

# HEARING LOSS AND THE MEDICAL HOME: FAMILIES, PROVIDERS AND COMMUNITY AGENCIES

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# MEDICAL HOME FOR CSHCN – CATCH GRANT

- How is a Medical Home provided to CSHCN and their families in Queens County?
  - Pediatricians
  - Families
  - Community agencies
- Strengths and needs of the healthcare system for CSHCN
- Gaps in the way the Medical Home model is currently implemented.
- Recommendations for improvement

# THE MEDICAL HOME: A CONCEPT RATHER THAN A BUILDING

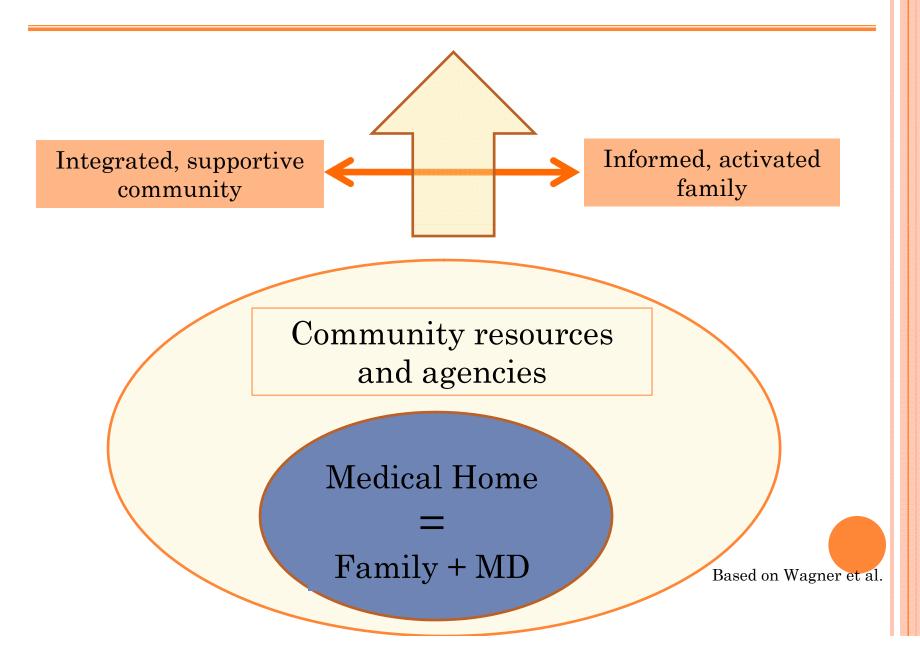
- Accessible
- Family-centered
- Continuous
- Comprehensive
- Coordinated
- Compassionate
- Culturally Effective



# INTEGRAL PART OF COMMUNITY-BASED SYSTEM

- Coordinates with community-based services designed to assist CSHCN and their families
- Facilitates access to and collaborates with a broad range of specialty, ancillary and related community services
- Provides case management

