and federal / state agencies**
    - **Professional organizations.**
    - **Health Care Specialists**
    - **Funders (government, insurers and other health care payers)**
-



# Youth Transition to Adult Services

- 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 transition plan should address the stated goals of the youth and family and include:
  - Medical
  - Mental health
  - Educational
  - Social /recreate
  - 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
- *Families and youth*
- *Families and PCP*
- *Educational System*
- *Employers*
- *Government, Federal, State and Local agencies*



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# NEXT STEPS ....

- Development of process for collecting and selecting “Promising Practices”
  - Meetings and forums with stakeholders
  - Development of website for dissemination of the Autism Service Guidelines
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# Abstract for Promising Practice

- ❑ Submitted on “PROMISING PRACTICES” abstract form to the National Medical Home Autism Initiative
  - ❑ Plan is to have abstracts reviewed and selected by a committee
  - ❑ Promising Practices can serve as a resource for others so that system change efforts can be expedited and done in an efficient manner.
  - ❑ Promising practices may be in any of the guideline categories: organizing the medical home; screening and surveillance; on-going medical care, coordination of community services; professional development and training; transition to adulthood; funding
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# Abstract for Promising Practice

- **Lead Agency / Organization responsible for Implementation of the Promising Practice**
    - Name
    - Location
    - Contact Information
  
  - **Description:**
    - What was the purpose and objective and who are the key parties?
    - When was the practice implemented and for how long?
    - What was the geographic service area?
-

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# Abstract for Promising Practice

## □ **Methods/Approach:**

- What was done to get results?

## □ **Source of Funding:**

- Where did the funds come from?
  - Is the funding ongoing?
  - How much funding was provided?
-



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# Abstract for Promising Practice

## □ Evidence of Results:

- Provide information on impact
- Provide evaluation plan and results.

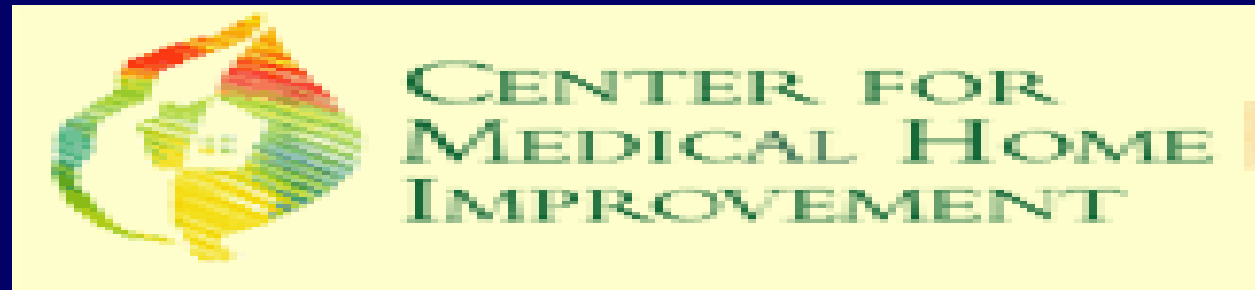
## □ References:

- Web site
  - Publications
  - Other citations
-

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# A PROMISING PRACTICE



- CMHI has worked to implement care process improvements in the medical home.
  - This involved teams of clinicians, families and care coordinators
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## Description:

- CMHI assisted ten primary care practices (NH/VT) to use a family-centered, team-based, medical home improvement process.
  - Two years project to implement a more fully developed medical home as measured by a 33% overall increase of their post *Medical Home Index*© scores
  - Each practice identified a cohort who would complete child and family measures of clinical, functional, satisfaction and cost outcomes pre and post intervention using the Medical Home *Family Index and Survey* (MHFI&S).
  - Completing the CAHMI Screener for their children shows 97.6% as positive for special health care needs.
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## Description:

- 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
    - technical assistance and support for medical home improvement.
-



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## Source of Funding:

- ❑ Funding was from the USMCHB Division of Children with Special Health Care Needs.
  - ❑ Grant funding was around 200K/year.
  - ❑ These have been competitive grants.
  - ❑ Sustainability lies within each state identifying strengths, resources and supports for the future of primary care.
-



# A PROMISING PRACTICE



- *The EDOPC project is a partnership with many organizations (ICAAP, the Illinois Academy of Family Physicians, the Ounce of Prevention Fund, and Advocate Health Care).*
  
- *Enhancing Developmentally Oriented Primary Care (EDOPC) and Autism projects offer*
  - *office-based presentations for primary care providers (professional development and training)*
  - *coordination of community services by working with practices to connect with their local community health providers, including Early Intervention.*



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## Description:

- The Early Autism Detection and Referral project offers office-based presentations to primary care providers throughout Illinois
  - The project began in 2004 with implementation and is on-going.
  - Five presentation topics are covered in EDOPC:
    - Early Autism Detection and Referral
    - Developmental Screening
    - Social/Emotional Screening
    - Perinatal Maternal Depression Screening
    - Referral and Domestic Violence: Effects on Children).
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# Source of Funding:

- *Funding for the Autism and EDOPC projects come from a variety of sources including:*
    - *private foundations*
    - *Medicaid*
    - *The Autism Program/Hope School in Illinois.*
  
  - *The continuation of funding has been variable, depending on the source.*
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# A PROMISING PRACTICE



## Parents as Teachers

Health, Information and Advocacy Center

Residency Training Program  
in collaboration with  
University of Minnesota – Minneapolis  
Minnesota Department of Health

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## Description:

- Families with a child with developmental disability (38 currently) are recruited and trained to provide on hands training with a resident from UMM
  - Residents in developmental/behavioral pediatrics rotation are attend orientation with PACER staff
  - Residents schedule one or two visits with their assigned family. Visits must allow resident to see family / child in several settings and several activities.
  - Residents and families provide feedback to the PACER staff.
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## Source of Funding:

- Family Health Center grant through the Maternal Child Health Bureau (MCHB)
  - Family Stipends provided through the University of Minnesota - Minneapolis
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# Contact Information

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