From Professional Evolution to Service Revolution:

Starting & Sustaining a Family-Centered ADHD Clinic in an Urban Community Health Center
Valerie F. Pietry, MD, MS
Medical Director, School Health Services
Family Health Center of Worcester
University of Massachusetts Medical School
Department of Family Medicine and
Community Health
Objectives

1) Understand health disparities in ADHD care as a rationale for care of underserved ADHD patients
2) Understand similarities/differences in values of the pediatric medical home for CSHCN within the larger context of a family medicine-model medical home redesign
3) Become familiar with resources for professional development in primary care of ADHD
4) Become familiar with a family-centered model for ADHD care in a community health center
Introduction: ADHD

- ADHD prevalence: estimated at 4% - 12% of general population of 6 – 12 year-olds (Brown et al, 2001)
- Neurobehavioral disorder with diagnosis based on DSMIV-TR criteria
- Symptoms exhibited in two settings, with impaired performance
- Multimodal treatment: meds, behavioral, school
Introduction: ADHD

- A primary care diagnosis
- Access issues for child mental health services can delay evaluation and treatment: 13 million children in need of MH/SA care (AAP, 2000)
- Disparities among underserved populations
ADHD and the Underserved

- Evidence base includes a minority of low-SES patients
  - MTA study: 579 children over 14 months
  - 19% low SES
  - 20% African American
  - 19% Hispanic, racially mixed, “other”
  (Jensen et al, 2001)
ADHD and the Underserved

- Large-scale studies are presumably conducted in English
- Divergent findings across smaller studies
- Underdiagnosis and undertreatment among African American and Latino patient populations? (Bussing et al, 1998; Bauermeister et al, 2003; Stevens et al, 2004)
ADHD and the Underserved

- Differing perceptions about medication and behavioral treatments across racial and ethnic lines (dos Reis, 2003; Arcia, 2004)
- Nonwhite parents found to be less likely to prefer medication to counseling, Latina mothers with negative perceptions of medication treatment (dos Reis, 2003; Arcia, 2004)
- Less frequent use of counseling in low-income groups (dos Reis, 2004)
- Combination of behavioral and medication treatment may be more effective in lower-SES groups (Jensen et al, 2001; Arnold et al, 2003)
Scant literature specific to family physicians treating ADHD, yet:

- “family physicians should be able to diagnose and treat the majority of patients who present with ADHD”
- “with time and interest, the family physician can develop the skills to treat this disorder” (Szymanski, ML and Zolotor, A, 2001)

- Future of Family Medicine Project practice model:
  - personal medical home for patients and **families**
  - patient-centered treatment delivered via a team approach
  - an orientation to the whole person within a culturally sensitive, **community** context
  - basket of services that are integrated as needed with appropriate specialty care

- Future of Family Medicine Project practice model:
  - focus on child development, patient advocacy and chronic disease management
  - eliminates barriers to access

Role of FP:
- fosters personal growth and behavior change
- takes into account patients’ culture and values
- collaborative communication with others involved in the care process (Future of Family Medicine Project Leadership Committee, 2004).

- Personal physician
- Physician-directed medical practice
- Whole person orientation
- Care is coordinated &/or integrated
- Quality and safety
- Enhanced access
- Supportive reimbursement structure

AAFP/AAP/ACP/AOA Feb 2007
FM Medical Home Model: Now

Questions for reflection:

1) Where is the family in this model?
2) Where is the child?
3) Where is the community?
Pediatric Medical Home: Then (2002)

- Medical home concept for infants, children, and adolescents:
  - “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective”
  - “delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care”
  - “partnership of mutual responsibility and trust” between physician and family (AAP, 2002)
Pediatric Medical Home: Then

- DB pediatrics focuses on the developmental, behavioral and psychosocial health of children
- Mental health care is an increasing focus in light of relative shortage of child psychiatrists
- Integrated approach to care: the biopsychosocial model, medical home
Pediatric Medical Home: Now (2009)

- **Family-centered partnership**: A medical home provides family-centered care through a trusting, collaborative, working partnership with families, respecting their diversity and recognizing that they are the constant in a child’s life.

- **Community-based system**: The medical home is an integral part of the community-based system, a family-centered coordinated network of community-based services designed to promote the healthy development and well being of children and their families. As such, the medical home works with a coordinated team, provides ongoing primary care, and facilitates access to and coordinates with, a broad range of specialty, ancillary and related community services.

- **Transitions**: The goal of transitions is to optimize life-long health and well-being and potential through the provision of high-quality, developmentally appropriate, health care services that continue uninterrupted as the individual moves along and within systems of services and from adolescence to adulthood.

- **Value**: Recognizing the importance of quality health care, appropriate payment for medical home activities is imperative. A high-performance health care system requires appropriate financing to support and sustain medical homes that promote system-wide quality care with optimal health outcomes, family satisfaction, and cost efficiency.