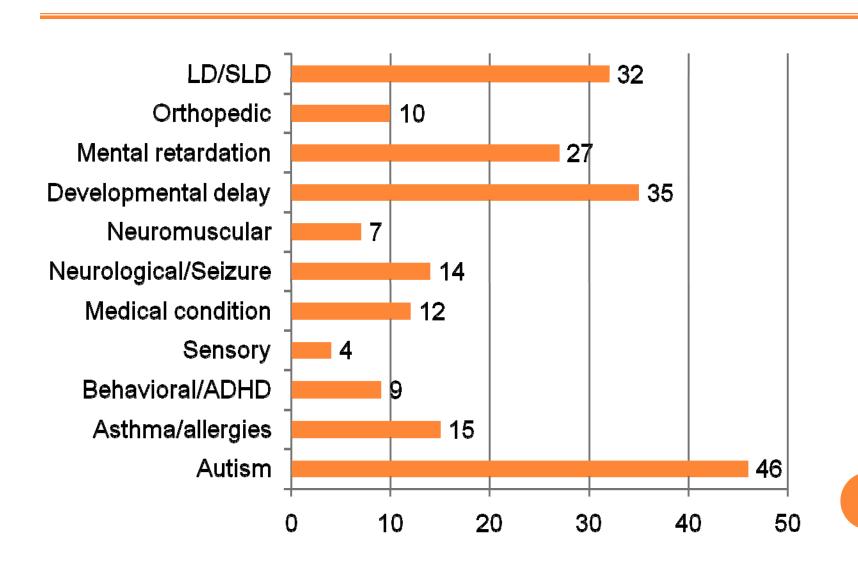
#### SUCCESSFUL CARE FOR CSHCN



#### **CSHCN - DEFINITION**

- Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally
- Maternal and Child Health Bureau and the American Academy of Pediatrics

#### CSHCN - CATCH Grant - 77 CHILDREN



## CSHCN – MEDICAL SERVICES IN PAST YEAR

- Community services by primary care pediatrician about 90%
- Medical sub-specialist 60%
- Case management services less than half!
- $\circ$  Hospital or ER 20%
- 121 general pediatricians, 19 hospitals, 10 child health centers



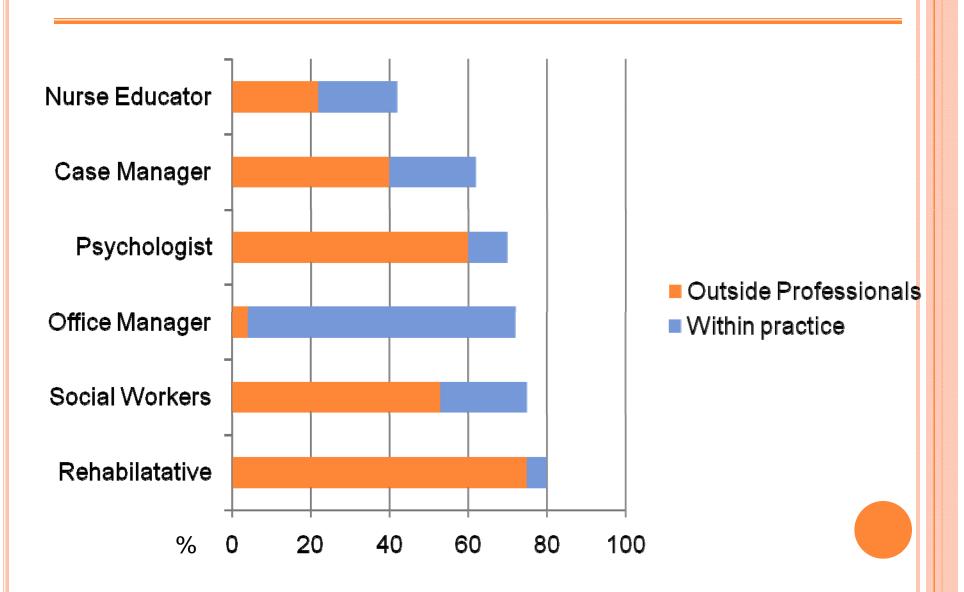
## **QUEENS COUNTY - CSHCN**

- About one third of CSHCN have inadequate insurance
- One third do not have family-centered care
- At least 20% of families report difficulty in getting all needed services.
- 16% of children live below the poverty level
- Almost half of the people in Queens were born outside of the US
- Over half speak a language other than English at home

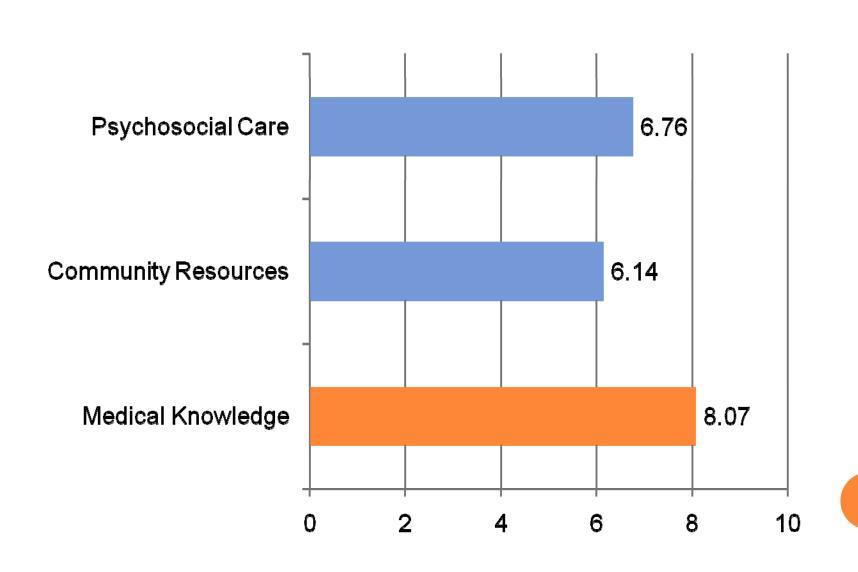
## MEDICAL PROVIDER SURVEY

29 Pediatricians

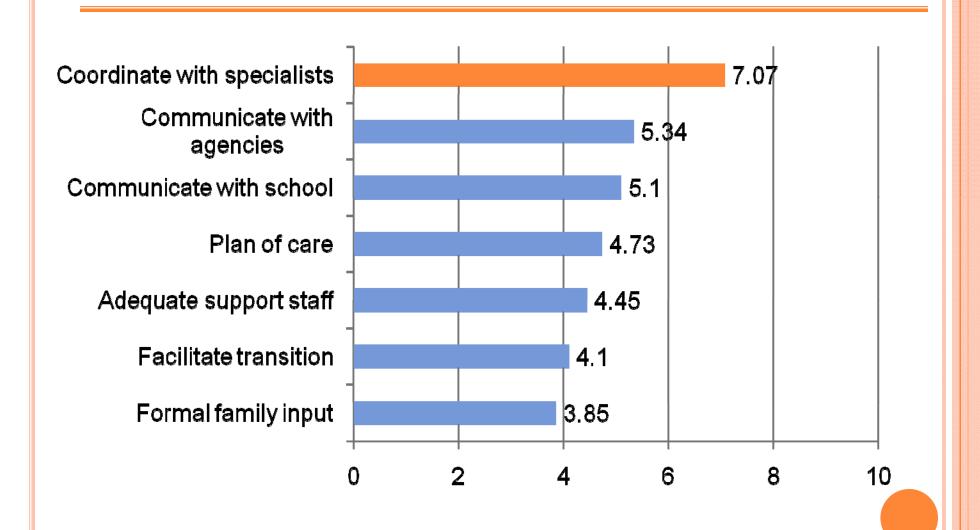
#### **MD** COLLABORATION



### WHAT MD'S KNOW!



#### BEST PRACTICE IMPLEMENTATION



#### MEDICAL PROVIDERS - SUMMARY

- Adequate medical knowledge and medical skills
- Interest in providing family centered care
- Skill in managing collaboration with sub-specialists
- Less confident in providing psychosocial and coordinated care
  - Schools
  - Community agencies
  - Family feedback and providing family-friendly documentation