AAP, May 2009
Pediatric vs. Family Medicine Model

Questions for reflection:

1) Where is the **family** in this model?
2) Where is the **child**?
3) Where is the **community**?
Residents of the Home: CYSHCN

“those who have or are at increased risk for a chronic physical, developmental, or emotional condition **and** who also require health and related services of a type or amount beyond that required by children generally”

AAP, 1998
Percentage Whose Care Met the Definition of a Medical Home: Children and Adolescents Ages 0–17 by Age Group, Special Needs, and Type of Insurance, 2003

CYSHCN within Our Home

- Child Behavioral Health screening at FHCW reveals ~18% rate of need identification vs. ~10% rate state-wide
- In 9 months from 7/1/08 – 3/31/09, 416 pediatric visits with behavioral “need identified”
- Encounter forms did not allow for accurate links to diagnoses
- Difficult to estimate true # CYSHCN
- “the EMR will fix it”? 
FM vs Pedi Model: Time for a New Perspective?

From:
- “family medicine and pediatrics are different”
- “pediatric care = WCC + immunizations”
- “childhood is only ¼ of the lifespan”
- focus on adult issues

To:
- “health behaviors in childhood impact health behaviors in adulthood”
- “health risks in childhood become chronic conditions in adulthood”
Professional Development: Evidence-Based ADHD Care

- ADHD as a primary care diagnosis—AAP 2001 article
- Evidence base merges with primary care practice guidelines
  - MTA study, 1999, & f/u studies 2007
  - AAP Clinical Practice Guidelines, 2000
  - NICHQ/AAP ADHD Toolkit, 2002
  - PATS study, 2006
MTA Study: Multimodal Treatment of ADHD

- 1999 study of 579 children was the first large-scale, randomized controlled trial of the comparative efficacy of medication, behavioral and combined treatments of ADHD, over a period of 14 months (Jensen et al, 2001)
Professional Development in ADHD Care: the ADHD Toolkit

- Follows DSM criteria and AAP Guidelines, now also in Spanish
- Free and downloadable: www.nichq.org and www.aap.org
Professional Development in ADHD Care

- Opportunities for provider education:
  - Faculty and practicing providers
    - CME: AAP National Conference D/B Peds track
      - BU D/B Pediatrics conference
      - ADHD-specific conferences
  - Mentoring: look for a variety of perspectives and disciplines: behavioralists, child psych, DB peds, family medicine, clinical social work, nursing
  - Observational experience: embed yourself in a clinic
  - Mini-fellowship?
Professional Development in ADHD Care

- Faculty and practicing providers
  - Literature—medical and lay
  - FDA Medwatch: medication safety alerts
  - Professional organizations, websites
    - AAP
    - www.dbpeds.org
    - CHADD
    - www.drthomasebrown.com
    - www.myadhd.com

- Residents and students:
  - Electives in D/B pediatrics, rotation through ADHD Clinic
  - Continuity clerkships with practicing physicians
  - Faculty mentoring
Professional Development in ADHD Care

- Next steps: Medical Home Initiatives merge with practice support in ADHD Care?
  - Best practice forums, eg, CHI, DPH
  - CHC Special Project Grants
  - PCMHI model?
  - CHIPRA?
- Training beyond the provider→practice team
A “fertile period”—convergence of:

- Physician’s developmental trajectory
  - Mini-sabbatical and shift of focus
- Health center systems evolution
  - Depression Collaborative: SS & Medical depts
  - Social work advocates
- A handy tool emerges: ADHD Toolkit
- Community factors: provider attrition
- Agreeable mentors
Family-Centered ADHD Clinic Model: Origins

- Supportive CHC leadership:
  - Met my need to take time out for reflection, which in turn started the whole process rolling
  - Saw service need within our CHC
  - Encouraged collaboration with health center systems and players
  - Ongoing support of evolving clinic and population needs
Family-Centered ADHD Clinic Model: Process of Development

- Concept development
  - From brainstorm to business plan
    - Concept emerged after a period of “immersion” in professional development
    - Multimodal treatment model
    - Unwittingly mirrored MTA elements and NICHQ concept
    - Business plan submitted to Medical Director
Family-Centered ADHD Clinic Model: Process of Development

- Consensus building
  - From buy-in to team-building
  - Team model required buy-in from all members
  - Serial group meetings
    - Social Service department staff
    - Psychologist
    - Nursing
    - Outside mentor from Pediatrics/FM
Family-Centered ADHD Clinic Model: Process of Development

- Implementation
  - From philosophy to systems and back again
  - Meds vs behavioral treatment: how to weight the process?
  - Development of patient care flowsheet
  - Multiple iterations and adjustments of the process: eg, role of team conference

- Space considerations
  - Child-friendly, safe, playroom + exam + consultation
Family-Centered ADHD Clinic Model: Program Structure

- Flow diagram
Family-Centered ADHD Clinic
Model: Program Structure

- Implementation: “the ADHD Clinic”
  1) Behavioral Intake and counseling
  2) Medical Evaluations and Follow-up
     - Weekly 3 hour session, afterschool thru evening
       - 30 minute consultations for in-house, SBHC pts
       - 15 minute follow-ups
     - ~30 -40% no-show rate at startup: health center willing to accommodate
     - Staff = MD(FP) + bilingual MA + appt clerk
     - Specialty referrals for complex or non-ADHD diagnoses
Family-Centered ADHD Clinic Model: Program Structure

- Links to community and other programs
  - Behavioral providers provide school advocacy
  - School-based health centers
    - Facilitate MD-school communication, follow-up on school issues, and care delivery on-site
  - Care coordination for comorbidities
    - MCPAP
    - Community mental health agencies
    - CBHI care coordination agency
    - Family stabilization units, Mobile Crisis Team, EMH
  - Afterschool programs, summer camps, therapeutic mentors
Family-Centered ADHD Clinic Model: Program Structure

- Learning curve for patients and health center staff
- Evolution from enabling to empowering approach with patients
- Current model: providers refer, parents collect data, intake when data returned by parents, behavioral care decoupled
- Controlled substances management
Family-Centered ADHD Clinic Model: Outcomes

- 7 years in operation
- ~70 patients seen in the first year
- ~120 active patients by year 2
- 196 patients served in past 3 years
- 84 patients served in 256 visits in past year
- ~80% male, ~80% Latino, majority school-aged
- Treatment outcomes tracked by Vanderbilt forms: goals = reduce Sx below diagnostic threshold, improve functioning & self-esteem
Hispanic Low-Income Parents’ Attitudes Toward Treatment of ADHD in a Community Health Center

Goal:
Describe parental ADHD knowledge, attitudes and barriers to treatment, in a low-SES, Hispanic, primary care population, using an existing survey tool (AKOS), and compare to national norms.

Findings:
Knowledge score for the entire sample was significantly lower than the norm (n = 32, P < 0.0001) Spanish speakers found counseling significantly more acceptable than the norm (P = 0.05). Parents without college education found medication more acceptable, counseling more feasible but not more acceptable, than norm (P = 0.04, P = 0.016). Parents’ beliefs about their roles, those of professionals and family systems regarding the treatment process were explored in focus groups.

Pietry et al, 2008, funded by UMass Commonwealth Medicine
Family-Centered ADHD Clinic Model: Research

Focus Groups: Parent, Provider, Family Roles

- “The behavior of my child is so difficult to control that I feel as a failure as a parent…. But I know that I am a good mother…. I know I need to help, I have to give them a lot of love.”

- “We also need someone who can inform the parents, especially the Latinos; many parents are afraid, or they do not know the language.”

- “…the children, they need the father, them as boys they need the father…the boys want a masculine figure around.”

- Pietry, Bacigalupe et al, 2008
Emerging Initiatives: Care Coordination

- High frequency of comorbidities:
  - Witness to domestic violence/PTSD
  - Mood disorders
  - ODD/CD
  - Learning disabilities
  - Family disruption
  - Medical diagnoses
  - Family systems issues, eg, parental depression
  - Court, foster care, DCF involvement

- Emerging necessity of Care Coordination services
DPH Care Coordination
Medical Home Project
2008 - 2011

• A new focus for our pediatric patients, emerging from ADHD Clinic needs
• Adult care coordination programs exist for chronic diseases, eg, diabetes, HTN
• Caseload of ~100 patients built by DPH Coordinator from provider referrals
• Majority have primary needs in behavioral health, school issues, some medical needs
• Current iteration is pilot project in school-based care coordination
Care Coordination: Obstacles

- Overloaded staff → hinders sustainability efforts
- Budget reductions/funding cuts
- Parents lacking in advocacy skills
- Funding sources drive focus on adult medical problems
- Buy-in re: importance of remembering pediatric needs in health center-wide systems development
Emerging Initiatives: EMR

- Software templates generic, primarily based on DSM IV criteria
- Impractical when comorbidities are being tracked and treated
- Customization of templates for intake and followup of urban underserved ADHD patients is underway (thanks again to supportive CHC Administration)
Future of ADHD Clinic and Care Coordination: Sustainability

- Customize EMR templates → data collection
- Focus on SBHCs for expanded access
- Care coordination by FHCW staff
- Parent volunteer/parenting support
- Role within PCMHI
- Growing the provider base in our CHC
- Teaching residents
“The $10 billion federal SSI program for children was created mainly for those with severe physical disabilities. But it has veered from that goal, sending most cash benefits to those with common behavioral and mental conditions, creating dangerous incentives for families to medicate the young.”

“To get the check,” [one parent] has concluded with regret, “you’ve got to medicate the child.”

*Boston Globe 12/10*
You are influencing the growth and development of a person, so:

- Work redemptively with parent and child
- Instill optimism and hope
- Build self-esteem
- Plant seeds of a dream for a brighter future

Mel Levine
“All this fires my soul, and provided I am not disturbed, my subject enlarges itself, becomes methodized and defined, and the whole, though it be long, stands almost complete and finished in my mind, so that I can survey it, like a fine picture or a beautiful statue, at a glance. Nor do I hear in my imagination the parts successively, but I hear them, as it were, all at once. What a delight this is I cannot tell.”

-Mozart, quoted in A Mind at a Time, by Mel Levine, MD, 2002
References: Available upon request

Questions?

Valerie F. Pietry, MD, MS
Medical Director, School Health Services
Family Health Center of Worcester
Valerie.Pietry@umassmed.edu