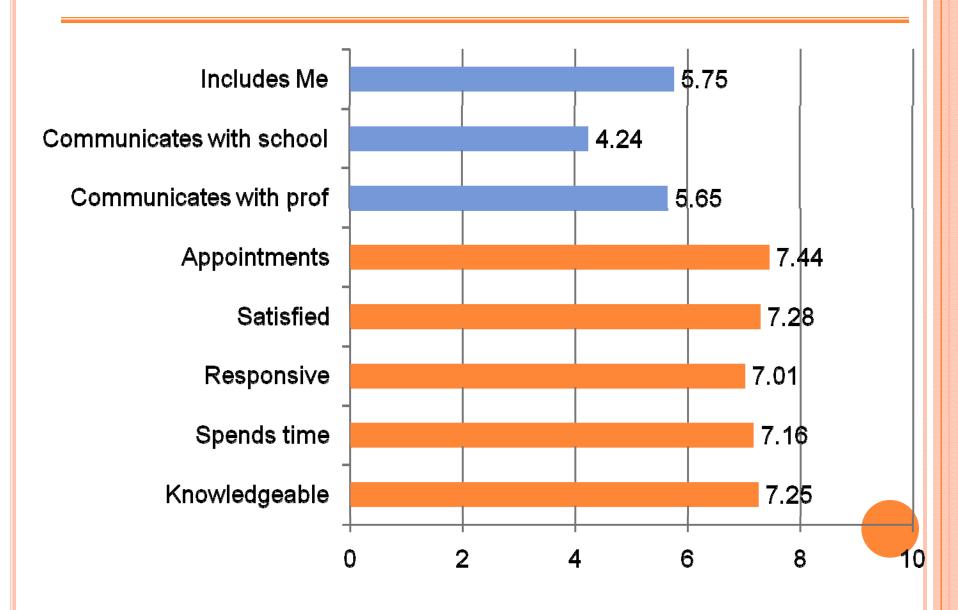
#### MEDICAL PROVIDERS - SUMMARY

- Financial pressures caused by insurance and time constraints were greatest obstacles
- Inadequate staffing for care coordination
- Pediatricians rely on their office managers to provide comprehensive care. However, office staff are felt to be relatively unfamiliar with medical home concepts
- Providers feel that a lack of availability of community resources is one of the greatest obstacles to providing a medical home

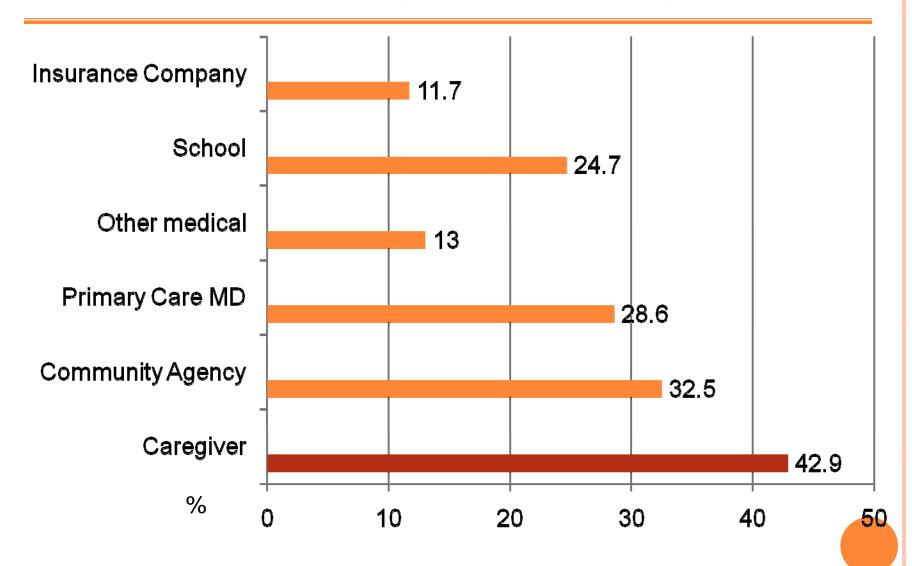
## **FAMILY SURVEY**

77 Families

#### PARENTS' PERCEPTION OF MD



#### WHO HELPS COORDINATE CARE?



#### FAMILIES - SUMMARY

- High levels of satisfaction
  - Medical expertise
  - Primary care pediatrician.
- Less satisfaction with communication, coordination and collaboration
  - Specialists
  - Schools
  - Community agencies.
- 50% felt that they were coordinating the care of their child without assistance.
- Improved coordination of services was one of the MOST important issues

# COMMUNITY AGENCY FOCUS INTERVIEWS

8 Agencies

# COMMUNITY AGENCIES AND THE MEDICAL HOME

- Parents manage medical care
  - Community pediatricians were rarely seen as case managers
  - Management and coordination clearly fell on the caregiver
  - Service coordination was somehow distinct from medical care
  - As medical needs became more complex, it was the parent who was given the additional responsibility of managing the additional services

#### COMMUNITY AGENCIES - CONCLUSIONS

- Intermittent, and incomplete collaboration between community agencies and medical providers
- Concerned by time constraints and communication and cultural barriers
- Parent is responsible for advocacy, coordination and for serving as the liaison between physicians and community agencies.
- The observed gaps in communication between medical providers and community based professionals appear to be one of the reasons that has required the caregivers themselves to fill the void and coordinate the care of their children

## RECOMMENDATIONS - QUEENS COUNTY

- Training for case managers from community agencies about Medical Home model and how to work with medical providers
- Training for pediatricians to learn about community agencies and their range of services and how to collaborate, coordinate care and improve communication
- Public health agencies and pediatric organizations should provide this training and develop tool kits
- Clearinghouse, website or 1-800 number that can offer advice and recommendations

## RECOMMENDATIONS – QUEENS COUNTY

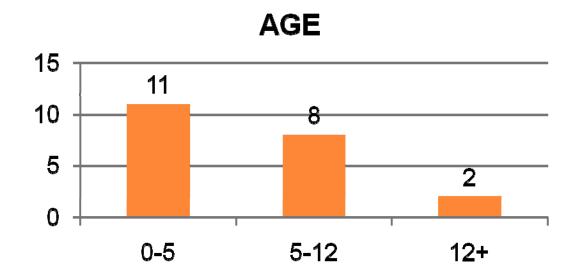
- Develop models and provide assistance to physicians to provide case management
- Training pediatric office staff in case management, care coordination and collaboration with community agencies. Include written documentation and written care plan.
- Adequate reimbursement including care coordination and case management services
- Lobbying to encourage third party payment for case management services
- Medicaid and private health insurance companies to consider providing case management services for practices that serve CSHCN

## RECOMMENDATIONS - QUEENS COUNTY

- Improved access to interpreters and additional training in cultural competence
- Parent training and advocacy to access appropriate services and seek case management
- Support for ongoing meetings of families, healthcare providers, and community agencies who provide services to CSHCN
- Establishment of common language and goals to improve Medical Home for CSHCN

#### CHILDREN WITH HEARING LOSS

- EMR 389.xx ICD codes
- o 21 children from birth to 18 years
- 13 with mild conductive loss
- o 8 with other
- o Chart review: 12/01/08 12/01/09



#### "HOMES" - COMPLEXITY SCORE

- Center for Medical Home Improvement
- www.medicalhomeinfo.org
- 5 Categories
  - Hospitalizations, ER usage, Specialty visits
  - Office visits, phone calls (above well visits/regular care)
  - Medical condition(s)
  - Extra Care and services (meds, technology, therapeutic assessments/treatment/procedure, care coordination)
  - Social concerns
  - 0-3 Low . 4-6 Moderate . 7-10 High

#### MEDICAL HOME SERVICES

- Medical Home Coordination Measurement Tool -AAP Medical Home Initiatives for CSHCN
- Richard Antonelli, MD
  - Subspecialty referrals and contact
  - Prescription, supplies
  - Care coordination services payers, agencies
  - Meeting with clinical care coordinator
  - Forms/reports
  - Contact with community agency
  - Home care orders
  - Early Intervention/school contact
  - Extra visits or phone contacts requiring extended time

#### CHILDREN WITH HEARING LOSS

- Subspecialty referrals and contacts
  - Range from 0-4 per child/year
- Extra visits or phone contacts
  - Range from 0-6 per child/year
- Care coordination services insurance
  - 0-3 instances per child/year
- RN visits care coordinator
  - 0-2 meetings per child/year
- Early Intervention contact
- Prescriptions, supplies, equipment

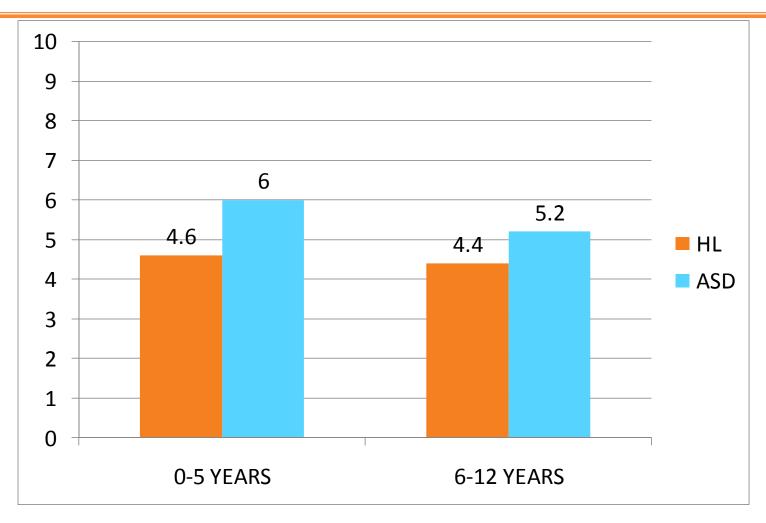
### CARE COORDINATION - HEARING LOSS

- Subspecialty referrals
  - Genetics
  - ENT
  - Audiology
  - Ophthalmology
  - Cardiology
  - Endocrinology

#### CARE COORDINATION - HEARING LOSS

- Procedures
  - CT scan
  - Audiogram
  - VRA
  - Tympanogram
  - OAE
  - ABR
- Surgery
  - Myringotomy and tubes
  - Adenoidectomy
  - Tonsillectomy
- Equipment
  - Hearing Aids

# HOMES – COMPLEXITY SCORES COMPARED WITH AUTISTIC SPECTRUM DISORDERS



No significant difference

## CARE COORDINATION – CHILDREN WITH HEARING LOSS

- Subspecialty referrals and contact
  - Mean 2 visits /year
  - Range: 0-4 visits
- Extra visits or phone contacts beyond normal care
  - Mean of 1 contact/year
  - 1.5 contacts in younger group
  - Range 0-6



# CARE COORDINATION – CHILDREN WITH HEARING LOSS

- Other activities were much less frequent
  - Prescriptions/supplies
  - Care coordination
  - RN manager visits
  - Forms, reports
  - Contact with community agencies
  - School contacts

# Younger Children - Compare with ASD

- Age Adjusted Little difference
- Subspecialty referrals and contact
- Extra visits or phone calls
- Prescriptions/supplies
- Care coordination
- RN manager visits
- Slightly significantly higher in children with ASD:
  - Forms and reports
  - Contact with community agencies
  - Contact with schools

# OLDER CHILDREN – COMPARE WITH ASD

- Age adjusted Little difference
- Subspecialty referrals and contact
- Extra visits or phone calls
- Prescriptions/supplies
- Care coordination
- School contacts
- Slightly significantly higher in children with ASD
- RN manager visits
- Forms and reports
- Community agencies

#### LESSONS LEARNED

- Children with hearing loss require substantial care coordination!!
  - Regardless of severity
  - Subspecialty referral and contacts
    - HCP strength and parents are satisfied
  - Parent education
    - HCP strength
    - Need to help and/or prepare for case management

#### LESSONS LEARNED

- A Medical Home is a Medical Home is a Medical Home
  - All CSHCN need intensive services
  - Care coordination may vary somewhat
  - Standardize approach to payment and office flow
- Medical home "Welcome Mat" needs to be out for all children and especially CSHCN
  - Providers
    - What we do well
    - What we need to improve
  - Families
    - Expectations of medical home
    - Assistance with coordination
    - Advocate for good medical homes

#### LESSONS LEARNED

- HCP need to do a better job with community organizations and schools
  - Outreach to school and agencies
  - Parents as allies and advocates
  - Education of HCP and community agencies
- Concerns:
  - Time constraints
  - Insurance payment
  - Office flow
  - CASE MANAGEMENT

